Accessibility & Digital Environments

Erin E. Templeton
George H. Williams
Welcome to DHSI 2019!

Thanks for joining the DHSI community!

In this booklet, you will find essential course materials prefaced by some useful information about getting settled initially at UVic, finding your way around, getting logged in to our network (after you’ve registered the day before our courses begin), and so on.

Given our community’s focus on things computational, it will be a surprise to no one that we might expect additional information online for some of the classes - your instructors will let you know - or that the most current version of all DHSI-related information may be found on our website at dhsi.org.

Do check in there first if you need anything that’s not in this coursepak.

To access the DHSI wifi network, simply go into your wireless settings and connect to the “DHSI” network and enter the password “dhsi2019”.

And please don’t hesitate to be in touch with us at institut@uvic.ca or via Twitter at @AlyssaA_DHSI or @DHInstitute if we can be of any help....
DHSI Wi-Fi

Network name: DHSI
Passkey: dhsi2019
The 2019 schedule is just taking shape nicely! A very few things to confirm, add, etc, still but this is the place to be to find out what is happening when / where ...

Sunday, 2 June 2019 [DHSI Registration + Suggested Outings]

If you're here a day or two before we begin, or staying a day or two afterwards, here are a few ideas of things you might consider doing ....

Suggested Outing 1, Botanical Beach (self-organised; car needed)
A self-guided visit to the wet, wild west coast tidal shelf (and historically-significant former research site) at Botanical Beach; we recommend departing early (around 8.00 am) to catch low tide for a better view of the wonderful underwater life! Consider bringing a packed lunch to nibble-on while looking at the crashing waves when there, and then have an afternoon drink enjoying the view from the deck of the Port Renfrew Hotel.

Suggested Outing 2, Butchart Gardens (self-organised)
A shorter journey to the resplendently beautiful Butchart Gardens and, if you like, followed by (ahem) a few minutes at the nearby Church and State Winery, in the Saanich Peninsula. About an hour there by public bus from UVic, or 30 minutes by car.

Suggested Outing 3, SaltSpring Island (self-organised; a full day, car/bus + ferry combo)
Why not take a day to explore and celebrate the funky, laid back, Canadian gulf island lifestyle on SaltSpring Island. Ferry departs regularly from the Schwartz Bay ferry terminal, which is about one hour by bus / 30 minutes by car from UVic. You may decide to stay on forever ....

Suggested Outing 4, Paddling Victoria's Inner Harbour (self-organised)
A shorter time, seeing Victoria's beautiful city centre from the waterways that initially inspired its foundation. A great choice if the day is sunny and warm. Canoes, kayaks, and paddle boards are readily rented from Ocean River Adventures and conveniently launched from right behind the store. Very chill.

And more!
Self-organised High Tea at the Empress Hotel, scooter rentals, visit to the Royal BC Museum, darts at Christies Carriage House, a hangry breakfast at a local diner, whale watching, kayaking, brew pub sampling (at Spinnaker's, Swans, Moon Under Water, and beyond!), paddle-boarding, a tour of used bookstores, and more have also been suggested!

9:00 to 4:00
Early Class Meeting: 4. [Foundations] DH For Department Chairs and Deans (David Strong Building C124, Classroom)
Further details are available from instructors in mid May to those registered in the class. Registration materials will be available in the classroom.

3:00 to 5:00
DHSI Registration (Maclaurin Building, Room A100)
After registration, many will wander to Cadboro Bay and the pub at Smuggler's Cove OR the other direction to Shelbourne Plaza and Maude Hunter's Pub OR even into the city for a nice meal.

Monday, 3 June 2019
Your hosts for the week are Alyssa Arbuckle, Ray Siemens, and Jannaya Friggstad Jensen.

7:45 to 8:15
Last-minute Registration (Maclaurin Building, Room A100)
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<tr>
<th>Time</th>
<th>Event</th>
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<tbody>
<tr>
<td>8:30 to 10:00</td>
<td>Welcome, Orientation, and Instructor Overview (MacLaurin A144)</td>
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<tr>
<td></td>
<td>- Welcome to the Territory</td>
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<td>- Welcome to DHSI: Ray Siemens, Alyssa Arbuckle</td>
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<td>- Welcome from UVic: Jonathan Bengtson (University Librarian), Alexandra D'Arcy (Associate Dean Research, Humanities)</td>
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<table>
<thead>
<tr>
<th>Classes in Session (click for details and locations)</th>
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<tbody>
<tr>
<td>1. [Foundations] Digitisation Fundamentals and their Application (Clearihue A103, Lab)</td>
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<tr>
<td>2. [Foundations] Introduction to Computation for Literary Criticism (Clearihue A102, Lab)</td>
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<tr>
<td>3. [Foundations] Making Choices About Your Data (Digital Scholarship Commons, McPherson Library A308, Classroom)</td>
</tr>
<tr>
<td>4. [Foundations] DH For Department Chairs and Deans (David Strong Building C124, Classroom)</td>
</tr>
<tr>
<td>5. [Foundations] Developing a Digital Project (With Omeka) (Clearihue A031, Lab)</td>
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<tr>
<td>8. [Foundations] Fundamentals of Programming/Coding for Human(s)ists (Clearihue A108, Lab)</td>
</tr>
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<td>9. Out-of-the-Box Text Analysis for the Digital Humanities (Human and Social Development A160, Lab)</td>
</tr>
<tr>
<td>10. Sound and Digital Humanities (Cornett A120, Classroom)</td>
</tr>
<tr>
<td>11. Critical Pedagogy and Digital Praxis in the Humanities (Clearihue D132, Classroom)</td>
</tr>
<tr>
<td>12. Digital Humanities for Japanese Culture: Resources and Methods (McPherson Library A003, Classroom)</td>
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<tr>
<td>13. Conceptualising and Creating a Digital Edition (McPherson Library 210, Classroom)</td>
</tr>
<tr>
<td>14. Retro Machines &amp; Media (McPherson Library 129, Classroom)</td>
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<tr>
<td>15. Geographical Information Systems in the Digital Humanities (Clearihue A105, Lab)</td>
</tr>
<tr>
<td>16. Introduction to IIIF: Sharing, Consuming, and Annotating the World’s Images (Cornett A121, Classroom)</td>
</tr>
<tr>
<td>17. Web APIs with Python (Human and Social Development A170, Lab)</td>
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<tr>
<td>18. Ethical Data Visualization: Taming Treacherous Data (Cornett A128, Classroom)</td>
</tr>
<tr>
<td>19. Linked Open Data and the Semantic Web (Cornett A132, Classroom)</td>
</tr>
<tr>
<td>20. Palpability and Wearable Computing (McPherson Library A025, Classroom)</td>
</tr>
<tr>
<td>21. The Frontend: Modern JavaScript &amp; CSS Development (Clearihue A030, Lab)</td>
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<tr>
<td>23. Conceptualising and Creating a Digital Edition (McPherson Library 210, Classroom)</td>
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<tr>
<td>24. Information Security for Digital Researchers (David Strong Building C114, Classroom)</td>
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<tr>
<th>10:15 to Noon</th>
<th>Lunch break / Unconference Coordination Session (MacLaurin A144) (Grab a sandwich and come on down!)</th>
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<tr>
<td></td>
<td>Discussion topics, scheduling, and room assignments from among all DHSI rooms will be handled at this meeting.</td>
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<tr>
<th>1:30 to 4:00</th>
<th>Classes in Session</th>
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<tr>
<td></td>
<td>Institute Lecture: Jacqueline Wernimont (Dartmouth C): &quot;Sex and Numbers: Pleasure, Reproduction, and Digital Biopower&quot; Chair: Anne Cong-Huyen (U Michigan) (MacLaurin A144)</td>
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| 4:10 to 5:00  | Abstract: Drawing from Numbered Lives (MIT 2018), this talk will consider a long history of sex-number entanglement in Anglo-American Cultures. Drawing on historical and contemporary objects and practices, Wernimont will ask "in what ways do theories of biopower, critical gender and critical race studies, and media studies" suggest that we can understand this set of entanglements and their impacts. NB: While relevant, this talk will not include discussions of sexual trauma or violence. It will include frank discussion of sex acts and various ways of translating sexual behavior into numbers. |

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<tr>
<th>5:00 to 6:00</th>
<th>Opening Reception (University Club)</th>
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<td><strong>Tuesday, 4 June 2019</strong></td>
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<tr>
<th>9:00 to Noon</th>
<th>Classes in Session</th>
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<td>Lunch break / Unconference</td>
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<tr>
<th>12:15 to 1:15</th>
<th>&quot;Mystery&quot; Lunches</th>
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<tr>
<td></td>
<td>Lunch break / Unconference</td>
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<td>**Mystery&quot; Lunches</td>
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<tr>
<th>1:30 to 4:00</th>
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<tr>
<td></td>
<td>DHSI Conference and Colloquium Lightning Talk Session 1 (MacLaurin A144)</td>
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Wednesday, 5 June 2019

9:00 to Noon
Classes in Session

12:15 to 1:15
This presentation introduces Manifold Scholarship, a Mellon-funded digital publishing platform developed by the CUNY Graduate Center, The University of Minnesota Press, and Cast Iron Coding. Manifold allows you to create beautiful, dynamic open access projects that can include text, images, video, embedded resources, and social annotation. We will provide an overview of Manifold and demonstrate how faculty, students and staff in the digital humanities can use Manifold to publish open access scholarly works, conduct and participate in peer review, and create custom edited versions of public domain course texts and OER.

1:30 to 4:00
Classes in Session

4:15 to 5:15
DHSI Conference and Colloquium Lightning Talk Session 2 (MacLaurin A144)
Chair: Kim O'Donnell (Simon Fraser U)

- Catherine Ryu (Michigan State U), “Tone Perfect: Developing a Multimodal Audio Database for Mandarin Chinese as an Open Source"
- Jessica Linzel (Brock U), “The Shopkeeper Aristocracy: Mapping Trade Networks in Colonial Niagara”
- Kirsten Painter (U Washington), “From Bogatyr to Bread: Digitization & Online Exhibition of Rare Russian Children’s Books at the U Washington”

6:00 to 7:00
"Half Way There!" [An Informal, Self-Organized Birds of a Feather Get-Together] (Felicitas, Student Union Building)
Bring your DHSI nametag and enjoy your first tipple on us! [A great opportunity for an interest group meet-up ....]

Thursday, 6 June 2019

9:00 to Noon
Classes in Session

12:15 to 1:15
"Mystery" Lunches

1:30 to 4:00
Classes in Session

4:15 to 5:15
DHSI Conference and Colloquium Lightning Talk Session 3 (MacLaurin A144)
Chair: Kim O'Donnell (Simon Fraser U)

- Colleen Kolba (U South Florida), “What Comics can Teach our Students about Multimodal Literacy”
- Trish Baer (ETCL; U Victoria), “Preserving Digital Legacies: Archived Websites and Digital Discoverability”
- Suchismita Dutta (U Miami), “The Importance of Archival Transcription for Genre Building”
- Jeffrey Lawler (California State U, Long Beach), “Twining our way through the Past: Video Game Authoring as History Pedagogy”
Friday, 7 June 2019 [DHSI; ADHO Pedagogy SIG Conference Opening]

9:00 to Noon
Classes in Session

12:15 to 1:15
Lunch Reception / Course E-Exhibits (MacLaurin A100)

1:30 to 1:50
Remarks, A Week in Review (MacLaurin A144)

2:00 to 3:00
Joint Institute Lecture (DHSI and ADHO Pedagogy SIG Conference):
Matt Gold (CUNY Graduate Center and Association for Computers and the Humanities): “Thinking Through DH: Proposals for Digital Humanities Pedagogy”
Chair: Diane Jakacki (Bucknell U) (MacLaurin A144)

Abstract: How do we teach digital humanities, and how should DH be taught? What, indeed, should we teach when we teach DH? This talk will present a proposal for grounding digital humanities pedagogical practice in the research interests of our students and the epistemological foundations of our methods rather than through an approach grounded more central in data and methods.

3:30 to 5:00
Joint Reception: DHSI and ADHO Pedagogy SIG Conference (University Club)
E-Poetry Event (Chris Tanasescu)
Watch this space for details, including how to participate!
DHSI Conference and Colloquium Poster/Demo Session
Pia Russel (U Victoria); Emily Stremel (U Victoria), “British Columbia’s Historical Textbooks Digital Library”
Cody Hennesy (U Minnesota); Rachael Samberg (U California, Berkeley); Stacy Reardon (U California, Berkeley), “Finding the Haystack: Literacies for Accessing and Using Text as Data”
Paula Johanson (ETCL; Independent Scholar), “Proving Seahorses and Juan de Fuca’s Travels in The Curve of Time”
Tara Baillargeon (Marquette U); Elizabeth Wawrzyniak (Marquette U), “FellowsHub: J. R. R. Tolkien Fanzine Portal”
Graham Jensen (U Victoria), “Canadian Modernist Magazines Project”
Caterina Agostini (Rutgers U), “Art at the Time of Syphilis: A First-Person Medical Narrative in Benvenuto Cellini’s Vita”
Lauren Elle DeGaine (ETCL; U Victoria), “Women at the Front: A Digital Exhibit of Victorian Frontispiece Illustrations”
Adam Griggs (Mercer U); Kathryn Wright (Mercer U); Christian Pham (Mercer U); Gail Morton (Mercer U); Stephanie Miranda (Mercer U), “Digitizing Middle Georgia’s History of Slavery”

Saturday, 8 June 2019 [Conference, Colloquium, and Workshop Sessions]

8:00 to 9:00
Conference / Workshop Registration (MacLaurin A100)
The day’s events are included with your DHSI registration. If you’re not registered in DHSI, you’re very welcome to join us by registering here as a Conference / Colloquium / Workshop participant. We’ll have a nametag waiting for you!

Coffee, Tea, &c?
Looking for some morning coffee or tea, or a small nibble? Options and hours of operation for weekend campus catering are available here. Mystic Market usually opens around 10.00.

9:00 to 4:00
DHSI Conference and Colloquium Sessions
ADHO Pedagogy SIG Conference Sessions
Right2Left Workshop Sessions

9:00 to 4:00
All Day DHSI Workshop Session (click for workshop details and free registration for DHSI participants)
55. Introduction to Machine Learning in the Digital Humanities [8-9 June; All day, each day] (David Strong Building C124, Classroom)

9:00 to 9:10
Informal Greetings, Room Set-up (Lobby, outside Hickman 105)

Session 1
DHSI Colloquium and Conference (Hickman 105)
Digital Humanities & Literature, Chair: Kim O'Donnell (Simon Fraser U)
- Youngmin Kim (Dongguk U), “Transdiscursivity in the Convergence of Digital Humanities and World Literature”
- Caroline Winter (U Victoria), “Digitizing Adam Smith's Literary Library”
- Kaitlyn Fralick (U Victoria); Kailey Fukushima (U Victoria); Sarah Karlson (U Victoria), “Victorian Poetry
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<tbody>
<tr>
<td>9:10 to 10:30</td>
<td>ADHO Pedagogy SIG Conference (Hickman 110)</td>
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<td>Chair: Katherine Faull (Bucknell U)</td>
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<td>- Aaron Tucker and Nada Savicevic (Ryerson U), “Write Here, Right Now: An Open Source eTextbook for the Flipped Classroom”</td>
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<td>- Heather McAlpine (U Fraser Valley), “Digital Meters: Using Text Encoding to Teach Literature in the Undergraduate Classroom”</td>
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<td>- Tiina H. Airaksinen (U Helsinki), “Digital Humanities in Cultural Studies: Creating a MOOC course for University Students and A-Level Students”</td>
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<td>Right2Left Workshop (Hickman 116)</td>
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<tr>
<td>10:30 to 10:40</td>
<td>Break</td>
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<td>10:40 to Noon</td>
<td>Session 2</td>
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<td></td>
<td>DHSI Colloquium and Conference (Hickman 105)</td>
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<td>Digital Humanities &amp; Society, Chair: Eleanor Reed (Hastings C)</td>
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<td>- Joel Zapata (Southern Methodist U), “Uncovering the Southern Plains’ Mexican American Civil Rights Movement”</td>
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<td>- Brendan Mackie (U California, Berkeley), “Visualizing Long-Term Cultural Change: An Example From The Birth of Civil Society”</td>
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<tr>
<td>10:40 to Noon</td>
<td>ADHO Pedagogy SIG Conference (Hickman 110)</td>
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<td>Chair: Laura Estill (St Francis Xavier U)</td>
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<td>Jane Jackson (Chinese U of Hong Kong), “Interrogating digital spaces for intercultural meaning-making”</td>
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<td>Ryan Ikeda (UC Berkeley), “Disrupting Digital Literacy: Situating Electronic Literature Among Public Education Initiatives”</td>
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<td>Christopher Church, Katherine Hepworth (U Nevada, Reno), “We’re STEAMed! A call for balancing technical instruction and disciplinary content in the digital humanities”</td>
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<td>Noon to 1:10</td>
<td>Lunch (We recommend Mystic Market on weekends!)</td>
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<td>1:10 to 2:30</td>
<td>Session 3</td>
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<td></td>
<td>DHSI Colloquium and Conference (Hickman 105)</td>
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<td>Digital Humanities &amp; Community, Chair: Claire Carlin (U Victoria)</td>
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<td></td>
<td>- Pia Russel (U Victoria); Emily Stremel (U Victoria), “Mentorship and disability: Supporting disabled employees in digital humanities”</td>
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<td>- Amy Lueck (Santa Clara U), “Virtually Emplacing Indigenous Memory”</td>
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<td>- Md. Shehabul Alam (National U Bangladesh), “Integrating Library Service with Union Information and Service Center: A Joint Initiative towards Digital Bangladesh”</td>
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<td>- Veronica Gomez (Instituto de Humanidades y Ciencias Sociales (HuCSo) - UNL-CONICET), “Latin American E-literature and Location: The Nation Revisited in Electronic Literature Organization (ELO)”</td>
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<tr>
<td>1:10 to 2:30</td>
<td>ADHO Pedagogy SIG Conference (Hickman 110)</td>
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<td>Chair: Chris Tănăsescu (UC Louvain)</td>
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<td>Laura Estill (St Francis Xavier U), “One Assignment, Three Ways: Assessing DH Projects in a Literature Course”</td>
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<td>Shu Wan (U Iowa), “A digital ‘historical gaze’ of Chinese students in Iowa, 1911-1930”</td>
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<td>Francesca Giannetti (Rutgers U, New Brunswick), “So near while apart: Correspondence Editions as Critical Library Pedagogy and Digital Humanities Methodology”</td>
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<td>Right2Left Workshop (Hickman 116)</td>
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<td></td>
<td>- Najla Jarkas (American U Beirut) and David Joseph Wrisley (NYU Abu Dhabi), “RTL Software Localization and Digital Humanities: the Case Study of Translating Voyant Tools into Arabic”</td>
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**Sunday, 9 June 2019 [Workshop Sessions]**

DHSI Registration (MacLaurin Building, Room A100)

8:00 to 5:00

The day’s events are included with your DHSI registration. If you're not registered in DHSI, you're very welcome to join us by registering here as a Conference / Colloquium / Workshop participant. We'll have a nametag waiting for you!

Coffee, Tea, &c?

Looking for some morning coffee or tea, or a small nibble? Options and hours of operation for weekend campus catering are available here. Mystic Market usually opens around 10.00.

9:00 to 4:00

- 55. Introduction to Machine Learning in the Digital Humanities [8-9 June; All day, each day] (David Strong Building C124, Classroom)
- 56. Pedagogy of the Digitally Oppressed: Anti-Colonial DH Methods and Praxis [9 June; All Day] (Hickman 116, Classroom)
- 57. Natural Language Processing and Network Coding Apps for Text & Textual Corpus Analysis in the Humanities [9 June; All Day] (David Strong Building C114, Classroom)

AM Workshop Sessions (click for workshop details and free registration for DHSI participants)

9:00 to Noon

- 59. 3D Visualization for the Humanities [9 June; AM] (Cornett A229, Classroom)
- 60. It’s All Relational: AbTeC’s Indigenous Video Game Workshops as Storytelling Praxis [9 June; AM] (Cornett A121, Classroom)
- 61. Spatial DH: De-Colonizing Cultural Territories Online [9 June; AM] (Clearihue D130, Classroom)
- 63. Creating a CV for Digital Humanities Makers [9 June; AM] (David Strong Building C108, Classroom)

Noon to 1:00

Lunch (We recommend Mystic Market on weekends!)

PM Workshop Sessions (click for workshop details and free registration for DHSI participants)

1:00 to 4:00

- 65. Indigenous Futurities in the Classroom and Beyond [9 June; PM] (Cornett A121, Classroom)
- 66. DHSI Knits: History of Textiles and Technology [9 June; PM] (Fine Arts 109, Classroom)
- 68. Linked Open Datafication for Humanities Scholars [9 June; PM] (McPherson Library A003, Classroom)
- 69. Stylo - WYSIWYM Text Editor for Humanities Scholars [9 June; PM] (McPherson Library A025, Classroom)

After the day, many will wander to Cadboro Bay and the pub at Smuggler’s Cove OR the other direction to Shelbourne Plaza and Maude Hunter’s Pub OR even into the city for a bite to eat.

**Monday, 10 June 2019**
Your hosts for the week are Ray Siemens and Jannaya Friggstad Jensen.

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<td>MacLaurin A144</td>
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<td>Classes in Session (click for details and locations)</td>
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<td>28. [Foundations] Text Encoding Fundamentals and their Application</td>
<td>Digital Scholarship Commons,</td>
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<td>30. [Foundations] Databases for Digital Humanists</td>
<td>McPherson Library 210, Classroom</td>
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<td>33. Digital Storytelling</td>
<td>Clearihue A120, Classroom</td>
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<td>34. Text Mapping as Modelling</td>
<td>Clearihue D131, Classroom</td>
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<td>35. Stylistometry with R: Computer-Assisted Analysis of Literary Texts</td>
<td>Clearihue A102, Lab</td>
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<td>36. Open Access and Open Social Scholarship</td>
<td>Clearihue D130, Classroom</td>
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<td>37. Digital Games as Tools for Scholarly Research, Communication and Pedagogy</td>
<td>Cornett A229, Classroom</td>
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<td>38. Queer Digital Humanities</td>
<td>David Strong Building C114, Classroom</td>
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<td></td>
<td>39. Parsing and Writing XML with Python</td>
<td>Clearihue A108, Lab</td>
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<td>40. Introduction to Electronic Literature in DH: Research and Practice</td>
<td>Cornett A128, Classroom</td>
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<td>41. Surveillance and the Critical Digital Humanities</td>
<td>David Strong Building C108, Classroom</td>
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<td>42. Text Analysis with Python and the Natural Language Toolkit</td>
<td>Clearihue A103, Lab</td>
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<td>43. Creating LAMP Infrastructure for Digital Humanities Projects</td>
<td>Human and Social Development A170, Lab</td>
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<td></td>
<td>44. Processing Humanities Multimedia</td>
<td>Human and Social Development A150, Lab</td>
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<td>46. Digital Humanities Pedagogy: Integration in the Curriculum</td>
<td>Cornett A121, Classroom</td>
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<td>47. Accessibility &amp; Digital Environments</td>
<td>Priestly Law Library 265, Classroom</td>
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<td>48. Agile Project Management</td>
<td>Cornett A132, Classroom/Lab</td>
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<td>49. XPath for Processing XML and Managing Projects</td>
<td>Clearihue A105, Lab</td>
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<td></td>
<td>50. Endings: How to End (and Archive) your Digital Project</td>
<td>Priestly Law Library 192, Classroom</td>
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<td></td>
<td>51. Text Processing - Techniques &amp; Traditions</td>
<td>McPherson Library A025, Classroom</td>
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<td>52. Introduction to Humanities Data Analysis &amp; Visualization in R</td>
<td>Human and Social Development A160, Lab</td>
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<td>53. Introduction to Network Analysis in the Digital Humanities</td>
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<td>12:15 to 1:15</td>
<td>Lunch break / Unconference Coordination Session</td>
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<td>Institute Lecture: Angel David Nieves (San Diego State U): &quot;3D Mapping and Forensic Traces of Testimony: Documenting Apartheid-Era Crimes Through the Digital Humanities&quot;</td>
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Tuesday, 11 June 2019

Abstract: In 1989 the killing of a queer, 14-year-old youth in Winnie Mandela's house named Stompie Seipei (an event that few in South Africa are willing to recall, let alone discuss, in any detail) -- is perhaps one of the most glaring examples where the queer and activist community was suppressed or erased from anti-apartheid/liberation histories. Digital humanities may actually help both reconstruct and recover a history that is still very early in the telling, despite what is commonly believed about the liberation struggle and the contributions of queer activists in the dismantling of apartheid. Perhaps it could explain why a youth such as Seipei was killed -- or at the very least, provide a more complex and messy narrative that permits one to know more how the history of queer anti-apartheid activists was suppressed. This talk outlines a methodology for "messy thinking and writing" in the digital humanities that -- through a queer and feminist intersectional framework -- permits a more complex layering of oral histories and 3D historical reconstructions.
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<tr>
<td>1:30 to 4:00</td>
<td>DHSI Conference and Colloquium Lightning Talk Session 4 <em>(MacLaurin A144)</em> Chair: Lindsey Seatter (U Victoria)</td>
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<td></td>
<td>• Ashley Caranto Morford (U Toronto); Kush Patel (U Michigan); Arun Jacob (McMaster U), “OurDHIs anti-colonial: Questions and challenges in dismantling colonial influences in digital humanities pedagogy”</td>
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<td>• Julia King (U Bergen), “Developing Network Visualizations of Syon Abbey's Books, 1415-1539”</td>
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<td>• Luis Meneses (ETCL; U Victoria), “Identifying Changes in the Political Environment in Ecuador”</td>
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<td>• Alicia Brown (Texas Christian U), “Digital Cartography of the Ancient World”</td>
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<td>• Laura Horak (Carleton U), “Building the Transgender Media Portal”</td>
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<td>• Andrew Boyles Peterson (Michigan State U), “Last Mile Tracking: Implications of Rental Scooter Surveillance”</td>
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<td>4:15 to 5:15</td>
<td>DHSI Conference and Colloquium Lightning Talk Session 5 <em>(MacLaurin A144)</em> Chair: Lindsey Seatter (U Victoria)</td>
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<td>• Calin Murgu (New College of Florida), “Putting local metadata to strategic use: A Dashboard for visualizing 60 years of theses metadata”</td>
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<td>• Jason Lajoie (U Waterloo), “Queer Critical Making and the Logic of Control”</td>
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<td>• John Barber (Washington State U), “Zambezi River Bridge”</td>
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<td>• Kent Emerson (U Wisconsin-Madison), “Digital Mappa and the George Moses Horton Project”</td>
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<td>6:00 to 8:00</td>
<td>DHSI Newcomer's Gathering <em>(Grad House Restaurant, Graduate Student Centre)</em> Come down, buy a meal and a beverage, and make some new friends!</td>
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**Wednesday, 12 June 2019**

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<td>9:00 to Noon</td>
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<td>12:15 to 1:15</td>
<td>Lunch break / Unconference</td>
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<td>“Mystery” Lunches</td>
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| 12:15 to 1:15| Presentation: An Introduction Jupyter Notebooks for Researchers *(MacLaurin A144)*  
This presentation introduces Jupyter Notebooks for researchers, via a partnership between Compute Canada and the Pacific Institute for the Mathematical Sciences (PIMS) including a large number of Canadian institutions. Read more [here](#). Presenting is James Colliander, PIMS Director and team. |
| 1:30 to 4:00 | Classes in Session                                                     |

**Thursday, 13 June 2019**

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<td>“Mystery” Lunches</td>
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<td>[Instructor lunch meeting]</td>
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<td>1:30 to 4:00</td>
<td>Classes in Session</td>
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 Institute Lecture: Karina van Dalen-Oskam (Huygens Institute and U Amsterdam; Alliance of Digital Humanities Organizations): “The Riddle of Literary Quality: Some Answers” Chair: Aaron Mauro (Penn State, Behrend C) *(MacLaurin A144)*

4:10 to 5:00 Abstract: What is literature, and can you measure it? That is the key question of the project The Riddle of Literary Quality. “The Riddle” is a research project of the Huygens Institute for the History of the Netherlands (Amsterdam) in collaboration with the Fryeke Akademy (Leeuwarden) and the Institute for Logic, Language and Computation (University of Amsterdam). The Riddle combines computational analysis of writing style with the results of a large online survey of readers, completed by almost 14,000 participants. In my talk, I will go into...
some of the main results of the project.

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<td>12:15 to 1:15</td>
<td>Lunch Reception / Course E-Exhibits (MacLaurin A100)</td>
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<tr>
<td>1:30 to 2:00</td>
<td>Closing, DHSI in Review (MacLaurin A144)</td>
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Contact info:  
institut@uvic.ca  P: 250-472-5401  F: 250-472-5681
Accessibility and Digital Environments

DHSI 2018
Erin Templeton, Converse College
George H. Williams, University of South Carolina Upstate

Course Description

It might sound obvious to say that not everyone accesses information in the same way, but in practice, we often assume otherwise. People with disabilities of many different kinds--sensory, physical, and cognitive--represent a significant percentage of users for many digital projects. Digital humanists can ensure that they are designing for a wide range of users by taking accessibility into account from the beginning of a project, and existing projects can be adjusted and modified to improve their accessibility.

This course will take a two-fold approach to issues of accessibility and the digital humanities: students will read and discuss key works from disability studies in order to consider various applications for DH; these readings will form a critical framework for students’ hands-on work with tools that enable them to evaluate and create accessible digital resources. Students are encouraged but not required to bring their own projects or project ideas in order to evaluate them for accessibility and to make (or anticipate) changes as appropriate. Knowledge of and experience with web design is not required, but curiosity and a willingness to learn are a necessity.
# Course Schedule Outline

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<th>Day</th>
<th>Morning</th>
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<td>• Course overview</td>
<td>• Social model of disability</td>
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<td>• Introductions</td>
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<td>• Working with audio &amp; video</td>
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<td>• Audio descriptions, captions, transcripts</td>
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<td>• Accessibility audits (built environment)</td>
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Talking Blind: Disability, Access, and the Discursive Turn

Amanda Cachia
University of California, San Diego
E-mail: amanda@amandacachia.com

Keywords:
blind artists, inclusive design, accessible exhibit design, the discursive turn, the Berkeley Art Museum, the Cantor Fitzgerald Gallery

Abstract

The author describes two exhibits: Blind at the Museum at the Berkeley Art Museum in 2005, and What Can a Body Do?, at the Cantor Fitzgerald Gallery at Haverford College in 2012. She argues for inclusive design in the exhibits themselves, as well as what she calls the exhibit’s discursive elements—catalogues, docent tours, symposia, and websites—that not only extend the life of such exhibits but also expand access for attendees and others.

Introduction

"You're standing too close to that painting. You have to stand back to really see it," says a male museum visitor. 1 In her book Sight Unseen Georgina Kleege recounts the story of how a fellow visitor criticized her in this fashion for behaving "inappropriately" during the 1992 Matisse exhibition at New York’s Museum of Modern Art. According to this visitor, in Kleege's words, "there is a right way and a wrong way to see" because "sight provides instantaneous access to reality." 2 Kleege didn't get the chance to tell the visitor that she has macular degeneration, and so needed to stand very close to the paintings in order to get even the most general sense of their overall composition. In many ways Kleege's experience remains emblematic of ongoing problems. The well-established discourse of
museum accessibility often works against its own stated goals and I argue that this must be productively destabilized.

Traditionally, issues of accessibility in a museum are confined to programs for those who are blind, deaf, or use wheelchairs. Generic examples of these programs include touch tours of museum collections for those who are blind (at major museums like the Metropolitan Museum of Art in New York) or tours of exhibitions using an ASL interpreter for the deaf which are popular at museums like the Guggenheim and the Museum of Modern Art also in New York. A museum might also be concerned with ensuring that the museum building is physically accessible for disabled patrons, such as including wheelchair ramps or large font and Braille wall labels.

But this preoccupation with a limited concept of access has ironically obscured the possibility of more generative disability-related content within exhibitions, displays, and other curatorial practices. We might see such moves as the first step towards re-thinking issues of disability and access in an art museum. In other words, I would like to suggest that curators must first express interest in exhibiting critical work about disability and persuade institutions to do so in ways that don't simply reproduce existing biases. Second, curators must take a more critical approach to disability, both conceptually and practically. Often disability is confined to the education or visitor services department of an art museum. The fact that such departments are often quite separate from the curatorial department is itself revealing, in that disability is not widely considered a topic that needs thought, as opposed to treatment. Museums might think of disabled visitors as having so-called medical conditions and requiring physical access, but often they miss the cognitive or cerebral aspects of disabled embodiment.

In particular, I argue that the concept of access should be broadened and extended to exhibition forms that have traditionally been deemed supplementary, such as lectures, symposia, workshops, educational programs, audio guides, and websites. This paper will examine the role of disability—in this case blindness—within the expanded field of discursive art, not only as a practical problem that governs form and access but also an object of representation. Exhibitions that explore themes of disability and normativity redefine viewers' perceptions, and raise new implications for contemporary art exhibition making and discursive programming. The discursive turn has much to offer the disabled subject in its representation in the museum.

We need to rethink some of the key assumptions behind notions of access and accessibility. Instead of merely extending access, institutions need to question how such gestures can in fact perpetuate repressive norms. Often this means asking how their own practices reproduce hierarchies of visibility and recognizability. I'd like to suggest that in pushing the normative regime of disability even further, we
must also move beyond the usual understanding of access and re-think what the phrase, visual culture, means in our society, and how our museums and galleries are arbiters for this culture. What would happen if the museum began to re-think of itself as an institution for sensorial culture rather than purely visual culture? This would indeed be radical, given that much of art history itself would be turned on its head.

In experiencing the world upside down, we'll not gain just a new visual experience, but an entirely new sensorial and conceptual one also, and this is exactly the point. Perhaps it is the museum and artists that can lead the way in the challenge to overturn the discursive regimes that simplify disabled communities into reductive binaries. Disability studies scholar Tobin Siebers speaks to this prospect when he writes that "the disabled body changes the process of representation itself. Blind hands envision the faces of old acquaintances. Deaf eyes listen to public television … Mouths sign autographs … Could [disability studies] change body theory [and contemporary art] as usual?" 3 Imagine encountering a gamut of atypical physical experiences inscribed in a work of art. These experiences might range from blindness to deafness, from dwarfism and challenges with scale to how bodies engage with the built environment as a paraplegic in a wheelchair or as an amputee with a prosthetic leg or arm. Other experiences would cultivate a heightened sense of sound, touch, smell, taste, or body language.

Ultimately, I will suggest that we might even need a different concept than access if we mean to engage disability along more productive terms. In order to do so, I will analyze the ways in which disability and accessibility can be problematized within the museum through the use of discursive formats, relying on two case studies: the conference and website that accompanied the exhibition, *Blind at the Museum*, which took place in 2005 at the Berkeley Art Museum, CA and the website, audio guides and *Blind Field Shuttle* walk by Carmen Papalia, all attached to the exhibition, *What Can a Body Do?* that was hosted by Haverford College, PA in 2012. My discussion analyzes how the notion of access informed both shows, and closes by considering how the exhibitions might serve as a model for efforts to rethink reductive or normative understandings of disability and access.

**The discursive turn and combatting ocularcentrism**

In an essay on curating and the educational turn, Paul O'Neill and Mick Wilson provide an excellent summary of how discussions, talks, education programs etc. have always played a supporting role to the exhibition of contemporary art, but in recent times, the discursive intervention has not only taken on a more central focus, it has *turned* to become the main event. 4 These discursive practices are framed in terms of education, research and knowledge production and they are often produced as platforms separate to established formats of museum education.
The role of the curator has expanded to take on not only the organizational aspects of working with artists, gathering artwork and arranging loans and shipment of work, but it now involves the administration of these discursive mediums.

O'Neill and Wilson also discuss how the rhetorical device of the turn usefully suggests a "logic of development" and a "process of change." 5 We might see the issue of disability as relating to such developments in two ways. On the one hand, exhibitions like Blind at the Museum can be situated within the context of the discursive turn, insofar as they turn away from autonomous exhibition formats. On the other, they also remind us that the discursive turn has largely overlooked the question of disability, and would do well to think hard about the issues that this omission raises. If a turn is by nature about shifting territories, stabilities, and normative positions — its "mere existence...making apparent the need for a more differentiating and discerning perspective" — this would seem perfectly compatible with the objective of creating new discourse around disability itself. 6 If the discursive turn wants to make good on its emancipatory promises, as articulated above, then it needs to turn towards questions of access for the widest possible range of audiences.

The discursive turn bears a larger potential outside the museum as well, insofar as it could help us rethink the disabled subject in terms of the critique of ocularcentrism — the longstanding bias toward vision in Western thought and culture. As historians like Martin Jay and David Levin have shown, such a tendency goes back as far as Plato's notion that ethical universals must be so-called accessible to the ostensible mind's eye, and continues through the Renaissance into modernity. 7 What if the clarity of truth was not beholden to vision or the mind’s eye? As demonstrated by Georgina Kleege's experience at the Museum of Modern Art, many still believe that there really is a right and a wrong way to see, even a true and false way.

Against such tendencies, Georgia Warnke has cited contemporary critics who argue that "ideology is no longer connected to distortions in vision but to distortions in language." 8 For example, scholar Michael Davidson points out how blindness, like other social categories, is constituted within discursive regimes that assign it with specific values. 9 While vision is typically identified with knowledge, blindness is often equated with lack, as in expressions such as "I must have been blind not to see the implications," or "I've lost sight of the goal." Davidson suggests that in order to counter ocularcentrism, more discursive events need to take place so that an alternative regime can be generated. The Blind at the Museum conference, to be discussed below, is a concrete example of what form this alternative regime might take. At a major event such as this, scholars come together that either have direct or indirect experience with blindness and interacting with objects in a museum. They have opportunity to discuss issues of access and how a new
language might be created that is more inclusive and minimizes patronizing expressions (such as the ones discussed above) that many people often take for granted. In other words, many people often don't think about the exclusionary impact of these words towards the blind community.

Events such as the *Blind at the Museum* conference then, heralds great promise for the role that the current trend or move towards discursive practice plays in art museums in relationship to disability rights. Rethinking language around disability and access within the current societal discursive regime as articulated by Davidson in order to combat ocularcentrism goes hand-in-hand with re-thinking curatorial and exhibition practices within the discursive turn in the museum. This will ultimately expand what we might like to think of as "access." 10

**Blind at the Museum**

*Blind at the Museum*, in the Berkeley Art Museum's Theater Gallery, which was curated by curator Beth Dungan and artist Katherine Sherwood, asked how blindness might change our sense of what it means to view a work of art, ultimately prompting viewers to imagine new ways of seeing and knowing. Twelve artists participated in the exhibition, most of them blind, and one of them deaf, among them Sophie Calle, the French neoconceptualist artist; the sculptor Robert Morris; multimedia artists Theresa Hak Kyung Cha and Joseph Grigely; and photographers John Dugdale and Alice Wingwall (*fig. 1*). Rather than thinking about blindness and sight as polar opposites, the artists explored a wide range of optical experiences—peripheral vision, distortion, floaters—along a continuum. The artists emphasized sound, touch, and multisensory expression through a variety of media; they investigated the unreliability of vision and re-thought the activities of viewing within the museum. Some offered a meditation on the limits of the optical; others explored the metaphors and stereotypes of blindness; and a few highlighted the embodied experience of visual impairment.
My analysis will focus on two key aspects of the exhibition: the two-day conference that accompanied the show; and the exhibition’s website, which linked to an interview carried out for local radio.

**Blind at the Museum conference**

On March 11-12, 2005, the *Blind at the Museum* conference brought together scholars, artists, and museum professionals to explore issues surrounding access to visual art. Questions under discussion included: What are the relations between seeing and knowing, or between words and images? To what extent are traditional notions of beauty founded in sight or seeing, and how are these notions being transformed and called into question precisely within that site of beauty, the museum? How do artists with impaired sight represent their visual experience? What role can technology play, as both tool and artistic medium, in the accessible museum of the future? Some of the most compelling answers to these questions are to be found in the paper delivered by Michael Davidson.

Michael Davidson's talk, entitled "Nostalgia for Light: Being Blind at the Museum," focused on the theme of recent exhibits and colloquia exploring blindness and museums: how the blind have a great deal to teach the sighted, "not only about blindness but about seeing and about the assumptions that sighted persons bring to the larger cultural field." Davidson describes in detail how some of the pieces in the BAM exhibition attempt such teaching, in addition to undertaking visual
analysis of a number of other sources pertaining to his topic, ranging from photographs and films to philosophical approaches to curating (Derrida's *Memoirs of the Blind* at the Louvre). For example, Davidson says that the ocularcentric focus of modern art is dramatically contested when we consider the work of blind photographers in the *Blind at the Museum* exhibition such as Alice Wingwall, who re-site the visual through the technological means by which modernist ocularity was created and more. Davidson says:

> In their work the meaning of the photograph is diverted from the developed print to the discursive processes that precede and accompany the clicking of the shutter. In each of these cases, the great theme of modernist defamiliarization is revived to ask for whom is the familiar familiar and by what presumption of access is it made strange? 12

Specifically, in Alice Wingwall's work, *Hand Over Dog, Joseph at the Temple of Dendur* (1995; fig. 2) the artist uses her beloved guide dog named Joseph, her camera, as well as her own distorted eyesight as a layering of lenses to present a unique perspective. It features a zoomed out perspective of the museum room housing the Temple of Dendur, which is situated at the top center, at the Metropolitan Museum of Art in New York. The photographer's hand can be seen in the bottom center of the image as a hazy and ambiguous form pointing in direct alignment towards the center of the temple entrance. Joseph is seated attentively in profile facing this hand. Wingwall is pointing towards the temple as if directing our attention to the theatricality of the events taking place around the platform. Because her hand is the only element not in focus, she seems to be drawing a relationship between her own blindness and Joseph's role as her alternative tool of vision.
Most appropriately, given the context of Davidson's paper, he advocates for the discursive construct evident in the artists' work and within the institutional infrastructure of the museum in concert with my intimation that the discursive turn has much to offer the disabled subject in its representation in the museum. He applauds the artistic framing of optical and ocular character of art not simply to "reinforce the imperative of sight but to resite seeing as a discursive construct, embedded in debates about what it means to live in the modern world." 13 He concludes by again emphasizing how the blind artists in Blind at the Museum provide a new rhetoric to see the image in an ocular-centric world. Davidson's paper does much to support the move away from ocularcentrism and how the discursive turn has an important role in shifting perceptions of the blind subject— what seeing can become and can mean in new contexts, as demonstrated in the photography of both Wingwall.

www.blindatthemuseum.com

Following on from the power of the discursive construct discussed in Davidson's paper, the still-operational Blind at the Museum website also allows us to think through these questions with respect to virtual platforms. A website has the potential to function as a critical form of discursive exhibition as it broadens access to those who can't visit and acts as an archive for future use. It also enables discussion in forums on the subjects emanating from the show so that intelligent conversations can evolve and develop comprehensively. In the Blind at the
Museum website, visitors encounter a fully active, comprehensive site with main subject headings such as "Conference," "Forum," "Artists" and "Links." The "Conference" heading includes links to some of the papers that were given and the "Artists" link provides both image and text for what was seen at the exhibition (fig. 3). Importantly, the website also provides a link to the MP3 of the original audio descriptions for each of the works, keeping true to the theme of the show being accessible to the blind. The website is accessible for the deaf in providing all the sound-based information on the MP3 tracks in written form, so that it becomes multi-sensorial.

![Screen Shot Of Home Page For Blind At The Museum Website](image)

**Figure 3: Screen Shot Of Home Page For Blind At The Museum Website.**

The website also includes a link to a broadcast on the local public radio station KQED, in which the program Forum interviewed two of the artists, John Dugdale and Pedro Hidalgo, along with the curator Beth Dungan and the conference keynote speaker Georgina Kleege. While the interview was mostly informational, a telling moment occurred when the interviewer opened up the conversation to include questions from the listening public. A woman named Esther called in and described her visit to the exhibit with her blind father, commenting on how disappointed she felt that the art in the exhibit ultimately perpetuated the museum as a space that privileges those with vision, given the work was primarily visual. Esther said that apart from Joseph Grigely's audio installation, *You* (2001), there was very little work that her father could enjoy. Despite Davidson's earlier assertion in his paper that blind artists were attempting to resituate seeing as a discursive construct and demonstrate how seeing could be seen differently, the work was still predominantly visual, thus reinforcing the hierarchy of the ocular. The curator, Beth Dungan, seemed awkward and uncomfortable with Esther's criticism, and did not really offer a satisfying reply. Instead she was evasive and changed the subject. Perhaps Dungan realized that the exhibit had its shortcomings in this ostensible sense and didn't care to elaborate on this oversight.
However, Kleege suggested that even though *Blind at the Museum* had offered many typical accessible components to the display — such as ASL interpreters at the conference and for hearing impaired guided tours, as well as audio descriptions at the exhibition and Braille wall labels — what was really important about *Blind at the Museum* was the suggestion that the museum and artistic practice were at a sort of threshold or juncture. Kleege imagined that artists in the future would be inspired by the exhibition to create art that can be experienced by a number of different modalities, such as tactility, verbal or sound elements. While many artists have done precisely this, such as installations that create immersive environments, like the work of Brazilian artist Ernesto Neto, or the Happenings of Allan Kaprow, we shouldn't rule out the possibility that additional innovation that will come from artists with vision impairments or other disabilities, such as the blind artists in *Blind at the Museum*. 17

**What Can a Body Do?**

In this section, I will reflect on how notions of access and the discursive turn (with emphasis on the blind visitor experience) were broadened and deepened as a development of and extension to *Blind at the Museum*, by analyzing the *What Can a Body Do?* exhibition, curated by myself and presented at Cantor Fitzgerald Gallery at Haverford College from October 26 — December 16, 2012 (fig. 4). The exhibition attempted to narrow the question originally posed by French philosopher Gilles Deleuze into: "what can a *disabled* body do?" In my Introduction to the catalogue essay, I write: "Further, this exhibition asks, what does it mean to inscribe a contemporary work of art with experiences of disability? What shapes or forms can these inscriptions take? How, precisely, can perceptions of the disabled body be liberated from binary classifications such as normal versus deviant or ability versus disability that themselves delimit bodies and constrain action? What alternative frameworks can be employed by scholars, curators, and artists in order to determine a new fate for the often stigmatized disabled identity?" 18 Nine contemporary artists participated in the exhibition, including Joseph Grigely, Christine Sun Kim, Park McArthur, Alison O'Daniel, Carmen Papalia, Laura Swanson, Chun-Shan (Sandie) Yi, Corban Walker and Artur Zmijewski. They each demonstrated new possibilities for the disabled body across a range of media by exploring bodily configurations in figurative and abstract forms.
In the foreword to the exhibition catalogue for *What Can A Body Do?*, faculty members at Haverford College Kristin Lindgren and Debora Sherman write of the exhibition's commitment to access: "Access involves more than checking off a list of practical accommodations. It is a way of thinking about the world that challenges us to imagine how another body, another self, experiences it... [in this exhibition] access is treated not as an afterthought but as a creative process intrinsic both to art practice and curatorial practice." 19 Even more than art and curatorial practice though are the various discursive elements of the exhibition that included the catalogue that is accompanied by a CD with audio versions of all the catalogue text, which features the voices of the curator, artists and students from Haverford College. The extensive exhibition website, still active, provides audio links to the catalogue essays and artists' bios as well as audio descriptions of the work written and recorded by the artists and Haverford students. Visitors could also access the descriptions via iPod while engaging with the work in the gallery. In addition, Vancouver-based visually impaired artist Carmen Papalia was awarded a Mellon Tri-College Creative Residency, and led students on a *Blind Field Shuttle* throughout the campus. I will elaborate on the website, audio guides and *Blind Field Shuttle*.

http://exhibits.haverford.edu/whatcanabodydo/ & Audio Guides

The *What Can a Body Do?* website was designed by Haverford College web team
Sebastianna Skalisky and David Moore and is the first exhibition website of its kind for the College in that it is the most comprehensive universally-designed website. Apart from the entire content of the website being available to blind readers via screen reader, the website also includes almost all text and image-based content in the exhibition in audio form. Conversely, any image-based content that incorporates sound is accessible for a deaf visitor through written audio transcripts. Under the heading "Media," visitors will find the audio descriptions of all the art work, and under the other headings, such as "Essay and Bibliography" (fig. 5), or "Artist Biographies," audio transcriptions of this text can be found. Also embedded into this section are the mostly captioned videos of some of the works in the show, including Artur Zmijewski's *Eye for an Eye* (1998), the trailer for Alison O'Daniel's *Night Sky* (2011) and Park McArthur's *It's Sorta Like a Big Hug* (2012). An interview with Christine Sun Kim, artist and Mellon Tri-College Creative Resident, can also be watched here, that documents her sound performance at the opening reception, alongside an essay film entitled *The Rupture, Sometimes* (2012) by PhD Communication student at the University of Pennsylvania, Kevin Gotkin, that features nine artists and scholars discussing the potential of disability to expand and enrich our ways of thinking.

![Figure 5: Screen Shot From The What Can A Body Do? Website, Featuring Audio Transcriptions Of All Text And Image-Based Content In The Exhibition](http://dsq-sds.org/article/view/3758/3281)
Focusing specifically on the audio descriptions, I invited both the artist and the students (facilitated by faculty members) to contribute to the audio and written transcripts. First off, it was important to include the artists in this process as a means to titillate their thinking towards access and how it might form a productive dialogue with their art-making process, now and in the future. In some instances, some of the artists commented that they had never thought about audio description for their work before, and found the process interesting and useful. The gallery’s student staff and exhibition interns, led by Aubree Penney and Michael Rushmore, also wrote and recorded audio descriptions of each piece. Of this experience, Kristin Lindgren says that, "Most students brought to this task a strong interest in visual art but no previous engagement with disability studies. Indeed, some were skeptical that an exhibition focused on disability would be aesthetically and conceptually compelling. Producing an audio description, however, enabled each student to engage intimately with the work of one of the artists and to envision its place in the exhibition." 20 Naturally, then, incorporating the voices of the curator, the artists and the students as part of this audio description exercise really meant that the audio description, and consequently the exhibit website, began to function akin to the nature of a television, where various channels will instantaneously give you access to a multiplicity of styles, techniques, opinions and sensibilities. Similarly, the website and the various audio tracks and written audio transcriptions give the museum visitor to What Can a Body Do? a plethora of means in which to engage with the work, through various perspectives. In some cases, the visitor will have the opportunity to hear up to three different descriptions of the same work. According to Lindgren, "What Can a Body Do? really attempted to bring disability into conversation with multisensory experience, the literary practices of close reading and ekphrasis, and gallery protocols" through these discursive devices I mention. 21

Some of the multi-layered outcomes of the website and audio descriptions include the firm commitment by the gallery to create audio description for every future exhibition. These discursive tools also made an impact in scholarly circles where for instance, Mara Mills, Assistant Professor in the Media, Culture and Communication Department at New York University has expressed her interest at including the exhibition in her syllabus for her upcoming course, entitled Disability, Technology and the Media. She said of the exhibition, "it's one of the best models I can think of for arts inclusion / multimodal spectatorship." 22 However, while every effort was made by the gallery staff and curator to ensure the highest standards of accessibility (following Smithsonian Museum of American History guidelines) most of the work in the exhibition itself could not be touched and was still predominantly visual, thus still excluding audience members with hearing and visual impairments. Echoing the criticism the curators received in the radio interview for Blind at the Museum, a student/intern at the gallery explained her interaction with a mother who
visited the exhibition with her blind son. She had complained that while the show was important for offering inclusivity around differences, there were still problems around its various exclusions to certain types of audiences. So on the one hand, while the gallery (and curator) are being disciplinary towards certain established ADA guidelines of what is considered acceptable and accessible for a wider range of audience members, we are not being able to entirely overcome entrenched bias towards visual culture as the dominant mode of experiencing visual art within the museum/gallery context. My hope is that in my future curatorial endeavors with the rhetoric and discourse of disability, I'm able to push the normative regime of disability even further in tandem with moving beyond access and entirely re-thinking what visual culture means in our society. Such tension supports the argument of my paper, in promoting the possibilities for a new form of access, where the physical limitations in a gallery context can be flipped into more hopeful pathways within the discursive turn.

**Blind Field Shuttle by Carmen Papalia**

Students from Haverford College and two other colleges in the surrounding area, Bryn Mawr, and Swarthmore, had the opportunity to work directly with Carmen Papalia through the Mellon Tri-College Creative Residencies Program. Carmen led various students and faculty members on his *Blind Field Shuttle*, that involved navigating the Haverford College campus using unfamiliar modes of orientation (fig. 6). In Papalia's work, relationships of trust and explorations of the senses unfold as the artist leads walks with members of the public in *Blind Field Shuttle* as part of his experiential social practice. This work is a non-visual walking tour where participants tour urban and rural spaces on foot. Forming a line behind Papalia, participants grab the right shoulder of the person in front of them and shut their eyes for the duration of the walk. Papalia then serves as a tour guide — passing useful information to the person behind him, who then passes it to the person behind him/her and so forth. The trip culminates in a group discussion about the experience. As a result of visual deprivation, participants are made more aware of alternative sensory perceptions such as smell, sound, and touch — so as to consider how non-visual input may serve as a productive means of experiencing place.

Kristin Lindgren reports on her experiences of Papalia's work that included students from one of her classes:

> Eyes closed, one hand on the shoulder of the person in front of us and the other grasping the air for tactile clues, we moved as one winding organism, passing information down the line through touch and voice. Occasionally the organism broke apart, hand slipping off of shoulder, a
disorienting, generative rupture. The texture of the ground beneath us—grass, gravel, pavement, cobblestone—became a source of information and orientation. The warmth of the early December sun, the sudden chill as the sun was blocked by a wall or a building, the flicker of light and dark, noticeable even with eyes closed, helped us to locate ourselves in space. The whirring of heating condensers signaled that we were near a building. Gnarly tree limbs, rough stone faces on a sculpture, the predictable geometry of a chainlink fence: all provided clues in this new landscape. We were still inexperienced in navigating by these compass points, however, so most of us had no idea where in the world we were. 23

Figure 6: Carmen Papalia On Leading His Blind Field Shuttle On The Haverford College Campus, December, 2012.

This testimony gives proof to how discursive practices, such as the social practice of Papalia's walk, can really be used as a tool for widening a visitor's (or in this case a student's) engagement with work that posits themes of disability. Papalia's navigation of the walk as someone who is blind opened new pathways for using the senses that we often taken for granted, such as smell, touch and sound, given his instructions to close one's eyes during the walk and so removing access to the visual. The students were able to grasp new ways of orienting themselves in a familiar environment that became dynamically unfamiliar through the walk. This moment of disorientation and reorientation, emphasized by multi-sensory modes of being, hand in hand with access to multi-channel audio description, really gave the exhibition an edge. These discursive components add much value, longevity and permanency to not only the images in the exhibition, and the textual analysis around it, but also to the thinking, interacting with and destabilizing of access itself.
The Future of Museums & Access

In conclusion, while the *Blind at the Museum* and *What Can a Body Do?* exhibitions served and still effectively serve to raise issues around the possibilities and limitations of access, there is still more work to be done. More elaborate and accessible discursive programs need to be introduced across a broader range of museums and galleries in order for issues concerning disability to find a permanent place in its rooms and in the minds of those who work in them. For example, as technology evolves, audio description and interactive touch-screens in museums are becoming more complex, as visitors deal with interfaces beyond a painting, sculpture or even video. How can text, Braille and other forms of signage contribute to an intertextual experience of an exhibit? Can new modes of access become part of the discourse that an exhibit generates or into which it intervenes? These questions will serve as important paradigms for building museums and planning exhibitions in the decades ahead.

The future of museums depends on their creating a site for meaningful, activist, discursive and intellectual exchanges between the widest possible range of people in order to account for a greater spectrum of human physical, perceptual, cognitive and sensorial experience. Disabled communities can no longer be segregated to special collections or special, adjunct programming. The contemporary art world and beyond can begin to shift negative perceptions and meanings of the disabled body in order to make room for its more nuanced, complex representation across diverse artistic fields. *Blind at the Museum* and *What Can a Body Do?* stand as the beginning of possible alternative framework that can be employed by scholars, curators and artists in order to determine a new fate for the disabled figure in contemporary art and in life. In other words, more than just offering a conventional exhibition that explores the experience of blindness or other types of impairments, the new discursive format can open the door for a huge variety of programming regarding complex embodiment. Conferences, websites, audio guides and blind walks are just the start.

Further, if access is no longer relegated to the education or visitor services departments of an art museum, and spreads not only through the curatorial department but through every department, wall, door and window of an art museum, what would that mean for the art museum? Perhaps access would no longer be an add-on to a museum budget, or as an after-thought for a curator when installing an exhibit without large-print labels. Perhaps programming material that is accessible will no longer be considered unattractive, but can be treated with more aesthetic potential, care, sensitivity and intelligence. It might be embedded into all exhibition planning in the future as a matter of course, rather than as a last-minute addition. Access can be approached as a tool that will widen perspectives and thinking around practices that are in need of reinvention and revision. Ultimately, if
access is to be made radical and controversial, as these scholars have called for, the very concept of access also needs to be re-visited in order to develop new attitudes, perceptions, and language that counter its stigmatized status.

Given that disability's marginalized position is generated by a mainstream societal discursive regime, the museum's discursive turn offers an important solution to combating and shifting disability's loaded language and thinking. Discursive practices must initiate much more fluid and organic conversations about how art moves us and why it matters, incorporating multiple sensorial perceptions where the ocular and the discursive can work cohesively. Talking in this way will strengthen and make more complex the point of the discursive turn. Not only should the voice of disability become a participant in such conversations, it needs to be a vital one, instead of marked absences, awkward silences and skewed representations surrounding disability.

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Amanda Cachia is an independent curator from Sydney, Australia and is currently completing her PhD in Art History, Theory & Criticism at the University of California, San Diego. Her dissertation will focus on the intersection of disability and contemporary art. She held the position Director/Curator of the Dunlop Art Gallery in Regina, Saskatchewan, Canada from 2007-2010, and has curated approximately 30 exhibitions over the last ten years in London, New York, Oakland, and various cities across Australia and Canada.

Endnotes

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2. Ibid., 96.
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6. Ibid.

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8. Ibid.

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10. However, I also want to be quick to point out that there need not be an opposition between the ocular and the discursive. David Levin has said that Georgia Warnke develops the idea that "the cultivation of perception and sensibility exemplified by an 'aesthetic education' could multiply our perspectives, expand our horizons and deepen our moral vision, contributing significantly to the discursive formation of those fusions." In other words, while the anti-ocularcentric potential of the discursive turn has an important combative role in support of the disabled position, the possibilities retained within other modes of sensorial perception, not excluding vision, must ideally be intertwined with it in a museum for a more powerful and well-rounded discursive form. After all, it is also in the material forms of representation that identities become sedimented, so perhaps it is worth thinking about the discursive construct more scrupulously within and without these boundaries in order to break down binaries (like "normal" versus "pathological"). Levin, David Michael. "Introduction." Modernity and the Hegemony of Vision. Edited


12. Ibid.

13. Ibid., 166.


15. Despite this, it is not clear to me if the website is easily navigable for a blind person so that they can locate the MP3 tracks.


17. Despite these promising implications, curators and artists remain creatures of habit and are still working with material and with artists that for the most part excludes any discourse or framing around disability. While there are certainly prominent "mainstream" artists that have disabilities, such as Chuck Close and Ryan Gander, both of these artists remain silent about their disabled experiences. In other words, their disabled experiences are rarely mentioned or discussed in the context of their art practices, by both the artists themselves and the critics who write about their work. While this is a personal choice by the artist and is to be respected, Close's work particularly has a very clear connection to his disability (prosopagnosia - face recognition deficit) so it is unusual that this connection between his paintings and his diagnosis isn't mentioned more frequently and with comfort. Further, while
there are institutions such as Creative Growth in Oakland and Creativity Explored in San Francisco that work with mentally and intellectually disabled communities, these institutions remain arguably ghettoized and for the most part remain separated from mainstream art discourse and exhibition venues. In 2011, British artist Aaron Williamson said, "In the mainstream, the stakes for critical appreciation are high and artists expect a rigorous consideration of their efforts … criticism, rather than celebration is the bedrock of mainstream art and, in many ways, forces artists to take risks and to oppose cultural complacency. [But] with disability art today, mainstream art critics may simply be unprepared to comment negatively on artists who they consider to be socially disadvantaged, or, even worse, deserving of pity. The critical silence towards disability art might, therefore, be considered to operate from both within and without." If the majority of mainstream critics believe this is their only recourse in writing and talking about disability, the language and attitudes surrounding the work need to be reformulated. Aaron Williamson, "In the Ghetto? A Polemic in Place of an Editorial" in Parallel Lines Journal, In the Ghetto, ed. Aaron Williamson, 2011, 5 Mar 2012
http://www.parallelinesjournal.com/

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21. Ibid., 8.
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22. Mara Mills email message to author, December 26, 2012
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Disability
Rachel Adams, Benjamin Reiss, and David Serlin

In the 2009 documentary film Monica and David, Monica, a woman with Down syndrome, is asked to define the word “handicap.” She responds, “When someone is in a wheelchair,” adding that the term may also apply to people who cannot hear or walk. “It's a sickness,” she concludes. When presented with the same question, her husband, David (who also has Down syndrome), says he does not have a handicap. Asked if he has Down syndrome, he answers, “Sometimes.” In this brief exchange, Monica and David exemplify the challenges of defining disability as a coherent condition or category of identity. Yet David’s assertion that “sometimes” he has Down syndrome suggests that he understands a central tenet of disability studies: that disability is produced as much by environmental and social factors as it is by bodily conditions. While Down syndrome may prevent David from driving a car or managing his own finances, for example, his genetic condition is not a defining feature of his home and family life.

These insights by Monica and David remind us that the meanings we attribute to disability are shifting, elusive, and sometimes contradictory. Disability encompasses a broad range of bodily, cognitive, and sensory differences and capacities. It is more fluid than most other forms of identity in that it can potentially happen to anyone at any time, giving rise to the insiders’ acronym for the nondisabled, TAB (for temporarily able-bodied). As David suggests, disability can be situational;
it can also wax and wane within any particular body. Disability brings together people who may not agree on a common definition or on how the category applies to themselves and others. Yet those same definitional challenges are precisely what make disability such a rich concept for scholars, activists, and artists. Because “disability” is this volume’s organizing term, it is important that we explore how it became attached to such diverse experiences and meanings, and produced such a wide range of social, political, and personal consequences.

The word “disability” has been part of the English language since at least the sixteenth century. According to the Oxford English Dictionary, the current sense of “a physical or mental condition that limits a person’s movements, senses, or activities [or] the fact or state of having such a condition” was first used in 1547. But the term also covered a broad range of “inabilities” or “incapacities” that included inability to pay a debt or to worship God with a full heart, while some conditions currently treated as disabilities were not regarded as such. Some—like autism or chronic fatigue syndrome—had not been discovered (or invented, depending on one’s perspective); others, like chronic pain or various disfigurements, were simply considered inevitable facts of life.

For much of its historical run, “disability” has brushed up against words like “infirmity” and “affliction,” both of which held connotations usually ascribed to disability today, as well as phenomena like poverty, ugliness, weakness, sickness, or simply subjection to an unfortunate experience (Baynton 2011). Disability also shared ground with the early modern term “monstrosity” and the classical-era term “deformity”—the former having supernatural overtones and the latter representing a failing away from godliness into a particular kind of moral and physical ugliness (see Helen Deutsch’s entry on “Deformity” in this volume). By contrast, the word “cripple,” which derives from the idea of one who creeps, represented an attempt to characterize various physical impairments that impeded mobility. Similarly, “invalid” was an early medical shading of a broad range of infirmities resulting from injury or illness.

It was in the nineteenth century that disability became firmly linked, through the discourses of statistics, medicine, and law, to words such as “deviance,” “abnormality,” and “disorder.” Lennard Davis (1995) argues that during this time the modern conception of disability emerged as a by-product of the concept of normalcy. Earlier human bodies were measured against idealized and often spiritual standards of perfection and ability that no earthly individual could match. With the development of statistical science and the bell curve, human ability came to be understood as a continuum, with disability and disabled people occupying the extreme and inferior end of the spectrum.

During the late nineteenth and early twentieth centuries, protecting the normal from the abnormal became a broad medical and social imperative undertaken in the name of progress. Vocabulary terms associated with disability reflect these shifts. Just as the eugenics movement attempted to rid the world of many disabilities through sterilization and segregation, disability terminology emphasized backwardness, atavism, and interruption: people with disabilities were said to be “slow,” “retarded,” or in a state of “arrested development.” Hereditary explanations stressed the degenerate threat disability posed to the white race. People with intellectual disabilities (classified under the broad term “feebleminded”), in particular, were said both to exemplify the debilitating effects of modernity and to represent instances of exceptional regression (Valente 2013). At a time when the industrialized world prized speed and efficiency, the temporal lag associated with disability amounted to being “handicapped in the race for life.”
Many of these terms remain as residual signifiers for disability in contemporary society. As Douglas Baynton argues, by the early twentieth century, one had only to say “handicapped” to indicate disability, while in France the primary translation for disabled remains handicapé (Baynton 2011; Stiker 1999). On a global scale, however, “disability” has now become the preferred term. It began its ascent in the United States during the Civil War, when “disability” measured one’s capacity to serve in the armed forces or one’s right to compensation from injuries incurred in military service. As the welfare state developed in the twentieth century, the term came to incorporate chronic illnesses and conditions of impairment that impeded one’s ability to work (Linker 2013, 503–505). But paradoxically, as “disability” has muscled out older competitors, it has also grown more ambiguous and unstable in its meanings. This is because as the term has expanded to include new categories of experience and perception as well as phenomena once labeled by other terms, those meanings have simultaneously been challenged by scholars and activists (Kudlick 2003).

Although now someone with a visual impairment may recognize “disability” as the structure that links her to a wheelchair user or a person labeled as autistic, it thickens our sense of such alliances to study how people in earlier times understood—or, alternately, did not understand—their connections to each other. The historical record provides glimmers of cross-disability awareness but also of obstacles to finding common ground or shared values. A 1641 law in colonial Massachusetts, for instance, provided exemptions from public service for settlers who could claim “greatness of age, defect in mind, failing of senses, or impotency of Limbs” (Nielsen 2012, 21). Such unfitness for work ultimately led to organized systems of charity—and, by the nineteenth century, institutional quarantining and attempts at medical “correction” for people with a wide range of impairments.

Paradoxically, such quarantining sometimes promoted social cohesiveness within and even across different types of institutions. In nineteenth-century asylums and other specialized “total institutions,” blind and deaf people, people defined as mentally ill or deficient, and other disabled people often came into contact with large numbers of other members of their group for the first time. Thomas Gallaudet, the cofounder of the American Asylum for the Deaf, characterized the typical student at his school as “among his countrymen, for [they] use his native language.” Occasionally, this fellow feeling extended across categories of impairment. A patient-run literary journal published in a public nineteenth-century asylum for the insane, for example, records a visit by students from a school for the blind; another article in the journal speculates on the increased susceptibility of blind and deaf people to mental illness, showing an appreciation for the shared social vulnerability of all of these groups. Such institutional dispatches suggest a flickering awareness of institutionalization as the grounds for identifying a common set of experiences. Such connections were the grounds for political activism. Early American deaf-rights activist John Jacobus Flournoy, for instance, was one of the first to use the word “disability” in relation to deafness among a range of physical and mental differences when he wrote in 1855: “The old cry about the incapacity of men’s minds from physical disabilities, I think it were time, now in this intelligent age, to explode!” (Krentz 2007, 155).

As with segregation, colonialism, and apartheid, shared experiences of social separation and political disenfranchisement ultimately galvanized many people with disabilities and their supporters toward a common purpose. However, before the 1960s, politicized protests
against the oppressive features of institutionalization and discrimination were scattered and generally did not speak for broad categories of disability. For instance, in the United States during the 1930s, when the League of the Physically Handicapped decried the Works Progress Administration's policy of failing to employ people with physical disabilities, it did not include people with mental or developmental disabilities in its list of those who had suffered discrimination (Nielsen 2012, 132). And when the league approached leaders of the Deaf community to make common cause, they were rebuffed on the grounds that the Deaf were not disabled or unemployed (Burch 2002, 126). (Today, the Deaf community tends to regard deafness as a culture; whether it is also a “disability” is a contentious point.)

In this volume, the entry by Denise Nempweu on “Activity” tells how isolated protest movements cohered into the broad disability rights movement, which, by the late 1960s, was agitating for inclusion and access on many fronts, and which strengthened the sense of disability as a positive identity category rather than a stigmatized designation of inferiority or lack. Political organizing within the incipient disability rights movements of the 1960s and 1970s attempted to shift “disability” from an exclusively medical concern to a broadly social one, an effort that eventually won important battles. Major legislation and policy initiatives in the United States and worldwide reflect this shift, with profound implications for governments, businesses, and citizens—disabled and non-disabled alike. For example, the first two definitional prongs of the Americans with Disabilities Act (ADA; 1990; amended 2008) locate the meanings of disability within the body: “A physical or mental impairment that substantially limits one or more major life activities of such individual; a record of such an impairment.” These definitions are surprisingly similar to the long-standing dictionary definition of “a physical or mental condition that limits a person's movements, senses, or activities” or “the fact or state of having such a condition.” However, the third definitional prong of the ADA, which adds “being regarded as having such an impairment,” put perceptions and social attitudes squarely in focus (Emens 2013). The UN Convention on the Rights of Persons with Disabilities (2008) goes even further in defining disability's social dimensions. Disability, according to the convention, “results from the interaction between persons with impairments and attitudes and environmental barriers that hinders their full and effective participation in society on an equal basis with others.” Perhaps most expansively, the vision of accessibility propounded by Ron Mace and the universal design movement since the late 1980s was born out of a belief that particular physical or sensory differences only become disabling when the environment creates barriers to access. These recent developments all emphasize meanings of “disability” that are external to the body, encompassing systems of social organization, institutional practices, and environmental structures. Disability studies scholars refer to this approach as the “social model,” which challenges the medical understanding of disability as located exclusively in an individual body, requiring treatment, correction, or cure (Shakespeare 2006b).

Although the social model predominates, in much recent scholarship, disability refers to a subjective state, the condition not only of identifying as disabled but also of perceiving the world through a particular kind of lens. As Sharon Snyder and David Mitchell (2006) note, narratives of disability history that focus on legislative triumphs, social inclusion, and the breakdown of stigma risk losing sight of the distinct, individual, and subjective experiences that make up disability's history. Disability subjectivity, they argue, does not come either from bodily impairment or from the socially
constructed world outside; instead, they argue for a “cultural model” of disability that explores the disabled body’s interface with the environments in which the body is situated. While it may be true that to lose one’s leg, or to be visually impaired, or to have a chronic illness, the twenty-first-century United States is incommensurate with what those impairments or conditions meant in eighteenth-century Europe or ancient Egypt, disability itself always begins and ends with the subjective impressions of the individual who experiences the world through her body. Despite the lingering popular sense that disability represents deficiency or defect of body or mind, the cultural (or, alternately, biocultural) model of disability as a relationship between body and society is gaining increasing legitimacy in law, policy, and the social environment worldwide.

Part of the transformation of “disability” from stigma and object of medical correction to source of knowledge reflects this new attention to inwardness. Disability becomes a mode of situating one’s understanding of self rather than a marker of isolation, what the late disability historian Paul Longmore (2003, 246) called the “social death” sometimes experienced by people with disabilities. Whereas too often the experience of disability entered the historical record only through the words of those who tried to cure, tame, correct, or end it, disability studies scholarship is now focused on building—as well as excavating from the past—a rich and self-conscious record of the perspectives of disabled people themselves. Memoirs, films, journals, performance spaces, and online social networks promoting what is sometimes defiantly referred to as “crip” culture are all regular features of this new landscape of disability; meanwhile, academic conferences, journals, and degree programs have made disability studies a prominent force on many campuses. Such new developments parallel feminist epistemologies—including what used to be called “women’s way of knowing”—as well as postcolonial and critical race theorists’ critiques of hybrid identities and psychic displacements, and queer theory’s blending of social analysis and subjective expression. Each of these political-cultural-academic movements began with a first wave of identifying and resisting oppressive structures, which was followed by attempts to recover a cultural heritage as a backdrop for individual and collective expression in the present.

Intersectional modes of analysis point to the common interests, struggles, and pleasures these movements can promote. Deaf artist and activist Joseph Grigely (2005) works in this vein when he speaks of a “proactive” disability studies: one that is focused not just on attaining rights and accommodations for people with disabilities but also on developing dynamic, interactive, and collaborative projects that challenge the tyranny of “normal” in all areas of social and political life. To this end, the subjective experiences of people on the wrong side of “normal” can be used, in the words of the Dutch educational philosopher Pieter Verstraten, “to expose the self to the other,” rather than merely to “reduce the other to the self” (2007, 63). Vivid examples of this work of mutual “belonging” rather than objectifying “staring” can be found in Rosemarie Garland-Thomson’s (2009) discussion of disabled artists who turn the unwanted attention of others into the subject of their own work.

While some scholars and activists claim or assume that disability is a category that cuts across cultures, others have noted that disability studies rests on assumptions derived from and specific to the Western world, and that its histories and archives continue to have a strongly Euro-American orientation. Disability scholarship and activism in Europe and North America have long sought independence for people with disabilities, a demand that arose in reaction against being
treated as passive, voiceless, and dependent. In the 1970s, the independent living movement was born in Berkeley, California, and quickly took hold throughout the United States and Europe, with the goal of achieving greater autonomy and inclusion by providing people with disabilities with personal assistants and adaptive technology. However, as Eva Kittay (1999) has noted, largely overlooked in the quest for autonomy is the fact that the independence of disabled consumers is contingent on the labor of personal assistants who are almost always immigrant women, sometimes with unclaimed disabilities of their own. “Independence” and “autonomy” are concepts that are deeply embedded in the Western philosophical and political traditions of liberalism and are not universally desirable goals in all cultural contexts (Nussbaum 2006).

The global ambitions of the universal design movement, which upholds the worthy goal of a barrier-free environment, also sometimes founder on the realities of global inequalities: this approach relies on architectural innovations and the use of technologies that may be too costly to be realistically implemented in many areas of the developing world. Moreover, the technologies that enable people with disabilities in the Western world are often manufactured by workers who cannot afford to use them, and who may themselves be disabled. For example, the smartphones and computer tablets that give students with disabilities in the West tools to learn alongside their nondisabled peers and that supply increasingly ingenious apps to allow blind, deaf, and mobility-impaired people to navigate their environments are likely to have been assembled under harsh and potentially disabling conditions in China. Michael Davidson argues that a more global disability studies must refine the concept of universal design to account for variations in resources and cultural values. In this way, disability studies can prompt us to consider how “many aspects of modernity are founded upon unequal valuation of some bodies over others” (Davidson 2008, 171).

Some scholars have offered the concept of “debility” as a supplement to disability, which they see as entangled with Western ideas about individuality, autonomy, and bodily integrity. The dictionary meaning of “debility” overlaps with “disability”: it is the “condition of being weak or feeble,” in either physical or mental capacity. But a secondary meaning—“political, social, or pecuniary weakness”—makes it useful for scholars attuned to populations made vulnerable by political and economic forces globally. For instance, Jashir Puar uses the term to signify an “aggregate” condition in which some bodies worldwide are made to pay for “progress” that others enjoy. “Debility,” she writes, “is profitable for capitalism” (2012, 153). Like Puar, Julie Livingston uses the term “debility” to supplement the concept of disability and its attendant assumptions about a liberal, rights-based understanding of personhood. In Botswana, for instance, AIDS activists have sought the equal participation of persons with disabilities in the public sphere, but Livingston shows how the liberal model of personhood at the heart of their activism is undercut by Botswana’s notions of moral sensibility, which include both an ethos of communal care and an intense aversion to certain types of bodily disfigurement or unruliness. While Euro-American versions of disability rights focus on “enabling persons to participate equally in rational-critical discourse in the public sphere regardless of the vagaries of any individual’s particular bodily state,” such goals collide with cultural systems that shape the circulation of bodies, emotions, and values differently (Livingston 2008, 289).

Obscuring these different constructions of disability and debility, human rights activists and policy makers around the world tend to idealize Western—and often
specifically American—attitudes and practices concerning disability, while labeling those in the “developing” world as “backward” (Kim 2011). Certainly, the United States has done much to bring forward disability rights as a concept to be emulated elsewhere, but the social situation of people with disabilities is by no means uniformly secure. In the United States, health and physical beauty are marketed as commodities more aggressively than in any other culture. The rhetoric of the beauty, fashion, diet, and fitness industries, illustrated by the allure of cosmetic surgery, equates failing from these ideals with moral failure. So, too, in times of economic scarcity in the United States and other market-driven societies, people with disabilities and their supporters are often seen as a burden on public resources. Programs for education, transportation, and public services for people with disabilities are often the first to be cut by budget-conscious politicians. A backlash against civil rights accomplishments blames disability legislation for, in effect, “crippling” the economy. And many who claim accommodation or compensation under the law are viewed with suspicion of malingering—especially those whose disabilities are not immediately visible. The mapping of the human genome has also had ambivalent consequences for disability. Research that promises to cure or prevent disease and to bring new understanding of human character and potential often does little more than succeed in producing a new class of people whose genes tell us that they may someday become disabled by diseases like breast cancer, cystic fibrosis, or Huntington’s disease—thereby creating a pervasive anxiety about disability as a future risk. So, too, new technologies for prenatal testing seek to eliminate some types of genetic disability through the termination of fetuses. Such tests further stigmatize genetic conditions by making them seem like preventable mistakes. And in the eyes of many disability rights advocates, they augur a new era of eugenics, in which disability is eradicated before it comes into the world.

Our understanding of disability is enhanced by awareness of the term’s complex genealogy, as well as by the enormously varied experiences of embodiment across cultures and socioeconomic locations. If history is any indication, the meanings of disability and the words we use to describe its various manifestations will no doubt undergo profound shifts as a category of identity; a social, legal, and medical designation; and an embodied condition. As a way of perceiving the world, it will help us to understand—and to influence—the way that future takes shape.
The noun form of the word “access”—meaning “the power, opportunity, permission, or right to come near or into contact with someone or something”—first appears in published texts in English as early as the 1300s. It has been used to characterize the relationship between the disabled body and the physical environment since the middle to late twentieth century. More specifically, it refers to efforts—most prominent in the United States—to reform architecture and technology to address diverse human abilities.

In its most literal form, “access” describes the ability to enter into, move about within, and operate the facilities of a site, and it is associated with architectural features and technologies, including wheelchair ramps, widened toilet stalls, lever-shaped door-handles, Braille lettering, and closed-caption video. Figuratively, however, it can suggest a much broader set of meanings linked to a more inclusive society with greater opportunities for social and political participation. Given these technical and metaphorical interpretations, the push for access has yielded some contradictory results. While improved public infrastructure has been a major success of the disability rights movement of the last half-century, technical change does not necessarily translate to the deeper goals of openness, inclusion, or opportunity. In fact, in some cases technical compliance can replace and even obscure the movement’s broader goals of social, political, and economic integration.
Though “access” and its corresponding adjective “accessible” have distinct meanings in relation to disability rights, both terms convey broader arguments about rights and opportunities. Discussions of social and economic justice often refer to an ideal of access: “access to jobs,” “access to housing,” “access to health care,” and so forth. These expressions convey the importance of recognizing external barriers that prevent disenfranchised persons from gaining access to resources. They exist in contrast to debates over inherent or biological inequality, such as sexist or racist arguments that view women or nonwhites as physically and mentally incapable of equality. A focus on access is a shift away from attempts to fix or cure disability on an individual level, and toward an emphasis on social or legal interventions. Access implies social potential not dependent on correcting the disabled body, but instead made possible through institutional and material change.

In the history of disability rights, the concept of access linked disabled people’s material struggles with other civil rights causes. In debates over the U.S. Civil Rights Act of 1964, President Lyndon B. Johnson declared that “all members of the public should have equal access to facilities open to the public” (tenBroek 1966, 849). The disability rights movement emerging in the same period interpreted this language for its own cause. The legal scholar Jacobus tenBroek wrote in 1966 of a “right to be in the world,” rooting the rights of the disabled in core principles of citizenship. Barriers to free mobility, tenBroek wrote, violated a “basic sense of the right not to be unjustly or causelessly confined,” a right he traced to the Magna Carta and major Western constitutions (848). Legal advocates Marcia and Robert Burgdorf similarly linked “access” to core American rights. “Free access to public buildings and transportation systems,” they wrote in 1975, was a key component of disabled persons’ rights to equal protection under the law (Burgdorf and Burgdorf 1975, 855–866).

Access holds the curious distinction of being seemingly easy to define and comprehend but difficult to create. As early as the 1960s, for instance, building codes in the United States defined access in clear, specific terms. Local regulations mandated such features as wheelchair ramps of less than 1:12-foot rise; doorways of at least thirty-two inches in width; and grab bars in toilets (American National Standard Specifications 1961). The difference between the ideal and the real, however, often proved significant. The first national law that addressed access, the Architectural Barriers Act of 1968, required that architects design or renovate buildings purchased and leased by the U.S. government “to insure whenever possible that physically handicapped persons will have ready access to, and use of, such buildings.” The phrase “ready access” suggested the possibility of a site’s availability to any given disabled person. In reality, the components of legal compliance were often piecemeal and failed to add up to overall improvements in usability. Early regulations applied to specific buildings, so a courthouse or hospital might be technically accessible, but without sidewalks, curb cuts, or usable public transportation, actually getting to and into the building remained difficult for many. Even in the present day, compliance with the law can be fleeting when building tenants or managers leave elevators or ramps locked, allow accessible features to fall into disrepair, or obstruct spaces and passageways.

The demand for improved access follows the logic of the “social model” of disability, which shifts attention from the impaired body to the surrounding environment. Early advocates used the term in a very literal way, evaluating sites and products in terms of their function for people with physical and sensory limitations. The
category “accessible” delineated the reachable from the unreachable; ramped entrances and clear pathways from stairs and cramped passages. In technical guides and government policies, “accessibility” and “usability” often appeared with the related term “barrier-free.” If “access” was the outcome of diligent planning, “barriers” were the existing conditions, often characterized as needless or “thoughtless” obstacles. These analyses of “access” and “barriers” pointed to problems and solutions in the physical environment, not fixes for the individual body. Disability activists likewise point to architecture as an external barrier that prevents people otherwise willing and able to participate in society from doing so. In a 1990 transportation protest, a black disabled man taped a sign to the back of his wheelchair stating, “I can’t even get to the back of the bus,” linking lack of physical access to the history of racial segregation (“Civil Rights, Disability Rights”). In a number of protest actions—including the occasion of a 2004 Supreme Court ruling on disability discrimination lawsuits—wheelchair users left their chairs at the bases of grand staircases to government buildings and crawled up the steps (Shapiro 2004). These actions perform the argument that it is not physical inability but the absence of architectural accommodation that keeps people with disabilities excluded from the public spaces identified with civic life.

While the most extensive requirements for access mandated by law originated in the United States, access has proven a powerful concept in disability rights discourse on a global level. Architectural access is now included in civil rights legislation in Australia, the United Kingdom, South Africa, and the province of Ontario, Canada. The UN Convention on the Rights of Persons with Disabilities, ratified in 2008, requires signatory nations to provide “reasonable accommodation,” including technological and architectural access. Still, the American model of building ramps, expanding doorways, and installing technologies to improve access does not translate immediately to global contexts, particularly for areas without extensive paved roads or centralized transit infrastructure. Furthermore, in a human rights framework accessibility can describe not only the concerns of those considered “disabled” but also those of women, children, migrants, and others who experience constraints of movement and expression (Meekosha and Dowse 1998). Attention to access, therefore, proves most powerful when interpreted broadly, bringing notice to mobility and communication barriers that may not be as tangible as sidewalk curbs and public announcement systems.

Mandates requiring accessibility remain fraught even after decades of legal battles and new legislation governing arenas ranging from private offices to online shopping. At stake in these debates are core American and Western values of individual and social citizenship. Rights discourse often centers on the value of “independence”—that is, being able to move about and do things on one’s own, without the assistance of doctors, nurses, parents, or charitable strangers. The ideal of an accessible public environment follows this conception of citizenship as autonomy. And yet, in practice, claiming the rights to autonomy through accommodation can be interpreted as a neoliberal critique of the welfare state, which fosters the notion that individualism and independence are prerequisites for good citizenship. The late historian Paul Longmore details the “ceremonies of social degradation” that accompany social welfare and other entitlements, inculcated in endless paperwork and bureaucratized misdirection (2003, 240). Access, too, comes with its rituals of shame, as in cases when disabled citizens must pursue legal action to demand usable workplaces or accommodating schedules, leading to frequent accusations of fraud,
moneygrubbing, or selfishness. Lennard Davis describes the sense, rooted in modern psychological theory, of disability as a form of narcissism, and the demands for accommodation as “self-concern rather than a societal concern” (2002, 124).

In recent years, some scholars and activists have questioned the centrality of access to the mainstream disability rights agenda. While the principle of access seems infinitely expandable, it often narrows to discussions of architectural details such as stairs and ramps. The International Symbol of Access—the white figure in a wheelchair against a blue background—seems to exemplify the problem of representing disability solely in terms of mobility impairments, and access solely in terms of wheelchair access. It centers the ideal of access on overcoming the realities of barriers. While few would question the importance of establishing and enforcing architectural access, these laws also show some of the limitations of technological interventions in a neoliberal political economy. Access can represent a form of outsourcing, as authorities implement technological change without addressing underlying prejudices and misconceptions. As disability advocates shift their rhetoric, they urge a look “beyond ramps” and emphasize those disabilities (including psychological and intellectual concerns) for which accommodation may not take tangible form (Russell 1998).
Aesthetics
Michael Davidson

Whether addressing ideas of beauty in nature or works of art, aesthetic judgments implicate disability insofar as they presume a normative standard of perception and an ideal of bodily perfection as the object of affective response. Although theories of taste and beauty have been in existence since Plato and Aristotle, the term "aesthetics" emerges centrally in the eighteenth century as a discourse about perception and feeling. For Immanuel Kant, for instance, an aesthetic judgment is distinct from one involving deductive reasoning or conceptual information concerning the object. He distinguishes between teleological and aesthetic judgments, the former of which concern objects, purposes, and intentions; the latter are disinterested, based on subjective apprehension. Kant implies that disinterested pleasure is distinct from the self-interested pleasure we obtain from satisfying a drive or solving a problem. In a paradoxical move, however, he also claims that my feeling of pleasure is validated by my presumption that others would feel the same way ("when [a man] puts a thing on a pedestal and calls it beautiful he demands the same delight from others" [Kant 1952, 50]). This conflation of noncontingent personal pleasure with collective assent is the cornerstone of bourgeois aesthetics, from Karl Marx to Herbert Marcuse. It is also the source of ableism as the ideology of bodily normalcy.

The claim of disinterestedness presents a conundrum for disability studies. It represents an attempt to legitimate judgments of taste by removing the body that makes such responses possible, or more precisely by diverting bodily responses onto objective forms. But judgments of taste are always framed by social attitudes and cultural contexts. Such values constitute forms of cultural capital in the reinforcement of class privilege, and as such restrict competing views of beauty, sensory satisfaction, and human variety. When the seventeenth-century Spanish artist Diego Velázquez places the Infanta at the center of his painting Las Meninas, for instance, he includes a court dwarf at her left, as a grotesque contrast to her youthful perfection. An aesthetic of disinterestedness is never far from a formalist desire to project the work of art as a cordon sanitaire against bodily variety and corporeal mutability.

Eighteenth-century and early nineteenth-century aesthetic treatises attempt to provide for subjective experience the kind of authority claimed by empirical science. Yet the criteria for judgment often presuppose an ideal of embodiment. Johann Joachim Winckelmann, for instance, sought artistic perfection in classical sculpture based on the perfect Greek body. He argued that "masterpieces [of classical art] show us a skin which is not tightly stretched, but gently drawn over a healthy flesh, which fills it out without distended protuberances and follows all the movements of the flesh parts of the body in a single unified" direction (1985, 37). By contrast, Gottfried Lessing felt that certain emotions—such as pain—can be better expressed in poetry, while bodily infirmity and variety may be the ideal subject for painting, since they create a challenge for the artist's mimetic potentiality. Lessing believed a modern artist would declare, "Be you as misshapen as is possible, I will paint you nevertheless. Though, indeed, no one may wish to see you, people will still wish to see your picture; not in so far as it represents you, but in so far as it is a demonstration of my art, which knows how to make so good a
likeness of such a monster” (1985, 63). For Lessing, realistic depiction of a “misshapen” man is less important for its verisimilitude than for its demonstration of artisanal superiority.

In both Winckelmann and Lessing, the ability of aesthetics to define affective and sensory response depends on—and, indeed, is constituted by—bodily difference. In Kant, by contrast, the aesthetics of beauty is only one half of a dialectic between bounded and unbounded sensations. The latter, associated with theories of the sublime, is the inevitable site of cognitive and physical difference in their challenge to our reasoning faculty. Theories of the sublime during the eighteenth century were inspired, to some extent, by the eighteenth century’s discoveries in medical science or what Michel Foucault (1984) calls the “politics of health.” In Edmund Burke’s *Philosophical Enquiry into the Origin of Our Ideas of the Sublime and Beautiful* (1968), the sublime is defined through the author’s medical researches into physical pain. For Burke, the sublime is superior to beauty because it leads to further consciousness and action, whereas beauty recedes into indolence and passivity. The experience of pain is beyond reason and comprehension, a state that challenges ideas of mortality and finitude. Once released from pain, the individual enjoys the “joys of convalescence” whereby we learn to appreciate a health we had previously taken for granted.

A key theater for theories of the sublime can be found in the Gothic tradition. As an antidote to Enlightenment rationalism, Gothicism engages with various forms of bodily difference and psychological otherness. Where Winckelmann vaunts human perfection in health, smoothness, and unity, the Gothic explores the pathological, uncanny, and monstrous. David Punter observes that “the history of . . . the Gothic [is] a history of invasion and resistance, of the enemy within, of bodies torn and tortured, or else rendered miraculously, or sometimes catastrophically whole” (2000, 40). Gothic fiction offers a catalog of characters who exhibit bodily deformities, mental disability, or psychic distress: from Mary Shelley’s Frankenstein to the blind rabbi of Charles Robert Maturin’s *Melmoth the Wanderer* to the giant of *The Castle of Otranto*, the One-Handed Monk and the narrator in Edgar Allan Poe’s “The Fall of the House of Usher.” As a camera obscura on Enlightenment aesthetics, the Gothic displays, according to Ruth Anolik, “human difference as monstrous, and then, paradoxically, [it] subverts the categories of exclusion to argue for the humanity of the monster” (2010, 2).

David Mitchell and Sharon Snyder (2000) refer to such images or metaphors as “narrative prostheses,” since their appearance in literary works provides a figurative (and, often, a literal) crutch to a redemptive story of bodily renewal. Oedipus’s self-blinding is an inaugural moment in Western art’s linkage between moral life and bodily deformity. Similarly, Shakespeare’s Richard III’s hunchback is a physical embodiment of his corrupted sense of power, while Dickens’s Tiny Tim’s limp facilitates Scrooge’s redemptive vision of charity. The function of such narrative prostheses is to provide readers with a model of bodily difference from which they may distance themselves. What the disabled body disturbs in the moral universe, the redeemed, healthy body recuperates, just as the death of the monster or the villain restores the health of court and state. As Mitchell and Snyder summarize, “While an actual prosthesis is always somewhat disconcerting, a textual prosthesis alleviates discomfort by removing the unsightly from view” (2000, 8). The rhetorical trope of pathos, the appeal to an audience’s emotions, is often purchased by an identificatory logic that turns aesthetics into pedagogy. Pity and fear, those qualities Aristotle ascribed to tragedy, may be aesthetic criteria for mimesis, but they are embodied in a blind and crippled Oedipus.
Since the late nineteenth century, modernist art has had recourse to deformed or grotesque bodies to metaphorize the condition of what Matthew Arnold called "this strange disease of modern life" (2004, 1993). The canon of high modernism is replete with representations of physical and mental disability—from aestheticism's convalescents to Expressionist portraits of demenated urban denizens, to the blind and neuroesthetic figures in T. S. Eliot's poem The Waste Land, to Andre Breton's cognitively disabled heroine in Nadja, to Henry James's invalids Ralph Touchett and Milly Theale, to William Faulkner's cognitively disabled Benjy Compson, to the consumptive heroines of opera, to the incarcerated narrator of Charlotte Perkins Gilman's "The Yellow Wallpaper." Nazi Entartete Kunst ("degenerate art") exhibitions of the late 1930s used modernism's depiction of "defective" or dysgenic persons in Expressionism or Surrealism as a sign of Western culture's decline, in contrast to the idealized Aryan bodies in rural settings depicted in the "Great German Art Exhibitions" endorsed by Hitler. If the salient feature of modernist art and literature was its emphasis on the materiality of the medium and the defamiliarization of everyday life, its thematic focus was embodied in a blind soothsayer, a child with Down syndrome, a tubercular artist, and a hysterical woman (Davidson 2008).

The turn in modern aesthetics' dependence on discourses of disability is powerfully evident in art's reliance on a disabled person to symbolize moral flaws or frame the able-bodied hero's moral recovery. In the late nineteenth century, for instance, convalescence became a key trope for philosophical acuity and aestheticism. Literary figures such as Edgar Allan Poe's narrator of "The Man of the Crowd," des Esseintes in Joris-Karl Huysman's Au Rebois, or the title character in Friedrich Nietzsche's Zaratustra are only three of many convalescents whose return to avidity from illness inaugurates a new intense, passionate interest in the world. Modern aesthetic theories also have a taxonomic function insofar as they attempt to organize and rationalize sensory experience. For Jacques Rancière, "the practices and forms of visibility of art... intervene in the distribution of the sensible and its reconfiguration" (2009, 29). This distributive or categorical function parallels in many ways the biopolitical rationalizing of bodies and cognitive registers that emerged in medical science during the eighteenth and nineteenth centuries but was refined and perfected in the twentieth.

Modernist aesthetics is also dominated by the idea that literature "lays bare the device" of language through formal rupture and non sequitur (Shlovsky 1965). Twentieth-century Russian formalists such as Viktor Shlovsky, Boris Eichenbaum, and Roman Jakobson have theorized that literary devices such as metaphor, patterned rhyme, and narrative frames "make strange" the everyday and quotidian so that it can be experienced anew. Disability theorists have come to similar conclusions about the ways that disability unsettles ideas of bodily normalcy and averageness. Ato Quayson (2007) calls the discomfort that disability occasions among able-bodied persons "aesthetic nervousness," a recognition of bodily contingency that arises in the presence of the nontraditional body. Lennard Davis (2002) argues that disability, because it crosses all identity categories, "dis-modernizes" biopolitical regimes that attempt to fix and categorize bodies through medical technologies and population control. Aesthetic defamiliarization and disability deconstruction are joined by their critique of mimesis—the idea that there is a putatively "real," "given" world that must be represented and cited. When art foregrounds its own operations, when disability unsettles the normative body, mimetic criteria are shattered and the means of aesthetic and social reproduction exposed.
The attempt to differentiate the "normal body" in modernity was aided by a number of developments in visual culture that made the nontraditional body more visible. Photography was enlisted by eugenics and race theorists to catalog aberrant or dysgenic "types," while films such as The Black Stork (1917) provided documentary evidence justifying fetal euthanasia, sterilization, and incarceration. Antivagrant laws or "ugly laws" were instituted in a variety of U.S. cities to prevent "unsightly" or disabled persons from appearing on the street (Schweik 2009). As Martin Pernick (1996) observes of such developments, aesthetic values were often used to define those "lives not worth living" and remove them from public view. Modern reform movements in favor of suffragism, birth control, women's health, workplace improvements, and settlement houses were often fueled by eugenict ideas about health, genetic purity, and ability. In Lennard Davis's terms, "enforcing normalcy" becomes a preoccupation of modern social and medical sciences for which both high art and mass culture provide prosthetic reinforcement.

The twin legacies of an aesthetics of disinterestedness and a biopolitics of health and genetic improvement have helped to shape what Tobin Siebers calls "an aesthetics of human disqualification," a "symbolic process [that] removes individuals from the ranks of quality human beings, putting them at risk of unequal treatment, bodily harm, and death" (2010, 23). Fitter family contests, "ugly laws," and freak shows of the modernist era provided individuals with an opportunity, during a period of social fluidity and change, to imagine themselves as not "ethnic," not "feebleminded," and not disabled. Mass cultural spectacles and modernist art both contributed to such an aesthetics by making visible bodies with which one would not want to be associated while validating sensory responses to bodies that confirmed one's own integrity and vitality.

Siebers (2010) uses the phrase "disability aesthetics" to draw attention both to the formative role of disability in aesthetics and the aesthetic practices of disabled artists whose work engages in a critique of ableist attitudes. In 1990, for instance, when disability activists from American Disabled for Accessible Public Transits (ADAPT) left their wheelchairs to crawl up the steps of the U.S. Capitol building in support of the Americans with Disabilities Act, it was an act of civil disobedience. But it was also—vividly—a form of disability performance art. Such theatrical gestures blur the boundary between art and activism that has characterized much disability aesthetics in the recent period. The performance artist Mary Duffy, born without arms, poses nude while adopting the position of classical sculpture. She uses her posture as a nude Venus de Milo (who also lacks arms) to address her audience and rearticulate feminine beauty from a disabled and gendered perspective. The deaf artist Joseph Grigley makes installations out of the "conversation slips" (matchbooks, bar napkins, Post-its) he exchanges with his hearing interlocutors. The neurodiversity activist and autistic artist Amanda Bagg uses a software interface to transcribe her written text into an electronic voice that urges her audience to learn "her" language of repetitions, scratchings, and monotone humming. The blind photographer Evgen Bavcar photographs classical sculpture and archaeological sites, often intruding his hand into the image to instantiate his reliance on a tactile rather than retinal relationship to objects.

The situation of deaf poets and performers presents a specific challenge to traditional aesthetic ideals based on printed or verbal representation. Many deaf persons think of themselves not as disabled but as a linguistic minority who compose their poems and performances through sign language. Many of the themes of d/Deaf performances involve the history of oralist pedagogy that emerged in the mid-nineteenth century and that
dominated attitudes toward the assimilation of deaf people into hearing culture (Baynton 1996). Poets such as Clayton Valli, Debbie Rennie, Patrick Graybill, and Ella Mae Lentz create works in American Sign Language (ASL), most often repudiating voice-over translation in order to “speak” directly to a nonhearing audience (Brueggemann 1999). Deaf artists' interest in differentiating themselves from disability illustrates the difficulty of defining disability aesthetics within a single category with a common history. Furthermore, it forces us to rethink the largely ocularcentric character of aesthetic discourse and configure it around other sensory avenues and cognitive registers.

“There is no exquisite beauty, without some strangeness in the proportion.” Edgar Allan Poe's quotation of Francis Bacon in “The Philosophy of Composition,” summarizes the crucial link between art and otherness, between the aesthetic and the different bodies that constitute it. In an essay that advocates the most extreme example of artisanal control, Poe's belief in poetry's need for “strangeness” exemplifies the aesthetic's uncanny dependence on difference. What Terry Eagleton calls “that humble prosthesis to reason,” the aesthetic depends on a body that reason refuses to recognize. One must remember that the ideal forms that the humanities vaunt as epitomes of proportion and grace—the Venus de Milo, La Victoire de Samothrace, Leonardo’s Vitruvian man—are, respectively, armless, headless, and possessed of multiple arms and legs. The aesthetic discourse that creates disinterested appreciation of the beautiful is also the one that has historically relegated the hunchback to the dungeon, the fat lady to the freak show, and the deaf person to the asylum. The close proximity of aesthetic judgment to carceral isolation and rationalized euthanasia is the darker side of Enlightenment knowledge, even as the increased visibility of the disabled body creates the occasion for its liberation.
Blindness is a condition of the flesh as well as a signifying operation. William R. Paulson maintains that blindness “means very different things, and moreover it is very different things, at different times, different places, and in different kinds of writing” (1987, 4). Such a critical stance can lead the field of disability studies to analyze disability in a manner that reckons with both the ways that bodies are made accessible through language and the ways that bodies exceed language. The state of visual impairment long ago assumed a metaphoric plasticity, making literal blindness serve as a figurative marker for other diminished capacities. This interplay permeates, for example, one of the West’s foundational texts, Sophocles’s version of the story of Oedipus. It is evident in the confrontation between Tiresias, the blind prophet, and the figuratively blind Oedipus, as well as in the ghastly scene where Oedipus literally blinds himself upon gaining his figurative sight (Stiker 1999).

Perhaps the earliest English-language example of blindness’s physical/metaphysical conflation occurs in the tenth-century Blickling Homilies. The narrator of the second quire, Quinquagesima Sunday, observes of the blind beggar of Jericho, “Right was it that the blind man sat by the way begging, because the Lord himself hath said, ‘I am the way of truth,’ and he who knows not the brightness of the eternal light is blind; and he liveth and believeth who sitteth by the way begging, and prays for the eternal light, and ceaseth not” (Morris 1880, 16). This exegesis clearly demonstrates a transformation
of the physically blind beggar into a surrogate for the intransigent spiritual blindness of all sinners. By taking care of the blind beggar, sinners can move closer to Christ and therefore erase their own metaphoric blindness. In his examination of l'Hospice des Quinze-Vingts, the institution founded in Paris by Louis IX in 1256, Edward Wheatley (2002) argues that the church treated physical blindness as evidence of sin, which could be ministered to in order to imitate Christ's role as protector and healer.

During the European Enlightenment, blindness became fetishized in debates among both rationalists and sensualists. As in the Middle Ages, though, it was not really visual impairment itself that was central to such debates; rather, blindness became a form of “narrative prosthesis” (Mitchell and Snyder 2000; Davidson 2008). Blindness aroused the thoughts of several Enlightenment philosophers because of an intellectual quandary posed by William Molyneux, a Dublin lawyer, to John Locke in 1688. Molyneux asked whether a man born blind who had tacitly learned to tell a globe from a cube would be able, upon having his sight restored, to immediately distinguish through vision one object from the other. In later printings of An Essay Concerning Human Understanding (1754), Locke answered Molyneux's epistemological problem by arguing that such a man would be incapable of distinguishing the objects by sight alone. Inclusion of the query and Locke's response in Locke's seminal text brought the hypothetical scenario to the attention of eminent philosophers such as Berkeley, Condillac, Leibniz, and Voltaire, who regarded blindness as a mere intellectual puzzle that held no social value by itself. By contrast, it formed the impetus for Diderot's Letter on the Blind for the Use of Those Who See, which explored blindness as a valid subject unto itself.

Against a backdrop of emerging industrialization and modernization, blindness became not a marker of sin, as it had been during the Middle Ages, but a marker of sloth. James Gall, a pioneering Scottish educator of the blind, for instance, declared that a blind person's “condition is a state of continuous childhood. . . . He can produce for himself neither food nor clothing; and without the unceasing assistance of his friends he would of necessity perish” (1834, 13). Without intervention, it was feared that the blind would wallow in unproductivity and gross dependence. In the nineteenth-century United States, pedagogy for blind students heavily emphasized Protestant Christianity and nationalistic ideals; together they were meant to implant in blind students an ethos of independence, thereby making them capable of performing sighted normalcy. Furthermore, through educational and vocational institutions blind people were disciplined toward industrious participation in the nation. Such disciplinary practices were intended to transform them into facsimiles of the sighted. Additionally, this inculcation was meant to ameliorate the anxiety many sighted people had over blind people's inability to join the imagined community of the nation.

Throughout the nineteenth and twentieth centuries, blindness was increasingly indexed according to complicated metrics of visual acuity, and there were tremendous efforts to achieve complete empirical exactitude. A universal medical definition, however, has proven elusive, and various global institutions have come to employ different quantitative standards. The inability to secure total agreement regarding the measurement of blindness demonstrates how “the evaluation of impairment is . . . full of errors of reification and false precision” (Stone 1984, 116). As such, the failed quest for an absolute metric has given rise to multiple classification schemes, all of which measure degrees of blindness.

This is illustrated by the U.S. Bureau of the Census and the World Health Organization, which use different.
criteria for diagnosing what constitutes blindness. For both institutions, the logic of categorization is buttressed by ophthalmological measurements of blindness. Such definitions may prove useful in terms of policy decisions and the disbursement of financial benefits, but they also have the effect of dividing the blind community. Kenneth Jernigan, for instance, a long-serving former president of the National Federation of the Blind, observed in an essay originally published in 1962 that “the complex distinctions which are often made between those who have partial sight and those who are totally blind, between those who have been blind from childhood and those who have become blind as adults are largely meaningless” (2005). For Jernigan, as for many activists and scholars in disability studies, organizing around a common identity for social gains has proven more relevant than classificatory nuances.

Perhaps because no universal technical definition of blindness exists, the scale incorporating multiple measures of blindness employed by different medical domains has not significantly influenced sighted culture at large. Sighted culture accepts only a total, plenary blindness, a stark binary of presence/absence. One either sees nothing or one sees everything; there is no allowance for a liminal state of partial blindness or partial sightedness, what Beth Omansky (2011) has termed the “borderland of blindness.” This may explain why sighted people still experience both trepidation and wonder at imagining the phenomenological dimensions of blind people’s existence, stemming largely from the belief that the blind body has only limited access to the world through a pitiable, incomplete sensorium. Georgina Kleege wryly recognizes how many sighted people go “into raptures” when describing a blind person’s “ability to recognize . . . voices, to eat spaghetti, to unlock a door. People sometimes express astonishment when I find the light switch or pick up my coffee cup” (1999, 27). Guided by such erroneous presumptions, sighted culture fashions the blind body into a totem of daily miracles, where even the most quotidian activities seem extraordinary.

Anxiety among the sighted makes it seem that a life of blindness is necessarily devoid of autonomy, agency, or the possibility for any positive affect. Such a broad cultural misconception empowers the dominant non-disabled culture to believe that blindness is existentially incomplete, a stigmatized state of deprivation. As Michalko (1999) has noted, blindness represents a lack that menaces sighted culture; it is an absence not only of sight but also of independence, intellectual acumen, morality, and productivity. Blind people are thus confronted with two options: either succumb to disciplining practices in order to perform normalcy—that is, some version of sightedness—or else face rejection.

One curious aspect of medical discourse is that it opens the definition of blindness to perpetual revision because the clarity and focus of the techno-medical gaze are always becoming sharper. For example, the reductive social binary of being either sighted or nonsighted diverges from medical conceptualizations of blindness, which acknowledge that people experience various forms of blindness in different and uniquely subjective ways. Some experience a mélange of colors; some see eruptions of paramecium-like shapes; and for some photophobia precludes direct exposure to light. Less than 10 percent of people who identify as blind possess no light perception whatsoever.

Medicine’s perpetually revised definitions of blindness imply that the sought-after complete description and comprehension of blindness will someday be the precursor of techno-medical mastery. Moreover, it is presumed that such mastery will cross a biological horizon and at some imagined point take the form of absolute cure. This is not new; medicine has conceived of
blindness as being an inevitably conquerable condition, a belief that stretches from the second-century AD cataract surgeries by Galen of Pergamon to the first recorded reversal of blindness, performed by English surgeon William Cheselden in 1728, to the exuberant contemporary fantasies of the posthuman in the early twenty-first century.

Such efforts at mastery are problematic because they often displace efforts to improve the social conditions of current blind people. Future inquiries centered on blindness should instead assist in establishing a greater understanding of how human variation is an asset, and not a liability. Several disability studies scholars have created a foundation upon which future inquiries might be built. Robert McRuer's (2006) work, for example, can facilitate an understanding of how blindness "crips' sighted culture. The concept of the "normate," proposed by Rosemarie Garland-Thomson (1997, 2009), challenges oculocentricism, including the presumptive right to stare at others that saturates sighted culture. In addition, Shelley Tremain's (2001, 2008) application of Foucauldian theories to the ethics of disability demonstrates how poststructuralism can productively influence new conceptualizations of blindness and sightedness. Finally, the study of blindness can lead to fresh insights in fields outside of disability studies. Because so many cultural categories and disciplinary practices are based on sight and the visual inscriptions of the body, blindness can reveal how sight influences negative constructions of people of color, women, queer people, and disabled people without visual impairments, thereby recasting modernity's problematic foundational assumptions so that a richer inclusivity might be gained.
Cognition
Ralph James Savarese

To understand the relationship between cognition and disability, let us appeal to the concept of “situated cognition” in cognitive neuroscience. The field of disability studies attests, after all, to the situatedness, or social construction, of disability. The two branches of situated cognition—embodied and embedded—can help to illuminate how a different kind of body and a different kind of environment generate a different kind of thought. Embodied cognition repairs the traditional mind-body divide, whereas embedded cognition reveals the extent to which we all depend on our physical and social environments to think. The former thus blurs the line between “physical” and “mental” disabilities because no condition is strictly one or the other, and the latter points to complex accommodative ecologies that enhance cognition by imaginatively distributing it beyond the individual.

According to Vittorio Gallese and Hannah Chapelle Wojciechowski (2011), “Classic cognitive science heralds a solipsistic account of the mind. . . . The picture . . . is that of a functional system whose processes can be described in terms of manipulations of informational symbols according to a set of formal syntactic rules.” (Because sensing, acting, and thinking are not “separate modular domains” but, rather, a kind of dynamic feedback loop, embodied cognition insists that the mind be understood as both serving, and served by, a body. “By having fingers capable of grasping objects and legs capable of walking and climbing walls,” write Robert Wilson and Luca Foglia, “we sort and categorize stimuli in ways that are radically different from, say, the ways in which they are sorted by butterflies.” Sensorimotor experience, to put it simply, “frame[s] the acquisition and development of cognitive structures” (Wilson and Foglia 2011).

By this logic, the sensing and acting associated with congenital deafness or autism or even impaired mobility would spawn a different kind of cognition. Among deaf people, for instance, a study from 2001 reported that “visual attention to the periphery is more efficient than in hearing people” (cited in Campbell, MacSweeney, and Waters 2008, 16). As significant, the auditory cortex can be used for sight. In a 2005 study, the movement of visible dot patterns activated “regions that support hearing (and only hearing) in hearing people” (cited in Campbell, MacSweeney, and Waters 2008, 16).

Finally, while traditional language areas in the left cerebral hemisphere have been shown to support the use of sign language, the spatial processing demands of grammar in sign language appear to activate the right hemisphere more than processing spoken language does. All of this indicates at least a slightly different sensorimotor foundation or frame for deaf cognition.

And yet, what may seem modest on fMRI scans turns out to be quite significant in reality. That signing occurs in the open field of the hands, as opposed to the closed cave of the mouth, makes of language something truly kinesthetic. With two manual articulators, a face and a body, the signer can exploit simultaneity of expression—Indeed, grammatical structures are often expressed nonmanually. Iconicity further distinguishes spoken language from sign language, with the latter containing many more instances of the partial or full onomatopoeia-like union of signifier and signified. This fact makes plain, in a way that the arbitrariness of spoken language does not, that the origin of meaning begins in the body. Any account of deaf cognition must
recognize that distinctive sensing and acting have given rise to a distinctive language.

With autism, cognition is conspicuously embodied. Temple Grandin thinks in pictures, whereas Tito Mukhopadhyay thinks in fragmented, synesthetic sound. So significant are his sensory processing, proprioception, and facial recognition challenges that his published writings often seem like a marvel of literary defamiliarization: “Every time I have to hear Mr. Blake’s voice, I recognize it by a squished tomato smell. After that, I know that there ought to be Mr. Blake somewhere around carrying his voice with him” (Mukhopadhyay, qtd. in Savarese 2010). In her YouTube video, “In My Language,” Amanda Baggs treats what the medical community would call “perseverative behavior” as an attentional virtue. Extolling an autistic preference for detail over category (because the latter masters the world at the cost of seeing it), Baggs remarks, “The way that I move is an ongoing response to what is around me.”

Even mobility impairment would produce a different form of cognition, though it might not show up, as it does in autism, on fMRI scans. When Nancy Mairs entitles a book Waist-High in the World, she implicitly acknowledges a different form of sensing and acting: namely, that which takes place in a wheelchair.

In contrast to embodied cognition, embedded cognition foregrounds the role of the natural and social environment in thought. Andy Clark and David Chalmers remind us that “our visual systems have evolved to . . . exploit contingent facts about the structure of natural scenes . . . and they take advantage of computational shortcuts afforded by bodily motion and locomotion” (1998, 8). Or, as Wilson and Foglia put it, “Visual experience results from the way we are dynamically hooked up to the world” (Wilson and Foglia, 2011).

Of course, we are also “hooked up” to other people as well as to forms of organized cultural behavior. Lucy Suchman (1987) has shown that workplace activity conditions what we do with our senses and hence how we cognitively operate. Airplane mechanics, for example, engage in a highly particular kind of seeing. We have long known that infants need the environment to shape sensory processing, but they also need other humans to develop intersubjective capacities, not to mention the language that so enhances them.

To capture the symbiotic nature of cognition, Clark and Chalmers deploy a provocative analogy:

The extraordinary efficiency of the fish as a swimming device is partly due . . . to an evolved capacity to couple its swimming behaviors to the pools of external kinetic energy found as swirls, eddies and vortices in its watery environment. These vortices include both naturally occurring ones (e.g., where water hits a rock) and self-induced ones (created by well-timed tail flaps). The fish swims by building these externally occurring processes into the very heart of its locomotion routines. (1998, 9)

By referring to the fish and water as a “device,” the authors move us beyond the individual organism to a larger ecology. “In such cases,” they write, “the brain . . . complements the external structures, and learns to play its role within a unified, densely coupled system” (Wilson and Foglia, 2011).
Clark and Chalmers (1998, 12) cite the example of a person with Alzheimer's disease who must use a notebook to remember where he is geographically. “Coupled systems” allow many people with disabilities to function more successfully. Indeed, these systems prove the fundamental point of the social model of disability: that the disabling aspects of physiological distinction are largely manufactured. Stephen Kuhsto captures the machine ensemble of blind man and guide dog when he writes: “Our twin minds go walking. And I suspect as we enter the subway / on Lexington / That we’re a kind of centaur— / Or maybe two owls / Riding the shoulders of Minerva” (2009, 20–21). A more complex coupling—and, in fact, an elaborate ecology—is what enables a young woman with significant cerebral palsy to attend an elite liberal arts college in Iowa. Without a motorized wheelchair, a computer with eye-blinking text-to-voice capabilities, a classroom aide, a personal care assistant, accessible learning spaces and dorms, not to mention her own native intellectual gifts and what might be called external attitudinal energy (those progressive swirls, eddies, and vortices of nondisabled opinion), she would not be able to do it.

The embedded and distributed nature of cognition becomes strangely literal when we consider psychiatric medicines and neuroprostheses such as cochlear implants. The coupling may be internal rather than external, but such couplings are themselves embedded in larger cultural debates about curing disability and medicating purported emotional dysfunction. People with disabilities come to different conclusions about these interventions. Of the decision to treat her own bipolar disorder with Depakote, Suzanne Antonetta remarks, “It’s hard to explain how I can believe the ‘medical model,’ the model of mental difference as straight illness, like a never-ending flu” (2009–2010, 73). Although she believes in “mad gifts” (73), she prefers the “difference in [her] mind” (70) that the drug enables.

While the disabled “device” is potentially emancipatory—and in many ways equivalent to the nondisabled one—it is often coded as lack. In the case of cognitive disability, intense stigma persists. The historical conflation of physical disability with cognitive impairment suggests a perverse reconciliation of mind and body, and the belief that learning is impossible while being cognitively impaired continues to do great damage. At the same time, the neurodiversity movement has begun to attract scientists and doctors—one prominent researcher has referred to autistics as “just of another kind” (Wolman 2008). Embedded and distributed cognition might put pressure on narrow notions of personhood, which have traditionally excluded those deemed “profoundly retarded,” encouraging us to see how the shibboleth of rugged individualism does not even apply to the most cognitively competent among us.
13

Communication

Carol Padden

The word “communication” first appeared in 1422, according to the Oxford English Dictionary, and was used to refer to “interpersonal contact, social interaction, association.” By the sixteenth century, the word had acquired another sense: “the transmission or exchange of information, knowledge or ideas.” The plural form, “communications,” was introduced in 1907, to refer to transmission by way of machine or technology. Even in this technological sense, however, the notion of communication implies a transmission of information from one biological entity to a similar one. In recent years, technologies and techniques of communication associated with disability are transforming all of these meanings by extending the notion of transmission of information well beyond the circuit of biologically similar speaking bodies. Disability studies and sign language studies have concerned themselves with what have been considered “nontypical” communications, conducted by differently abled bodies, via different appropriations of technology.

All animals communicate, but only humans use language. Bees dance to indicate where pollen is found, but only humans have words and sentences to indicate ideas and concepts, including the dance behavior of bees. Other forms of communication may parallel and at times substitute for speech, but they are not primary linguistic systems.

Sign languages—which are found in all inhabited parts of the world—are similar to spoken languages (Sandler and Lillo-Martin 2006). Sign languages have phonology, as do spoken languages, except instead of vowels and consonants, signs are made up of combinations of movements, locations, and hand shapes. Sentences in natural sign languages display hierarchical organization and exhibit syntactic structure. Young signing children, deaf and hearing (such as those with signing parents), acquire sign language in ways that are not different from children acquiring spoken language (Corina and Singleton 2009). When deaf signers suffer stroke and have damage to the language areas of the brain, they too, like hearing aphasics, can show loss of sign language ability (Hickok and Bellugi 2010). Sign languages may differ from spoken languages in the modality of expression, but in terms of their organizational properties, they are fundamentally linguistic. Sign languages of deaf communities may be fully expressive linguistic systems, but they are often viewed as secondary replacements when speech—the default modality in human language—is not possible.

A unimodal view of language, as primarily spoken, ignores contrary examples in human communities of how the body is used for language. Among the Walmiri of western Australia, widows observing a period of mourning do not speak, instead using sign language to communicate with others (Kendon 1988). There are yet more examples of the flexible possibilities of the human body for language. Khoisan languages of southern Africa use clicks as phonemes in addition to the more familiar vowels and consonants of most spoken languages. The existence of clicks is comparatively rare in the world of spoken languages but demonstrates that speech can be molded in diverse ways. In deaf-blind communities, signers communicate by tactile means with each other, holding each other’s hands as they sign. It is common to think of these as adaptations, or unusual modifications made to accommodate a special need. “Adaptation”
follows from thinking of language as having a basic template, or universal properties, upon which modifications are made. But these examples show that languages are systems that can employ different signaling properties. The body offers multiple communicative resources that are organized differently in different contexts. The ways that language can be built from different parts of the body are surprisingly myriad. If language is viewed as inherently multimodal, then humans’ ability to move between different modalities in different communities seems less exotic and more indicative of flexibility.

Studies of new sign languages emerging in small villages around the world show that when deaf children are born into a community, hearing residents adapt their gestures to produce longer signed strings in an effort to communicate. As more deaf children enter the community across more than one generation, the community changes from an exclusively speaking community to one where a sign language is a common second language in the community in addition to a spoken language (Meir et al. 2010).

Beyond stretching our notion of how languages transmit information via means other than speech, disability studies can help us to move beyond a transmission view of communication. James W. Carey’s “ritual view of communication” focused not on “the act of imparting information but [on] the representation of shared beliefs” (1992, 15). A focus on “ritual” shifts away from the idea of messages and their properties, to performance, activity, and the materiality of communication itself. In this framework, meaning is not so much the definition of a word or sentence but instead is constructed in situ, in social and cultural activity. Human actions are not simply executed but are “situated” in time and place. In this framework, language is not a disembodied, logical system but is perpetually constructed and reconstructed in social and cultural activity. The concept of activity as a unit of analysis recognizes all levels of expression, from the minute details of discourse—from pitch, emphasis, gesture, head tilts, and eye gaze—to the performative aspects of making meaning within the institutions of the home, school, and the workplace.

The foundation of this communicative ability is “shared intentionality,” or the ability to engage with others in a common activity. Humans have a unique predisposition to follow the eye gaze of others and to comprehend others’ pointing and indexical reference. A similar construct is “intersubjectivity” (Cole 1996; Wertsch 1991), or the ability of humans to recognize in each other their expressive states, including their emotions, plans, and goals. Understanding the basis of shared intentionality and intersubjectivity necessitates a notion of the mind that encompasses more than the individual and his or her internal space, but is extended through the body and distributed in social interaction (Bakhurst and Padden 1991). Communication exists in what Ludwig Wittgenstein referred to as a “web of meaning,” an ecologically coherent system that locates human bodies in an interrelated moment.

Such notions from the field of communications as distributed cognition and situated practice overlap conceptually with disability studies’ repositioning of the human body. In both fields, human bodies are not simply vessels containing brains but are themselves complicit in human sociality, cognition, language, and social interaction (Rohrer 2007). Bodies interact with and on the world, grasping objects or modeling them abstractly in gesture. A physicist describing the structure of molecules gestures as she speaks in order to show the shape of what is unseen. A young child tries to grasp an object out of reach, and her hand changes into an indexical point producing joint reference (Vygotsky 1978). A group of officers stand around a table and jointly solve the problem of navigating a ship into harbor by moving
their hands around a map (Hutchins 1995a). Configuring the mind as an extension of the body leads to a concept of communication as fundamentally **multimodal**, in which all parts of the body are orchestrated together as it interacts with the world.

Multimodality and embodiment together with distributed and situated practice open up ways to conceive of communicative forms and practices in diverse bodies, but disability is not explicitly treated in this work except for a few notable articles. Goodwin (2000) describes an aphasic who, despite a greatly reduced vocabulary and repeated use of gestures, manages to push caregivers into expanding their abilities to interpret his wishes and intentions. A differently abled body does not merely attempt to communicate, but by his realignment of himself with material and communicative resources, he compels new forms of engagement and interaction. In such scenarios, communication is an aspect of human functioning that is always being constructed. For instance, parents of a blind child achieve intersubjectivity and shared intentionality not by shared eye gaze but by coordinating their actions with her hand movements (Bigelow 2003). Autistic children are said to lack shared intentionality because they do not track the eye movement of others, but as recent research has shown, their sociality and interest in others are simply achieved by other means, such as physical proximity and verbal engagement (Akhtar and Gemsbacher 2007).

Disability studies can also shed light on the centrality of technology to notions of communication. In the broad sense of the word, technology is about material objects, the fund of knowledge about their use, and the institutionalization of the technology in cultural life. Technology refers to material and cognitive tools that are extensions of minds and bodies. Counting by use of an abacus is both a technology and a cognitive tool for computation. In such a view of technology, the relationship between the material and the cognitive is continuous, that is, antidualist, and not defined strictly by materiality. Ideas about mind, body, and technology have consequences for communication and disability. If technology is described as an appendage, then it can seem “secondary,” “supplemental,” “compensatory,” or “ventriloquist,” all terms which suggest that it adds to or amplifies human behavior. But if technology is seen as extensions of the body and mind, then technology is one part of an activity within which the human body operates rather than a supplement to that activity.

The rapid expansion of technologies of the body—particularly as tools of accommodation for people with disabilities—has led to changing notions of personhood. One recent case involves individuals with “locked-in syndrome” (LIS), who experience minimal outward body movement resulting from trauma that affects their motor behavior, making it difficult if not impossible to ascertain their communicative intentions. One such individual successfully petitioned the Spanish courts to restore his legal rights, namely, the ability to vote and to manage his financial affairs. The Spanish Supreme Court agreed that his use of a digital voice demonstrated that he can “materially carry out his decisions” (Domínguez Rubio and Lezaun 2012, 69). Domínguez Rubio and Lezaun argue that “those capacities and processes that have customarily defined the person—agency, intentionality, speech—need not be performed within the confines of the biological body, but may be enacted through extended systems of care and knowledge” (74). It is such cases of disability, of “extended systems” that stretch beyond the normal speaking body that have redefined communication and language for the present century.
Deafness is not what it used to be. Nor has it ever been just one thing, but many. Typically it refers to those who cannot understand speech through hearing alone, with or without amplification. Colloquially, it may also refer to any hearing impairment, as when a person is described as “a little deaf.” Professionals in education and communication sciences distinguish prelingual from postlingual deafness, in recognition of their different implications for speech and language learning. Within the deaf community, in contrast, the term “deaf,” as well as its signed equivalent, usually refers to people who identify culturally as deaf, and is sometimes capitalized (“Deaf”) to distinguish the culture from the audiological condition.

In the nineteenth-century United States, culturally deaf people frequently referred to themselves as “mutes,” while educators used “semi-deaf” as a synonym for hard of hearing, “semi-mute” for the postlingually deafened who retained intelligible speech, and “deaf-mute” or “deaf and dumb” for the prelingually deaf. Deafness also has long been a common metaphor for a refusal to listen or to learn, as when the French writer Victor Hugo declared that “the one true deafness, the incurable deafness, is that of the mind” (qtd. in Lane 1984, lx).

In 1772, British writer Samuel Johnson called deafness the “most desperate of human calamities,” a view expressed more often by hearing than by deaf people. Deafness acquired after early childhood is usually experienced as a loss and a sorrow, at least for a time. Of this
experience, we have many accounts. In her essay “Letter to the Deaf” (1836), British author Harriet Martineau confessed that becoming deaf as a young woman had been “almost intolerable,” but now, at the age of thirty-four, she realized her suffering had arisen almost entirely from “false shame” (448–449). John Burnet, who became deaf at the age of eight, wrote in Tales of the Deaf and Dumb (1835) that while deafness “shuts its unfortunate subject out of the Society of his fellows,” this is due not to being “deprived of a single sense,” but rather to the circumstance “that others hear and speak.” Were everyone to use “a language addressed not to the ear, but to the eye,” he maintained, “the present inferiority of the deaf would entirely vanish” (47). The poet David Wright, who lost his hearing at age seven, wrote in 1869 that despite its impact on his life’s trajectory, “deafness does not seem to me to be a disproportionate element of the predicament in which I find myself; that is to say the predicament in which we are all involved because we live and breathe” (1993, 7).

Acquired deafness begins as hearing loss but becomes something different, a state of being in all its complexity. Deafness from birth or early childhood begins as a state of being. Martineau observed that “nothing can be more different” than the two experiences, for “instead of that false shame, the early deaf entertain themselves with a sort of pride of singularity” (1836, 248–249). Wright maintained that he was “no better placed than a hearing person to imagine what it is like to be born into silence” (1993, 236). Historically, the early deaf have been far more likely to form communities and develop a mode of communication better adapted than speech to the visual sense than those who acquire deafness later on.

Hundreds of distinct sign languages are in use around the world today, in which the shape, orientation, position, and movement of the hands, combined with facial expression and movements of the head and body, generate a range of linguistic possibilities as vast as the combinations of sounds used in spoken languages. Yet aside from scattered references, we know little about deaf communities prior to the eighteenth century. The literary scholar Dirkse Bauman has described the search for them as “a bit like tracing the paths of fireflies: the field is mostly dark, except for scattered moments of illumination” (2002, 452). In Plato’s Cratylus (ca. 350 BCE), for example, Socrates briefly refers to deaf people who “make signs with the hand and head and the rest of the body” but elaborates no further. In seventeenth-century Europe, with the growth of great cities, observations begin to multiply: in London, for instance, the diarist Samuel Pepys recorded an encounter with a “Dumb boy” who communicated fluently in “strange signs” (November 9, 1666), while the physician John Bulwer wrote of “men that are born deaf and dumb, who can argue and dispute rhetorically by signs” (1644, 5). In Paris, the philosopher René Descartes observed that “the deaf and dumb invent particular signs by which they express their thoughts” (1892, 283), while in the Dutch city of Groningen, the physician Anthony Deusing described deaf people who communicated with “gestures and various motions of the body” (1656; qtd. in Van Cleve and Crouch 1989, 16). Isolated communities carrying a recessive gene for deafness have occasionally appeared in which the proportion of deaf people was such that all of their members, hearing and deaf, became fluent in a sign language. The anthropologist Nora Groce (1985) discovered such a community on Martha’s Vineyard that lasted from the seventeenth to the early twentieth century.

Deaf communities come into clear view in the eighteenth century due to urbanization and the advent of schools for deaf children. In 1779, the deaf Parisian Pierre Desloges wrote that while the communicative ability of deaf people in the French provinces was
“limited to physical things and bodily needs,” in Paris, they conversed “on all subjects with as much order, precision, and rapidity as if we enjoyed the faculty of speech and hearing” (qtd. in Lane 1984, 36). The Abbé Charles-Michel de l'Épée encountered that community by happenstance, studied its sign language, and founded the National Institution for Deaf-Mutes in Paris in 1776. The school gathered young deaf people from across the country, provided them with an education, and introduced them to the urban deaf community. The school had a profound influence on deaf education globally, with teachers and graduates bringing Parisian sign language to other countries in Europe and the Americas, and later to Asia and Africa.

Schools for deaf students greatly accelerated the process of creating a sense of shared identity and distinct cultures. The existence of deaf communities and their languages became increasingly controversial in the latter half of the nineteenth century, spawning a campaign to exclude sign language from the schools. The movement for “pure oralism” was rooted in a burgeoning nationalism that led many nations to suppress minority languages, as well as interpretations of evolutionary theory that cast sign languages as relics of savagery, and eugenic fears that deaf marriages would lead to the proliferation of “defectives.” The movement achieved an important symbolic victory when the Milan Congress of 1880, an international conference of educators of the deaf, affirmed the “incontestable superiority of speech over signs.” Deaf people and their organizations rallied against pure oralism, arguing that complete reliance on speech inevitably impaired the educational and linguistic development of many if not most deaf children. Nevertheless, oralism soon became the new orthodoxy in deaf education and remained so until the 1970s.

While childhood disease had long been the most common cause of deafness, its rapid decline in Western countries in the second half of the twentieth century meant that those born deaf became increasingly predominant in the community, a demographic shift with profound implications. Whatever successes supporters of oralism had been able to claim earlier in the century had been based largely on the prevalence of postlingually deafened children. Now, success was increasingly rare and educators began to reconsider long-held assumptions. The character of the deaf community also began to change, as native or early signers became the majority. A confluence of factors—among them movements for minority rights, changing attitudes toward the body, and a growing acceptance of cultural diversity—furthered the development of a deaf rights movement based on pride in sign language and deaf identity.

The academic field of deaf studies arose from this movement. Repudiating the pathological model of deafness, it focused on the study of deaf cultural attributes, among them linguistic practices, literatures, rules of etiquette, values, marriage patterns, and community institutions. Ethnic studies rather than disability studies was its primary model. The term “deafness” came to be used mainly to denote hearing loss, as opposed to “deaf” (or “Deaf”) cultural identity. “Deafhood,” first proposed by British scholar Paddy Ladd (2003), is sometimes used as an alternative. Recent work in the field, however, has brought considerations of the body and concepts from disability studies into deaf studies. A growing emphasis on the centrality of vision to the deaf experience, and the ways in which deaf people process visual information differently from hearing people, has led some to suggest that deaf people might be better referred to as “visual people.” Dirksen Bauman and Joseph Murray (2009) have proposed the concept of “deaf gain” (as opposed to “hearing loss”) to suggest that diverse sense experiences can lead to valuable alternative ways of understanding.
Today multiple forces are confounding older conceptions of deafness. University students and scholars now study sign language, a movement begun by William Stokoe's linguistic research at Gallaudet University in the late 1950s. In many areas of the world, the stigma of deafness has been much reduced, while opportunities for higher education and employment have improved. At the same time, the majority of deaf children no longer attend separate schools, disrupting the intergenerational transmission of deaf cultural values and languages. Minority groups generally remain cohesive and distinct commensurate with their exclusion by the majority; like other minority groups that have gained social acceptance, the deaf community has seen many of its organizations, which proliferated in the twentieth century, disappear. An oft-discussed question is whether this signals the end of deaf culture or merely its adaptation to changed circumstances.

When the use of cochlear implants in children became widespread in the 1990s, a National Association of the Deaf (NAD) position paper called it "ethically offensive" (1997), and many deaf people viewed it as "cultural genocide." Today, with implants increasingly common, opposition has diminished. The current NAD position, adopted in 2000, accepts implants as "part of today's reality" and calls for "mutual respect for individual and/or group differences and choices." Deaf people are very aware, however, that advances in implant technology, coupled with genetic and stem cell medicine, may in the foreseeable future mean an end to deafness itself. George Veditz predicted a century ago that "as long as we have deaf people, we will have signs" (qtd. in Padden and Humphries 2005, 77). What if there are no deaf people? Among wealthier countries, where implantation rates now range from 50 to 90 percent of deaf children, the continued existence of viable deaf communities is in doubt (Johnston 2004). Markku Jokinen, the former president of the World Federation of the Deaf, argued in 2001 for a community defined by the use of sign language rather than deafness. But whether a sign language-using community can persist without some critical number of deaf members is an open question. The phenomenon of deaf communities was born of a particular moment in history that may now be coming to an end. It was technological developments in agriculture, industry, and transportation that made modern cities—and thus modern deaf communities—possible. A new phase of technological innovation may soon bracket the other end.
Design
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Disability is an ever-present human condition, an integral part of the continuum of every individual’s life. Because everyone will be disabled at some point, disability is not a condition of a minority market (Davis 1995, 2002). Yet designing for disability is often regarded as a specialty area among architects or product designers, who often have to work within legal constraints, such as the building accessibility guidelines set forth in the Americans with Disabilities Act (ADA), in order to accommodate the needs of disabled individuals. Prior to the ADA, the work of very few architects and designers considered sensory impairments or wheelchair access and maneuverability in interior spaces, much less in public ones. By failing to consider and integrate limited perceptual and mobility levels, their designs posed barriers to some users. These barriers, as well as social and economic attitudes and policies that ostracize and exclude, socially construct “disability.” In contrast, “inclusive design” is a practice that seeks to avoid such barriers, so that individuals with a diverse range of abilities can function more easily and fluidly within the built environment. The inclusion of curb cuts in sidewalks as a result of disability activism offers a famous early example of a simple change that benefits all users, from wheelchair users to cyclists to people wheeling luggage.

Designers can better serve humanity by integrating human changeability and rangeability into design theory and practice from the outset, rather than isolating less common or less frequent ability ranges within the categories of “disability.” This is especially so if designers are serious about a vision of sustainability that not only entails environmental and economic concerns but also strives for social equity (Braungart and McDonough 2002). Spaces and products designed for longevity and usefulness could easily support an individual’s transition through a full range of abilities. For example, by designing all buildings with full accessibility features in the form of grouped apartments, the assisted living community Ros Anders Gård in Västerhaninge, Sweden, eliminates the need for disruptive relocations as seniors lose abilities. The apartments open onto common spaces and common kitchens, and they are domestic and homelike rather than institutional, so that residents can come early and live there, as independently as possible, for the duration of their lives (Evans 2009).

Because this type of inclusive design is not yet widespread, consumers accept that they will likely need to buy a new house or cooking tools or clothes as they age or gain some weight. Built-in product limitations, combined with manufacturer’s cultivation of planned obsolescence and expendability of goods, which force the purchase of specialty designs for changed abilities, have increased the profitability of mass production. In fact, this unsustainable but profitable design strategy stems from twentieth-century machine-based methods of mass production and standardization. Before the emergence of the industrial processes that made large-scale production possible, clothes were sewn for individual bodies to include the possibility of alterations. The onset of mass-produced clothing arose concurrently with social scientific methods of biometrics, anthropometry, and statistical averaging. Consumers became accustomed to the codification of bodily diversity into a small number of normalized sizes and body types, to the exclusion of others (Banta 1995). This process was carried
to an extreme in clothing made for individuals in state institutions offering physical and mental care; not just the working professionals but also those receiving their care were made to wear uniforms. This "institutional" culture and aesthetic has marked design for nonnormative populations throughout the twentieth century, and only recently have wheelchairs, hearing aids, and fashion become much more stylish, decorative, and customizable for individual preference, expression, and need.

Early twentieth-century institutional practices, such as the medical model of rehabilitation that isolated disabled individuals from society, reinforced ideas of disability as difference from an idealized normality (Silvers 1998; Serlin 2004; Linker 2011). Many modernist designs of the 1930s and 1940s furthered this approach, as principles of streamline design mirrored progressive eugenic sociopolitical policies aiming to eliminate "degeneracy" from the modern world, at the same time emphasizing the "ideal" as standard (Cogdell 2004; Gorman 2006). Marking the beginnings of a changing attitude in the mid-twentieth century, the firm of Henry Dreyfuss Associates created the ergonomic templates for "Joe" and "Josephine," statistical representations of imaginary male and female types that each encompassed a range of sizes (Dreyfuss 1955). Dreyfuss used Joe and Josephine as the basis for ergonomic design, exemplified by the iconic Bell telephone design in which the handheld portion conformed to size and angle constraints that would be comfortable to human hands.

This new approach, whereby a single design could serve a wide range of sizes and abilities, laid the foundation for the principles of universal design, initially promoted by designer and disability rights advocate Ron Mace in the late 1980s and popularized later by OXO's Good Grips line of cooking utensils. Inclusive design, Europe's counterpart to universal design, identifies how particular designs exclude users and attempts to promote inclusion throughout the design process (Clarkson et al. 2003; Pullin 2009; Williamson 2011; Hopper 2012). As the most widespread approach today, inclusive design inherently recognizes that disability and difference are normal, aiming to affirm human rights and dignity by designing for all without stigma. Promising trends in culture and design—such as the recent revival of handcraft and the local, and greater attention to fostering human diversity and biodiversity—suggest a changing mind-set that facilitates broader factoring of full rangeability into all levels of design ideation and production.
Embodiment
Abby Wilkerson

One of the earliest goals of disability studies was to expose the various methods by which some bodies are marked as different and deviant while others are marked as normal. Disability studies scholarship focused on medicalization, rehabilitation, segregation, institutionalization, sterilization, and genocide demonstrated how such practices were instrumental to ideas of normalization and deviance. More recently, however, disability scholarship and disability culture more broadly have turned away from forces of institutionalization or medicalization to explore the relationship between disability and the concept of "embodiment." Embodiment is a way of thinking about bodily experience that is not engaged solely with recovering the historical mistreatment of disabled people. Rather, it includes pleasures, pain, suffering, sensorial and sensual engagements with the world, vulnerabilities, capabilities, and constraints as they arise within specific times and places.

Although embodiment sometimes serves as a synonym for corporeality—the state of living in/through/as a body—disability studies scholars have tended to use the term in relation to phenomenology, the philosophical study of conscious experience from an individual person’s subjective perspective. This approach to the concept of embodiment is intended to serve as a corrective to Cartesian dualism, the historic Western legacy derived from the French philosopher René Descartes that posits a strict dichotomy between mind and body.
in which the former assumes rational control over the latter's messiness and irrationality. Thomas Hobbes's *Leviathan*, for instance, affirms the political value of discrete and rational independent subjects who are the authors of their own existence. Hobbes regarded "men as mushrooms," originating out of nothing, born of no woman (Benhabib 1992, 156), thereby implying that by being "self-made" some men could achieve rational control of mind over body. Many disability studies scholars have suggested that Hobbes's definition of personhood is a normative fantasy of the physically and cognitively privileged.

Feminist phenomenology engages with ideas of rationality and body to understand embodiment as a form of gendered experience. This approach to phenomenology, which takes its cues from Edmund Husserl and Simone de Beauvoir, understands embodiment as a form of subjectivity that is manifested bodily, a ground of intentional activity and the means of encountering the world. Feminist phenomenology's version of embodiment reveals how bodily normativity is coded as masculine and constant. Bodily changes—such as aging, menstruation, menopause, or pregnancy—are regarded as forms of risk, disturbance, or breakdown, and irrationality (as in the womb-related derivation of the word "hysteria"). Seen through the lens of disability studies, embodiment frames bodily change as a horizon for self-understanding and self-definition, and the body as an agent interacting with others and with the world more generally (Weiss 1999).

Embodied disability perspectives not only generate incisive critiques of social norms and practices; they are also the basis for understanding and critiquing other areas of philosophical inquiry such as ontology, epistemology, political economy, and aesthetics. Along with feminist, postcolonial, and critical race approaches to embodiment, disability studies offers a distinct departure from Western liberalism's understanding of personhood as rational and disembodied. Taken together, these perspectives produce a radical cultural/material politics of disability while bringing new insights to the phenomenology of embodiment more generally. Indeed, a disability studies approach to embodiment contributes significantly to intersectional critiques of liberal individualism as expressed (or, rather, embodied) historically in the interests and expectations, all normative and invisible, of able-bodied white bourgeois heterosexual men.

Many disability theorists insist on a pluralistic understanding of embodiments as multiple, intersectional, and interdependent. Some clearly convey that individuals experience forms of interdependence that often shift and change over time, rather than strict independence (Pazzarino 1994). The survival and well-being of human bodies, they argue, require extensive networks that orchestrate caregiving, personal assistance, and many other forms of labor (Kittay 1999). Witness, for example, the dehumanization of people who rely on feeding tubes or feeding assistance. Bodies that require nonnormative means of taking nourishment risk a socially imposed loss of personhood (Gerber 2007; Wilkerson 2011). Theories of interdependence and collaboration repudiate the concept of autonomy and control over one's body as authentic measures of personhood and expand normative definitions of what constitutes social and political inclusion.

Disability-informed theories of embodiment also provide the basis for rethinking the parameters of selfhood and identity, especially in relation to caregivers and prosthetic devices (Bost 2006, 358). Some Latina feminist narratives, for example, are structured by a critical sensibility of chronic illnesses such as AIDS and diabetes. "Bodily matter" and "its friction against existing material boundaries" demonstrate that "the
language of illness provides a metaphor for politics based on wounds and connections rather than universalizing identities” (Bost 2008, 353). While disability itself is not synonymous with illness—a significant insight of disability culture and activism—illnesses and wounds can serve to ground a radical disability politics. Their material presence can unsettle abstract and totalizing identity categories—the idea of “health” and “illness” as diametrically opposite rather than mutually reinforcing—while also fostering solidarity and coalition against ablest and otherwise oppressive social definitions of normacy.

Disability narratives involving chronic illness often rely on embodiment to establish a sense of identity “predicated on fluid boundaries” (Lindgren 2004, 159). They convey a phenomenological sense of illness as “uncannily both me and not-me,” suggesting possibilities for “models of identity that incorporate difference” (159). In addition, disability perspectives significantly advance the phenomenological concept of “intercorporeality,” which “emphasizes that the experience of being embodied is never a private affair, but is always already mediated by our continual interactions with other human and nonhuman bodies” (Weiss 1999, 5). Intercorporeality, as a concept, allows scholars to pay close attention to the dynamics of care relations (Kittay 1999), prosthetic relations between bodies and medical devices, and other forms of social and technological interdependence.

Disability intercorporealities also have the capacity to “crip” conventional understandings of kinship. For instance, families with disabled children are “rewriting kinship” and finding routes to collective action through shared resistance to public policies and cultural norms that devalue or marginalize disabled relatives, or that pressure women to abort disabled fetuses (Rapp and Ginsburg 2001). Queer disability narratives also rewrite kinship in new ways, including Latina feminist notions of “queer familia” as a condition for survival and connection (Bost 2008, 355; Panzarino 1994). Disability theories of intercorporeality also attend to new forms of “embodied pleasure,” such as the “bodily attunement” of a child and occupational therapist who are both engaged in the poetics of autistic speech and movement (Park 2010).

Disabled embodiment provides epistemological resources for working through vexed questions of suffering and impairment. A phenomenologically grounded notion of embodiment can generate knowledge of pain as suffused with social meaning. Indeed, for some scholars, a focus on embodiment entails respect for experiences of suffering (Lindgren 2004, 151). At the same time, focusing on illness and suffering can “expand one’s sense of embodiment” (Bost 2008, 350) through, for example, opening up an experience of physical pain as a channel of vital knowledge that can include politically radical possibilities.

In recent years, disability-informed theories of embodiment grounded in political economy have inspired analyses of globalization. In these approaches to embodiment, disability is understood as materially and geographically based, rather than a mere effect of discourse or flaws located within individual bodies or minds, as dominant paradigms of globalization would have it (Davidson 2008, xviii). Embodiment becomes a mode of material/cultural analysis that illuminates “the political economy of difference” (Erevelles 2001, 99) by attending to whose bodies are affected, and how, as capitalist profit imperatives meet changing labor and market structures. Work in this area of disability studies ranges from critiques of “disembodied citizenship” and the global organ trade (Davidson 2008) to analyses of political subjection in late capitalism (Erevelles 2001), to examinations of the global agro-industrial food
system and claims of an obesity pandemic (Wilkerson 2011), and the neoliberal demand for flexible bodies (McRuer 2006). Such work advances disability studies’ imperative to situate embodiment within specific environments and attend closely to material circumstances.

Finally, disability perspectives on embodiment have also produced a generative and critical aesthetics. Disabled embodiment refutes social conceptions of disability as pathology and social norms of productivity by providing “different conceptions of the erotic body” that contest hegemonic notions of beauty and vitality (Siebers 2008a, 302). Thus, thinking critically about embodiment helps facilitate the politically radical potential of a “critical disability aesthetics” to create identifications beyond normative notions of bodies, lives, and persons (Davidson 2008, xvii). As a result, the embodied experiential knowledge of disabled people has become a fundamental resource for disability cultures and modes of disability activism: as the late Latina feminist scholar Gloria Anzaldúa once observed, “Along with your dreams the body’s the royal road to consciousness” (Bost 2008, 350).
Gender and disability, along with race, class, nationality, and sexuality, are constitutive features of the ways in which our fully integrated selves—what Margaret Price (2011) calls “bodyminds”—are lived and known. Gender has emerged as a key site of disability critique in four general areas: (i) sex, impairment, and the “realness” of the body; (ii) the medicalization of gender; (iii) the mutually reinforcing structures of gender and disability oppression; and (iv) the reconfiguration of gender through disability experience. Thus, if disability theorists hope to understand and critique norms of bodily appearance and bodymind functioning, as well as offer meaningful alternative conceptions of the world and being, they must attend to how gender structures and is structured by those norms. Similarly, feminist and queer theorists cannot develop adequate accounts of gender without attending to the entanglement of the meaning and materialization of gender and disability.

Just as disability theorists have distinguished between impairment and disability, feminist theorists have distinguished between sex and gender. Sex refers to the chromosomal, anatomical, and physiological characteristics that mark the body as male, female, or intersex. Gender, by contrast, refers to socially, culturally, and historically contingent norms of appearance, bodily comportment, behavior, and desire that define what it means to be masculine, and thus a man, and feminine, and thus a woman. In this picture, those who queer gender norms, such as butches, femmes, trans-identified people, and other gender-transgressive people, fall along a gender continuum. Feminist and disability theorists have worked diligently to show how gender and disability are socially and culturally produced in order to combat the naturalization and regulation of “woman,” nonnormative gender, and disability. In oppressive contexts, naturalized conceptions of gender and disability operate to rationalize and normalize injustice against women, gender-transgressive people, and disabled people.

One consequence of sex-gender and impairment-disability distinctions is the relegation of sex and impairment to the body. Some feminist and disability theorists are concerned about the extent to which those distinctions lead to a devaluation of the material body, in particular purportedly real physical dimensions of gender and disability (Alaimo and Hekman 2008; Siebers 2008a, 2008b). In defense of a “materialist turn” in feminism, Stacy Alaimo and Susan Hekman contend that focusing on ideology or representation alone neglects attention to, among other things, bodily pain and diseases that affect women’s “real” bodies (2008, 3-4, 6). For them, understanding the body and nature as produced by interactions between the material and the discursive (7) enables a more constructive critical attention to bodily conditions, like pregnancy, that must be acknowledged as sex-linked to a certain extent in order to understand them and provide access to the best care possible. This recent feminist turn to “the material” has a corollary in some disability discussions about pain and impairment. For example, Tobin Siebers argues for a realism about the disabled body that attends to the body’s agency and the “real” embodied lives of disabled people (2008b, 67-68).

Other feminist, queer, and disability theorists question the assumption that sex and impairment are mere facts of bodily materiality (Hall 2005, 2009; Kafer 2013;...
Salamon 2010). As Gayle Salamon (2010) and Alison Kafer (2013) point out, it is difficult, if not impossible, to know what impairment and sex mean or how they are inhabited independent of the social and cultural context in which bodies are lived and assigned meaning. In addition, assuming the facticity of sex naturalizes binary understandings of sex and gender, which is often made possible by ignoring the lived bodily experience of gender-transgressive people (Salamon 2010; Spade, “About Purportedly Gendered Body Parts”). Among other negative consequences, naturalizing binary sex and gender often results in pathologizing gender-transgressive people and inhibits their access to health care.

Feminist theorists have rigorously critiqued the heteronormative gender bias that informs the medicalization of gender (Fausto-Sterling 2000; Butler and Weed 2011). As Fausto-Sterling (2000, 3) argues, the medical model relies on a flawed view of nature, and biomedical knowledge about sex difference reveals much more about dominant gender beliefs than about nature. The medical model conceptualizes disability, transgender, and intersex as problems in need of cure/elimination. In the case of intersex, “cure” involves surgical creation of binary sex; in the case of transgender, “cure” has involved sex reassignment surgery to fix gender identity disorder (GID). While trans people who desire sex reassignment surgery and hormone replacement therapy may not perceive these procedures as a cure for “misaligned” sex and gender, they have been forced to submit to a GID diagnosis in order to receive permission to access the medical services they need to exercise gender autonomy. The most recent edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), published in 2013, replaced GID with a new category, gender dysphoria (Beredjick 2012). The effects of this new diagnosis for gender-transgressive people remain to be seen. While many trans activists welcome the end of characterizing gender transgression as a disorder, they also wonder about the implications for legal advocacy because of the strategic use of the GID diagnosis in fighting discrimination against trans people (Beredjick 2012). Still, the introduction of gender dysphoria into the DSM-5 does not signal an end to the medical regulation of gender.

In recognition of some degree of overlap between trans and disability experience, one can consider the successful, but fraught, use of state disability statutes in legal advocacy for trans rights. Like disability advocates, trans advocates can and have used state disability discrimination laws to locate the problems of exclusion and discrimination in the built and conceptual environment rather than in the bodies of trans people (Spade 2003, 32–33). Both disabled and trans people are stigmatized, a problem that can be addressed by changing dominant beliefs, attitudes, and environments, not by “curing”/eliminating nonnormative bodyminds.

Identifying the mutually reinforcing structures of gender and disability oppression involves understanding how other axes of identity, such as race, class, and sexuality, inform gender and disability. Spade’s use of the Americans with Disabilities Act in legal advocacy for trans rights is often on behalf of poor people and people of color who have no health insurance and are most vulnerable to regulation of myriad state institutions such as prisons and foster care systems. Eugenics and “eugenic logic” (Garland-Thomson 2012) are also sites where gender, race, class, and sexuality oppression converge to the detriment of nonnormative bodyminds. Susan Burch and Hannah Joyner (2007) describe the life of Junius Wilson, an African American deaf man born in North Carolina in 1908 and imprisoned in 1925 in the then-named State Hospital for the Colored Insane, where he was sterilized and castrated. Burch and Joyner
explain how white racist mythologies of the black male rapist, along with Wilson's inability to communicate with others because of his deafness (and because others could not comprehend his Raleigh signing), were used by white state authorities to diagnose Wilson as a sexual pervert and prescribe sterilization and castration as a cure (2007, 47). Had Wilson been white, his experience would have been different. Historically, beliefs about gender have informed definitions of and treatments for mental disability. Thus, racialized, classed, and heteronormative gender regulation has been an important function of the diagnosis of mental disability (Carlson 2001, 2010; Price 2011).

In addition to making visible and analyzing the intersectedness of gender, race, class, disability, sexuality, and other axes of identity, feminist queer disability theorists understand how disability experience can be a site for critical reconstructions of gender. While some disability theorists argue for recognition of disabled people as "real men" and "real women," others have used disability as a critical resource through which to reimagine gender beyond heteronormative and able-bodied binaries. Embodying "normate" (Garland-Thomson 2011) gender, for example, requires having a body whose appearance and capacity are in conformity with dominant gender norms (Garland-Thomson 2011; James 2011; Mintz 2011; Serlin 2003). Naomi Finkelstein (2003, 317) describes feeling "emasculated" by fibromyalgia-rheumatoid arthritis while also understanding it as an experience that enables reconfiguring what it means to be butch. Being a "crip butch" reconfigures masculinity as openness to vulnerability and simultaneously exposes cracks in narrow gender norms (317). Similarly, Eli Clare (1999) writes about the complex process of trying to reclaim one's gendered disabled body, a process that involves negotiating categories like "woman" and "tomboy" that don't quite fit, as well as urban markers...
Normal
Tanya Titchkosky

When we know that norma is the Latin word for T-square and that normalis means perpendicular, we know almost all that must be known about the area in which the meaning of the terms “norm” and “normal” originated... A norm, or rule, is what can be used to right, to square, to straighten... to impose a requirement on an existence.


Thinking critically about disability requires exploring the normative order of the social and physical environment that—as Canguilhem suggests—straightens out the lives of disabled people, T-squaring and otherwise measuring some people’s minds, bodies, senses, emotions, and comportments against the rule of normed expectations. Both in everyday life and in the human sciences, “normal” often appears as if it is a static state of affairs, and when people are said to have an unwanted condition, they may be deemed to have an abnormality. Disability studies, in contrast, has shown not only that norms change radically over time and from place to place but also that the seemingly omnipresent commitment to seek and measure the normal is in fact a rather recent historic development (Davis 1995; Garland-Thomson 1997; Stiker 1999; Finkelstein 1998). Still, the prevailing assumption in educational, health, and rehabilitative sciences, as in everyday life, is to treat norms as static and subsequently to measure how others appear to depart from them. It is this way of treating norms that socially produces a sense of normalcy as if it is an objective and universal phenomenon.
Disability studies maintains a unique relation to what counts as normal by examining “normal” as a historical and cultural production. The term, as well as the consequences of its production and its use, are artifacts of history. While group life may have always been tied to collective expectations, Lennard Davis argues that “it is possible to date the coming into consciousness in English of the idea of ‘the norm’ over the period 1840–1860” (1995: 24). Tracing out this development, Michel Foucault says that the sense of a normative order required that the human sciences not only make “man” (humans) an object but also make them knowable, to one another, through “norms, rules and signifying totalities” (1970, 296, 364). This normative order is today the dominant version of self-understanding within modernity. We are measured through psychometric and intelligence tests, weight and height charts, and demographic surveys, or measured in more everyday ways by, for example, showing how a child departs from age-specific norms for walking, talking, thinking, or interacting. These measures show that the power of normalcy is to convince us that measurement and comparison are reasonable and that they can be “used to right, to square, to straighten” all conflicts, differences, ideals, or values in relation to a taken-for-granted sense of normal life.

That norms are used to evaluate with reference to group expectations demonstrates that the normal is a referential system of sense making and not a natural or pregiven condition of existence. Using the word “normal” followed by the suffix “ity,” for example, reflects the common notion of “normal” as a static thing. In contrast, disability studies’ focus on the creation of normal as it is produced and applied is reflected in the word “normalcy,” where the use of the suffix “cy” emphasizes action and doing. Against the backdrop of “normal,” disability is ordinarily made to stand out in a stigmatized fashion. This stigmatizing action is conveyed by “abnormal,” where the prefix “ab” means “away from.” “The ‘problem,’” Davis writes, “is not the person with disabilities; the problem is the way that normalcy is constructed to create the ‘problem’ of the disabled person” (1995, 24). Normal, therefore, is a position from which people deem other people to be lacking, different, dysfunctional, deformed, impaired, inadequate, invalid.

That “normal” can be understood as a vantage point is reflected in Rosemarie Garland-Thomson’s development of the term “normate,” which she describes as “the constructed identity of those who, by way of the bodily configurations and cultural capital they assume, can step into a position of authority and wield the power it grants them” (1997, 8). An ordinary practice in the production of normalcy is to make it noticeable to the normative order that one has noticed that the other departs from normalcy—“What are you, crazy?” or “I don’t mean to pry, but have you always been disabled?” or “I would kill myself, if it happened to me.”

Disability studies has responded to the norming of all of existence by the sciences (Canguilhem 1978; Foucault 1970; Stiker 1999) by critically attending to the “production” and “validation” of the normal (cf. Darke 1998, 183; Goodley, Hughes, and Davis 2012; Snyder, Bruegeman and Garland-Thomson 2002), the “ideology of normality” (Finkelstein 1998, 30), and the hegemony of normativism” (cf. Coker and Shakespeare 2002, 14; Davis 1993). This work shows us how the “normal” is enforced, imitated, enacted, taught and bought; sold and recycled; enhanced, longed for, and resisted. It documents how normalcy’s standards and measurements contribute to racist, sexist, and other forms of human diminishment that position some humans on the edges of belonging.

Disability studies also shows how the “normal” is never static but changes from group to group, over time, and from place to place. For instance, most people will
live at least part of their lives with disability. Yet, despite this statistical probability, disability generally remains an unacknowledged feature within social structures and forms of interaction (see McRuer 2006, 30; Titchkosky 2011, 30). As a result, disability is treated as an exceptional state of being. “Normal,” thus, does not describe what the majority is or does; rather, it represents what a given population is expected to be and to do. This means that appearing as normal takes work or, as Harvey Sacks puts it, each of us has “as one’s job, as one’s constant preoccupation, [the] doing of ‘being ordinary’” (1984, 414). To “become normal,” then, is to manage the appearance of any departure from the expected as an unwanted difference; to “act normally” or “to pass” means to be perceived by others as moving squarely within the realm of the expected; to “be normal” is to do what needs to be done to be taken as the expected. Thus, “abnormal” is not an objective departure from the norm; it is what is produced when a perceived difference is taken as an affront to ordinary group expectations. The social process of perceiving “undesired differences” is what Goffman studied as stigma (1963, 5, 137).

By exploring the constructed nature of normalcy—and rejecting the notion that normality is “just there”—disability studies is uniquely positioned to examine the power of normalcy to exclude and to stigmatize. But, as Rod Michalko reminds us, “One of the most ‘abnormal’ things about being ‘normal’ is attending to its production” (2002, 82), and thus the importance of examining the way that role obligations are used to conform to, resist and even re-create the normal. Still, scholars, artists, and activists have shown us that even as we are subjected to the daily demands to structure our perception of self and others in normalized ways, we can nonetheless crisp, queer, and otherwise question the modern demand that all group expectations can and need to be normed (Titchkosky and Michalko 2009).

But queering and crippling normalcy can also entail questioning whether the system of reference that is the normalcy orientation is the only way to take group expectations and human difference into account. Every departure from normalcy can easily be rerouted to a new normal that can put a lid on imagination. There are, after all, “normal” ways to be disabled, to become disabled, to act as a disabled person, or even to do disability studies. For example, in inclusive design, as well as in some aspects of inclusive or special education, it is sometimes said that it is “normal to be different.” Medical sciences and corporate culture have made selective use of this rescripting of the language of normalcy, as in a recent Tylenol advertisement’s demand to “get back to normal, whatever your normal is.” Following disruption, trauma, injury, or illness, we are told to accept a “new normal.” Navigating these shifting meanings of “normal” implies reconceiving expectations about how to live as embodied beings. While resistance to dominant conceptions of normal experiences of embodied existence has been central to disability studies, there is no agreement on how best to resist. The work of disability studies will need to continue to consider whether and how forms of resistance and conceptions of “new normals” might enhance our lives together or continue to T-square life to those powers that already organize the exclusive character of everyday existence.
Prosthetics
Katherine Ott

Prosthetics fall within the broad category of assistive devices that people use to support what they want to do. Assistive devices, in general, enhance such capacities as mobility and agility, sensory apprehension, communication, and cognitive action. But the field of prosthetics, in particular, refers to those artificial body parts, devices, and materials that are integrated into the body’s daily routines. Because “prosthetics,” as a term, encompasses the way people select hardware, undergo procedures, and understand the results, there is no one immutable definition for it.

Prosthetics runs the range of detachable, wearable, implanted, or integrated body parts and may be functional, cosmetic, decorative, or hidden. It covers a wide range of components: from familiar designs such as peg legs, split-hook hands, and myoelectric limbs that yoke nerve signals from remaining muscles, to artificial skin, replaced hip joints, eyeglasses, hearing aids, strap-on penises, and reconstructed bones. Some prosthetics use sensory feedback, thought control, or neuronal elements to move limbs, process speech, or simulate vision. Implant engineering, by contrast, repairs the body from the inside out through integration of artificial tissue.

For most of history, prosthetics was a do-it-yourself enterprise and continues to be so in many parts of the world (Putti 1930). Because each human body and its prosthetic need are unique, each device is customized. The person takes possession of the device through alteration, decoration, daily use, and further fitting with accessories such as shoes, makeup, stump socks, gloves, and attachment methods. Society mobilizes to study the problem and provide solutions when historical events—most often wars, natural disasters, and the application of new technologies to human endeavors such as work, transportation, sports, and entertainment—create large numbers of people in need of prosthetics.

The object most commonly associated with the word in medical and popular literature is the lower limb prosthesis (Ott, Serlin, and Mihm 2002). The 1851 Great Exhibition, held in London’s Hyde Park, brought attention to these objects as makers displayed the first modern prosthetics as consumer goods. During the U.S. Civil War, battlefield tactics and the weapons used produced injuries and infections that resulted in a high rate of amputation. A ball of soft lead made a ragged entry and shattered bone. Battlefield conditions, inadequately trained surgeons, and no understanding of asepsis resulted in necrosis, gangrene, and amputation. The surgical outcome often produced a painful stump, despite new flap techniques.

In the last half of the nineteenth century, a proliferation of injured people—civil war veterans, industrial workers, and those hurt in railroad, trolley, auto, and other accidents—fuelled change in medical procedures and design of devices. Middle-class consumers embraced the aesthetics of lifelike designs instead of peg legs and eye patches (Herschbach 1997). The popularity of social Darwinism further increased the stigma of having a body that might use a prosthesis, and municipalities began to outlaw begging, a common livelihood for such people. Yet, veterans often preferred the valorous empty sleeve or pant leg to an awkward and heavy commercial device, even though after 1870 every honorably discharged Union soldier of the Civil War was entitled to a modern limb.
World War I brought widespread attention to veterans in Europe, the Soviet Union, and the United States who had suffered amputation on the battlefield and became wearers of prosthetic limbs as part of their transition to civilian life and the postwar industrial workforce (Panchasi 1995). The Great War also brought attention to the emerging surgical specialty of facial reconstruction and, consequently, facial prostheses, which gained relevance through the work of Anna Coleman Ladd and others. The most significant advances in prosthetics and rehabilitation began with World War II (Sauerborn 1998; Ott 2005). Not only were so many soldiers wounded, but many more survived their injuries. In 1945, the U.S. surgeon general requested that the National Academy of Sciences initiate a research program related to rehabilitation of the injured. This project generated the field of biomechanics and its understanding of body forces. As a result, prosthetics began to be imagined differently, using robotics, ergonomics, kinesiology (movement), and human engineering (Serlin 2004). By the 1950s, professionals working in prosthetics and orthotics needed board certification. Government-funded research during wartime or related to war's consequences has continued to generate innovations in prosthetics. For example, a contemporary soldier injured by shrapnel from an improvised explosive device ripping through an exposed extremity will likely learn to use an Otto Bock “Utah” limb with a microprocessor chip that reads the environmental interface hundreds of times a second to facilitate motion—a user no longer “swings” the leg.

Medicine, science, and engineering have regularly deployed prosthetics to “fix” bodies perceived as having deficits, such as skeletal deficiencies, including those born without various bones or those with atypical bodies resulting from medical treatment, such as infants born in the late 1950s with physical anomalies after their mothers took the drug Thalidomide. The advent of microsurgery, skin grafting, burn treatment, medications, and a range of medical techniques influenced both survival and the nature of the outcome for people who use prosthetic devices. For example, metal and wood were good for limb but not for facial designs. Rubber, latex, vulcanite, and plastics were appropriate for facial appliances and as components of more complicated limb designs. Acrylic resins, introduced in the 1930s, silicones in the 1960s, and hydroxyapatite in the 1980s have enabled implanted and integrated devices to take shape.

Because the contexts in which prosthetics may occur are so varied, the disciplines that engage with and discuss them are equally varied. Where technology is understood as a medium for breaking boundaries, pushing into the next frontier, and creating a new body-machine interface, the prosthesis-as-metaphor is especially rich. In the popular imagination, prosthetics has a rich visual, political, and material vocabulary. Historians, looking at prosthetics, examine macroforces that brought them into being such as war, industrialization, medicine, accident and injury, and materials science, as well as individual and community experience. Product designers deal with aesthetics of the hardware (Pullin 2009). Rehabilitation focuses on the process of incorporation of the artificial part into one's mechanical and psychic sense of self. In sociology, psychology, and anthropology, a prosthesis can function as a social symbol and a political allegory for one's self. As metaphor and metonymy, the concept of the prothetic may compensate for an injury, serve as a symbol of devotion to country, provide an object of sexual fetish, or act as an anodyne for grief and mourning (Wills 1995; Mitchell and Snyder 2001). A prosthesis can serve as an index of modernity, manhood, or malevolence—or sometimes all three.
In disability studies, prosthetics is not typically the stuff of performance art or Hollywood special effects makeup. Yet scientists, designers, engineers, and journalists have come to rely on these metaphors and narratives of inspiration in framing analyses of prosthetics. As interpreted by journalists who cover this technology, as well as science fiction writers, filmmakers, video gamers, and graphic artists, prosthetics turns a person into a cyborg or bionic human. Such cultural producers commonly approach the subject based upon technological potential, while the actual disabled body plays only a minor role. For example, when the media feature wounded soldiers as recipients of prosthetics, the practical utility of the device is often secondary to its status as an example of bionic technology. (“Bionics” describes both the application of biological principles to engineering and design and the replacement of biological entities with electronic and mechanical components.) Discourse about cyborgs began in earnest with Donna Haraway’s “Cyborg Manifesto” (1991; originally published in 1985) which offered a feminist critique of the military-industrial character of the cyborg, a hybrid term announcing the integration of the cybernetic and the organic. For Haraway, the cyborg consciously transcends human material limits and collapses the boundaries between machine and organism. The romance of the cyborg in the popular imagination is exemplified by a disabled or typically abled body that can become super-abled when engineered with superpowers that enhance human potential.

The political development of a disability rights movement in the twentieth century has gradually altered the cultural environment in which designers, engineers, and medical practitioners work. As disability became understood as a civil rights issue, the inclusion of users as authorities gained prominence. Consumer and creator input brought the split-hook hand, the Flex-Foot and sprint leg, and countless changes in medical practice. This is because while biomechanical invention has expanded the functionality of the human form, it has also raised significant ethical and political issues, such as using a device to “pass” as nondisabled, or for what age or demographic group a particular device is appropriate, or whether the benefits of an appliance are sufficient to be subsidized by insurance. Other debates focus on the implications of runners who use prosthetic devices in athletic competitions, or whether cochlear implants foster cultural genocide, or what it means to be disabled, and who should pay the costs for artificial hearts.

These arguments go beyond those about replacements or technological interventions. For example, for many people with disabilities, acquiring and using a prosthetic limb is most often a strategy for creating access or restoring function rather than for enhancement. According to the U.S. Centers for Disease Control and Prevention, of the approximately 65,000 amputations performed each year in the United States, some 82 percent are of lower extremities and the result of vascular deficiencies such as occur with diabetes. Thus, presenting prosthetics as a superhuman or transcendent technology eclipses the everyday needs of those who use such technologies.

A critical and interdisciplinary approach to prosthetics, such as that offered by disability studies, leads to a more complex and nuanced comprehension of the human body and the role of culture, politics, and engineering in defining capacity. Unlike rehabilitation medicine or engineering science, disability studies asks questions about the role of prosthetic technology not only in relation to design and function but also in relation to disability rights, political autonomy, and cultural citizenship. Indeed, much critical disability studies scholarship examines the enduring relationship between
prosthetic technologies and histories of capitalism, empire, and the military-industrial complex. The use of a prosthetic is thus not a mark of deficiency or postmodern transcendence but rather an important dimension of human experience that demands thoughtful and empathic analysis.
Historically, the term “queer” was a stigmatizing label that often included disabled people in its purview. A century ago, for instance, someone with a missing limb or a cognitive impairment might be called “queer.” In recent decades, sexual minorities have reclaimed “queer” as a badge of pride and a mark of resistance to regimes of the normal, mirroring the embrace of terms like “crip” and the capaciousness of the term “disability” itself. These are all political, highly contested terms that refuse essentializing meanings. In the late 1980s and early 1990s, the activist group Queer Nation’s chant “We’re here, we’re queer, get used to it” was historically concurrent with the disability rights activist slogan “Not dead yet.”

What the field of queer studies shares most fundamentally with disability studies is a critique of the effects of normalization on embodiment, desire, and access. “Queer” opposes not heterosexuality but heteronormativity—the often unspoken assumption that heterosexuality provides the framework through which everything makes sense. Before Michael Warner invented the term “heteronormativity” in the early 1990s, scholars had been working with a notion of “compulsory heterosexuality” coined by the lesbian feminist writer Adrienne Rich (1983). Disability theorist Robert McRuer picked up Rich’s account two decades later in order to argue that compulsory heterosexuality depends upon compulsory able-bodiedness, since heteronormativity assumes first and foremost that sexual subjects
must be able-bodied, healthy, and therefore "normal." Indeed, able-bodiedness appears to be even more compulsory than heterosexuality because the latter requires the former. Normal sex—as opposed to its deviant or perverse forms—requires a normal body. Articulating disability theory with queer theory, McRuer (2006) thus developed a "crip theory" in which a critique of sexual normalization goes hand in hand with a critique of ableist assumptions about embodiment.

Critiques of normalization have a substantial history in the fields of both disability studies and queer studies. Indeed, those critiques generated their own critical terminology in their respective areas of humanities scholarship during the 1990s. In addition to Warner's coinage of "heteronormativity," Rosemarie Garland-Thomson deployed the concept of the "normate" in her influential book Extraordinary Bodies to designate "the social figure through which people can represent themselves as definitive human beings" (1997, 8). Similarly, Lennard Davis's Enforcing Normalcy (1995) described the cultural processes that perpetuate exclusionary corporeal norms and ideals. As with Warner's critique of heteronormativity, the central claim of this area of scholarship is that, beyond examining the bodily conditions or the physical environments that produce disability, disability studies should also examine those less tangible but profoundly distorted social expectations that presume what bodies should look like and be able to do.

Queer approaches to thinking about disability and sexuality argue that neither the human body nor its capacities are biologically determined; rather, both disability and sexuality are constituted via sociocultural processes of normalization. Sociologist Erving Goffman's Stigma (1963), for instance, influenced both disability studies and queer studies, in part because Goffman routinely refers to "cripples" and "homosexuals" in the same breath, as parallel examples of stigmatized identities. What remains crucial in Goffman's account is his insight that everyone falls short of identity norms; we are all potentially vulnerable to the injurious effects of social stigma. In other words, normalization does not exclusively bolster the interests of the so-called normal, since it also puts them at risk. Insofar as "queer" and "disabled" designate contingent identities, anyone can be queered or become disabled by failing to live up to particular norms or ideals.

The influential philosopher Michel Foucault broadens the scope of Goffman's sociological analysis by showing that power in modern society is exerted less through the channels of regulation and prohibition than through those of normalization and rehabilitation. Foucault's critique of normalization derives, in part, from the work of French medical historian Georges Canguilhem, whose study The Normal and the Pathological (1978) demonstrated that illness is routinely yet erroneously understood in terms of its departure from biophysical norms. Canguilhem's point was that significant variations from what is statistically normal for a population need not imply pathology. Only when mathematical norms get conflated with evaluative norms do such variations indicate sickness. This distinction between statistical and evaluative norms, which has been indispensable for the strand of queer theory developed by Warner, is also highly relevant for disability studies. In both queer theory and disability theory, the demystification of social categories as well as medical metrics helps to highlight the ways in which illness, health, and normality are constructed.

Nowhere have social and medical norms intersected so powerfully as with the phenomenon of AIDS. As literary scholar Ellis Hanson has contended, "Queer theory itself may be said to have begun as disability studies, sparked as it was by activist energies around the AIDS crisis" (2011, 113). Queer politics grew out of the AIDS
activism of the late 1980s, largely in order to insist that AIDS is not a disease of identity—that is, a disease pertaining only to pathologized social groups such as gay men or IV drug users. Among its many effects, the AIDS epidemic fostered a coalitional politics that cut across established lines of sexual, racial, and disabled identity, resulting in a specifically queer politics.

Disability studies may have catalyzed the origins of what scholars now think of as queer studies. But it is only once the two have been explicitly articulated relative to one another that the extent of their connection becomes clear. The connection enables literary scholar Anna Mollow to suggest that sex itself, in its effects on coherent selfhood, may be regarded as disabling. Drawing on a psychoanalytic strand of queer theory associated with Leo Bersani, Mollow argues that “disability” and “sex” represent “two names for the same self-rupturing force” (2012, 287). Here the connection between queer and disability stems not from social processes of normalization but from the impact of sexual intensity on bodily coherence. Mollow’s challenging hypothesis points toward a possible future for queer theory and disability studies by rethinking the extent of their mutual interdependence.
Race
Nirmala Erevelles

Race and disability, two significant categories of difference that shape the social, have often been conceptualized as analogous to each other. Disability has often been described as being “like race” and race as being “like disability” in attempts to shift the experience of disability from the debilitating conceptual space of individual pathology to a broader social recognition of disabled people as members of a political minority. Thus, for example, Rosemarie Garland-Thomson (1997) describes disability as a “form of ethnicity” (6), while Lennard Davis (1995) maps similarities between the disabled body and “the body marked as differently pigmented” (80). Foregrounding this analogous relationship between race and disability has helped propel the disability rights movement and disability studies scholarship forward into an alternative space of empowering possibility.

In the field of critical race studies, however, there are few echoes of a similar reciprocity with regard to disability. The act of correlating race and disability is often fraught with violent and oppressive overtones. For example, the historian Douglas Baynton (2001) has noted that “non-white races were routinely connected to people with disabilities . . . [and] depicted as evolutionary laggards or throwbacks” (36) to justify discrimination based on embodied difference from a mythical norm. Literary theorist Hortense Spillers (1987) documents the unimaginable brutality of such discrimination when she describes how the representational and physical
violence meted out to the black captive body during the Middle Passage and slavery enabled the slave's body to become a site where the battered flesh (disability) was transformed into the prime commodity of exchange in a violent conflation of profit and pleasure (Erevelles 2011).

These oppressive overtones continued to echo from within the Enlightenment discourses of the early eighteenth century and much of the nineteenth century, where philosophers like Hume and Kant utilized the analogy between race and disability to distinguish among "different breeds of men." Buttressed by an emerging science that proposed linkages between human anatomy and human capability (and, later, for Freud, the notion that "anatomy is destiny"), the racist practice of eugenic sterilization or selective breeding was institutionalized (Mitchell and Snyder 2003). Eugenic science sought to stem the threat of degeneration by controlling the reproduction of those designated as "feebleminded," which was fueled in part by the social and economic upheavals caused by industrialization. By the early twentieth century, the concept of feeblemindedness came to operate as an umbrella term that linked ethnicity, poverty, and gendered and racialized conceptions of immorality together as "the signifier of tainted whiteness" (Stubblefield 2007, 162). The fear of degeneracy associated with a "tainted whiteness" extended not only to Jewish Americans, African Americans, Puerto Ricans, Mexican Americans, Asian Americans, and American Indian women but also to lower-class white women based on their assumed shared "biological" inferiority and their reproductive incapacity to bear children that would assimilate into mainstream white society.

Mitchell and Snyder (2003) argue that it is necessary to recognize eugenics as a transatlantic cultural exchange—what they call the "eugenic Atlantic"—to mark how the discourse of disability was deployed throughout the European colonial diaspora. In this context, the concept of disability justified oppressive social, political, cultural, and economic policies based on the argument that racial difference and class inequalities represented pathological defects otherwise known as "disability." These ideologies of disability enabled European expansionists to justify the conquest of racialized others while simultaneously retrieving "an unspoiled, pre-modern version of an ever more complex western self" (848). With its commitment to a doctrine of human purity, eugenic science continued to erase the "histories, bodies, [and]/or cultures" (Jarman 2006, 149-150) of despised Others, as manifested in "protective" practices like genocide, forced sterilizations, rigid miscegenation laws, and residential segregation in ghettos, barrios, reservations, and state institutions like prisons and asylums.

In an ironic twist, the very same pathologized bodies made to disappear from polite society via regulatory or eugenic practices were rendered highly visible as "freaks" and transformed into spectacles for popular consumption and economic profit (James and Wu 2006; Adams 2001; Garland-Thomson 1997). For instance, the public's morbid fascination with the sexualized bodies of Saartjie Baartman, the South African woman known as the "Hottentot Venus," or other racialized freaks such as Ota Benga, and Hiram and Barney Davis, "the Wild Men of Borneo," was proof of the brutal conflation of race and disability. Such racial freaks were collectively represented to the public as the unbearable physical excesses that had to be shed to confer entry into the realm of normalcy (Adams 2001). Thus, for example, both scientists and policy makers involved in the "eugenic Atlantic" and proprietors and showmen involved in the freak show circuit presumed that it was the "natural" deviance of disability ascribed to the racialized body that constituted it as either the despised Other or the
profitable freak. In both cases, science and entertainment referenced “race” as the social locus of ascribed insufficiency while leaving disability as the default category of ‘real’ human incapacity” (Mitchell and Snyder 2003, 851).

Given this history, it has been difficult for critical race scholars to conceptually engage with the category of disability beyond the simplistic and problematic assertion that there is an analogous relationship between race and disability. Claiming that “race is like disability” or that “disability is like race” does nothing to engage the complex ways in which race and disability are imbricated in the construction of the pathological Other. For example, when disability is invoked in critical discourses of race, it usually suffers from what Chris Ewart (2010) has described as disappropriation. Here disability is used “to affirm (an often subordinate) voice to elucidate agency and figurative empathy for other oppressed and exploited populations” (152). Used in this context, critical race scholars, such as Stuart Hall, have described the life experiences of a racialized subject as “crippling” and “deforming.” In doing so, they fail to recognize that, rather than rejecting oppressive biological criteria, they unwittingly reaffirm an imagined biological wholeness (normativity) that was instrumental in the propagation of the same oppressive ideologies they were seeking to dismantle in the first place (Erevelles 2011). They inadvertently deploy disability as a master trope of disqualification that one should escape rather than embrace.

Rather than treating the analogous relationship between race and disability as prosthetic metaphor and/or nuanced intervention, it may be necessary to engage the historical contexts and structural conditions within which the identity categories of race and disability intersect. For example, special education classes became the spaces where African American and Latino students were ghettoized even after the Brown v. Board of Education legislation, which was supposed to make segregation on the basis of race in education unacceptable (Connor and Ferri 2005; Artiles 2011). But in recognizing the conjunction of race and disability rather than highlighting only one or the other, race and disability become clearly interdependent as disabled subjectivities are racialized and racialized subjects are disabled simultaneously. Blanchett, Klingner, and Harry (2009) have illustrated how the politics of race, class, and disability intersect when students of color in low-income, high-poverty schools “become” mildly mentally retarded and emotionally disturbed. Even when compensatory services are available, white privilege and institutional racism obstruct access to these services. Additionally, these students of color find themselves in the most segregated and punitive spaces in the public school system—social conditions that often extend into their adult lives via the school-to-prison pipeline (Erevelles 2011). Thus, in the historical context of Brown v. Board of Education, the oppressive practices of white supremacy and pedagogical ableism were mutually constitutive.

Social conditions of poverty also contribute to racialized subjects “becoming” disabled. The incidence of physical and mental illness in people of color communities, for instance, differs drastically from that of their white counterparts. According to the Centers for Disease Control and Prevention, African American children are disproportionately more likely to suffer from exposure to lead and toxic waste, well-known causes of developmental delays, because they are disproportionately more likely to live in old and run-down housing with lead pipes and peeling lead paint near hazardous waste sites (Stubblefield 2009; Erevelles 2011). Furthermore, people of color, especially African Americans, are less likely to be diagnosed with depression or prescribed medication when they report symptoms to a doctor,
and are also institutionalized involuntarily more often, in part because racial stereotypes affect psychiatrists’ assessments of their “dangerousness” (Mollow 2006, 74; Metzl 2011). Extending beyond the local context of the United States, in neocolonial and postcolonial contexts, war and Intra-ethnic strife create actual physical disabilities as well as trauma in societies where there are few economic, social, and emotional supports. Race drastically transforms the life experience of becoming disabled and living with disability in both historical and contemporary contexts.

While it may be politically expedient for disability studies scholars to argue that disability is the most universal of human conditions because almost anyone can become disabled (Garland-Thomson 1997), there is often an implicit assumption that the acquisition of a disabled identity always occurs outside historical context. But rather than conceiving of “disability” and “race” as interchangeable tropes in order to foreground the ubiquity of oppression, the categories of race/ethnicity and disability might be better invoked to demonstrate how they constitute one another through social, political, economic, and cultural practices that have kept seemingly different groups of people in strikingly similar marginalized positions (James and Wu 2006; Erevelles 2011). Thus, more robust and complex analyses of race and disability are necessary for us to move beyond the initial conceptual space of analogy.
Senses
Kathryn Linn Geurts

The “senses” often are treated by science, medicine, and humanistic scholarship as a phenomenon affecting distinct individual bodies, but much contemporary scholarship has revolutionized how we think about the senses. For the past few decades, at approximately the same time that disability studies has developed as an academic discipline and professional field, the “anthropology of the senses” has grown in importance and has contributed to the emergence of the interdisciplinary field known as sensory studies (Bull et al. 2006). New work in sensory anthropology challenges not only the five senses model but also the notion that the experience of sensing is individualized and distinct. For example, while the term “senses” typically connotes the five modalities of hearing, taste, touch, smell, and sight, our capacities for sensory experience are not confined to these discrete channels. Humans actually possess and rely on far more than five senses. This becomes more clear when we acknowledge both exteroceptors and interoceptors—the former being organs that process olfaction, gustation, aurality, tactility, and visuality, and the latter referring to processes such as the vestibular system, kinesthesia, and proprioception (Geurts 2002). In addition, human sensory experience is even more complex if we are willing to include phenomena such as pheromone receptivity or a biosonar capacity called “echolocation.” Any and all of these biological systems, however, can become impaired. For this reason, there is an obvious yet often neglected relationship between thinking about the senses and human experiences of disability (blindness and deafness being exceptions, since medicine has traditionally classified these conditions as “sensory impairments”).

In the past few decades, sensorial anthropologists have argued for the sociality of sensations and the intersubjective dimension of sensory processes and experience. As David Howes, one of the pioneers of sensory studies, puts it: “To a greater or lesser extent, every domain of sensory experience, from the sight of a work of art to the scent of perfume to the savor of dinner, is a field of cultural elaboration. Every domain of sensory experience is also an arena for structuring social roles and interactions. We learn social divisions, distinctions of gender, class and race, through our senses” (2003, xi). Still, the phenomenology of the senses has not been, generally speaking, as thoroughly engaged by scholars in disability studies as it might be.

Some senses have, by necessity, been used in autobiographical and narrative writing in relation to disability; accounts of “blindness” and “deafness” as well as forms of mobility impairment or neurocognitive difference always draw on the senses to establish traction. For example, Helen Keller organized her autobiographical account The World I Live In (1908) around classic sensory modalities. She described how her “seeing hand” guided her through the material world and how those tactile views could, in turn, stimulate her mind and imagination. With olfaction so vital to her experience, she reflected on why smell had been relegated to a “fallen angel.” In many ways Keller deployed sense-based analogies to stress how she was more like her readers than they might think: “I understand how scarlet can differ from crimson because I know that the smell of an orange is not the smell of a grapefruit” (1908, 105). Jacques Lusseyran’s And There Was Light (1963)
recounts his first twenty years, including an accident in a schoolyard that transformed his limited eyesight into blindness. As a small child he held colored crayons and blocks in his hands, bringing them close to his eyes, to experience “light.” He could identify various buildings throughout town by their smells—a perceptual experience undoubtedly shared with sighted people, though their awareness of it may not be as keen as Lusseyran’s. Denying that blindness is even an impairment, Lusseyran asserts, “The only way to be completely cured” of blindness “is never to treat it as a difference, a reason for separation, an infirmity... The cure is to immerse oneself again and without delay in a life that is as real and difficult as the lives of others” (36).

The sensorially rich narrative accounts of Keller, Lusseyran, and others help readers to understand that despite their impairments, these disabled individuals continue to share with all humans the spirit and consciousness that mark our species. Jean-Dominique Bauby’s autobiography The Diving Bell and the Butterfly (1997), for example, sensuously depicts his experience with locked-in syndrome: he had no ability to speak and virtually no capacity to move; he was deaf in one ear, and he had both a numb zone and an area with some feeling on his face. Humanity often deems a person in this state to be a “vegetable,” but Bauby’s autobiography reveals that despite his locked-in syndrome, he continued to experience intense pleasure through conjuring up vibrant sensory imagery.

Yet the sensory autobiography approach to disabled experience has some inherent limitations. It has been referred to by some as auto/somatography and characterized as a genre of writing “devoted to exploring bodily experience” and to depicting “lives distinctly shaped by anomalous bodies or unusual somatic conditions” (Couser 2009, 164). Although the writing or the prose in these works is often lyrically descriptive and sensual, for some scholars such “autopathographies” often seem to hew too closely to the medical model of disability’s understanding of the body rather than to that of the social model.

Furthermore, disability studies has intentionally downplayed attention to the senses because of its commitment to advancing the social model of disability. As Mitchell and Snyder have argued, disability studies “strategically neglected the question of the experience of disabled embodiment in order to disassociate disability from its mooring in medical cultures and institutions” (2001, 368). Detailing the sensory experiences of anomalous/monstrous bodies arguably was a form of exoticizing and fetishizing, or else putting a microscope to disabled people’s sensory-affective experiences for the voyeuristic use of the audience. From such a position one could conclude that disability is an individual experience that does not require social action and structural change. Mitchell and Snyder further argue that “since disabled bodies had endured such a history of debilitating classifications, disability studies purposely refrained from formulating the embodied experiences of disabled people. This neglect was willful and strategic: it explicitly sought to leave an overanalyzed entity mercifully alone” (374). For decades, therefore, disability studies actively discouraged a phenomenological or sensory approach, favoring instead political accounts that focused on social exclusion.

Some feminist theorists within disability studies have consistently critiqued this avoidance of sensory/embodied elements (e.g., Shildrick and Price 1998). In “Sensing Disability,” Marian Corker argued that ignoring sensibility perpetuates “masculinist notions of presence, visibility, material ‘reality,’ and identity as ‘given’” (2001, 39). Corker’s powerful “critique of ontological imperialism” suggests that even disability studies has promoted an understanding of “being” that reifies
bifurcation, ocularcentrism, and stable or fixed realities. The masculinist “givenness” that she points to underlies the way that our understandings of presence, visibility, material reality, and identity deny mutability, fluidity, and transience—all of which come to the fore when we focus on the senses and sensory practices. “Sensibility” by necessity is premised on the understanding that biological difference and sociocultural difference are mutually constitutive so that one’s body and one’s sociocultural surroundings change continuously (36).

Feminist scholars in general rejected pathological constructions of the female body, as well as overdetermined notions of the female or feminine. But when it came to eliding sensation, Coker argued that the “disabling of sensibility effects a closure on valuable, insightful, and imaginative ways, sensed ways of being and knowing that can make collective expressions of disability more responsive and responsible” (42).

As the sensual revolution in scholarship has spread, disability studies has responded by fusing poetics and politics and attending simultaneously to sensory practices and social critique. For instance, in Too Late to Die Young (2005), Harriet McBryde Johnson broaches hard-hitting topics such as disability legislation, selective infanticide of disabled infants, and muscular dystrophy telethon fraud even while acknowledging the importance of sensory perception and human sensuousness. Michael Schillmeier’s Rethinking Disability: Bodies, Senses, and Things (2010) exemplifies the potential to explore and theorize how sensory practices can enable and/or disable. He shows how close study of the relations among bodies, minds, senses, and things is necessary for a deeper understanding of “the social” and the ways in which “inclusive differences highlight the connection between human and non-human relations that make up the different enabling and/or disabling scenarios of societal realities” (167). These are exciting critical moves, for they demonstrate that sensory studies and disability studies can stimulate growth through cross-fertilization. A disability studies perspective is vital for sensory studies to stay grounded in the difficult political reality of diverse human bodies consistently experiencing exclusion in social organization across the globe. And sensory studies can encourage scholarship in disability studies to continue pushing human sensuousness—in all its myriad forms—as a critical research agenda.
Sex
Margrit Shildrick

There can be few practices in everyday life that arouse such strong responses—both positive and negative—as sex. For all its joys and pleasurable connotations, sex always has the capacity to make people feel uncomfortable, even ashamed. Nowhere is this more evident than in the conjunction of disability and sexuality. Even in the twenty-first century, there is still a widespread public perception that people with disabilities are either asexual or, the complete opposite, sexually out of control and requiring management. Either pole leads to damaging consequences not just for disabled people themselves but, arguably, for “normal” nondisabled society at large, which remains unable to acknowledge diversity fully and locked into rigid and conventional models of what sex consists.

What, then, is meant by that seemingly simple term “sex”? For many, sex begins and ends with one's own relationship to sexual practice, itself a fraught area of inquiry. In its most basic form, sex is taken to be an innate biological attribute that enables human beings to reproduce themselves over time. Sex is also usually taken to encompass issues of self-identity, self-esteem, interdependence, and social relations, all of which are typically gathered under the rubric of sexuality. Religions of all cultures have played a major part in propagating restricted views of sexuality, and historically have set strict parameters around the contexts in which sex, as a practice, should occur. Sex is, for example, usually highly gendered. Heterosexual sex is the approved form; it involves just two adults (male: active and female: passive); intercourse is understood as the proper medium; and its primary purpose is not pleasure but the propagation of children.

Clearly, the traditionally dominant model of sex is for many people a historical relic. Nevertheless, it continues to exert a real force on prevailing attitudes and values, even in the most developed Western societies. The presumptive link between sex and reproduction is particularly pernicious with regard to disability. Even when the biological urge to procreate is acknowledged among those whose embodiment differs from the norm, the overriding response is that people with disabilities should not be entitled to sexual relations for fear that they will pass on congenital abnormalities. Even with knowledge of the worst eugenic excesses of the last century, the question of sterilization—usually in relation to cognitively disabled young women—still crops up with some regularity. Social policies that concern people with disabilities continue to see sex as a problem to be managed. Sex education for young people with disabilities is rarely provided, while institutions, group homes, and families often seek to limit expressions of disabled youths' sexuality to something more like friendship.

Yet disabled people, like everyone else, understand their own sexualities in multiple different ways, which do not easily fit within convenient models of social management. There is, of course, sometimes a real need to protect disabled people from sexual exploitation, particularly where power relations are in evidence. But regulation is not always the right answer. Would it not be better to provide targeted sex education that maximizes and supports opportunities for personal choices and exploration rather than trying to channel sexual feelings into “safe” asexual outlets or to silence them altogether? In The Sexual Politics of Disability, Shakespeare, Gillespie-Sells, and Davies (1996) gave a variety
of disabled people the opportunity to talk about sexual needs and desires that far exceeded prevailing myths of sexual indifference. As their title implies, the book demonstrated—much as feminism and gay liberation had done in previous decades—that talking about disabled sexuality is about more than just recognizing and voicing individual sexual practices. The large-scale empirical project by Nosek et al. (2001) into the sexuality of physically disabled women also brings to attention both the magnitude of sexual experience and the degree to which it is thwarted, while Russell Shuttleworth’s (2002) research with men with cerebral palsy does the same for male sexuality.

Why has the topic of sex within disability rights activism and disability studies taken so long to arrive alongside other more widely acknowledged political and disciplinary concerns? If those who count themselves as nondisabled have largely disavowed the conjunction of disability and sexuality, experiencing what can only be regarded as the “yuck factor” when faced with the realities of sexual desire in all of their anomalous forms, then we might conclude that it is because sexuality is always a site of deep-seated anxieties about normative forms of embodied being (Shildrick 2009). We should not be surprised, then, if people with disabilities exhibit many of the same conventional negative feelings toward sex. Indeed, though scarcely acknowledged, many physically disabled people hold dismissive views of the sexuality of those with cognitive and developmental disabilities. Beyond a shared entanglement in the sociocultural imaginary, however, the influence of the medical model of disability has dominated discussions of disabled sexuality, leading to measures as varied as eugenic sterilization and the well-meaning but controlling machinations of social workers.

For many, the emergence of the social model of disability in the early 1990s was a huge advance over the existing medical model, which blatantly pathologized disabled people’s bodies even in the absence of what could be called disease or ill health. The social model focused on countering discriminatory law and policy by identifying the social and political obstacles routinely experienced by people with bodily or cognitive impairments. Over the past few decades, rapid improvements—at least in the Global North—in access to jobs, housing, leisure activities, and education have led to positive outcomes for people with disabilities. The downside, however, is the relative neglect of issues relating to disabled embodiment and subjectivity. The practical, affective, and emotional dimensions of living with a disability, not least in the arena of all things pertaining to sex, were until quite recently given little voice. The dominant discourse surrounding legislation and rights for people with disabilities has to an appreciable extent drowned out any adequate consideration of more nebulous issues. It is true that the demand for sexual citizenship is gaining momentum in activist contexts; yet such demands often reduce sexuality to that which can be measured, categorized, and, one could argue, domesticated (Shildrick 2013). As Gayle Rubin (1984) pointed out in her essay on the “charmed circle” of normative heterosexuality, gaining entrance to the citizenship club fails to challenge the normative organization of sexual matters.

Far more progressive, and often radical, understandings of disability and sex have encouraged scholars and activists to confront questions of embodiment and, more specifically, the circulation of desire. In conventional, and certainly psychoanalytic terms, desire—for nondisabled and disabled people alike—is always a response to a lack that, ultimately, is never satisfied. For Deleuze and Guattari (1987), bodies are never whole, singular, and autonomous but are simply part of extensive assemblages that include not simply human beings
but animal and mechanistic components of all kinds. According to this Deleuzian model, desire is not centered on sexual practice between autonomous bodies but between those disparate elements, without fixing on any particular sexual aim (e.g., reproduction) or sexual object (e.g., the penis or vagina). Desire, then, figures both “a network of flows, energies and capacities that are always open to transformation [that] cannot be determined in advance” (Shildrick 2009, 132) and a move away from unsatisfied internal drives to the positivity of mutual becomings.

The implications of such a Deleuzian model of sexuality for people with disabilities is considerable, given that embodied desire enacts all sorts of differential couplings, with no single privileged form. The reliance of many disabled people on assistive or prosthetic devices, for instance, or the support of other human bodies, to facilitate sexual encounters becomes thus unremarkable. Embodiment no longer implies separate and self-contained entities but operates intercorporeally on a “plane that is as hospitable to disabled people as it is to any others” (Shildrick 2009, 140). In the terrain of assemblages, corporeal difference loses its normative significance. At the same time, desire itself—pleasure, danger, uncertainty, joy—takes on multiple different forms and possibilities that can be regarded as much the province of disabled people as they are for the nondisabled majority.

Such new ways of imagining the relationship between disability and sex are far from mainstream, and are often alien to those struggling against the legacies of eugenics or the common prejudices that equate disability with sexual dysfunction. But they are rapidly gaining ground among disability theorists, such as Gibson (2006), Goodley and Lawthom (2011), Shildrick (2004, 2009), and others who have similarly made linkages between disability and queer theory. Many people with disabilities do, of course, identify as nonheterosexual and face similar difficulties to other LGBT people, but the term “queer” goes much further in being explicitly defined against all forms of normativity, not just sexual norms (see especially McRuer 2006). As Serlin notes, it is a matter of “demystifying the cultural and political roots of terms like normal and healthy and whole at the same time [as seeking] to destigmatize the conceptual differences implied by those terms” (2006, 159). Far from thinking about the conjunction of disability and sexuality as a site of fear and voyeuristic fascination for mainstream society, or else something to be monitored and controlled, sex in this expanded mode of desire celebrates the as-yet unrealized potentials of all anomalous embodiment. Opening up the meanings of sex and sexuality for disabled people entails rethinking the whole nexus with respect to us all.
Sexuality
Robert McRuer

The history of the keyword “sexuality” is inextricably interwoven with the history of a range of other disability keywords, including “freakish,” “innocent,” and—most important—“normal” and “abnormal.” As philosopher Michel Foucault has demonstrated, for the past few centuries, we have inhabited a culture of “normalization” that categorizes individuals and populations, marking certain bodies (for instance, those understood as disabled, ill, or lacking) and certain desires (for instance, those understood as perverse, queer, or mad) as “abnormal.” Systems of surveillance, control, intervention, incarceration, correction, or “cure”—what Foucault (2003) would describe as “technologies of normalization” administered by authorities assumed to possess “expert opinion”—emerged in the eighteenth century and intensified over the course of the nineteenth to facilitate this categorization. Sexuality was one of the most distinct areas of social life to succumb to these systems of control and cure.

In the first volume of his book The History of Sexuality (1978), Foucault argued that a widespread belief emerged by the late nineteenth century that sexuality was simply “repressed” and in need of “liberation.” The History of Sexuality worked to challenge this truism and illuminate the ways in which the contours of “sexuality” were clearly visible within a history of normalization (rather than beyond, in some imagined future when “repression” would have supposedly withered away). Foucault thus excavated how “sexuality” experienced an “incitement to discourse”; far from being (simply) repressed, in other words, sexuality was endlessly talked about, managed, pathologized, and (often) “corrected.”

Although disability is not one of Foucault’s topics in The History of Sexuality, his discussion of sexuality as a product of endless discourse could also be true of “ability.” Through what Foucault understood as a “proliferation of discourses,” “ability” and “disability,” like “sexuality,” materialized as supposedly knowable entities. The emergence and naturalization of these discourses positioned sexuality and ability not only as culturally and historically specific modes of experience but also as cross-temporal and in some cases even universal components of what it means to be a human being. The naturalization of sexuality and ability both privileged and linked what eventually came to be understood as “able-bodiedness” and “heterosexuality” (McRuer 2002). For instance, professional psychologists and sexologists (most notoriously, Richard von Krafft-Ebing and his study Psychopathia Sexualis [1886]) pathologized homosexuality and other perversions, linking them to a wide array of physical and mental impairments or disabilities.

Since the 1970s, historians of sexuality such as John D’Emilio (1983) have more specifically demonstrated the ways in which the processes of putting sexuality into discourse produced a binary system of understanding human sexuality that ultimately privileged “heterosexuality” and subordinated “homosexuality” and other so-called perversions. The sexualities known as “heterosexual” and “homosexual,” then, are not somehow timeless and natural but socially constructed or “invented” (Katz 1990). In his influential essay “Capitalism and Gay Identity” (1983), D’Emilio tied this invention of sexuality to the history of industrial capitalism, arguing that as work (for men and some women)
became increasingly associated with a “public” space outside the home, a homosexual or gay identity became available to certain people who discovered each other in “homosexual” locations (bars, clubs, bathhouses) that emerged throughout the West. The home, meanwhile, was no longer understood primarily as a space where inhabitants worked together for survival but rather as an ideological (private and newly “heterosexual”) space where one could expect to find happiness and respite from the public world of work. This new heterosexual space was also arguably able-bodied as well, as “disability” was purged from the home (McRuer 2006). Rates of institutionalization (removal from private home spaces) skyrocketed by more than 1500 percent, for instance, between 1870 and 1915, particularly marking those deemed “feebleminded” as in need of relocation, regulation, containment, and control (Trent 1994).

D’Emilio’s history fleshed out what Foucault himself famously insisted: that discourses of homosexuality materialized a “new species” of person. This new “species” was increasingly regulated by the state over the course of the late nineteenth century and into the twentieth century (Canaday 2009). Heterosexuality, in turn, solidified as the identity of the normal and healthy dominant group, and “heterosexuals” began to understand themselves as such. This period of increasing state control, as the institutionalization of the “feebleminded” and others suggests, was characterized by extreme intervention and regulation around disability as well (Longmore and Umansky 2001). The parallel control of disability suggests that disability in its modern form always has been implicitly, if not explicitly, integrated into the complex discursive emergence of “sexuality” in the West. Among the many ways the histories of sexuality and disability are intermeshed, we might highlight at least three. First, like “homosexuals” more generally, disabled people were subject to pathologization and normalization. “Abnormal” sexuality, for instance, was understood to be the cause of, or at least be related to, illness and disability, such that “abnormal” embodiment was often understood to be accompanied by “abnormal” desires and (consequently) an “abnormal” sexuality. A longstanding belief that certain disabled people have “excessive” sexual desires and thus an excessive sexuality emerges from this linkage.

The generally accepted (and often causally created) link between these two perceived forms of pathological excess entailed at times excessively cruel and permanently damaging forms of “rehabilitation,” such as shock therapy, sterilization, or castration. In 1927, for instance, the U.S. Supreme Court famously ruled that Carrie Buck, who had been deemed “feebleminded” and institutionalized for “incorrigible” and “promiscuous” behavior and who became pregnant after being raped, must be compulsorily sterilized. “Three generations of imbeciles is enough,” Chief Justice Oliver Wendell Holmes declared for the court’s majority opinion, reflecting the belief that both disability and perversion could be transmitted to future generations (Trent 1994). The early twentieth-century notion that disabled people’s sexuality is excessive also can be traced in numerous cultural sites—from the freak show, where visitors might be titillated by exhibits representing both bodily difference and excessive sexuality, to literary representations such as William Faulkner’s The Sound and the Fury (1929), in which a cognitively disabled figure, Benjy, is castrated because he is perceived to be dangerous.

During the twentieth century, a second intertwining of sexuality and disability has also emerged: not of pathological excess but of the seemingly paradoxical notion that disabled people are outside of the system of sexuality altogether. Disabled people often have been discursively constructed as incapable of having sexual desires or a sexual identity, due to their supposed “innocence.”
The distinction between “excessive” and “innocent” often drew upon caricatures of race and class, as poor or working-class people (such as Carrie Buck) or people of color more likely were understood as excessive and dangerous than their white, middle-class, disabled counterparts. Still, the line between innocent and excessive was often very thin, and a given disabled figure (such as Faulkner’s Benjy) could quickly cross from one side to the other.

A third intertwining of sexuality and disability can be identified in the form of disabled people’s complex positioning in new systems of sexual and disabled identities. These newer, more generative understandings of the relationship between disability and sexuality have allowed, at times, for the development of alternate forms of sexual experience and subjectivity that were potentially outside of the increasingly rigidified heterosexual/homosexual binary. Historian David Serlin (2012), for example, recounts how some mid-twentieth-century sexologists, working with and interviewing disabled women about their bodies and pleasures, were confounded by forms of intimacy, touch, and autoeroticism that did not fit neatly into emerging understandings of sexuality or sexual identity. Exclusion from normality or a presumption that one could not be part of the heterosexual/homosexual system, in other words, sometimes allowed for disabled pleasures and disabled ways of knowing that were not reducible to dominant systems of heterosexuality that were dependent on able-bodied definitions of sexual norms.

These three distinct though overlapping components in a disabled history of sexuality have become legible in late twentieth-century and early twenty-first-century deployments of “sexuality,” particularly by and around activists in the disability rights movement. As disabled people began to speak or sign back to the systems that historically had contained them, they deliberately confronted ideas of excessive, innocent, or alternative sexuality. This entailed at times asserting that disabled people, too, did not have excessive or unusual but “normal” (and heterosexual) sexualities. In the United States, for instance, many activists strategically challenged federal marriage penalties that would cut off benefits such as Supplemental Security Income (SSI) for disabled people who married. Activists also argued for “liberation” from “repressive” ideas, thereby repudiating the widespread notion that disabled people’s sexuality was innocent or nonexistent (Shakespeare, Gillespie-Sells, and Davies 1996). Disabled activists also worked with and through theories of disability to discover or invent new (and often queer) pleasures and sexualities. Many writers, performers, artists, and activists in disability culture as it has flourished in the early twenty-first century represent the possibilities inherent in this third intertwining area of sexuality and disability. They include Mark O’Brien, Loree Erickson, Terry Galloway, Mat Fraser, Eli Clare, Greg Walloch, and Bethany Stevens, the last of whom is a self-proclaimed “uppiecrip scholar activist and sexologist.” Using this language, Stevens joins other disabled activists and artists who are self-consciously appropriating and resignifying terms from the oppressive history of sexology. Mark O’Brien’s poetry and creative nonfiction, perhaps especially his essay “On Seeing a Sex Surrogate” (1990; the basis for the film The Sessions [2012]), mark a particular turning point toward this third strategy.

In 1992, Anne Finger asserted, “Sexuality is often the source of our deepest oppression; it is also often the source of our deepest pain. It’s easier for us to talk about—and formulate strategies for changing—discrimination in employment, education, and housing than to talk about our exclusion from sexuality and reproduction” (9). Finger’s assertion—which might serve as a gloss to all three strategies for responding to the
disabled history of sexuality—had become well known and had traveled through a range of locations in both disability rights and disability studies, as the twenty-first century began (Siebers 2008b; McRuer and Mollo 2012). Sexuality does indeed remain, two decades later, a "source of oppression" for disabled people, but it has also become a profoundly productive site for invention, experimentation, and transformation.
Space
Rob Imrie

A fundamental part of people's existence is their emplacement in space and their relationships with objects that are geographically located at different points or places. Space is one of the major axioms of being and of life itself. It is where we are located, the places where we live and move around, and the multiple relationships that take shape among them. Space is characterized by the primacy of what Paterson and Hughes (1999, 607) describe as "non-impaired carnality," or the projection of the body-normal as the embodiment of those without impairment. Wherever one goes, one is reminded of the absolutism of the nonimpaired body and the crafting of space as places that are not easily accessible to, or usable by, people with different types of impairment. For example, from the design of steps into public buildings that prevent wheelchair access, to the absence of legible signage that may prevent ease of way finding, the construction of space is characterized by an inequality of provision. This is a world that Tony Fry aptly describes as "surrounded by things designed to function in ways that go unquestioned and absolutely taken for granted" (2009, 29).

For David Harvey, paraphrasing Raymond Williams (1983, 88), space is "one of the most complicated words in our language" (2006, 270). Although it has diverse meanings, it is most commonly defined with reference to three types: absolute space, relative space, and relational space. Writing in 1689, Isaac Newton regarded absolute space as "without relation to anything

external . . . always similar and immovable and Motte 1934, 6). For example, objects, suchings, have such qualities by occupying a spec and are bounded by a fixed and delimited, us territory. Buildings also can be considered relative space, positioned, geographically, in other objects that they depend upon to function environment. For instance, a care facility is part of a space of flows, of goods, empl residents, all of which emanate from different points or locations. The care facility is also as of a relational space in which what happens ter)related with events occurring in other places. legal rules passed by national and supranational bodies specify minimum standards of see.

However space is defined, it is intrinsic existence, and for Newton the fundamental space as place is that "part of space which a1 up" (Newton and Motte 1934, 6; also see Mer 1962). The human body is always emplaced unless in concentration, in part, by the soci and context of a place. Thus, the impaired historically, been constructed as not normal, and "out of place" in everyday environment one was permitted to exist was resolved by its spatial regulation, or placing certain categor people, such as those with learning difficulties, in incarceration that, at their extreme, were asial schools, prisons, and other places of cor For instance, following the passage of the 19 Incapacity Act, 40,000 people in Britain, as "feebled-minded" and "morally defective," w away in institutions (see Brignell 2010). So served as absolute spaces or physical cont signed to segregate populations on the basis differences. They reflect what de Certeau (1999) refers to when he calls a space "a practiced pla
external . . . always similar and immovable" (Newton and Motte 1934, 6). For example, objects, such as buildings, have such qualities by occupying a specific terrain and are bounded by a fixed and delimited, usually legal, territory. Buildings also can be considered as part of relative space, positioned, geographically, in relation to other objects that they depend upon to function as a living environment. For instance, a care facility's functioning is part of a space of flows, of goods, employees, and residents, all of which emanate from different multiple points or locations. The care facility is also an example of a relational space, in which what happens there is (inter)related with events occurring in other places, such as legal rules passed by national and supranational governments that specify minimum standards of service.

However, space is defined, it is intrinsic to human existence, and for Newton the fundamental element of space as place is that “part of space which a body takes up” (Newton and Motte 1934, 6; also see Merleau-Ponty 1962). The human body is always emplaced, and its placement is conditioned, in part, by the social context and context of a place. Thus, the impaired body has, historically, been constructed as not normal, unsightly, and “out of place” in everyday environments. Where one was permitted to exist was resolved by recourse to spatial regulation, or placing certain categories of people, such as those with learning difficulties, in spaces of incarceration that, at their extreme, were asylums, special schools, prisons, and other places of confinement. For instance, following the passage of the 1913 Mental Incapacity Act, 40,000 people in Britain, categorized as “feebleminded” and “morally defective,” were locked away in institutions (see Brignell 2010). Such places served as absolute spaces or physical containers designed to segregate populations on the basis of bodily differences. They reflect what de Certeau (1984, 117) refers to when he calls a space “a practiced place,” where understanding the body, according to biological and physiological characteristics, shapes the creation and maintenance of spaces of demarcation and exclusion as “natural.”

Such shaping is part of the purposive production of space, by architects, designers, and others involved in the design and emplacement of objects in space (see Imrie 1996). Their actions are part of a broader, structural value system that fails to engage with, or respond to, the complexities of corporeal form and performance. It is one that devalues “not normal” bodies, a devaluation reflected in disabled people’s difficulties in seeking to overcome the frictions of distance or the spaces between different places. As a result, many disabled people often have difficulty navigating what de Certeau (1984) describes as the “intersection of mobile elements” and the “ensemble of movement” that are intrinsic to spatial experiences. For instance, moving between places brings disabled people into conflict with disabling design and frictions that routinely exclude them from interfacing with the world around them in ways that they would choose. The examples of this are manifold and include bus timetables that rarely provide information in forms accessible to vision-impaired people, and steps into shops and other public buildings and commercial buildings that may prevent wheelchair users from undertaking or completing a journey.

In both instances, the design of space, and the objects emplaced within it, has the potential to influence life opportunities. Deaf people, for example, describe space as perpetuating the hegemony of aurality—sonic places created for, and by, hearing people. Space is suffused with sound, and spatial legibility is defined, in part, by the primacy of auricular values and the interplay between place and the hearing body. By contrast, vision-impaired people are subjected to definitions of space as “that which is seen,” where the (re)production
of place is premised on visuality. Here, the primacy of ocular values, as evidenced in the shaping of space by visual cues, signs, and symbols, disregards those without sight or the means to make sense of seeing-sensory spaces. In both cases, the lack of attentiveness to the interrelationships between (their) bodily sensing and spatial perception draws attention to issues of social justice, and the less-than-equal opportunities afforded to disabled people in accessing, and moving in and across, space. In other words, the construction of place is entwined with the status of disabled people as citizens and the exercise of their citizenship. Their access and attendant rights to full and equal participation in society require, arguably, a spatial politics, a deliberate politicization of the processes shaping the uneven (re)production of space.

Modern disability history may be characterized, in large part, by people seeking to contest spatial inequality and the unjust nature of the social production of space. For instance, the American disability rights organization American Disabled for Accessible Public Transit (ADAPT) spent much of the 1980s campaigning, with some success, for bus lifts for wheelchair users. In the United Kingdom, vision-impaired people are, at the time of writing, challenging urban design practices that seek to create shared streets, or places where all users, including motor vehicle drivers and pedestrians, share the same spaces (see Imrie 2012). For vision-impaired people, such spaces are tantamount to the loss of safe pavement environments and the creation of a new layer of spatial inequality that will lead, potentially, to their involuntary withdrawal from such places. Here, disabling design values intercede with corporeal realities, and future research about space and disability may be to deploy, analytically, the notion of “rights to the city” (see Lefebvre 1991). These rights challenge conventional liberal citizenship and its failure to recognize the illiberal nature of spatial practices. They are also the basis for campaigning for disabled people’s rights to spatial equality to be enshrined in a politics of participation. For many disability rights activists, these are non-negotiable prerequisites for shaping the right to access, occupy, and use space.
Stigma is part of the complex of factors that transform impairment into disability. The term refers to the disapproval and disadvantage that attach to people who are seen as different; its repercussions can be far-reaching. Stigma affects employment, social recognition, educational opportunities, friendship and sex, housing, and freedom from violence. Stigma in Greek means to prick or to puncture, and the word originally referred to a sharp instrument used to brand or cut slaves or criminals. The fact that stigma is still closely associated with visible forms of difference—leprosy, needle tracks, missing limbs, and obesity, for instance—recalls this history, as does the fact that it retains associations of moral disgrace. Today, the term is more abstract and more general and refers to social forms of stigma—to the discredit or dishonor that attaches to a wide range of human variation.

Stigma’s associations with enslavement lasted through the nineteenth century, when the term described the brands and marks used to identify and to punish enslaved people in the United States, and it also connoted a moral taint or sign of disgrace. Along with these associations of infamy, the term is linked via the Christian tradition to the idea of grace. Stigmas (or stigmata) refer to the spontaneously bleeding wounds of saints, understood to imitate the wounds of Christ.

Since the late nineteenth century, stigma has been more stably correlated to pathology and to kinds of people rather than to individuals. Paralleling the large-scale processes of normalization and the management of populations that Michel Foucault has identified with Western modernity, stigma gradually lost its punitive and religious connotation; instead, it was associated with medical pathology and social groups deemed inferior as a result of poverty, racial and ethnic difference, occupational status, gender and sexual nonnormativity, and many forms of cognitive and physical difference. For scholars of disability, the rise of statistics in the nineteenth century was essential in shifting views of the visibly different from wonder to deviation from the norm (Davis 1995; Garland-Thomson 1997). The emergence of a “normal body” is instrumental in shifting stigma from individuals to broader, more systematic forms of oppression.

Human difference and its regulation have long been an object of study, but the modern concept of stigma emerges around the same time as the discipline of sociology, where it played an important role in Émile Durkheim’s (1895) account of social deviance. Durkheim understood deviance as relative, the product of the sorting processes internal to communities, and as an effect of asymmetrical power relations. His understanding of deviance was crucial to the development of labeling theory, which argues that deviant behavior is not inherently pathological but is categorized by society as aberrant. During the twentieth century, stigma was understood as a sign of deviance, and it continues to play an important role today in sociology as well as in anthropology, legal studies, psychology, education, ethnic studies, and the medical humanities.

Stigma is crucial to the emergence of disability studies as a field and to the definition of disability itself. The Americans with Disabilities Act (ADA) of 1990 recognizes the importance of social opprobrium to determining who will qualify for benefits. In defining disability, the law covers not only those with impairments but also
those who “are regarded as having such an impairment” (Section 12102 [3]), the authors of the ADA have deemed that the discrimination attending physical and mental impairment is disabling even in the absence of such conditions. The American Medical Association’s *Guides to the Evaluation of Permanent Impairment* (2007) also incorporates stigma. Stigma is central to its criteria for compensation and accommodation, which judge facial differences as some of the most disabling impairments. How the effect of social stigma might be quantified, for instance, in cases of employment and other forms of discrimination, remains a pressing legal and political question.

The sociologist Erving Goffman developed the most influential account of stigma in his classic study *Stigma: Notes on the Management of Spoiled Identity* (1963). Although he was not solely concerned with disability, Goffman has been influential in disability studies. His account of the maintenance of social norms through the rituals of everyday life and his emphasis on the discrediting effects of stigma have set the terms for contemporary discussions of stigma in relation to disability and beyond. Goffman defines stigma as a break with expectations for “normal” appearance or behavior that results in the denigration of the stigmatized person. His definition emphasizes copresence and perception. He is less concerned with the inherent trait or the nature of the behavior than he is with the societal perception of the “stranger” who appears “different from others.” Like Durkheim, Goffman understands stigma as a dynamic social situation where fitness is defined in the context of the community rather than in absolute terms. As his description of the stigmatized person as “bad, dangerous, and weak” implies, Goffman is blunt in representing the effects of stigmatization, and he does not offer a positive account of difference. His writing highlights a paradox of scholarship on stigma: in describing the conditions of stigmatization, one risks repeating them, making a spectacle of the denigrated object.

Goffman identifies three categories of stigma: “abominations of the body,” his term for physical “deformities”; “blemishes of individual character,” which refers to moral transgressions such as homosexuality; and, finally, “the tribal stigma of race, nation, and religion” (1963, 4). Of these three categories, the last gets the least attention: race, ethnicity, nationality, and religion appear fairly rarely in his examples, in part because his definition of stigma turns on an individual out of place rather than the fate of an oppressed group. The rise of the disability rights movement over the past half-century has shifted the understanding of mental and bodily difference from an individual to a group phenomenon.

Moral taints are of interest to Goffman because of the way such faults discredit the entire person. While many of his examples seem dated, his analysis of blemishes of character remains relevant. The stigma attached to sexual or social deviance such as HIV infection or drug addiction is powerful, all the more so because, as Goffman argues, stigmatized people may internalize rather than contest the norms by which they are judged inferior.

Visible disability (or “abominations of the body”) furnishes key examples for Goffman because of his emphasis on live scenes of interaction. Lennard Davis (1995) has argued that appearance is one of the main modalities by which disability is constructed. Rosemarie Garland-Thomson (2009, 44) considers the social dynamics and effects of staring, tracing the power of the starer over the staree. Public scenes of staring produce conditions of vulnerability for people with visible differences; however, under usual conditions not only the staree but also the starer is exposed to view. As the title
of the edited collection *Staring Back* implies, people with disabilities are not the passive objects of stigmatization but rather engage in a range of strategies for resisting, refusing, and reversing stigma.

Although stigma is primarily associated with forms of difference that are readily visible, nonvisible and transient forms of stigma have equally powerful effects. Invisible disabilities such as forms of cognitive and affective difference, epilepsy, and vocal impairment raise important questions about disclosure, secrecy, and information management. Goffman and others have analyzed the acts of passing that stigmatized persons engage in on a temporary or permanent basis. While passing might shield an individual from certain forms of denigration or abuse, lack of recognition can also have negative consequences. In an essay on the complexity of passing, Tobin Siebers (2008a) argues for the significance of "disability as masquerade," or the performative acts people with disabilities engage in to minimize or exaggerate impairments in order to gain control over self-representation, as well as access to accommodations.

Such control is always tenuous, since the attribution of stigma is volatile. As work on the experience of the parents, children, and siblings of people with disabilities has shown, stigma is contagious. To be seen in the company of someone who is visibly different is to be understood as different oneself. In addition, stigmatized traits or behaviors can amplify each other, as Susan Schweik (2009) demonstrates in her study of the "ugly laws" in the late nineteenth- and early twentieth-century United States. These laws legislated against the public appearance of beggars and people with disabilities, categorizing both as "eyesores" and confounding them with each other. Once a person is stigmatized, other qualities tend to be interpreted through the lens of this trait; even relatively minor differences can have major and snowballing consequences in the life of an individual.

Writing on stigma invariably raises questions about the constitution of social norms. In a memorable moment from the end of *Stigma*, Goffman quips, "In an important sense there is only one complete unblushing male in America: a young, married, white, urban, northern, heterosexual Protestant father of college education, fully employed, of good complexion, weight, and height, and a recent record in sports" (1963, 128). Disability studies scholars have followed Goffman in interrogating the category of the "able-bodied" or "non-disabled" in order to undermine the self-evident distinction between the normal and the pathological.

This view is valuable because it suggests that stigma is not essentially linked to particular traits or behavior, nor is it permanently fixed to individuals or groups. A person who is stigmatized in one context may be seen as unexceptional in another; once-stigmatized behavior or traits may become acceptable or even enforced as new norms down the line. According to this view, stigma is a system, a way of sorting persons into categories of normal and deviant along the lines of preexisting social hierarchies. Still, there are drawbacks to this universalizing account. It tends to underestimate the extent to which stigma attaches to individuals who are visibly marked as different. In order to understand stigma's role in the construction of disability, we must recognize its status not just as a universal experience of difference but also as a concrete force in the lives of particular individuals.

The disability rights movement has been instrumental in transforming the meaning and public perception of the stigma associated with disability. Collective redefinitions of what counts as normal and the standards for ethical treatment of those perceived as different are crucial. Nonetheless, stigma remains a powerful and unpredictable force in the lives of many, and it shapes the
way individuals and groups can expect to navigate the social world. In the concrete effects of stigma, we see the afterlife of its origins as both a punishment and a technique of identification. Stigma is sticky, and it has the power to confer identity; it is general, but it attaches to particular individuals; once one is marked with stigma, it may be difficult to escape its hold.
The definition of technology has been the subject of considerable philosophical debate. Technology was a relatively derided topic in Western philosophy until the early modern period, as a result of the unfavorable distinctions—dating to ancient Greece—between *technē* (craft knowledge) and *epistēmē* (theory or science). “Technology” most commonly refers to manufactured things: artifacts, handiwork, devices, and machinery (Kline 1985, 215). The term “biotechnology,” coined in the twentieth century, refers to the manufacture or gainful modification of organisms, tissues, and life processes. Examples of biotechnology range from plant breeding to genetic engineering. Some scholars broaden the category of technology to include *technics*: technical skills, methods, and routines. More broadly still, others consider technologies to be “sociotechnical systems of use,” defined by Stephen Kline as “combinations of hardware and people” brought into being “to accomplish tasks that humans cannot perform without such systems—to extend human capacities” (1985, 216). Until recently, technology has been the subject of forceful critique rather than sustained analysis in the field of disability studies. According to the social model of disability, the lack of access to technological systems, especially those required for the performance of citizenship—from workplace architecture to municipal infrastructure to telecommunications networks—is a principal source of disability.

The notion of technology as an “extensor of human capacities” has given rise to speculation about the intrinsic relationship of technological innovation. Some scholars have projected the bodied inadequacy or impairment as the grounds for innovation. Arnold Gehlen, for instance, a German philosopher, surveyed European technology from the eighteenth through the twentieth century and concluded, “The necessity for technology derives from man’s organ deficiencies” (1964, 216). Disability theorists have offered less uniform accounts of impairment as a source of invention. Siebers contends that sensory disabilities are communicative practices: “The disabled body is the process of representation itself... blinding the vision the faces of old acquaintances. Deafness, public television... different bodies require new modes of representation” (2008a, 54). So the field of Deaf studies, hearing loss is reframed to signal the linguistic and cultural benness (Bauman and Murray 2009, 3). Exclusions of innovation, as a device or technic is transformed by the imperative to accommodate. For example, talking books and text scanning machines for people with print disabilities have spurred the widespread development of audio formats.

Other theorists instead emphasize the “disability” of modern technology. Disability is a trope for critics of mechanization and automation, supplementation and replacement of human by machines. Many of these critics have noted the prevalence of scientific management, specific Ford and Frank and Lillian Gilbreth, integrate workers onto assembly lines. The “breaking human motion into its components, the unit of apparatus for some of these micro-motor
The notion of technology as an “extension” of generalized “human capacities” has given rise to speculation about the intrinsic relationship of technology to disability. Some scholars have projected the body’s natural inadequacy or impairment as the grounds for technical innovation. Arnold Gehlen, for instance, a right-wing German philosopher, surveyed European history of technology from the eighteenth through the twentieth century and concluded, “The necessity for technology derives from man’s organ deficiencies” (2003, 213). Disability theorists have offered less universalizing accounts of impairment as a source of invention. Tobin Siebers contends that sensory disabilities effect new communicative practices: “The disabled body changes the process of representation itself...blind hands envision the faces of old acquaintances. Deaf eyes listen to public television...different bodies require and create new modes of representation” (2005a, 54). Similarly, in the field of Deaf studies, hearing loss is reframed as deaf gain to signal the linguistic and cultural benefits of deafness (Bauman and Murray 2009, 3). Exclusion can be a source of innovation, as a device or technical system is transformed by the imperative to accommodate disability. For example, talking books and text-to-speech scanning machines for people with “print disabilities” have spurred the widespread development of new reading formats.

Other theorists instead emphasize the “disabling” effects of modern technology. Disability is a frequent trope for critics of mechanization and automation—the supplementation and replacement of human activities by machines. Many of these critics have noted that the founders of scientific management, specifically Henry Ford and Frank and Lillian Gilbreth, integrated disabled workers onto assembly lines. The “breaking down” of human motion into its components, the substitution of apparatus for some of these micro-motions, and the proximity of people with disabilities to other laborers lead these commentators to claim, syllogistically, that “everyone is disabled” by industrialization. The rehabilitation of people with disabilities—their accommodation into the workplace—is thus problematically deployed to warn of the injuries that result from rationalized, repetitive factory work. This formulation overlooks the social context of efficiency and statistical reasoning that encompassed all bodies in the early twentieth century. “Disability” was marked as a distinct problem—a scalar difference from other human “limitations.” More often than not, the incorporation of “human factors” into design gave rise to standardization technologies for statistically average users, excluding those with disabilities.

Postmodern theorists issue similar warnings about the pathological effects of digital, networked technology on embodiment and perception. Perhaps most dramatically, Paul Virilio describes the “plugged-in” users of computers and telecommunications as “terminal citizens,” catastrophically “handicapped” by isolation, immobility, and suspicious equipment (1997, 20–21). Most scholars assume, however, that technology exhibits a “double logic,” with additive and subtractive effects. Marshall McLuhan (1994, 42) famously proposed that electronic media at once extend and “auto-amputate” human faculties, the latter occurring through overuse or atrophy. S. Lochlann Jain cautions that “it is usually not the same body that is simultaneously extended and wounded” (1999, 36). An extension for one person might come at another’s expense, as when certain users are excluded from a technical system, or a test subject does not benefit from the risks she has taken.

Disability theorists have critiqued the academic fields of science and technology studies and media studies for routinely exploiting disability as metaphor and exemplar in wide-ranging theories of prosthesis, the cyborg,
and posthumanism. As David Mitchell and Sharon Snyder argue, “disability underwrites the cultural studies of technology writ large” (1997, 8). In such scholarship, disabled figures betoken technological dystopia, the exaggerated effects of new media on human bodies and relations, or the perfunctory celebration of hybridity and difference. Representations of disability in texts and audiovisual media do not simply reflect broader patterns of discourse, however. They create new symbolic associations, disseminate terminology, transmit affect, and discipline practices of looking. Thus historians Katherine Ott, Stephen Mihm, and David Serlin (2002) have called for more work on the everyday contexts of prostheses, as ballast for the term’s metaphoric proliferation. Alison Kafer similarly recommends “bringing a disability consciousness to the cyborg, attending to the specific benefits and dangers it harbors for disabled people. This shift requires an acknowledgment that human/machine interfaces are not always beneficial or pleasurable; an awareness that many disabled people lack access to the cybertechnologies so highly praised in cyborg writing; an accounting for the ways in which cybertechnologies rely on disabling labor practices across the globe; and a realization that not all disabled people are interested in technological cures or fixes” (2013, 118).

Media activists and disability theorists alike have urged critical attention to the prevailing “visual rhetorics” of disability in photography and film, as well as the ways these rhetorics might be subverted or supplemented (Garland-Thomson 2001).

The category of “assistive technology” is likewise contentious within disability studies. John M. Williams, a disability journalist who has used various communication aids for stuttering, is widely credited with coining the phrase in 1982. In fact, “assistive” apparatus began to be discussed in such domains as occupational therapy, medicine, and education following World War II. In the United States, the 1988 Technology-Related Assistance Act for Individuals with Disabilities (the “Tech Act”), provided an influential definition of assistive technology, which was taken up in subsequent legislation such as the U.S. Assistive Technology Act of 1998, the Americans with Disabilities Act, the Telecommunications Act, and the Individuals with Disabilities Education Act. The 1988 act is based on a circular logic that defines assistive technology as any technology gainfully used by a person with a disability: “The term ‘assistive technology device’ means any item, piece of equipment, or product system, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities.” Katherine Ott points out that the phrasing is also redundant: “Since all useful technology is assistive, it is peculiar that we stipulate that some devices are assistive while others need no qualification. Besides serving to stigmatize and segregate a benign and inanimate entity—a device or appliance—the term ‘assistive technology’ also needlessly complicates understanding of the devices so designated” (Ott 2002, 21). Richard Ladner further argues that the term “assistive” “has the ring of paternalism, a view that people with disabilities need lots of extra help, are dependent and are not capable human beings” (2010, 26). The phrase advances a technological fix that is unconcerned with education, community support, or social change.

The umbrella category of assistive technology includes medical products such as prosthetics, which “replace” human anatomy or function, and orthotics, which “support” anatomy. The category includes items sold on the consumer and medical markets as well as those made by hand. Mobility, sensory, instructional, and “daily living” devices such as shoehorns become “aids” when used by people with disabilities, as do communication technologies such as speech synthesizers.
and smartphones. From pillboxes to screen readers, many assistive technologies are designed to accompany or provide access to other technologies. “Adaptive technology” is a synonym for “assistive”; however, it can also refer to equipment—especially computer-related—that is explicitly designed for people with disabilities. While these distinctions have a legal and financial rationale, many “adaptive” items simply repurpose the same components found in “mainstream” technologies, as is the case with hearing aid amplifiers and other electroacoustic devices. Some “assistive” technologies, such as curb cuts, are shared between different user groups.

What these technologies “assist” is sometimes questionable. They may be designed for “compensation” or extension, augmented or alternative communication. They may promise to facilitate independence but instead require new patterns of dependence upon biomedicine. Biomedical technologies might themselves be “disabling” through the establishment of norms and diagnostic categories, segregating or stigmatizing regulatory practices, and unwanted therapies or “adverse effects.” These technologies may be at once rehabilitative and painful. They may become “stigma symbols,” or they may serve purely cosmetic purposes to accommodate popular discomfort with difference. They draw attention to otherwise “invisible” disabilities, as in the case of the hearing aid or the white cane. They may exhibit a medical aesthetic that compounds disability. They might assist some users while “enforcing normalcy” for others. Cochlear implants, for instance, offer a partial and atypical mode of hearing, while at the same time threatening a minority linguistic culture.

According to Martha Scherer, “use” itself is a complex activity. Assistive technologies have high rates of abandonment, “noncompliance,” and nonuse (2002, 2). Sally Wyatt has identified four general categories of nonuser: resisters (those who choose never to use a technology), rejectors (who stop using a technology voluntarily), the expelled (who stop using a technology involuntarily), and the excluded (those without access for social or technical reasons). In terms of use, Wyatt (2005, 76) notes that it may be forced, reluctant, or partial. Relationships to technology, moreover, are generally far more intimate than implied by the term “user”, or by the related term, “wearer.” Identity formation can occur through technological use, as exemplified by self-advocacy groups for “cochlear implant users.” Group affiliation also results from technical exclusion, as with the category of “print disability,” which unites disparate individuals who cannot read printed materials. Finally, access to assistive devices is always stratified; the devices are not equally available or affordable to those who might benefit from them.

Some scholars of disability and technology have urged universal or inclusive design to render the special category of assistive technology unnecessary. Given that true universality is unachievable, Graham Pullin suggests “resonant design,” which attracts small subgroups of disabled and nondisabled users based on coincident needs. Voice-enabled smartphones, for example, are at once “hands-free” and “eyes-free” (2009, 93). Other possibilities include “critical design” (or “design for debate”), which aims to raise questions and unsettle established assumptions about disability, and “interrogative design,” which protests or provokes strong interventions into ableist structures. Regardless, all work on technology risks assimilating what Tobin Siebers calls the “ideology of ability” (2006a, 7). Technology theory exhibits a ruling preoccupation with development and capacity. It emphasizes invention over the vagaries of use; moreover, it tends to neglect the piecemeal, the homemade, the low-tech, and the long-lasting.
Universal Design in a Digital World

"Web accessibility enables everyone to utilize websites, regardless of personal capability or technology used."

(Glenda Watson Hyatt, 2009)

"In the Maguire case we now have a firm worldwide precedent that inaccessible Web sites can be and are illegal."

(Joe Clark, 2002)

When Russian programmer Dmitry Sklyarov, an employee of Moscow-based ElecomSoft, travelled to the United States in 2001 to demonstrate the Advanced eBook Processor at the Def Con hacker show in Las Vegas, he was arrested by the FBI (Federal Bureau of Investigation) under the United States' Digital Millennium Copyright Act (DMCA). The DMCA criminalizes technologies which circumvent a program's access controls (such as DRM) with regard to their copyright — Sklyarov's software was designed to remove such restrictions on Adobe eBook format files, thereby allowing them to be accessed on other platforms. Sklyarov's arrest attracted considerable media attention and an international internet movement — freesklyarov — swept the blogosphere. When Sklyarov was found not guilty — in large part due to the complicated nature of the DMCA — the extent of control that publishers could expect when releasing their content digitally became tenuous. The disability community likewise became concerned about the implications these legal measures would have on the development and use of such assistive technologies — although not their primary motivation, and not referred to in court documents not in ElecomSoft's (Katalov, 2001) press release, the Advanced eBook Processor benefited people with disability as it enabled the copying of Adobe eBooks into more accessible formats.

The legal ramifications of manipulating data in order to access it are of significance to many people with disability. Wilkinson feared that the case represented a precedent:
Developers of screen readers or other assistive software who find ways to access data may face prosecution themselves if the methods they use or the access they provide is deemed to constitute an infringement of the intellectual property rights of the companies that develop and own major operating systems. (Wilkinson, 2001)

The EcomSoft case highlighted the way that corporations seek to maximize their profits by trying to force consumers to buy their products—even though these may not be in a format appropriate to their needs. The ability to access Adobe eBooks on different platforms is an example of universal design and a recognition of consumer demand. Advanced eBook Processor benefited both people with disability and those without. Universal design is a core tenet of accessibility for people with disability, both within and outside the digital arena. While guidelines should be established to benefit as many people as possible, universal design is a broad concept which allows for accessibility on an individual level through adaptation. As Greg Vanderheiden suggests:

If you want to talk about accessibility, you have to talk about a single person. You can never talk about something being accessible to all people ... So, you can't create a one page fits all. But you can create a one page that can be adapted to fit a very, very wide variety. (quoted in Elcensor, 2010)

Accessibility and usability are important features of universal design. While accessibility enables people with disability to access the web, usability refers to simple and straightforward web content that can be used by all with minimal specialized knowledge (Elcensor, 2010). This book seeks to explore accessibility and usability in the context of web 2.0 platforms and connections, and to question the ways disability is reproduced and created in them. Before considering specific case studies and the ways in which they relate to a cultural construction of disability in later chapters, in this chapter, first, we develop a critical understanding of the forces that are driving universal design in the online environment and we examine popular perceptions about the potential internet technology holds for greater participation in social life for the disability community. Second, we examine the W3C, the main organization responsible for setting internet standards. Following this, we turn to various legal challenges in relation to accessibility and the ways they have been influenced by conflicting and confusing government policy. In the next section of the chapter, we suggest that recent changes in community expectations have reconfigured the way accessibility is understood and approached, this is highlighted with case studies, including the Sydney Olympics website and that of Target.com in the United States. Finally, we assess a new term in web accessibility—“accessibility 2.0”—the capacity to access information in the format of choice when working within the largely unstructured environment of user-generated content.

Driving Universal Design in the Online Environment

Despite a more widespread awareness of accessibility amongst web developers, as web 2.0 becomes increasingly complex and reliant on graphics and diversity of content, accommodating for the needs of people with disability could potentially become a low priority due to perceived financial and time constraints. While it can be argued that the web is more accessible now than even just a few years ago, most new advances in technology are usually inaccessible at the inception stage. Rather than being an integral part of their roll-out, accessibility only comes later, usually as a reaction to demand and not by way of proactive intention. Joshua Miele, a research scientist at the Smith-Kettlewell Rehabilitation Engineering Research Center believes that people designing new technologies should change their approach and make a serious commitment to universal design and in-depth planning in the initial stages. Miele, as cited by Martinez-Cabrera (2010), claims this “really would be an amazing new world.”

This “new world” discourse is invoked by both people with disability and the popular press. As Glenda Watson Hyatt (aka the left thumb blogger) articulates: “For someone who has always struggled to communicate verbally and who has often felt isolated and alone when in group gatherings, social networking has opened a world to me” (Watson Hyatt, 2008). While Watson Hyatt is an avid accessibility and disability advocate, the popular press, by comparison, does not usually consider the social responsibility nor civil rights requirement to make the web fully accessible — nor indeed recognize the flow-on benefits for able-bodied users (Elcensor, 2010). By suggesting that the web enables access to the complete range of social activity for all — including work, sex, education, and recreation — these popular articles disregard the problems frequently faced by people with disability trying to access this new world. For example, online shopping is frequently celebrated in the popular press. Although we agree that the advent of online shopping has improved the lives of people with disability in life-affirming and radical ways, this says more about how difficult it was to access offline shopping than it does about how easy it is to access the online version. By accepting systemic inaccessibility, people with disability are manipulated into reaffirming the “normality” of their oppressor and, by extension, their own perceived difference. Low-profile accessibility issues — such as inaccessible blogs or missing alternative texts (alt text) for images and scans — must be addressed alongside more high-profile cases of inaccessible websites such as Target.com or the Sydney 2000 Olympic Games.

The increasing use of DRM software to protect online content from copyright infringement further complicates any attempt to access the information in alternative formats. Skylar's arrest for breaching the DMCA motivated disability activists to consider the exclusionary nature of DRM despite copyright allowances for people with print impairments:
Mr Sklyarov’s case broke new legal ground and has been controversial for several reasons. Among these reasons are its potentially profound implications for those writing access software for use by people with disability. EFF [Electronic Frontier Foundation] Intellectual Property Attorney Robin Gross states, “Dmitry programmed a format converter which has many legitimate uses, including enabling the blind to hear e-books ... The idea that he faced prison for this is outrageous.” (Wilkinson, 2001)

The severe consequences of violating the DMCA foreshadowed a potential for further problems for people with disability attempting to access information via new technology. Digital rights management has consequences for reconfiguring portals and platforms in different ways and it is time for web designers and programmers, as well as legislators and corporate leaders, to address this issue. The Advanced eBook Processor had been used by both people with vision impairments, seeking to access inaccessible documents and others who wanted to copy an eBook from one computer to another. The case represented an astonishing deployment of criminal law to enforce copyright, particularly since a national (US) law was used to charge someone from another country. Many countries seek to regulate and influence the development of new media by passing laws such as the DMCA and the Australian Broadcast Services Amendment (Online Services) Bill 1999. While these laws are technically limited to a single sovereign territory, they still have the capacity to affect those who reside in, or wish to do business with, that territory. Although not an American citizen, Sklyarov was charged with several offenses including conspiracy, trafficking, and copyright infringement (Wilkinson, 2001). This was despite the fact that these offenses were allegedly committed in Russia — outside the jurisdiction of United States’ law.

The manipulation of data was central to the grand jury’s decision to indict Sklyarov. As all accessibility software involves the manipulation of data, the fear is that unless permission is explicitly granted in each instance, any developer of accessibility software could face the same fate as Sklyarov (although in 2002, a jury found that ElcomSoft had not willfully violated United States’ law). The legal system chose to foreground compliance with copyright legislation, even though this negated anti-discrimination initiatives. This cavalier disregard for the impact on people with disability is not really new in society, but many expected better now that guidelines exist to address this issue.

Invoking disability law in the online arena has been problematic due to both its subjectivity and confusion concerning governance. Accessibility operates in two ways — legal and professional. Voluntary guidelines around web accessibility are recommended by the Web Accessibility Initiative (WAI) section of the W3C, while legal standards in the United States are governed by Section 508 of the Rehabilitation Act, which applies to Federal agencies and their contractors in the United States, and by the Americans with Disabilities Act (ADA). In 2006, more than 70 percent of commercial sites failed to meet either the recommendations of the WAI or the requirements of Section 508 (Elcseros, 2010: 291). The various branches of the internet public service such as the W3C influence the discourse of accessibility. Yet while these bodies often argue that they make technical rather than political decisions, the two are intimately linked.

World Wide Web Consortium (W3C)

Tim Berners-Lee established the W3C in 1994 in order to maintain consistency and compatibility across the internet. It aims to enhance the web’s functionality through universality and operates on a broad scale to develop guidelines and specifications by means of consensus and endorsement from the wider community. However, the W3C is a technical organization and its guidelines for accessibility, although encouraged, are not legally enforced. Without dispute, accessibility is regarded as an important factor. According to the 1999 WAI guidelines, web content developers should scrutinize and prioritize aspects of the online environment in terms of the degree of impact on prospective users. Three accessibility priorities were established:

- **Priority 1**: A Web content developer must satisfy this checkpoint. Otherwise, one or more groups will find it impossible to access information in the document. Satisfying this checkpoint is a basic requirement for some groups to be able to use Web documents.
- **Priority 2**: A Web content developer should satisfy this checkpoint. Otherwise, one or more groups will find it difficult to access information in the document. Satisfying this checkpoint will remove significant barriers to accessing Web documents.
- **Priority 3**: A Web content developer may address this checkpoint. Otherwise, one or more groups will find it somewhat difficult to access information in the document. Satisfying this checkpoint will improve access to Web documents. (W3C, 1999)

Each priority group delineates a large number of checkpoints. For example, Priority 1 is divided into seven sections and has a total of 16 checkpoints, encompassing features such as providing text equivalent for non-text elements. Using style sheets and logical tab orders come under Priorities 2 and 3 respectively. The sliding scale of these priorities has been embraced to a greater or lesser extent by the various companies and individuals developing content for the web. The categorization was endorsed by the White House in 1997 and following a recent update in 2008, it is now known as the Web Content Accessibility Guidelines (WCAG) 1.0. While many Australian universities initially adopted Priority 1, in the last few years several have taken up adopting Priority 2 as well. Yet an accessibility
audit of a number of Australian university websites in 2003 found that 98 percent failed to meet basic criteria. When this audit was repeated in 2007, inaccessibility had increased to 100 percent (Alexander and Rippon, 2007). This disappointing result reveals a problematic tendency of accessibility being most devalued in the environments where it is most required. The full inclusion of people with disability in the tertiary arena is vital for social change to occur on a broader level — both through the education of people with disability and through exposure to diversity for all people.

This lack of compliance is partially due to the fact that the WCAG 1.0 guidelines were developed in 1999 within the web environment at that time. In this decade of enormous web change, developers have found it difficult to apply those rather specific and prescriptive categorizations within the web 2.0 environment. Unfortunately, WCAG 1.0 did not account for rapidly changing technology, such as JavaScript, nor encourage web developers to build accessibility into the early design phases.

The perceived deficiencies of WCAG 1.0 led to the development and release of WCAG 2.0 in 2009. Unlike WCAG 1.0 priorities, which could be only effectively applied to HTML, WCAG 2.0 is designed with web 2.0 applications in mind (Kelly et al., 2007). WCAG 2.0 is guided by the acronym, POUR — perceivable, operable, understandable, and robust:

- Perceivable: Content must be perceivable through sight, hearing or touch. One of the main keys to accessibility is ensuring that content is transformable from one format into another, enabling your ... readers to perceive it in multiple ways.
- Operable: Content must be navigable or operable by various input methods. This means content must not be device dependent; for example, not mouse only.
- Understandable: Content and navigation must be understandable by your readers. This means writing the content in plain language and using consistent and intuitive navigation.
- Robust: Robust content works across operating systems, different browsers, and even on mobile devices. Your ... readers should be able to choose their own technologies to access read and interact on your site. This allows them to customize their technologies to meet their needs. Web content that requires certain technology may exclude visitors who either don't want to use that technology or cannot use it because of their disability. (Watson Huyett, 2009)

WCAG 2.0 aims to guide web designers both now and in the future and encourages the use of complementary "technology specific" documents. Thus, WCAG 2.0 encourages flexibility and considers the needs and capabilities of individual users. POUR seeks to put people at the center of the accessibility process. While WCAG 1.0 focused on technique, WCAG 2.0 emphasizes principles in a way that allows greater flexibility and puts users' needs first. Technical documents specific to certain devices and code are available as attachments.

### Legal Challenges

Legal challenges in the area of web accessibility have been scant, in part due to the differences amongst jurisdictions and interpretations of the law. Here, we outline some of the significant laws and legal challenges regarding web accessibility and the ways companies, organizations for the disabled, and individuals have responded.

Effective communication and access to public spaces are central to the legal discourse of accessibility, both on the web and otherwise. Section 508 of the United States' Rehabilitation Act 1973 is the legal standard for web accessibility. The Act legislated against the exclusion of people, otherwise suitably qualified, on the basis of their disability (Ellc (2010). Earlier in the Act, Section 504 evidences a rights-based approach to disability by legislating against discrimination and exclusion on the basis of disability (Ellc (2010): 292).

Similarly, Section 255 of the Telecommunications Act came into effect in the United States in 1996. It applies to manufacturers of telecommunications equipment and requires that they consider ways to ensure accessibility and usability from the initial design process and that they outline ways the product can be used by people with disability when "readily achievable" (United States Access Board, 2010b). Section 255 posits that people with disability should be able to access the same information as easily as those without disability and, importantly, without having to use accommodating technology (Ellc (2010): 300-301). If accessibility and usability are not readily achievable (defined as able to be accomplished without excessive cost), then the manufacturer must ensure the equipment can be accessed by peripheral devices commonly used by people with disability (Access Board, 1998).

In 2008, the United Nations expanded its definition of accessibility to position internet accessibility in line with the built environment (e.g., roads, buildings, etc). The W3C provided input and members of W3C were part of the ad hoc committee that established the UN Convention on the Rights of Persons with Disabilities. While it is acknowledged that there are a number of different organizations attempting to improve digital standards, the W3C study illustrates that these standards can be overlooked, if not actively ignored, in actual web design.

Australia is currently at the forefront of the international community in relation to promoting accessibility (Accessit, 2009). In Australia, the legal requirement in relation to web accessibility is clear: Section 24 of the Disability Discrimination Act (1992) (hereafter, DDA), like Section 508 of the Rehabilitation Act in the United States, proceeds from a social constructivist standpoint:

24 Goods, services and facilities

1. It is unlawful for a person who, whether for payment or not, provides goods or services, or makes facilities available, to discriminate against another person on the ground of the other person's disability or a disability of any of that other person's associates:
by refusing to provide the other person with those goods or services or to make those facilities available to the other person; or
(b) in the terms or conditions on which the first-mentioned person provides the other person with those goods or services or makes those facilities available to the other person; or
(c) in the manner in which the first-mentioned person provides the other person with those goods or services or makes those facilities available to the other person.

(2) This section does not render it unlawful to discriminate against a person on the basis of the person’s disability if the provision of the goods or services, or making facilities available, would impose an unjustifiable hardship on the person who provides the goods or services or makes the facilities available. (Australian Government, 1992b)

Like Sections 504 and 508 of the United States’ Rehabilitation Act, Section 24 of the Australian DDA mandates that if goods and services are available to people without disability, then people with disability must be afforded the same access.

Changing Expectations

In the first successful legal challenge to an organization for discriminating on the basis of disability through an inaccessible website, Bruce Maguire was awarded AUD 20,000 in damages. Under Australia’s Disability Discrimination Act, it was found that the inaccessibility of the Sydney Olympics website resulted in an unjustifiable hardship to Maguire (Worthington, 2000).

The Sydney 2000 website was an important public space for people to engage with the Olympics. It provided news, latest results, and ticketing information. Maguire requested the ticketing information be provided to him in Braille and the Sydney Organising Committee for the Olympic Games (SOCOG) refused, suggesting that he get his wife to read it aloud to him or that he call a helpline that might establish for people with vision impairments (Lopez, 1999). Both options would involve Maguire listening to another person for several hours. For Maguire, who also has a hearing impairment, Braille provides a “greater sense of engagement with the text” (Hudson, 2009). The complaint requested that the SOCG:

- include all text on all images and image map links on the website;
- ensure access from the Schedule page to the Index of Sports; and
- ensure access to the Results Tables on the website during the Olympic Games. (Worthington, 2000)

The SOCG refused mediation and argued that the initial AUD 2,000 set-up cost to produce the document in Braille was an unjustifiable hardship on their part. While Part 2 of Section 24 of the DDA does allow exemptions if the cost of allowing access for people with disability poses an unjustifiable hardship on the company, in this case the Human Rights and Equal Opportunity Commissioner (HREOC) found that this did not apply. Since the ticketing system for the Sydney Olympics cost several million dollars, it was unreasonable for them not to provide the alternative format at the stated cost of AUD 2,000. The Commissioner argued that the SOCG should have thought about web accessibility when they began setting up their website, emphasizing that it would have been easy to do and beneficial for a number of people.

This kind of oversight is common and results in the internet being a disabling rather than enabling technology for many people with disability. Yet digital technologies are often presented as a way to eradicate disability as it is socially constructed, while issues regarding access are ignored or glossed over. This issue will be problematic as long as disability remains part of the private sphere rather than a civil rights or public sphere issue. Interestingly, Maguire was subjected to a backlash from both the general Australian community as well as those with disability. Maguire recalls the views expressed by both people with disability and those without following a talkback radio interview in which he argued that access to information was a right not a privilege:

One woman said, “I don’t know what it must be like to be blind, and my heart goes out to them — but he should get someone to read him the book”. Shortly after this, a blind man rang in and said, “That Maguire’s nothing but a troublemaker; doesn’t he realize that we just have to accept things and not rock the boat” (HREOC, 2003)

When disability is individualized in these ways, the broader community is absolved of the responsibility of access — individuals and their families must find ways to cope largely unsupported. Maguire further explains that:

In their different ways, these two callers were expressing the same underlying belief; while disability may be part of the reality of human experience, any suggestion that people with a disability can or have the right to participate with full equality is subversive. (HREOC, 2003)

Although he lodged the complaint for personal reasons, for Maguire this radio interview revealed that the broader impact was significant because everyone should have a right to public spaces, including the internet. The importance of laws such as the DDA should not be underestimated (HREOC, 2003).

The Internet will only become accessible when the civil rights discourse of social models of disability is extended to the web as a public space:

The web is not a barrier to people with disabilities, it is the solution. The web has the potential to revolutionize the day-to-day lives of millions of people with disabilities by increasing their ability to independently access information, communication, entertainment, commerce and other aspects of life that most people take for granted. However, for the web to reach its full potential for people with disabilities, web developers must commit to always designing with accessibility in...
mind. Failure to do so risks turning a revolutionary solution into yet another barrier in the lives of people with disabilities. (WebAM, 2010a; italics in original)

Maguire’s successful case against the SOCCO set an international precedent which has assisted people with disability to pursue their right to access information online. More recently, in 2006 the Californian arm of the National Federation of the Blind (NFB) pursued civil action against Target.com in the United States under the Americans with Disabilities Act (ADA), the California Unruh Civil Rights Act, and the California Disabled Persons Act. They claimed that Target’s inaccessible website was denying people with vision impairment the opportunity to access their goods and services online (Disability Rights Advocates, 2010). In 2008, Target reached an undisclosed settlement and pledged a commitment to accessibility. This favorable outcome for the NFB has raised not only community awareness but also the expectations of improved accessibility.

As part of the confidential settlement package, Target was required to make changes to its website and internal guidelines under the direction of the NFB (Arnold, 2008). Target.com is now recognized by the NFB as meeting the requirements of making the site equally usable by blind and sighted users. Indeed, the NFB has awarded Target a Nonvisual Accessibility Web Certification. Although Target.com is one of the first major retail websites to implement web accessibility, issues with keyboard navigation and color contrast remain a barrier for users with low vision or people who are keyboard dependent (Dolson, 2010). It is also significant to note that this renewed interest in accessibility is the result of legal action rather than an implementation of universal design. Accessibility is, however, receiving greater attention recently with other online retailers, including CVS and Staples, agreeing to adhere to accessibility standards as part of out-of-court settlements (Martinez-Cabrera, 2010).

Some in the disability and accessibility community were disappointed with the fact that the complaint was settled rather than proceeding to a legal resolution. This meant that there is still no precedent in the United States. Early attempts to sue companies in the United States for inaccessible websites under the ADA were thwarted when the advocacy group, Access Now attempted to bring a suit against Southwest Airlines. The judge presiding over the 2002 case refused to expand the definition of public accommodation beyond the physical built environment: “To expand the ADA to cover virtual spaces would be to create new rights without well-defined standards. The plain and unambiguous language of the statute and relevant regulations does not include internet websites” (McCullagh, 2002). However, as far back as 1999, this kind of view was contested: “For the rights of the disabled to mean anything in today’s world, they must be extended to cyberspace no less than to parking spaces... The Internet is a new and critical kind of public space” (A More Accessible Internet, 1999 quoted in Elleccor, 2010). In 2010, the equivalence between the public space of the built environment and the public space of the web is becoming more widely accepted. The UN Convention on the Rights of People with Disabilities now describes cyberspace as equal to public space and encourages private entities and the media to make websites accessible to people with disability as a basic right (United Nations, 2006).

In the United States, the Section 508 Amendment to the Rehabilitation Act 1973 was first introduced in 1986 in recognition of technological advancements in communications technologies. In 1998, it was amended in such a way as to allow for both the elimination of barriers and the encouragement of new and accessible technologies. It requires that websites be made accessible to people with disability. There are six criteria that must be adhered to in order to achieve a minimum level of accessibility.

These criteria address a range of different impairments and disabling aspects of website design and they deal with both software applications and operating systems. One example is that a website should be easily navigable using a keyboard without a mouse as some people with physical dexterity impairment are unable to use a mouse. Similarly, people with vision impairments may exclusively use a keyboard and not a mouse. The importance of allowing for the use of screenreaders or Braille display through the inclusion of alt text is recognized via a focus on web-based information and applications. In the telecommunications sphere, there is an emphasis on the importance of compatibility with hearing supports, hearing aids, cochlear implants, assistive listening devices, and telephone typewriters (TTYs). The ability to adjust volume is noted to be important. Further, more than one media must be available via a variety of video and multimedia products. Self-contained, closed products — including information kiosks, calculators, and fax machines for example — address embedded software and allow for assistive technology.

These criteria are wide-ranging with respect to the types of disability they address. In addition, they give general users options as to how they access the web, for example, volume control and choice of media (video, text, slide show, etc). However, it is ineffective to rely solely on legislation to ensure accessibility, especially when it applies only to a certain group of websites. Despite relevant laws, accessibility protocols are still often set aside. Particularly in light of the trend toward user-generated content, the only way that accessibility will be guaranteed is if the principles of universal design become widely accepted as a fundamental part of web design.

It is difficult to apply much of the disability discrimination legislation to the web 2.0 environment because they were established prior to the wide uptake of the web in homes, government, and business. Although the first case of successful litigation against an inaccessible website occurred in Australia, there were no further attempts at corrective litigation in that country until 2009 when Les Karr initiated action against Virgin Blue, and also signaled his intention to similarly sue Yahoo Seven and the Australian Competition and Consumer Commission websites.
Motivated by his experiences as a person with vision impairment trying to navigate the online environment, in 2008 Karr began the onerous task of examining 30,000 websites to test their accessibility for people with vision impairments. He believed about 99 percent of websites to be inaccessible and initiated contact with several sites via their online contact information. After explaining the difficulties he, as a vision-impaired visitor, experienced with the particular site, he outlined the WCAG principles and encouraged the organization to bring the site up to standard. Only if the response was not favorable did he consider making a complaint to the Human Rights and Equal Opportunity Commission under the DDA.

Kerr did pursue action against Virgin Blue, citing difficulties in relation to color contrast and hard-coded text size. However, unlike Maguire’s experiences with SOCOG, Virgin Blue agreed to mediation and made the necessary changes. This was applauded by the Australian Disability Discrimination Commissioner, Graeme Innes:

Travel is something that we are all doing more and more of, and it is important that people with disability can participate equally in this activity ... Virgin Blue have been working productively with peak disability and advocacy organisations to improve access and their Independent Travel Criteria. The result is a policy which is far less restrictive ... Australians with disability make up 20 percent of the population, so I am pleased that this significant segment of the travelling market will now be able to share in use of Virgin’s facilities more equitably ... I congratulate Virgin Blue on these changes, and the way that they have worked with people with disability to achieve a positive result. (Australian Human Rights Commission, 2009)

While it is good to see attitudes to accessibility on the web changing, this does raise some continuing questions. Why is it that these laws and regulations work, whether by design or practice, only in situations where a complaint is brought either by individuals with disability or by organizations outside of government acting on their behalf such as the NFB? In many cases, these laws and regulations seem to require that they are policed and enforced by the very people who are excluded from accessing the sites that require modification. While the FBI was active in seeking out and prosecuting Dmitry Sklyarov for breaching United States’ laws relating to copyright, there seems to be no equivalent extra-jurisdictional enforcement of laws and regulations relating to accessibility.

The Australian Human Rights Commission takes W3C compliance into consideration when mediating disputes regarding web inaccessibility. WCAG 1.0 was the internationally-recognized standard for accessibility; this standard has now moved into its second generation with WCAG 2.0 and focuses on principles rather than technical specifications. By encouraging sites to follow the POUR principles, WCAG 2.0 is not invalidated by technological advancement. Like Berners-Lee’s vision for the web, these guidelines highlight the importance of accessing the same information in different ways and using different adaptive technologies. They also fit into a core feature of web 2.0 whereby software is above the level of a single device (O’Reilly, 2005). This has become increasingly important as more people access the web, using a range of different portable devices. Robust sites which allow users to control and access information in a variety of ways are particularly important in the era of the mobile web.

At the time of writing, Section 508 is open for public discussion (for more, see Chapter 8). The move to update the Act is in response to the high level of non-compliance (including by the White House) and the emergence of social networking in e-government. Section 508 requires that all Federal online content is accessible to people with disability (Walker, 2010). As local governments look to moving their online content to Facebook and other social networking platforms (Towns, 2010), the accessibility of social networking sites is becoming increasingly important as a measure of Section 508 compliance. This update is long overdue.

Accessibility 2.0

Particularly in light of the expanding ethos of user-generated content, the spotlight on web accessibility must move beyond the domain of government regulation. This concept has been termed “accessibility 2.0.” We use this term to refer to the capacity to access information in the format of choice when working within the largely unstructured environment of user-generated content. The philosophy of web 2.0 is to relinquish control by sharing ideas and building on what came before. In this way, web 2.0 invites collaboration and participation, with the only barrier to full democratic engagement being a problem of access. Allowing users to access information in the ways they want without restrictions is both robust and future-directed. It is also markedly different from the previous generation of broadcast communications where audiences were dictated to by broadcasters. Web 2.0 flourished where the early web failed because sites gave users control. The phenomenon will be discussed further in Chapter 4.

Unfortunately, compliance with the standards suggested by the W3C is voluntary and there is no fully effective way to enforce it. The differing interpretations of legislation amongst judges and jurisdictions make it doubly problematic, with some areas recognizing disability discrimination acts and others arguing that online spaces do not fall within the definition of public spaces and are therefore deemed to be exempt. Further, most disability discrimination acts were established prior to the advent of the World Wide Web era and their concepts do not easily translate.

Kelly et al. (2007) argue that accessibility options can sometimes get in the way of a satisfying user experience and that people should have choice about how information is accessed. An accessibility 2.0 approach describes "a renewed approach to accessibility, which builds on previous work but prioritizes the
importance of the user.” Accessibility 2.0 follows a social understanding of disability by focusing on the purpose of the resource. It assumes different people use the web in different ways and that accessibility is a process rather than a finite solution. Although accessibility 2.0 is lauded for moving beyond regulations and groups such as W3C and WCAG, this does not imply that there is no value in either their existence or the guidelines they have developed. Indeed WCAG 2.0, with its emphasis on principles rather than prescriptions, was actually a step toward the notions of accessibility 2.0 by allowing users to control the way information is accessed.

Accessibility 2.0 has been credited with moving beyond content in recognition of a web environment in which people both read and write. However, this presents an entirely new challenge to web designers who are trying to “do the right thing” by following web content checklists. Brian Kelly, who possibly first coined the term accessibility 2.0, anticipates a new set of resistance from the group that, historically, has supported the implementation of accessibility most forcefully:

But how ... should we address the conservatism we’re likely to face within the institutions which have adopted an approach to web accessibility which is based on simple conformance with checklists which simply cover the Web content? And what about the Web developers and content creators who, possibly for a period of almost 10 years, have prided themselves on implementing such guidelines? How should we change this culture? (Kelly, 2008)

Perhaps part of the answer is that everyone has a role to play in the future of accessibility, from government and policy makers, to hardware and software creators and finally, the web 2.0 community and the people actually accessing the sites.

Toolkits must be better developed in order to anticipate ways to allow for different impairments because there are many web developers and no one single way to ensure accessibility for everyone. For example, some websites, with the social networking site MySpace being the obvious example, automatically load audio. In this example the problem could be seen to be emanating from the creator of the MySpace page, or the browser (such as Internet Explorer or Firefox) or the operating system. As this interferes with the functioning of screenreading software, an accessibility 2.0 approach, in conjunction with WCAG 2.0, would see web standards implemented in a way to block the automatic loading of sound without impacting on the functioning of the screenreader (Popov, 2006), yet without having to turn off all audio.

As in the case of Dmitry Sklyarov and his Advanced eBook Processor, it seems that, sadly, the needs of the disability community are deemed to be of no consequence:

But what about the fate of all those blind people who now won’t be able to read e-books because Adobe will have disabled the read-aloud feature at some pub-

lisher’s request? Typically, publishers ask Adobe to disable that feature when they fear it might violate their contracts relating to an existing audio version of the same book. But when you think about it, in those circumstances it might actually make more sense for a blind person to pay $15 to buy the audio book — a tape of a professional actor or the author of the work reading the book aloud — rather than pay $8 for an e-book and $99 for conversion software, in order to hear voice-simulation software articulating the words in a robotic monotone. (McCullagh, 2001)

Even in 2010, when accessibility to print materials for people with disability is more widely understood by publishers, libraries, and universities, this argument does not actually reflect the real world situation. Publishers regularly lock pdfs (Portable Document Format) of their book prints without providing an audio book alternative and DRM is introduced to force device-specific access. If people with disability were to do as McCullagh (2001) suggests then they could be forced to purchase a new eBook reader for every book they read. That would be clearly unfair and disabling — text-to-voice software is an important accessibility and usability feature.

Usability is an important feature of accessibility 2.0 and borrows from recent developments in human computer interaction (HCI):

The original and abiding technical focus of HCI is on the concept of usability. This concept was originally articulated naively in the slogan “easy to learn, easy to use”. The blunt simplicity of this conceptualization gave HCI an edgy and prominent identity in computing. It served to hold the field together, and to help it influence computer science and technology development more broadly and effectively. However, inside HCI the concept of usability has been reconstructed continually, and has become increasingly rich and intriguingly problematic. Usability now often subsumes qualities like fun, well-being, collective efficacy, aesthetic tension, enhanced creativity, support for human development, and many others. (Carroll, 2009)

In the web 2.0 era, usability is not just about being able to use a site, it now embraces the concept of fun. But some have questioned whether this creativity is compatible with the prescriptions about accessibility. However, Lembree argues against the portrayal of accessibility as detrimental to fun:

I think there’s a misconception that a “Web 2.0” site or app [application] can’t be cool or fun and be accessible at the same time. On the contrary, I find that it’s quite possible. It’s mostly a matter of planning it from the beginning, and implementing progressive enhancement. (quoted in Accessify, 2009)

Glenda Watson Hyatt (2009) acknowledges the balancing act between creativity, aesthetics and usability/accessibility but affirms that site visitors’ preferences should be paramount. People must be able to access information in any way they choose:

[balanced your blog’s aesthetics with usability and accessibility. Which do you value? Which is more beneficial to your readers? That is not to say a blog needs to
Conclusion

Web 2.0 is governed by a user-centric approach that assumes technological innovation and that users will access the same information in different ways. Although the web as a platform is a web 2.0 concept, its origins are in Tim Berners-Lee’s vision of the web as a platform to share information. Berners-Lee suggested that accessibility, regardless of disability, was a crucial aspect and established the W3C and WAI to ensure this vision was realized. WCAG 1.0 and 2.0, although released ten years apart, reveal much about the increasing value of universal design and differences amongst users and their access choices and requirements.

Legislation in both the United States and Australia embody civil rights terminology. Emerging alongside the W3C, their origins are in non-web telecommunications and accessible environments. This has been problematic to implement yet has resulted in some positive outcomes for accessibility. Despite initial reluctance, the public space of the web is now being conceptualized in the same way as the public space of the built environment.

Accessibility 2.0 embraces the underpinning philosophy of web 2.0 — the undeniable right of user choice — and could prove more effective than W3C in forcing large corporations to embrace accessibility. This is particularly important when we start to realize that new bottlenecks of resistance are emerging to thwart user choice of format. Although web 2.0 sites encourage community collaboration via user-generated content, surprisingly, many still attempt to force users to access information in a particular way. For example, Apple, whom we consider in-depth in the next chapter, has greatly improved their accessibility following user outrage. Yet they continue to operate outside of standards and dictate which technology users must adopt.

At the start of the century Skylarow was arrested, but was not convicted for circumventing DRM to grant a higher level of access, similarly at that time Maguire successfully pursued his action against SOCOG over the inaccessibility of their website. However by 2007, all Australian universities had websites that were no longer compliant with the WCAG guidelines. The legal action against Target.com was also successful in making the company’s web presence more accessible and similar agreements have been reached with both CVS and Staples. However, all these outcomes required legal action to be taken. It seems that heading into the second decade of the twenty-first century that we do indeed stand at a crossroads in relation to web accessibility. The great potential that access to digital communications technologies provides, particularly for people with disability, remains in danger of being unrealized, yet there are many positive signs and developments.
Disability, Neurological Diversity, and Inclusive Play:
An Examination of the Social and Political Aspects of
the Relationship between Disability and Games

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Abstract

This article explores existing connections between disability studies and game studies, and suggests how the two fields might greater inform each other. While existing research explores the use of games to reduce pain and achieve rehabilitative goals, new research on games from a disability studies perspective can also consider the persuasive messages that games advance about disability, and how these messages affect questions of identity, inclusion, and acceptance. By arranging the relationship between disability and games into four topics – therapeutic and educational tools, game simulations, accessible features and controls, and narrative inclusion and identification – this article explores, attempts to address, represent, and simulate autism in digital games. It focuses on Auti-Sim (2013), a simulation exercise, and To the Moon (2011), an adventure role-playing game. Drawing on the writings of autistic activists and existing scholarship on disability simulations, the author considers how these games may influence the player’s understanding of autism at social and political levels, and how these artifacts engage with the overarching goals of disability inclusion and autism acceptance.

Author Keywords
Disability studies; game studies; autism; Auti-Sim; To the Moon; inclusivity; disability in games

Game Studies and Disability Studies

Players engage with disability in games at multiple levels. Despite many points of intersection, few scholarly works consider disability studies approaches to games. Research approaches to disability and games often consist of studies of the efficacy of using games to achieve therapeutic outcomes. This article argues that the social and political aspects of disability deserve greater research attention. Disability studies perspectives allow for a consideration of the ideological and cultural implications of using games to manage and represent disability. The growing attention that games studies scholars devote to studying inclusion in games at the levels of access and representation with respect to other marginalized groups is meaningful for disability studies as well; game studies approaches to inclusion, which show how games engage with questions of identity, embodiment, and experience, can inform disability studies.

This article uses paradigms from disability studies to examine autism and games, devoting particular attention to Auti-Sim (2013), a simulation exercise, and To the Moon (2011), an
Disability studies is an interdisciplinary field devoted to examining disability as a social and political experience. Critiquing a medical model that characterizes disability as an individual problem, scholars emphasize the disabling impact of built environments and social attitudes. Many researchers work within the social model, which distinguishes between impairment as a bodily state and disability as an experience of marginalization (Pfeiffer, 2002). Other scholars critique the social model’s strict distinction between disability and impairment. Shelley Tremain (2002) explains that definitions of impairments are historically and culturally contingent, pointing toward a generative model of bodily difference (p. 34). The majority of early scholarship in the field focuses on the body, but increasingly researchers study intellectual, invisible, and psychological disabilities.

Disability studies research on autism examines how it has been understood through a series of neurological deficits. Many autistic people have deployed the concept of neurodiversity to speak back to discourses that construct autism as a tragic condition that needs to be cured. Ari Ne’eman positions neurodiversity against a deficit model of disability, defining it as “the idea that the paradigm of acceptance extended toward racial, religious, and other similar differences should apply to neurology as well” (in Broderick & Ne’eman, 2008, p. 470). Others use a rhetorical perspective to show how autistic communication is meaningful (Heilker & Yergeau, 2011; Walters, 2014). These developments in the study of autism are important for considering how games influence understandings of inclusion and acceptance.

While few academic articles discuss games from a disability studies perspective, many bloggers have chronicled experiences using systems like the Kinect to help reduce pain, and have evaluated the representation of disabled characters based on their experiences as disabled gamers. Groups like the AbleGamers Foundation and the Semaphore Research Cluster are working to make mainstream games more accessible, and promoting the role of people with disabilities as innovators (Ore, 2014). Although existing writing on educational and therapeutic games tends to be detached from writing about characters in popular titles, these games deserve to be discussed in conjunction. Scholars examining diversity in game culture focus on both representation and access. Similarly, supporting the inclusion of disabled people in game culture, industry, and research should involve looking at engagement as it occurs at multiple levels.

Rehabilitative and Educational Games

Games for Health and Normative Expectations

Games are increasingly used to promote health and manage disability in clinical settings. Some researchers have repurposed existing games for use in rehabilitation (Deutsch, Borbely, Filler,
Huhn, & Guarrea-Bowlby, 2008). Others have created games that are designed to help people achieve therapeutic outcomes (Annett et al., 2009). For example, researchers at the University of Washington HITLab and the Harborview Burn Center created SnowWorld, an immersive reality intended to encourage pain distraction for patients undergoing wound care; research has shown that the game mitigates the painful experiences of undergoing treatment (Hoffman, 2014). Other researchers have created educational tools like Re-Mission 2, a game that provides support to children with cancer by “giving players a sense of power and control and encouraging treatment adherence” (HopeLab, 2014). Another example is Audiopolis, an audio and haptic video game designed to help blind players develop wayfinding skills (Sánchez, de Borba Compos, Espinoza & Merabet, 2014). Social Clues, a game currently in development through the University of Southern California, aims to teach autistic children about appropriate behaviours. Players take on the role of communiKate or particiPete, learning about the meaning of facial expressions, the importance of eye contact, and the value of empathy (Social Clues, 2014). Since games like the ones listed above are designed to be enjoyable for younger patients, efforts to use them are praised without necessarily attending to how such games can expose our cultural investments in ‘normal’ bodies.

Coverage of disability in scholarship about games often takes the form of examining efforts to ameliorate experiences of living with disability and illness. Developers working on games designed to help autistic people and adults recognize different learning styles, and respect preferences for digital tools. However, efforts to change behaviour through gamification deserve critical attention. Disability studies approaches can allow for an exploration of whether the content of serious games allow for multiple understandings of disability. Ivan Leslie Beal (2011) argues that education and change should be the goal of games for health. In contrast, Danielle Stock (2013) argues that developers might move beyond correcting behaviour and recognize that other factors besides a lack of knowledge generate non-compliance. She explains that Beale “seems to understand illness as a series of physiological and psychological indicators, and thus, [his book] entirely dismisses opportunities to supportively intervene at the social or cultural levels” (Stock, 2013). Pointing to McGonigal’s SuperBetter, Stock argues that one of the meaningful differences between this game and other games for health is its recognition of the need for communal support. Researchers might also explore how games could make visible the cultural investments placed in returning to ‘normalcy’.

Our cultural scripts are filled with narratives of overcoming the body that elide the disabling role of inaccessible environments and present certain bodies as undesirable. Studies of the utility of games in achieving measurable outcomes take place, but researchers might also explore ways that games could provide alternative scripts that can question the ideological investments placed in returning to ‘normalcy’. The importance of walking is an unquestioned assumption in many rehabilitative practices, as Gibson et al. (2012) explain in their examination of beliefs about walking in rehabilitative settings: “independent walking and ‘standing on your own two feet’ symbolizes largely taken-for-granted virtues – rectitude, dignity, autonomy” (p. 62). With respect to Social Clues, eye contact also has cultural significance that we associate with values like trustworthiness and confidence. In a supportive article on Social Clues, Emily Payton (2014) points out that eye contact is a difficult social cue to teach because its significance varies across cultures; in some societies using eye contact is considered rude. Furthermore, many autistic people critique
the pressure that they face to modify their behaviour in ways that are painful or uncomfortable (Sequenzia, 2012).

A disability studies lens provides an alternative reading of Social Clues as implicated in attempts at normalization. Gibson and Teachman (2012) argue that “parents and children need exposure to counter-narratives of disability to help them write alternative life scripts that do not rely on pursuing an arbitrary construction of normal” (p. 481). While existing research in games studies examines the role games play in helping individuals achieve clinical outcomes, the possibility of games aiding in the formation of alternative life scripts deserves greater consideration. With knowledge of disability studies, game designers interested in using games as tools might explore alternatives to rule-based systems that normalize certain behaviours, and avoid positioning the movement toward a more able avatar as an achievement. A disability studies analysis of games as tools draws attention to the cultural narratives about normalcy that they risk reinforcing.

**Disabling the Player in Simulation Games**

Another way in which disability has been explored in video games is through simulations that allow players to explore alternative sensory or personal experiences. One such game is Auti-Sim, which was developed during the 2013 Hacking Health Vancouver Hackathon, an event designed to foster collaboration among health experts, programmers, and designers. The first person simulation game, created in the Unity engine and playable in browser, immerses the player in a children’s playground and uses overpowering sound effects and visual distortion to raise awareness of auditory hypersensitivity. As the player approaches the play structure, the screen fills with static and the background chatter intensifies. When she walks past the faceless children, one child begins to chant the alphabet over rising static punctuated by screams. Unlike other games for health that seek to change the behaviour of disabled people, Auti-Sim attempts to intervene at the level of social attitudes. It explores sensory experiences, experiences that are often elided in popular discourse and fiction about autism (Murray, 2012). Yet while the game aims to build understanding, many player responses suggest that their experience of the game was a fearful one that encouraged them to pity autistic people.

In Auti-Sim, there are no clear objectives that need to be achieved in spite of the environmental difficulty. Like many simulation games, it does not include a cohesive narrative structure or distinct player objectives, and it is not designed to be enjoyable. While the game presents no clear goal, the implied player objective is to find a means to relieve one’s senses. Analyzing the game at the level of procedural rhetoric, which Ian Bogost (2007) defines as “the practice of persuading through processes in general, and computational processes in particular” (p. 3), the connection between the player’s retreat from the playground and the corresponding decrease in noise highlights how quieter environments may be preferable for autistic people. As the player moves away from the source of the visual and audio distortion, the game instructs that autistic children may respond to overwhelming sensory experiences by moving away from large groups and retreating to quiet places.

Although disability studies scholarship of video games is still developing, many scholars have studied the use of simulation games in educational settings. Participant reviews following simulation exercises designed to raise awareness suggest that many leave such exercises with
confirmed beliefs that being able-bodied is objectively preferable to being disabled. Sheryl Burgstahler and Tanis Doe (2004) show how simulations reinforce understandings of disabilities as individual deficits, and overlook the disabling impact of social attitudes. They caution that trying on disability, by using a wheelchair, playing with a blindfold, or navigating an inaccessible website, does not teach people how individuals develop strategies over time to manage their environments. In other words, the panic that a player experiences during a simulation will not capture the daily experience of living with disability, and may reinforce ableist assumptions. More recently, research has shown that simulating physical impairments can negatively influence perceptions of the ability of disabled people to live and work independently (Silverman, Gwinn, & Van Boven, 2015). Disability studies scholarship that examines the process of turning embodiment itself into a game shows how some efforts toward awareness can increase stigma, rather than combat it.

Many player responses to Auti-Sim on its GameJolt page concern the instructive value of the experience as an exercise in empathy. However, while some players express the extent to which the game is a valuable tool and a viable representation of their own experiences, others offer critique. These critiques primarily consist of concerns surrounding the accuracy of the game’s portrayal, the lack of consultation with autistic adults during the design process, and the game’s representation of autism as a nightmare. On his developer’s blog at Toughcell games, Taylan Kadayifcioglu acknowledges many of these critiques. He writes of Auti-Sim, “[a]lthough it was built hastily in just about 12 hours and has its fair share of flaws, it went viral easily for having found an extremely receptive audience of people who care about the subject matter deeply” (Kadayifcioglu, 2013). Bearing in mind that sensory experiences differ from one autistic person to another, perhaps an important question is not necessarily whether the game’s representation is accurate, but whether the game’s use of fear to represent autistic people will encourage neurotypical players to be accepting of autistic difference. Player reviews on GameJolt, including that of one user who noted, “I feel sorry for children who really have this disease,” demonstrate how simulations can promote pity, and pathologize disability (Nodzi, 2013).

One of the main goals of neurological diversity is to critique efforts to cure autism, efforts that are often driven by fear. Reviewers describe how Auti-Sim borrows from the horror game genre through its use of audio and visual distortion, but they do not consider the implications of using fear to raise awareness of disability. One reviewer describes how “Auti-Sim draws on horror game tropes to rather brilliant effect” (Grayson, 2013). Another calls the game “shudder-worthy,” noting that, “Auti-Sim does a better job at distressing its player than any survival horror game” (Sterling, 2013). The work of autistic activists who question the perception that autism is a tragedy, and the work of scholars who question the value of disability simulations, suggest a need for critique of video game simulations of disability too. Associating neurological difference with fear and suffering encourages pity, which limits possibilities for accepting autism as a valuable state of being, and for helping to shape more accessible environments for people with sensory differences.

Scholars’ beliefs differ with respect to whether simulations should be reframed or abandoned entirely. Burgstahler and Doe (2004) argue that if disability simulations are to be used, they must be designed with attention to disability as a social and political experience. While disability simulations can be educative even if they include negative experiences, from a disability rights perspective, linking these experiences to social barriers avoids promoting pity, and directs player
attention toward action. One of the examples that they describe of a positive simulation was led by an instructor who was a wheelchair user. After students spent time in a wheelchair, their discussion centered on disabling social environments and enabling universal design principles. Although some suggest that simulations are always inappropriate, Burgstahler and Doe’s flexible conclusion creates space for a nuanced exploration of the expressive power of autobiographical games, a genre that shares some similarities with simulation games. Anna Anthropy’s *Dys4ia* (2012) and Zoë Quinn’s *Depression Quest* (2013) encourage players to empathize with experiences similar to those that the developers have personally experienced. *Dys4ia* combines narrative and mini-games to allow the player to experience many of the frustrations that accompanied Anthropy’s experience of hormone replacement therapy. Quinn’s *Depression Quest* is an interactive fiction that allows players to make decisions from the perspective of a person who experiences depression. These games come from creators that have been marginalized in the mainstream gaming industry, and criticized for making experiential games.

Games like *Dys4ia* and *Depression Quest* offer the player an opportunity to assume a social identity rarely explored in games. Quinn and Anthropy’s games might be understood as digital equivalents of Burgstahler and Doe’s simulations guided by people with lived experiences. Many *Depression Quest* players praise its use of the first person for encouraging empathy and dispelling stigma. Quinn told the *New Yorker* that, “some therapists even use the game as an exercise to generate empathy between a sufferer and his or her family” (in Parkin, 2014). The epilogue to *Depression Quest* includes an important caveat that the game itself is specific to one experience, and that the objective of the game is not for the player to overcome depression (Quinn, Lindsey, & Shankler, 2013). However, the endings to the games suggest that some outcomes are more favourable than others. Maddox Pratt (2013) critiques the biomedical treatment of depression in the game for portraying depression as “something to be moved through as quickly as possible.” She suggests personal experiences of depression can be valuable in a way that the game elides “[b]y claiming depression has a clear system, and designing a system around it in which players are encouraged to make the ‘correct’ choices – ones which lower depression levels in the status bar”. Pratt’s critique is a reminder that player responses are part of a game’s cultural meaning as well, and that while empathy is the desired result of a simulation exercise, other player responses are possible too. Pratt’s critique of how the game encourages players to move through the experience of depression quickly is relevant to *Auti-Sim* as the game similarly presents experiences of disability as negative.

While many autistic people do have painful sensory experiences, the game does not explore some of the more pleasurable aspects of sensation, as recounted in such resources as The YouTube performance piece “In My Language,” by Mel Baggs. The video is divided into two segments; the first part, “In My Language,” captures Baggs interacting with hir environment. The video shows hir engaging hir senses through such actions as stroking the surface of a laptop, pressing hir cheek against the page of a book, and waving hir hands while making an ‘e’ sound. In the second part of the video, “A Translation,” Baggs uses a text to speech synthesizer to create a monologue that serves as voiceover as sie continues in hir embodied language. Sie explains that being sensitive to hir surroundings is hir way of communicating with the world, stating, “..my language is not about designing words or even visual symbols for people to interpret. It is about being in a constant conversation with every aspect of my environment” (2007). Hir argument that hir movement constitutes a language in its own right calls attention to the normalizing aspects of efforts to teach
children to increase their eye contact, or refrain from stimming. While Auti-Sim attempts to intervene at the level of neurotypical perception, as opposed to at the level of autistic behaviour, its presentation of autism has unfortunately encouraged some players to pity autistic people. While games can create awareness, whether awareness is enough is a question that disability studies can bring to games studies scholarship.

**Popular and Independent Games**

**Accessible Content and Enabling Production**

Game studies explores the expressive power of video games, for both developers and players. Research has demonstrated that people with disabilities would prefer to play the same games as other players, but tangible barriers to access persist (Kearney, 2005). The AbleGamers Foundation is generating greater awareness of the lack of inclusion of disability at the level of game design, offering accessibility reviews and an *Includification* guide for developers. Alison Harvey (2013) notes that issues of access and inclusion are also present within the field of games studies in her report on the *Different Games* conference held in New York, in which she discusses concerns raised surrounding the absence of people with disabilities from panels.

Efforts to make games more accessible meet with overt and subtle resistance, as gaming fosters a culture of difficulty and a belief that only certain players deserve to advance. Consider, for example, the backlash against former Bioware writer Jennifer Hepler’s suggestion that players should have the option to skip combat, in the same way that they can elect to skip dialogue. Consider, as another example, when an EA Chief Creative Officer expressed concern that the company’s games were too difficult to learn, players responded with concern that games were becoming unnecessarily easy. Starkey (2015) explains that for these gamers, “the fact that most people feel locked out of the games was seen as a feature, not a bug.” While this backlash may not represent a calculated exclusion of disability, a belief that certain games should be “hard work” certainly leads to its exclusion (Gibbons, 2013). While individuals who argue against making games more accessible to new gamers may not be directly considering disability in their discussions, their wish that certain players be barred from accessing levels or narrative content if their play does not demonstrate sufficient skill represents exclusionary thinking.

Katherine Cross (2014) addresses harassment in gaming communities, arguing that we need to embrace new cultural scripts that will allow for greater inclusion of women, people of colour, and LGBTQ people in gaming culture and design. Representation can contribute to these new scripts. Steve Wilcox (2014) notes that while “systemic misrepresentations of cultures and subcultures, genders and races, are fair game in literary and film criticism…in games, however, there is little accountability of this nature…” Increased access to games as players, and greater inclusion at the level of representation in the stories games tell, are connected issues. Disabled gamers have often been excluded from gaming culture as players and creators, and the narrative inclusion of disabled characters, and particularly playable characters with disabilities, has also been limited. In the face of tangible barriers to access that players experience, issues surrounding the representation of disabled characters may seem less urgent. However, critical examinations of narrative in games from a disability studies perspective show how game narrative can serve as a powerful tool for identification.
**Disability, Narrative, and Identification**

Diane Carr (2014) points out that ability is so natural in games that “it hides in plain sight when it comes to critique or reflection.” While discussions of the need for more diverse characters in terms of gender, sexual orientation, and ethnicity are increasingly common, little attention has been paid to the presence of disabled characters in games (Disturbing Shadow, 2013). Jordana Erica Weber (2013) addresses this issue in her article “Patricia Tannis, Asperger, and Me,” in which she struggles with her feelings of whether the representation of Tannis is a caricature of Asperger’s syndrome, or a meaningful narrative of inclusion. In the absence of an answer from the writers, she decides that she appreciates knowing the character’s diagnosis (p. 260). New discussions of play from disability-identified players in games journalism demonstrate how analyzing the narrative content of games and their potential for allowing for what Gibson & Teachman (2012) call “alternative life scripts” is important cultural work (p.481).

One game that has resonated with autistic reviewers is *To the Moon*, an independent adventure role-playing game by Ken Gao. The player controls two scientists, Dr. Rosalene and Dr. Watts, who have been contracted to perform a memory alteration for Jonathan “Johnny” Wyles, whose dying wish is to go to the moon. To discover the reason for Johnny’s wish, the two scientists enter his memories and establish links that allow him to traverse from one point in his life to the next. The player gathers links and clicks through written dialogue between characters in Johnny’s memories. As the player enters Johnny’s past, she encounters Johnny’s deceased wife River, whom the narrative refers to as having a condition. The game does not name Asperger’s syndrome directly, but the player witnesses a memory in which River receives a diagnosis during an appointment with a doctor. He notes that her condition is a pervasive development disorder, and gives her a book by Dr. Tony Attwood. One autistic reviewer for Polygon describes River’s character as “the sort of representation we as a medium should be pushing toward: showing that there is hope for people with disabilities without erasing the very real problems we face” (Parlock, 2015). While analyzing game narrative about disability should not replace recognizing and fostering efforts to write or program games from disability – particularly when fictional depictions by non-disabled people often receive more recognition than depictions by disabled people – analyses of representation play a role in shaping a more inclusive gaming culture.

While the scientists manage to connect the majority of memory links with relative ease, they are not able to venture back to the earliest moments in Johnny’s childhood. Dr. Watts discovers that his client file did not indicate that he had been given beta blockers to suppress his memory of his twin brother Joey, who died when he was very young. The doctors learn Johnny had met River when he was a child, even though he believed that he had met her as a teenager. As children, the two had made a promise to one another that if they were lost they would meet on the moon. A dilemma arises for the scientists, who know that they are required to grant their client’s last wish, but who also know that he only wants his wish because of River. Believing that Dr. Rosalene is attempting to erase River from Johnny’s memories so that he can travel to the moon, the player assumes control of Dr. Watts and attempts to stop her. The player fails, and River is erased from the memory, and replaced with Joey, Johnny’s twin brother. As the player enters Johnny’s new memory of NASA, she discovers that River is there as a fellow recruit. In his final moments, Johnny experiences a memory of travelling to the moon with River.
Gao’s game is not necessarily more accurate than other representations of autism in games, as experiences of autism vary from person to person. Not everyone believes the representation is helpful; for example, Tucker (2015) felt that the game romanticized a diagnosis he shares. However, it is a powerful representation of a disabled character in a game that avoids using disability as a game mechanic, or a physical challenge to overcome. One of the central questions of the game is who has the ethical right to make decisions for others, a question raised by the narrative and paralleled by the player’s journey to balance the imperative to respect their client’s wishes with the imperative to act based on the information that they have discovered about his past. An argument could be made that River functions as a “narrative prosthetic,” a term referring to how disability functions as “a crutch upon which literary narratives lean for their representational power, disruptive potentiality, and analytical insight” (Mitchell & Snyder, 2001).

River’s inclusion and exclusion at key moments in Johnny’s life alters the plot of his story, but the player is ultimately controlling two different characters and working for Johnny. Reviewer Laura Kate argues that the character’s representation is ultimately more powerful because of its inclusion within the larger story arc:

“I’ve never seen such an amazingly handled piece of fiction on the subject before and the fact that this is all hidden inside a game that on the surface seems to be about time travelling and helping a Neurotypical (non Autism spectrum) man to achieve his personal goal is a stroke of brilliance. One of the most moving games I’ve played in a long time, as well as one of the best in terms of making me feel included by an industry that so often portrays me as essentially being Sheldon from The Big Bang Theory.

Kate (2013)

Kate’s review provides an important explanation of how the game moves beyond stereotypes associated with autism, but the game is also significant for its attempt to address disability in a social context. The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition suggests that autism is marked by a failure to communicate effectively, but does not consider the role that the listener plays in communicative interaction. One of the critical aspects of the narrative in this game is that it challenges the initial assumptions of the scientists that the difficulties that Johnny and River experienced were because of River; in other words, in its uncovering of the story of their relationship, the game insists that the neurotypical person has an obligation to listen, and this obligation is one that the player must fulfil.

Although the game never names River’s condition, it provides various clues that she has Asperger’s syndrome. River’s friend Isabelle is also autistic, which becomes apparent when Johnny tells her about a decision that he plans to make that he believes is in River’s best interest. Isabelle, who disagrees with Johnny’s plan to lie to River, tells him, “I really dislike when you neurotypicals think you know what’s best for others” (Freebird Games, 2011). When Johnny asks Isabelle why she often seems so normal, she responds by discussing what it means to ‘pass’:

With effort, it is possible to acquire a guise of social norms systematically. But you know what? I both envy and pity River. Me…? I’m an actress because I’ve been doing it all my life. Not only on-stage, but off-stage…and at practically every
moment. I’ve gotten good at it because acting is the only option I have. It is the only way for me to be ‘normal’. But River...she never did that. She remained an outcast and refused to learn how to step against it. I don’t know if it was by choice or by limit, whether by bravery or cowardice. There are days where I just can’t stand faking it anymore. And then I realise that it’s too late. The Isabelle that people know of is all an act and the real me has long become a stranger. I think in the end...I just envy her.

Freebird Games (2011)

Isabelle explores the idea that disabled people often work to pass as normal because of the pressures associated with identifying as disabled. Johnny’s question of why she appears so normal also raises the issue that society expects individuals on the spectrum to prove themselves by answering for their differences from other autistic people. Disability studies theorist Tobin Siebers describes the pressure that disabled people feel to ‘pass’ as normal in some situations, and the pressure that they feel to make disabilities that do not always have clear visual markers present in other situations. Anthropologist Dawn Prince-Hughes, who is autistic, addresses this issue in the introduction to her memoir, noting, “I am glad that I am so successful at appearing normal (whatever that is), but I also wish at times people knew how hard I work at it” (p. 2). Rather than making disability a condition that a player must overcome to progress, the game explores the implications of assumptions that other characters make about disability.

While To the Moon is in many ways an interactive fiction, it also requires the player to complete puzzles and gather key items. As the player proceeds through Johnny’s memories, she must gather items from each memory that serve as links. The central conflict of the game concerns River’s inclusion in the narrative of Johnny’s life that the player reshapes. The game’s exploration of Johnny’s memories in reverse forces the player to re-evaluate interactions between River and Johnny, including her creation of origami rabbits. The player encounters these creations in the basement of Johnny’s home upon receiving a tour from the children of his caretaker. In the later memories, River asks Johnny to describe her rabbits, asking him, “What else?” as he fails to remember what they signify (Freebird Games, 2011). During their childhood meeting, the two had traced a constellation of a rabbit in the sky, with the moon serving as its belly, but Johnny cannot recall this memory. The game’s narrative allows readers to uncover the communicative significance of River’s paper creations, and shows how the onus for effective communication should not only be placed on River.

Inclusion and Acceptance

Auti-Sim (2013) and To the Moon (2011) are two recent games that explore autism from different perspectives and with different rhetorical purposes. Studying the narratives and experiences of disability that they offer in conjunction with one another suggests the importance of using disability studies perspectives to analyze and explore disability in context. While much of the existing scholarship surrounding disability and video games focuses on utility, and the potential for using games to improve rehabilitative or behavioural outcomes, critical studies of narrative and play are also essential for considering how games, in their emerging popularity, shape our cultural understandings of disability.
While this article focuses on the overt engagement with and representation of disability in games, disability studies methodologies can also be useful for studying games that may not on the surface appear to be about disability. As Carr (2013) points out, “ability hides in plain sight”. Similarly, disability can be hidden but is always present. In many role-playing games, the ability to upgrade one’s characters becomes a means of rendering them more able, and more capable of succeeding in the given environment. An able body in a science fiction game setting, for example, differs from what we consider an able body in the present, demonstrating how what we consider a disability is historically and culturally contingent (Gibbons, 2013). Even games that are primarily understood as tools play a role in either reinforcing or challenging cultural beliefs about disability.

Progress toward the end goal of a game does not need to be progress toward overcoming or curing disability for a game to be meaningful for disabled people. While scholarship often focuses on how games might ameliorate experiences of disability, critical efforts to make disability a part of gaming can also echo the existing work that scholars, players and developers have begun with respect to fostering greater inclusion and representation of diversity. As with other efforts at ensuring greater inclusion and greater representation, efforts to include and represent disabled people should consider both access to playing and developing games, and greater narrative representation. In charting some of the ways games have attempted to ameliorate, recreate, or tell stories about autism, I argue that while effective and realistic representation has been one concern, another should be the potential for games to consider how autism is not only embodied, but how it is lived out in a social context.
References


Some articles that analyze representations of disability in games include Carr, 2014; Champlin, 2014; Gibbons, 2013 and Joyal, 2013.

For research on the efficacy of using games in rehabilitative settings, see, for example, Annett et. al, 2009 and Halton, 2007.

The social model creates a distinction between disability and impairment that is similar to the distinction that feminists created between gender and sex (Shakespeare and Corker 3). Iris Marion Young explains that “while the social model of disability destabilizes the assumption that the ‘problem’ with some people has to do with the attributes of their bodies and functions, it nevertheless continues to presume a certain fixity to these bodies…” (xiii).

For examples of bloggers, see Disturbing Shadow, 2013; Green, 2014; Parlock, 2015.

A related issue is the use of a child to represent autism. Although autism is a lifelong condition, misperceptions that it only affects children, or that children can be ‘cured’, continue to circulate. Although Auti-Sim does not show that autism is temporary, the use of a child to represent autism is a political choice in the context of these debates.

As Baggs identifies as genderless, I use the gender-neutral pronouns “sie” and “hir” outlined on hir Ballaexistenz blog. The term “sie” replaces he or she, and the term “hir” replaces his or her.

Meryl Alper’s model of a mixed-ability maker culture might serve as a model for game development too. She describes this culture as, “one committed to an equitable, ethical, and sustainable democratic future. It requires us to look closely not only at the materiality of making, but also the social context that surrounds participation in and exclusion from maker culture” (Alper, 2013).

Other writers, like Tucker (2015), express a preference for reading characters without labels as autistic.

Tony Attwood is a psychologist whose work focuses on Asperger’s Syndrome.

An accessibility feature that the game does not include is the use of audio cues to supplement visual cues. The game conversations are only available as written text.

Although this article refers to both autism and Asperger’s syndrome, it does not engage with the distinction between these two diagnoses. The decision is not simply to reflect the amalgamation of these diagnoses in the DSM-5, but to recognize activist concerns that using two different terms to describe a spectrum of conditions creates an artificial distinction.
Playing for Transcendence

Deus Ex: Human Revolution and Disability

Transhumanism
In *Deus Ex: Human Revolution* (2011), the player controls Adam Jensen, the chief of security at Sarif Industries. *Human Revolution* is a role-playing first-person shooter that takes place in 2027. The game commences with an attack on Sarif Industries, and with your discovery, upon reawakening from surgery, that the company has not only saved your life, but has also equipped you with advanced biomechanical augmentations. Another attack against a company warehouse sets events in motion, and you travel through Detroit, Hengsha, Montreal, Singapore, and the Arctic Panchea facility to uncover a vast corporate conspiracy. As you progress through the game, you visit L.I.M.B. (Liberty in Mind and Body) clinics to upgrade your augmentations.

*Human Revolution* explores the philosophy of transhumanism, or H+. Transhumanism is in many ways an extension of Renaissance humanism; transhumanists continue in the tradition of Enlightenment thinkers who believed that rationality and science would improve human life (Wolfe xiii). Art director Jonathan Jacques-Belletête has explained that he and his team created a ‘Cyber Renaissance’ look for the game, which involved blending sixteenth-century clothing fashions and architectural designs with cyberpunk noir amour, weapons, and cityscapes. This style was developed to draw attention to the connections between the anatomical drawings of the Renaissance and developments in cybernetics. While the Renaissance as a cultural and scientific revolution was characterized by new discoveries about the workings of the human body, for many characters in the game, a tranhumanist era of augmenting the body promises a similar cultural revolution. Tranhumanists today share the belief that technology will unlock human potential. The first principle of the Transhumanist Declaration reads:

“Humanity stands to be profoundly affected by science and technology in the future. We envision the possibility of broadening human potential by overcoming aging, cognitive shortcomings, involuntary suffering, and our confinement to planet earth.”

In practice, the methods and theories of transhumanists vary, from roboticist Hans Moravec’s dream of downloading human consciousness into a computer, to philosopher Nick Bostrom’s belief that death is uneconomical, to “scrapheap transhumanist” Lepht Anonym’s biohacking.

Overcoming the limitations of the flesh is a recurrent theme in video games that is central to the mechanics of play. Religious studies scholar Robert A. Geraci suggests that many transhumanists value connections between tranhumanism and gaming. His study participant, referred to as “Gwydion”, explains:

“In a sense transhumanism is gaming. It is the same idea that you can become something more than yourself. Thus, anytime you build a character and go “in-world” you have created an idealized or specialized extension of your being…” (qtd. in Geraci).

My commentary takes up the relationship between transhumanism and gaming in *Human Revolution*. I discuss narrative support for and against transhumanism, and argue that theories of posthumanism offer another area of inquiry with respect to embodiment. I suggest that as the game explores how technology changes our understanding of human ability, it also points toward how disability does not consist of a set of deficiencies, but is instead shaped by environments. Finally, I contend that the game’s inaccessibility is instructive for considering its imbrication in a culture of difficulty that valorizes overcoming the body.

**Human Enhancement**
Many non-player characters, including your ex-girlfriend, scientist Megan Reed, and your boss, David Sarif, express faith that augmentation will improve the human condition because everyone has the potential for improvement locked within their DNA. While wandering the streets, you learn that augmentation technology and its exclusivity have exacerbated existing social divisions. Only the wealthy can afford augmentations and nepropozyn, a fictional drug that prevents the body from rejecting implants. While you encounter opposition to augmentation from civilians who react to your appearance, the game also features organized opposition to enhancement. Purity First is a radical organization responsible for attacking the Sarif warehouse in the opening mission. Adherents have an essentialist conception of the human being and refer to individuals with augmentations or “Augs” as “body polluters”. Humanity Front, an organization that ostensibly favours peaceful tactics, presents another source of opposition to unregulated augmentation. Finally, Jensen, despite working for Sarif, voices skepticism in the game’s opening sequence. Megan assures you that augmentations are not only designed for military contracts, but for teachers and other professionals. As you pass a demonstration of the typhoon, or human landmine augmentation, Jensen quips, “A teacher would just love having one of those things”. As the player, you are able to select the views you want to express about augmentations based on sets of responses.

The game demonstrates how opposition to augmentation technology can stem from the fear that to develop this technology is to play God. Adam’s name suggests parallels to the biblical story of the tree of knowledge from Genesis. In the game’s trailer, Jensen appears on an operating table in a sequence referencing Rembrandt’s painting “The Anatomy Lesson of Dr. Nicolaes Tulp”. He rises above the operating theatre and flies toward the sun until his wings catch fire. Adam’s flight is an allusion to the Greek myth of Icarus, a story that illustrates the perils of hubris, of attempting to overcome human limitation. While many characters oppose or approve of augmentations, or occupy a space between both poles, the liberal humanist subject remains central to competing factions in the game. While Purity First adherents view augmentations as impure, biotechnology companies believe that each new product version represents an ideal form. Yet these groups similarly understand the body in ways that render certain forms normative and desirable.

Disability and Science Fiction

The interaction between narrative and play in Human Revolution demonstrates how what we consider an able body in a science fiction setting differs substantially from our definitions of an able body in 2013. The experience of the player whose difficulty navigating the game space depends on his or her chosen augmentations reinforces this idea. As Will Slocombe suggests in reference to the first two Deus Ex installments, augmentations, “demonstrate the weakness of the non-modified human in a technological environment; without such augmentations, the avatar would be, quite literally, ‘dead meat’” (38). Slocombe’s point illustrates how vulnerability is contingent upon the space that we inhabit, which points toward how disability is not rooted in fixed individual deficits. At the level of narrative, the poverty of individuals without augmentations illustrates how disability is connected to social identities like class. However, when disability is explicitly mentioned in the game, it is in the context of providing support for augmentations. The use of prostheses, for example, complicates the Purity First belief in wholeness. When Jensen remarks to Sarif’s assistant that, “Human augmentation can be pretty scary,” she replies, “Tell that to all the war amps whose lives have been improved because of it”.

Many scholars do suggest that individuals with disabilities are often the first users of new technologies, even as inaccessible design remains a concern. In “A Cyborg Manifesto," Donna Haraway suggests that people with disabilities often have “the most intense experiences of complex hyrbidization with other
communication devices,” which leads her to reject that our bodies end at the skin. N. Katherine Hayles similarly rejects wholeness as an ideal in her study of information and embodiment. She argues that the belief that subjects possess bodies and are not understood as being bodies informs the ideas of both liberal humanist thinkers and transhumanist thinkers, who share the perception that the body is separate from the self (5). Rather than clinging to a conception of the liberal subject, Hayles argues for the importance of materiality, offering her dream of “a version of the posthuman that embraces the possibilities of information technology without being seduced by fantasies of unlimited power and disembodied immortality, that celebrates finitude as a condition of human being…” (5). Often the result of merging the body and technology in science fiction, however, does not celebrate the generative possibilities of hybridity that Haraway and Hayles offer, but instead enacts the erasure of bodily difference or even materiality. A common trope in science fiction is the use of technology as a medical ‘cure’ that normalizes the disabled body (Allan). For example, in the film Avatar, wheelchair user Jake Sully escapes his body by transporting his consciousness into an alien avatar (Palmer).

The most prominent disabled character in Human Revolution is Hugh Darrow, the leading developer of augmentations, who ironically uses a cane. Eventually, I learned that this was not Darrow’s choice, but that his character did not possess the genes that allow for compatibility between the human body and augmentations. [Spoiler] In the final level, I uncovered that Darrow’s turn against his technology was motivated by his resentment that he would be unable to participate in the ‘human revolution’. While it was interesting that his experience with vulnerability led him to skepticism regarding the use of his technology for military purposes, his instigation of a biological attack to make his point evoked an uncomfortable history of associating disability with villainy in narrative and film (See Garland Thomson, Mitchell and Snyder, and Quayson). As I persuaded Darrow to abandon his violent plan, he exclaimed, “I was betrayed by my own genetics! Ruined by my own flesh!” It is worth noting, in the face of Darrow’s resentment against his own body, that many disability rights advocates resist the idea that disability is an illness in need of a medical cure, or that speaking, for example, is favourable to signing. They argue that the built environment should change as opposed to the bodies of individuals, a view which is instructive for thinking about game design.

Accessible Game Design

In many ways, gaming would seem to allow for the realization of fantasies of disembodiment. After all, the player’s avatar transcends her physical limitations within the space of the game world. Yet while the accessibility of virtual space, in contrast to built space, is often celebrated, many barriers to access are present in mainstream video games. To return to the theory that transhumanism is gaming, we can focus on the materiality of the body manipulating the controls. Michael Herron’s “Inaccessible through oversight: the need for inclusive game design” offers Human Revolution as an example of a popular title missing many crucial accessibility features. He notes that the texts found on in-game computers present difficulties for individuals with visual impairments, and that control mapping for console users is limited to inverting the x/y axis. While the game includes difficulty levels and allows for multiple play styles, boss fights are incredibly punishing for individuals who choose cranium enhancements over combat abilities (Herron 35). The AbleGamers Community gave Human Revolution an overall accessibility rating of 3.8/10, noting that despite some useful aiming features, the need for speed and stealth on the lowest difficulty level make this title unreasonably challenging for gamers with precision concerns. Commenting on the representation of disability at the level of narrative versus the lack of consideration for disability at the level of design, Scott Puckett notes:
“Interesting philosophical questions aside, *Deus Ex: Human Revolution* presents a number of significant accessibility concerns for disabled gamers, which – especially considering that the game specifically discusses disabilities in the debate over augmentation – seems somewhat ironic.”

I agree, but I also think that this irony is instructive for what it reveals about *Human Revolution* as an example of how design reflects ideology. In “Mapping Composition: Inviting Disability in the Front Door,” Jay Dolmage uses the metaphor of steep steps to describe the ways that the pedagogical space of the academy, like the physical space of the university campus, has traditionally excluded disability by fostering a culture that valorizes those who overcome barriers to make it to the top (14-15). While comparing video games with university classes and campuses might seem unusual, I think that gaming culture can also foster a culture of difficulty and a belief that only certain players deserve to advance. Consider the backlash against Bioware writer Jennifer Hepler’s suggestion that players should have the option to skip combat like they can skip narrative sequences. While I would not argue that backlash in this case represents a calculated dismissal of disability, a belief that games should be ‘hard work’ leads to exclusion.

If we believe that games are important artistic products that can foster empathy, inspire change, and encourage reflection, then accessible design is crucial. *Human Revolution* encouraged me to rethink my habits as a player. My assumption that I could spend my time hacking into computers and searching for credit chips instead of prioritizing a hostage scenario had clear narrative consequences. As well, because the reward system of the game consists of the augmentations that form the game’s central conflict, I questioned my desire to upgrade. And, unlike many similar games, *Human Revolution* allows you to create a relatively pacifist character who stuns rather than kills enemies. But I wonder how an accessible version of the game that affords greater inclusivity might influence our impressions of the ideological space of the game.

Drawing on Althusser’s concept of ideological state apparatuses, Slocombe contends that the first two *Deus Ex* games “dramatize the process of ideology masking its own presence” because they allow players to imagine that they have defeated ideology, when the constraints of interactivity reveal that the game is also playing the player (48). He attributes this effect to the ‘possibility space’ (Smith) generated by the interaction between the player and the game environment, an interaction that shows how Henri Lefebvre’s argument that ideology is inscribed into architectural space is relevant to game space as well (45). The game world of *Human Revolution*, including a decaying Detroit, and the layered city of Hengsha, in which the wealthy literally reside above the poor, shows how bodies are being designed to accommodate spaces, rather than the other way around. A limiting design that makes play nearly impossible for some gamers parallels the extent to which the future setting of the game welcomes some bodies and excludes others. While at the level of narrative, players can choose where they side with regard to augmentation technologies, the design reveals how the ideology underpinning the game mechanics is also informed by the belief that the player should overcome certain limitations, or more simply, that the player, as opposed to the game design, should evolve.

**Works Cited**


Universal Design and Its Discontents

by Rick Godden and Jonathan Hsy

INTRO:

Our online position paper is a two-headed reflection on disability and universalism in the fields of Digital Humanities (DH) and Universal Design (UD). One of the authors, Richard H. Godden, considers how particular experience of disability shapes his use of media and also informs his reactions to prescriptive statements about the use of technology; the other author, Jonathan Hsy, writes as a nondisabled ally who considers some of the discursive and practical complications that arise in efforts to make the web more accessible to people with disabilities. We come from different perspectives, yet both of us ask what it means for any community to establish “best practices” for technology use. Even the most well-intentioned universalist discourses risk effacing crucial particularities of embodied experience.
JONATHAN:

In my thoughts on Universal Design (UD) as a nondisabled person engaged with disability theory and Deaf culture, I make two counter-intuitive claims: 1. **UD is a myth**; and 2. **Inaccessibility can be socially productive**.

Media theorist Jane Bringold observes that UD is not a discrete goal but a “Utopian ideal” (47).[1] No platform will ever be accessible across every language (spoken, written, signed), every medium, and every embodied difference (sensory, motor, cognitive). Joe Clark, a specialist in technologies such as captioning and audio description disabled internet users, maintains **UD is a myth**.[2] I’d say UD is a motivating fiction or tantalizing impossibility: unicorn, Holy Grail, earthly Paradise, whatever. In its temporal deferral, UD replicates the unrealized futurity of disability itself. As Robert McRuer notes, disability does not designate a subset of humanity but a spectral prospect that haunts everyone: “If we live long enough, disability is the one identity that we all inhabit” (200).[3] In its deferred arrival, UD, like disability, conjures an elusive future.

Deferred futurity is precisely how mainstream social justice discourses of access and inclusion express dreams of shared (cyber)space, even as they acknowledge the vitality of embodied difference. The *Accessible Futures* workshop series embraces utopian discourse by teaching DH folks to make work accessible to disabled internet users.[4] The National Endowment for the Humanities (NEH), among others, have sponsored the workshop series assembling academics and designers to address access issues. I attended an iteration of this (along with Jesse Stommel) here in Austin on February 28-March 1, 2014 and find the series (and website) highly productive. The organizers Jennifer Guiliano, George Williams, and Tina Herzberg directed most of our time toward visual impairment and strategies for incorporating captions, alt-tags, and elements of website architecture that can be navigated by people using voiced screen readers.[5] We also held an “audit” of DH projects to consider how well they integrated such accessibility features.

One website under discussion was the *Deaf Studies Digital Journal* (DSDJ) published by the ASL (American Sign Language) & Deaf Studies Department at Gallaudet University in Washington, DC.[6] This journal’s use non-textual digital media for its linguistic content make it an intriguing case study. DSDJ is the first peer-reviewed academic journal to use ASL for its content (with some material in English).[7] Since ASL is a kinetic language using embodied actions including manual gestures and facial expressions as grammar,
Flash Video clips are crucial for content.

Gesturing towards universality, DSDJ seeks to reach non-US Deaf communities. Most contributions include a summary in sign language by the author. Many items have downloadable PDFs presenting equivalent content in English. Some items are in International Sign (IS), a Deaf contact language when signers have mutually unintelligible languages. By incorporating languages beyond ASL, DSDJ is partially accessible to users unfamiliar with ASL or English.[8]

One curious aspect of our DSDJ discussion in 2014 was discomfort with the lack of audio or captions in the video clips, as they made content “inaccessible” by one set of embodied norms (i.e., UD principles requiring embedded features for internet users with visual impairments). As I reflect on that conversation today, I realize that the uneven media functionality of DSDJ presented an awkward social reality for the workshop attendees: much of this Deaf-oriented journal was inaccessible to a hearing majority (i.e., online content was only partially accessible to non-ASL users). As a hearing person who does not know much ASL, I find it intriguing that a commentary section on the topic of audism or “audiocentric privilege” does not provide a link to a PDF that I can read in written English (perhaps one might appear in the future).[9] This current user interface fittingly forces me to confront my own audiocentric (and Anglophone) privilege. I find myself navigating a linguistic environment that is only unevenly or partially configured for my use.

RICK:

As a disabled academic reflecting on the intersections between Universal Design and Digital Humanities, I make two claims: 1. **Universal Design and the resistance to digital tools both posit a universal subject;** and 2. **DH needs to balance its embrace of UD with further attention to the particulars of embodied experience.**

George Williams, in his “Disability, Universal Design, and the Digital Humanities,” advocates that the field of Digital Humanities adopts the principles of Universal Design. [10] Ron Mace, working in architecture, developed “the concept of designing all products and the built environment to be aesthetic and usable to the greatest extent possible by everyone, regardless of their age, ability, or status in life.”[11] I very much agree with Williams. The goals of Universal Design stand in direct contrast to the often nostalgic (and ultimately hierarchical) expression of normativity we see in the repeated calls to re-
embrace physical books, pens, and paper. For such positions, one need only look to the
oft-cited (and oft-shared on social media) study on the efficacy of hand-written versus
digital note-taking.[12] However, I want to suggest that both positions engender a sense
of “best practice” that could obscure the specific sociopolitical and embodied orientation
of an individual user.

In his critique of UD, Rob Imrie interrogates the limitations of the universal subject that UD
posits, noting that “UD rejects design that fails to respond to, and interact with, everyone
irrespective of their socio-cultural status and bodily capabilities and capacities.”[13] While
maximum accessibility is a laudable goal, in practice UD often fails to attend to the
particular as it espouses the universal. Dominika Bednarska, for instance, examines how
voice recognition software for the visually impaired could be seen to eliminate the need
for assistants and note-takers.[14] This is, in fact, one of the great benefits of assistive
technology and UD – by building environments, physical and digital, that provide barrier-
free access, then People with Disabilities can function more independently, and with less
reliance on other people. As someone with a disability, I feel deeply and urgently the need
to be less reliant on other people, but sometimes existing technology can be inadequate
—it can break down, be unreliable, or may just be a poor substitution for human help
(even if I don’t want that help). Bednarska relates how, at her own institution, the
University of California at Berkeley, funding for disabled students to have assistants
became more restricted and limited because of the promise of available technologies. So,
a student who did in fact work best with someone providing note-taking services would
need to first demonstrate that available technologies were inadequate. This can provide
an unnecessarily difficult bar to clear for some.

As a medievalist also working in the field of Disability Studies, I have been trained to look
for the particular and the local, the anomalous and the perplexing. Rosemarie Garland-
Thomson describes the “extraordinary bodies” of the disabled,”[15] and in my own field of
medieval literature, Christopher Baswell has referred to nonstandard bodies as
“eccentric.”[16] Eccentric and extraordinary bodies have the potential to puncture the
illusion of the universal that UD champions, disorienting and, more importantly,
reorienting how we conceive of access and equality. Williams himself cites the work of
Garland-Thomson in his work on UD, and I do think that his analysis attends to the
particular in better ways than the more architecture-based UD that Imrie critiques. For
example, Williams encourages a reciprocity between user and designer, arguing that “by
working to meet the needs of disabled people—and by working with disabled people
through usability testing—the digital humanities community will also benefit significantly as it rethinks its assumptions about how digital devices could and should work with and for people.”[17] I would suggest that the goals that animate UD should be and will continue to be a powerful principle in DH, but such a design principle needs to accompany, not supplant, the attention to the particular. Reciprocity could mean mutual care, of and for each other, but it should not need to flatten us out into a universal subject in the process.

CONCLUDING THOUGHTS:

In our critical evaluations of UD, we share several conclusions and concerns with the contributors to the webtext *Multimodality in Motion: Disability and Kairotic Spaces.*[18] In their opening “Access Statement,” Yergeau et al. acknowledge that “Universal design is a process, a means rather than an end. There’s no such thing as a universally designed text. There’s no such thing as a text that meets everyone’s needs. That our webtext falls short is inevitable.” They caution that the inevitable failure of UD “is not a justification for failing to consider what audiences are invited into and imagined as part of a text.” Rather, the recognition of failure at the heart of Universalist paradigms can enable us to attend more closely to the particular embodied orientation of users and stakeholders. We would embrace this emphasis on process over product, on becoming and emergent technologies over closed-systems of top-down provisions for accommodation. While we agree UD is an unachievable goal, we would argue that the goal itself is problematic and ultimately inadequate to the continuously evolving situation of not only the inclusion of more and more disabled/extraordinary/eccentric bodies into “normal” society but also the ever-shifting ableness of any body as it moves toward inevitable failure.


[4] According to the *Accessible Future* website: “Building an Accessible Future for the Humanities Project* is organizing four 2-day workshops during which participants will learn
about technologies, design standards, and accessibility issues associated with the use of digital environments.” [http://www.accessiblefuture.org](http://www.accessiblefuture.org)

[5] For an excellent overview of the Austin workshop, see this blog posting by Susan Floyd (who is also on twitter as @ Texarchivist). [http://texarchivist.com/2014/03/14/thinking-about-accessibility-accessiblefu-2014-utaustin-2/](http://texarchivist.com/2014/03/14/thinking-about-accessibility-accessiblefu-2014-utaustin-2/)


[7] For more about DSDJ and what the academic and social functions it serves, see Charles Ainsworth’s interview with one of its co-managing editors Lauren Benedict (December 2, 2013): [http://www.thebuffandblue.net/?p=12662](http://www.thebuffandblue.net/?p=12662)

[8] Peter C. Hauser’s article “Deaf Eyes: Visual Learning and Deaf Gain” is presented by the author in ASL as well as IS. DSDJ 2 (Fall 2010). As of December 30, 2015 (the date upon which all these DSDJ links in this essay were accessed), the PDF of an English language equivalent of this particular piece is forthcoming. [http://dsdj.gallaudet.edu/index.php?view=entry&issue=3&entry_id=81](http://dsdj.gallaudet.edu/index.php?view=entry&issue=3&entry_id=81)


[11] This is Ron Mace’s definition as provided by the Center for Universal Design at North Carolina State University: [http://www.ncsu.edu/ncsu/design/cud/about_us/usronmace.htm](http://www.ncsu.edu/ncsu/design/cud/about_us/usronmace.htm)


Formations, v. 55 (New York: Peter Lang, 2009), 160.


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[Image “aLL_sTRenGTh...LOsS” by flickr user Sippanont Samchai]
DONNA HARAWAY

A CYBORG MANIFESTO
Science, technology and socialist-feminism in the late twentieth century

An ironic dream of a common language for women in the integrated circuit

This chapter is an effort to build an ironic political myth faithful to feminism, socialism, and materialism. Perhaps more faithful as blasphemy is faithful, than as reverent worship and identification. Blasphemy has always seemed to require taking things very seriously. I know no better stance to adopt from within the secular-religious, evangelical traditions of US politics, including the politics of socialist-feminism. Blasphemy protects one from the moral majority within, while still insisting on the need for community. Blasphemy is not apostasy. Irony is about contradictions that do not resolve into larger wholes, even dialectically, about the tension of holding incompatible things together because both or all are necessary and true. Irony is about humour and serious play. It is also a rhetorical strategy and a political method, one I would like to see more honoured within socialist-feminism. At the centre of my ironic faith, my blasphemy, is the image of the cyborg.

A cyborg is a cybernetic organism, a hybrid of machine and organism, a creature of social reality as well as a creature of fiction. Social reality is lived social relations, our most important political construction, a world-changing fiction. The international women’s movements have constructed ‘women’s experience’, as well as uncovered or discovered this crucial collective object. This experience is a fiction and fact of the most crucial, political kind. Liberation rests on the construction of the consciousness, the imaginative apprehension, of oppression, and so of possibility. The cyborg is a matter of fiction and lived experience that changes what counts as women’s experience in the late twentieth century. This is a struggle over life and death, but the boundary between science fiction and social reality is an optical illusion.

Contemporary science fiction is full of cyborgs – creatures simultaneously animal and machine, who populate worlds ambiguously natural and crafted. Modern medicine
It is also full of cyborgs, of couplings between organism and machine, each conceived as coded devices, in an intimacy and with a power that was not generated in the history of sexuality. Cyborg 'sex' restores some of the lovely replicative baroque of ferns and invertebrates (such nice organic prophylactics against heterosexism). Cyborg replication is uncoupled from organic reproduction. Modern production seems like a dream of cyborg colonization work, a dream that makes the nightmare of Taylorism seem idyllic. And modern war is a cyborg orgy, coded by C'I, command-control-communication-intelligence, an $84 billion item in 1984's US defence budget. I am making an argument for the cyborg as a fiction mapping our social and bodily reality and as an imaginative resource suggesting some very fruitful couplings.

By the late twentieth century, our time, a mythic time, we are all chimeras, theorized and fabricated hybrids of machine and organism. In short, we are cyborgs. The cyborg is our ontology; it gives us our politics. The cyborg is a condensed image of both imagination and material reality, the two joined centres structuring any possibility of historical transformation. In the traditions of 'Western' science and politics – the tradition of racist, male-dominant capitalism; the tradition of progress; the tradition of the appropriation of nature as resource for the productions of culture; the tradition of reproduction of the self from the reflections of the other – the relation between organism and machine has been a border war. The stakes in the border war have been the territories of production, reproduction, and imagination. This chapter is an argument for pleasure in the confusion of boundaries and for responsibility in their construction. It is also an effort to contribute to socialist-feminist culture and theory in a postmodernist, non-naturalist mode and in the utopian tradition of imagining a world without gender, which is perhaps a world without genesis, but maybe also a world without end. The cyborg incarnation is outside salvation history. Nor does it mark time on an oral symbiotic utopia or post-oedipal apocalypse. As Zoe Sofoulis (1987) argues in her unpublished manuscript on Jacques Lacan, Melanie Klein, and nuclear culture, Lacklein, the most terrible and perhaps the most promising monsters in cyborg worlds are embodied in non-oedipal narratxes with a different logic of repression, which we need to understand for our survival.

The cyborg is a creature in a post-gender world; it has no truck with bisexuality, pre-oedipal symbiosis, alienated labour, or other seductions to organic wholesness through a final appropriation of all the powers of the parts into a higher unity. In a sense, the cyborg has no origin story in the Western sense – a 'final' irony since the cyborg is also the awful apocalyptic telos of the 'West's' escalating dominations of abstract individuation, an ultimate self untied at last from all dependency, a man in space. An origin story in the 'Western', humanist sense depends on the myth of original unity, fullness, bliss and terror, represented by the phallic mother from whom all humans must separate, the task of individual development and of history, the twin potent myths inscribed most powerfully for us in psychoanalysis and Marxism. Hilary Klein (1989) has argued that both Marxism and psychoanalysis, in their concepts of labour and of individuation and gender formation, depend on the plot of original unity out of which difference must be produced and enlisted in a drama of escalating domination of woman/nature. The cyborg skips the step of original unity, of identification with nature in the Western sense. This is an illegitimate promise that might lead to subversion of its teleology as star wars.

The cyborg is resolutely committed to partiality, irony, intimacy, and perversity. It is oppositional, utopian, and completely without innocence. No longer structured by
the polarity of public and private, the cyborg defines a technological polis based partly
on a revolution of social relations in the aikes, the household. Nature and culture are
reworked; the one can no longer be the resource for appropriation or incorporation by
the other. The relationships for forming wholes from parts, including those of polarity
and hierarchical domination, are at issue in the cyborg world. Unlike the hopes of
Frankenstein’s monster, the cyborg does not expect its father to save it through a restora-
tion of the garden; that is, through the fabrication of a heterosexual mate, through its
completion in a finished whole, a city and cosmos. The cyborg does not dream of
community on the model of the organic family, this time without the oedipal project.
The cyborg would not recognize the Garden of Eden; it is not made of mud and cannot
dream of returning to dust. Perhaps that is why I want to see if cyborgs can subvert
the apocalypse of returning to nuclear dust in the manic compulsion to name the Enemy.
Cyborgs are not reverent; they do not remember the cosmos. They are wary of holism,
but needy for connection — they seem to have a natural feel for united front politics,
but without the vanguard party. The main trouble with cyborgs, of course, is that they
are the illegitimate offspring of militarism and patriarchal capitalism, not to mention
state socialism. But illegitimate offspring are often exceedingly unfaithful to their origins.
Their fathers, after all, are inessential.

I want to signal three crucial boundary breakdowns that make the following
political-fictional (political-scientific) analysis possible. By the late twentieth century in
US scientific culture, the boundary between human and animal is thoroughly breached.
The last beachheads of uniqueness have been polluted if not turned into amusement
parks. Language, tool use, social behavior, mental events, nothing really convincingly
settles the separation of human and animal. And many people no longer feel the need
for such a separation; indeed, many branches of feminist culture affirm the pleasure of
connection of human and other living creatures. Movements for animal rights are not
irrational denials of human uniqueness; they are a clear-sighted recognition of connec-
tion across the discredited breach of nature and culture. Biology and evolutionary theory
over the last two centuries have simultaneously produced modern organisms as objects
of knowledge and reduced the line between humans and animals to a faint trace re-
etched in ideological struggle or professional disputes between life and social science.

Biological-determinist ideology is only one position opened up in scientific culture
for arguing the meanings of human animality. There is much room for radical political
people to contest the meanings of the breached boundary. The cyborg appears in myth
precisely where the boundary between human and animal is transgressed. Far from
signalling a walling off of people from other living beings, cyborgs signal disturbingly
and pleasurably tight coupling. Bestiality has a new status in this cycle of marriage
exchange.

The second leaky distinction is between animal-human (organism) and machine. Pre-
cybernetic machines could be haunted; there was always the spectre of the ghost in the
machine. This dualism structured the dialogue between materialism and idealism that
was settled by a dialectical progeny, called spirit or history, according to taste. But basi-
cally machines were not self-moving, self-designing, autonomous. They could not achieve
man’s dream, only mock it. They were not man, an author himself, but only a carica-
ture of that masculinist reproductive dream. To think they were otherwise was paranoid.
Now we are not so sure. Late twentieth-century machines have made thoroughly
ambiguous the difference between natural and artificial, mind and body, self-developing
and externally designed, and many other distinctions that used to apply to organisms and machines. Our machines are disturbingly lively, and we ourselves frighteningly inert.

Technological determination is only one ideological space opened up by the reconceptions of machine and organism as coded texts through which we engage in the play of writing and reading the world. ‘Textualization’ of everything in poststructuralist, postmodernist theory has been damned by Marxists and socialist feminists for its utopian disregard for the lived relations of domination that ground the ‘play’ of arbitrary reading.

It is certainly true that postmodernist strategies, like my cyborg myth, subvert myriad organic wholes (for example, the poem, the primitive culture, the biological organism). In short, the certainty of what counts as nature—a source of insight and promise of innocence—is undermined, probably fatally. The transcendent authorization of interpretation is lost, and with it the ontology grounding ‘Western’ epistemology. But the alternative is not cynicism or faithlessness, that is, some version of abstract existence, like the accounts of technological determinism destroying ‘man’ by the ‘machine’ or ‘meaningful political action’ by the ‘text’. Who cyborgs will be is a radical question. The answers are a matter of survival. Both chimpanzees and artefacts have politics, so why shouldn’t we (de Waal, 1982; Winner, 1980)?

The third distinction is a subset of the second: the boundary between physical and non-physical is very imprecise for us. Pop physics books on the consequences of quantum theory and the indeterminacy principle are a kind of popular scientific equivalent to Harlequin romances as a marker of radical change in American white heterosexuality: they get it wrong, but they are on the right subject. Modern machines are quintessentially microelectronic devices: they are everywhere and they are invisible. Modern machinery is an irreverent upstart god, mocking the Father’s ubiquity and spirituality. The silicon chip is a surface for writing; it is etched in molecular scales disturbed only by atomic noise, the ultimate interference for nuclear scores. Writing, power and technology are old partners in Western stories of the origin of civilization, but miniaturization has changed our experience of mechanism. Miniaturization has turned out to be about power, small is not so much beautiful as preeminently dangerous, as in cruise missiles. Contrast the TV sets of the 1950s or the news cameras of the 1970s with the TV wrist bands or hand-sized video cameras now advertised. Our best machines are made of sunshine; they are all light and clean because they are nothing but signals, electromagnetic waves, a section of a spectrum, and these machines are eminently portable, mobile—a matter of immense human pain in Detroit and Singapore. People are nowhere near so fluid, being both material and opaque. Cyborgs are ether, quintessence.

The ubiquity and invisibility of cyborgs is precisely why these sunshine-belt machines are so deadly. They are as hard to see politically as materially. They are about consciousness—or its simulation. They are floating signifiers moving in pickup trucks across Europe, blocked more effectively by the witch-weavings of the displaced and so unnatural Greenham women, who read the cyborg webs of power so very well, than by the militant labour of older masculinist politics, whose natural constituency needs defence jobs. Ultimately the ‘hardest’ science is about the realm of greatest boundary confusion, the realm of pure number, pure spirit, C,1, cryptography and the preservation of potent secrets. The new machines are so clean and light. Their engineers are sun-worshippers mediating a new scientific revolution associated with the night dream of post-industrial society. The diseases evoked by these clean machines are ‘no more’ than the minuscule coding changes of an antigen in the immune system, ‘no more’ than the experience of
stress. The nimble fingers of 'Oriental' women, the old fascination of little Anglo Saxon Victorian girls with doll's houses, women's enforced attention to the small, take on quite new dimensions in this world. There might be a cyborg Alice taking account of these new dimensions. Ironically, it might be the unnatural cyborg women making chips in Asia and spiral dancing in Santa Rita jail whose constructed unities will guide effective oppositional strategies.

So my cyborg myth is about transgressed boundaries, potent fusions and dangerous possibilities which progressive people might explore as one part of needed political work. One of my premises is that most American socialists and feminists see deepened dualisms of mind and body, animal and machine, idealism and materialism in the social practices, symbolic formulations and physical artefacts associated with 'high technology' and scientific culture. From One-Dimensional Man (Marcuse 1964) to The Death of Nature (Merchant 1980), the analytic resources developed by progressives have insisted on the necessary domination of technics and recalled us to an imagined organic body to integrate our resistance. Another of my premises is that the need for unity of people trying to resist worldwide intensification of domination has never been more acute. But a slightly perverse shift of perspective might better enable us to contest for meanings, as well as for other forms of power and pleasure in technologically mediated societies.

From one perspective, a cyborg world is about the final imposition of a grid of control on the planet, about the final abstraction embodied in a Star Wars apocalypse waged in the name of defence, about the final appropriation of women's bodies in a masculinist orgy of war (Sonia 1984). From another perspective, a cyborg world might be about lived social and bodily realities in which people are not afraid of their joint kinship with animals and machines, not afraid of permanently partial identities and contradictory standpoints. The political struggle is to see from both perspectives at once because each reveals both dominations and possibilities unimaginable from the other vantage point. Single vision produces worse illusions than double vision or many-headed monsters. Cyborg unities are monstrous and illegitimate; in our present political circumstances, we could hardly hope for more potent myths for resistance and recoupling. I like to imagine LAG, the Livermore Action Group, as a kind of cyborg society, dedicated to realistically converting the laboratories that most fiercely embody and spew out the tools of technological apocalypse, and committed to building a political form that actually manages to hold together witches, engineers, elders, perverts, Christians, mothers and Leninists long enough to disarm the state. Fission Impossible is the name of the affinity group in my town. (Affinity: related not by blood but by choice, the appeal of one chemical nuclear group for another, avidity.)

Fractured identities

It has become difficult to name one's feminism by a single adjective — or even to insist in every circumstance upon the noun. Consciousness of exclusion through naming is acute. Identities seem contradictory, partial and strategic. With the hard-won recognition of their social and historical constitution, gender, race and class cannot provide the basis for belief in 'essential' unity. There is nothing about being 'female' that naturally binds women. There is not even such a state as 'being' female, itself a highly complex category constructed in contested sexual scientific discourses and other social practices. Gender,
race or class consciousness is an achievement forced on us by the terrible historical experience of the contradictory social realities of patriarchy, colonialism and capitalism. And who counts as ‘us’ in my own rhetoric? Which identities are available to ground such a potent political myth called ‘us’, and what could motivate enlistment in this collectivity? Painful fragmentation among feminists (not to mention among women) along every possible fault line has made the concept of woman elusive, an excuse for the matrix of women’s dominations of each other. For me – and for many who share a similar historical location in white, professional middle-class, female, radical, North American, mid-adult bodies – the sources of a crisis in political identity are legion. The recent history for much of the US left and US feminism has been a response to this kind of crisis by endless splitting and searches for a new essential unity. But there has also been a growing recognition of another response through coalition – affinity, not identity.7

Chela Sandoval, from a consideration of specific historical moments in the formation of the new political voice called women of colour, has theorized a hopeful model of political identity called ‘oppositional consciousness’, born of the skills for reading webs of power by those refused stable membership in the social categories of race, sex or class. ‘Women of color’, a name contested at its origins by those whom it would incorporate, as well as a historical consciousness marking systematic breakdown of all the signs of Man in ‘Western’ traditions, constructs a kind of postmodernist identity out of otherness, difference and specificity. This postmodernist identity is fully political, whatever might be said about other possible postmodernisms. Sandoval’s oppositional consciousness is about contradictory locations and heterochronic calendars, not about relativisms and pluralisms (see chapter 23).

Sandoval emphasizes the lack of any essential criterion for identifying who is a woman of colour. She notes that the definition of a group has been by conscious appropriation of negation. For example, a Chicana or US black woman has not been able to speak as a woman or as a black person or as a Chicana. Thus, she was at the bottom of a cascade of negative identities, left out of even the privileged oppressed authorial categories called ‘women and blacks’, who claimed to make the important revolutions. The category ‘woman’ negated all non-white women; ‘black’ negated all non-black people, as well as all black women. But there was also no ‘she’, no singularity, but a sea of differences among US women who have affirmed their historical identity as US women of colour. This identity marks out a self-consciously constructed space that cannot affirm the capacity to act on the basis of natural identification, but only on the basis of conscious coalition, of affinity, of political kinship.6 Unlike the ‘woman’ of some streams of the white women’s movement in the US, there is no naturalization of the matrix.

Sandoval’s argument has to be seen as one potent formulation for feminists out of the worldwide development of anti-colonialist discourse; that is to say, discourse dissolving the ‘West’ and its highest product – the one who is not animal, barbarian or woman; man, that is, the author of a cosmos called history. As orientalism is deconstructed politically and semiotically, the identities of the occident destabilize, including those of feminists.6 Sandoval argues that ‘women of colour’ have a chance to build an effective unity that does not replicate the imperializing, totalizing revolutionary subjects of previous Marxism and feminisms which had not faced the consequences of the disorderly polyphony emerging from decolonization.

Katie King has emphasized the limits of identification and the political/poetic mechanics of identification built into reading ‘the poem’, that generative core of cultural
feminism. King criticizes the persistent tendency among contemporary feminists from different 'moments' or 'conversations' in feminist practice to taxonomize the women's movement to make one's own political tendencies appear to be the telos of the whole. These taxonomies tend to remake feminist history so that it appears to be an ideological struggle among coherent types persisting over time, especially those typical units called radical, liberal and socialist-feminist. Literally, all other feminisms are either incorporated or marginalized, usually by building an explicit ontology and epistemology. Taxonomies of feminism produce epistemologies to police deviation from official women's experience. And of course, 'women's culture', like women of colour, is consciously created by mechanisms inducing affinity. The rituals of poetry, music and certain forms of academic practice have been preeminent. The politics of race and culture in the US women's movements are intimately interwoven. The common achievement of King and Sandoval is learning how to craft a poetic/politic unity without relying on a logic of appropriation, incorporation and taxonomic identification.

The theoretical and practical struggle against unity-through-domination or unity-through-incorporation ironically not only undermines the justifications for patriarchy, colonialism, humanism, positivism, essentialism, scientism and other unadorned -isms, but all claims for an organic or natural standpoint. I think that radical and socialist/ Marxist-feminisms have also undermined their/our own epistemological strategies and this is a crucially valuable step in imagining possible unities. It remains to be seen whether all 'epistemologies' as Western political people have known them fail us in the task to build effective affinities.

It is important to note that the effort to construct revolutionary standpoints, epistemologies as achievements of people committed to changing the world, has been part of the process showing the limits of identification. The acid tools of postmodernist theory and the constructive tools of ontological discourse about revolutionary subjects might be seen as ironic allies in dissolving Western selves in the interests of survival. We are excruciatingly conscious of what it means to have a historically constituted body. But with the loss of innocence in our origin, there is no expulsion from the Garden either. Our politics lose the indulgence of guilt with the naïveté of innocence. But what would another political myth for socialist-feminism look like? What kind of politics could embrace partial, contradictory, permanently unclosed constructions of personal and collective selves and still be faithful, effective – and, ironically, socialist-feminist?

I do not know of any other time in history when there was greater need for political unity to confront effectively the dominations of 'race', 'gender', 'sexuality' and 'class'. I also do not know of any other time when the kind of unity we might help build could have been possible. None of 'us' have any longer the symbolic or material capability of dictating the shape of reality to any of 'them'. Or at least 'we' cannot claim innocence from practising such dominations. White women, including socialist feminists, discovered the non-innocence of the category 'woman'. That consciousness changes the geography of all previous categories; it denatures them as heat denatures a fragile protein. Cyborg feminists have to argue that 'we' do not want any more natural matrix of unity and that no construction is whole. Innocence, and the corollary insistence on victimhood as the only ground for insight, has done enough damage. But the constructed revolutionary subject must give late-twentieth-century people pause as well. In the fraying of identities and in the reflexive strategies for constructing them, the
possibility opens up for weaving something other than a shroud for the day after the apocalypse that so prophetically ends salvation history.

Both Marxist/socialist-feminisms and radical feminisms have simultaneously naturalized and denatured the category ‘woman’ and consciousness of the social lives of ‘women’. Perhaps a schematic caricature can highlight both kinds of moves. Marxian-socialism is rooted in an analysis of wage labour which reveals class structure. The consequence of the wage relationship is systematic alienation, as the worker is dissociated from his (sic) product. Abstraction and illusion rule in knowledge, domination rules in practice. Labour is the preeminently privileged category enabling the Marxist to overcome illusion and find that point of view which is necessary for changing the world. Labour is the humanizing activity that makes man; labour is an ontological category permitting the knowledge of a subject, and so the knowledge of subjugation and alienation.

In faithful filiation, socialist-feminism is advanced by allying itself with the basic analytic strategies of Marxism. The main achievement of both Marxist-feminists and socialist feminists was to expand the category of labour to accommodate what (some) women did, even when the wage relation was subordinated to a more comprehensive view of labour under capitalist patriarchy. In particular, women’s labour in the household and women’s activity as mothers generally (that is, reproduction in the socialist-feminist sense), entered theory on the authority of analogy to the Marxian concept of labour. The unity of women here rests on a epistemology based on the ontological structure of ‘labour’. Marxist/socialist-feminism does not ‘naturalize’ unity; it is a possible achievement based on a possible standpoint rooted in social relations. The essentializing move is in the ontological structure of labour or of its analogue, women’s activity.11 The inheritance of Marxian-humanism, with its pre-eminently Western self, is the difficulty for me. The contribution from these formulations has been the emphasis on the daily responsibility of real women to build unities, rather than to naturalize them.

Catherine MacKinnon’s (1982, 1987) version of radical feminism is itself a caricature of the appropriating, incorporating, totalizing tendencies of Western theories of identity grounding action.12 It is factually and politically wrong to assimilate all of the diverse ‘moments’ or ‘conversations’ in recent women’s politics named radical feminism to MacKinnon’s version. But the teleological logic of her theory shows how an epistemology and ontology – including their negations – erase or police difference. Only one of the effects of MacKinnon’s theory is the rewriting of the history of the poly-morphous field called radical feminism. The major effect is the production of a theory of experience, of women’s identity, that is a kind of apocalypse for all revolutionary standpoints. That is, the totalization built into this tale of radical feminism achieves its end – the unity of women – by enforcing the experience of and testimony to radical non-being. As for the Marxist/socialist-feminist, consciousness is an achievement, not a natural fact. And MacKinnon’s theory eliminates some of the difficulties built into humanist revolutionary subjects, but at the cost of radical reductionism.

MacKinnon argues that feminism necessarily adopted a different analytical strategy from Marxism, looking first not at the structure of class, but at the structure of sex/gender and its generative relationship, men’s constitution and appropriation of women sexually. Ironically, MacKinnon’s ‘ontology’ constructs a non-subject, a non-being. Another’s desire, not the self’s labour, is the origin of ‘woman’. She therefore develops a theory of consciousness that enforces what can count as ‘women’s’ experi-
ence – anything that names sexual violation, indeed, sex itself as far as 'women' can be concerned. Feminist practice is the construction of this form of consciousness; that is, the self-knowledge of a self-who-is-not.

Perversely, sexual appropriation in this feminism still has the epistemological status of labour; that is to say, the point from which an analysis able to contribute to changing the world must flow. But sexual objectification, not alienation, is the consequence of the structure of sex/gender. In the realm of knowledge, the result of sexual objectification, not alienation, is the consequence of the structure of sex/gender. In the realm of knowledge, the result of sexual objectification is illusion and abstraction. However, a woman is not simply alienated from her product, but in a deep sense does not exist as a subject, or even potential subject, since she owes her existence as a woman to sexual appropriation. To be constituted by another's desire is not the same thing as to be alienated in the violent separation of the labourer from his product.

MacKinnon's radical theory of experience is totalizing in the extreme; it does not so much marginalize as obliterate the authority of any other women's political speech and action. It is a totalization producing what Western patriarchy itself never succeeded in doing – feminists' consciousness of the non-existence of women, except as products of men's desire. I think MacKinnon correctly argues that no Marxian version of identity can firmly ground women's unity. But in solving the problem of the contradictions of any Western revolutionary subject for feminist purposes, she develops an even more authoritarian doctrine of experience. If my complaint about socialist/Marxian standpoint is their unintended erasure of polyvocal, unassimilable, radical difference made visible in anti-colonial discourse and practice, MacKinnon's intentional erasure of all difference through the device of the 'essential' non-existence of women is not reassuring.

In my taxonomy, which like any other taxonomy is a re-inscription of history, radical feminism can accommodate all the activities of women named by socialist feminists as forms of labour only if the activity can somehow be sexualized. Reproduction had different tones of meanings for the two tendencies, one rooted in labour, one in sex, both calling the consequences of domination and ignorance of social and personal reality 'false consciousness'.

Beyond either the difficulties of the contributions in the argument of any one author, neither Marxist nor radical feminist points of view have tended to embrace the status of a partial explanation; both were regularly constituted as totalities. Western explanation has demanded as much; how else could the 'Western' author incorporate its others? Each tried to annex other forms of domination by expanding its basic categories through analogy, simple listing or addition. Embarrassed silence about race among white radical and socialist-feminists was one major, devastating political consequence. History and polyvocality disappear into political taxonomies that try to establish genealogies. There was no structural room for race (or for much else) in theory claiming to reveal the construction of the category woman and social group women as a unified or totalizable whole. The structure of my caricature looks like this:

socialist feminism – structure of class / / wage labour / / alienation labour, by analogy reproduction, by extension sex, by addition race
radical feminism – structure of gender / / sexual appropriation / / objectification
sex, by analogy labour, by extension reproduction, by addition race
In another context, the French theorist, Julia Kristeva, claimed that women appeared as a historical group after the Second World War, along with groups like youth. Her dates are doubtful; but we are now accustomed to remembering that as objects of knowledge and as historical actors, 'race' did not always exist, 'class' has a historical genesis, and 'homosexuals' are quite junior. It is no accident that the symbolic system of the family of man – and so the essence of woman – breaks up at the same moment that networks of connection among people on the planet are unprecedentedly multiple, pregnant and complex. 'Advanced capitalism' is inadequate to convey the structure of this historical moment. In the 'Western' sense, the end of man is at stake. It is no accident that woman disintegrates into women in our time. Perhaps socialist feminists were not substantially guilty of producing essentialist theory that suppressed women's particularity and contradictory interests. I think we have been, at least through unreflective participation in the logics, languages and practices of white humanism and through searching for a single ground of domination to secure our revolutionary voice. Now we have less excuse. But in the consciousness of our failures, we risk lapsing into boundless difference and giving up on the confusing task of making partial, real connection. Some differences are playful; some are poles of world historical systems of domination. 'Epistemology' is about knowing the difference.

The informatics of domination

In this attempt at an epistemological and political position, I would like to sketch a picture of possible unity, a picture indebted to socialist and feminist principles of design. The frame for my sketch is set by the extent and importance of rearrangements in worldwide social relations tied to science and technology. I argue for a politics rooted in claims about fundamental changes in the nature of class, race and gender in an emerging system of world order analogous in its novelty and scope to that created by industrial capitalism; we are living through a movement from an organic, industrial society to a polymorphous, information system – from all work to all play, a deadly game. Simultaneously material and ideological, the dichotomies may be expressed in the following chart of transitions from the comfortable old hierarchical dominations to the scary new networks I have called the informatics of domination:

- Representation
- Bourgeois novel, realism
- Organism
- Depth, integrity
- Heat
- Biology as clinical practice
- Physiology
- Small group
- Perfection
- Eugenics
- Decadence, Magic Mountain
- Hygiene
- Microbiology, tuberculosis
- Organic division of labour
- Simulation
- Science fiction, postmodernism
- Biotic component
- Surface, boundary
- Noise
- Biology as inscription
- Communications engineering
- Subsystem
- Optimization
- Population control
- Obsolescence, Future Shock
- Stress management
- Immunology, AIDS
- Ergonomics/cybernetics of labour
Functional specialization       Modular construction
Reproduction                Replication
Organic sex role specialization    Optimal genetic strategies
Biological determinism        Evolutionary inertia, constraints
Community ecology             Ecosystem
Racial chain of being         Neo-imperialism, United Nations humanism
Scientific management in home / factory   Global factory/electronic cottage
Family/Market/Factory         Women in the integrated circuit
Family wage                  Comparable worth
Public/private               Cyborg citizenship
Nature/culture               Fields of difference
Cooperation                  Communications enhancement
Freud                        Lacan
Sex                          Genetic engineering
Labour                       Robotics
Mind                         Artificial intelligence
Second World War             Star Wars
White capitalist patriarchy  Informatics of domination

This list suggests several interesting things. First, the objects on the right-hand side cannot be coded as ‘natural’, a realization that subverts naturalistic coding for the left-hand side as well. We cannot go back ideologically or materially. It’s not just that ‘god’ is dead; so is the ‘goddess’. Or both are revivified in the worlds charged with microelectronic and biotechnological politics. In relation to objects like biotic components, one must think not in terms of essential properties, but in terms of design, boundary constraints, rates of flows, systems logics, costs of lowering constraints. Sexual reproduction is one kind of reproductive strategy among many, with costs and benefits as a function of the system environment. Ideologies of sexual reproduction can no longer reasonably call on notions of sex and sex role as organic aspects in natural objects like organisms and families. Such reasoning will be unmasked as irrational, and ironically corporate executives reading *Playboy* and anti-porn radical feminists will make strange bedfellows in jointly unmasking the irrationalism.

Likewise for race, ideologies about human diversity have to be formulated in terms of frequencies of parameters, like blood group or intelligence scores. It is ‘irrational’ to invoke concepts like primitive and civilized. For liberals and radicals, the search for integrated social systems gives way to a new practice called ‘experimental ethnography’ in which an organic object dissipates in attention to the play of writing. At the level of ideology, we see translations of racism and colonialism into languages of development and under-development, rates and constraints of modernization. Any objects or persons can be reasonably thought of in terms of disassembly and reassembly; no ‘natural’ architectures constrain system design. The financial districts in all the world’s cities, as well as the export-processing and free-trade zones, proclaim this elementary fact of ‘late capitalism’. The entire universe of objects that can be known scientifically must be formulated as problems in communications engineering (for the managers) or theories of the text (for those who would resist). Both are cyborg semiologies.
One should expect control strategies to concentrate on boundary conditions and interfaces, on rates of flow across boundaries – and not on the integrity of natural objects. 'Integrity' or 'sincerity' of the Western self gives way to decision procedures and expert systems. For example, control strategies applied to women's capacities to give birth to new human beings will be developed in the languages of population control and maximization of goal achievement for individual decision-makers. Control strategies will be formulated in terms of rates, costs of constraints, degrees of freedom. Human beings, like any other component or subsystem, must be localized in a system architecture whose basic modes of operation are probabilistic, statistical. No objects, spaces or bodies are sacred in themselves; any component can be interfaced with any other if the proper standard, the proper code, can be constructed for processing signals in common language. Exchange in this world transcends the universal translation effected by capitalist markets that Marx analysed so well. The privileged pathology affecting all kinds of components in this universe is stress — communications breakdown (Hogness 1983). The cyborg is not subject to Foucault’s biopolitics; the cyborg simulates politics, a much more potent field of operations.

This kind of analysis of scientific and cultural objects of knowledge which have appeared historically since the Second World war prepares us to notice some important inadequacies in feminist analysis which has proceeded as if the organic, hierarchical dualisms ordering discourse in 'the West' since Aristotle still ruled. They have been cannibalized, or as Zoe Sofia (Sofoulis) might put it, they have been 'techno-digested'. The dichotomies between mind and body, animal and human, organism and machine, public and private, nature and culture, men and women, primitive and civilized are all in question ideologically. The actual situation of women is their integration/exploitation into a world system of production/reproduction and communication called the informatics of domination. The home, workplace, market, public arena, the body itself — all can be dispersed and interfaced in nearly infinite, polymorphous ways, with large consequences for women and others — consequences that themselves are very different for different people and which make potent oppositional international movements difficult to imagine and essential for survival. One important route for reconstructing socialist-feminist politics is through theory and practice addressed to the social relations of science and technology, including crucially the systems of myth and meanings structuring our imaginations. The cyborg is a kind of disassembled and reassembled, postmodern collective and personal self. This is the self feminists must code.

Communications technologies and biotechnologies are the crucial tools recrafting our bodies. These tools embody and enforce new social relations for women worldwide. Technologies and scientific discourses can be partially understood as formalizations, i.e. as frozen moments, of the fluid social interactions constituting them, but they should also be viewed as instruments for enforcing meanings. The boundary is permeable between tool and myth, instrument and concept, historical systems of social relations and historical anatomies of possible bodies, including objects of knowledge. Indeed, myth and tool mutually constitute each other.

Furthermore, communications sciences and modern biologies are constructed by a common move – *the translation of the world into a problem of coding*, a search for a common language in which all resistance to instrumental control disappears and all heterogeneity can be submitted to disassembly, reassembly, investment and exchange.
In communications sciences, the translation of the world into a problem in coding can be illustrated by looking at cybernetic (feedback-controlled) systems theories applied to telephone technology, computer design, weapons deployment or database construction and maintenance. In each case, solution to the key questions rests on a theory of language and control; the key operation is determining the rates, directions and probabilities of flow of a quantity called information. The world is subdivided by boundaries differentially permeable to information. Information is just that kind of quantifiable element (unit, base of unity) which allows universal translation, and so unhindered instrumental power (called effective communication). The biggest threat to such power is interruption of communication. Any system breakdown is a function of stress. The fundamentals of this technology can be condensed into the metaphor C'I, command-control-communication-intelligence, the military’s symbol for its operations theory.

In modern biologies, the translation of the world into a problem in coding can be illustrated by molecular genetics, ecology, sociobiological evolutionary theory and immunobiology. The organism has been translated into problems of genetic coding and read-out. Biotechnology, a writing technology, informs research broadly. In a sense, organisms have ceased to exist as objects of knowledge, giving way to biotic components, i.e. special kinds of information-processing devices. The analogous moves in ecology could be examined by probing the history and utility of the concept of the ecosystem. Immunobiology and associated medical practices are rich exemplars of the privilege of coding and recognition systems as objects of knowledge, as constructions of bodily reality for us. Biology here is a kind of cryptography. Research is necessarily a kind of intelligence activity. Ironies abound. A stressed system goes awry; its communication processes break down; it fails to recognize the difference between self and other. Human babies with baboon hearts evoke national ethical perplexity – for animal rights activists at least as much as for the guardians of human purity. In the US gay men and intravenous drug users are the ‘privileged’ victims of an awful immune system disease that marks (scribes on the body) confusion of boundaries and moral pollution (Treichler 1987).

But these excursions into communications sciences and biology have been at a rarefied level; there is a mundane, largely economic reality to support my claim that these sciences and technologies indicate fundamental transformations in the structure of the world for us. Communications technologies depend on electronics. Modern states, multinational corporations, military power, welfare state apparatuses, satellite systems, political processes, fabrication of our imaginations, labour-control systems, medical constructions of our bodies, commercial pornography, the international division of labour and religious evangelism depend intimately upon electronics. Microelectronics is the technical basis of simulacra; that is, of copies without originals.

Microelectronics mediates the translations of labour into robotics and word processing, sex into genetic engineering and reproductive technologies, and mind into artificial intelligence and decision procedures. The new biotechnologies concern more than human reproduction. Biology as a powerful engineering science for redesigning materials and processes has revolutionary implications for industry, perhaps most obvious today in areas of fermentation, agriculture and energy. Communications sciences and biology are constructions of natural-technical objects of knowledge in which the difference between machine and organism is thoroughly blurred; mind, body and tool are on very intimate terms. The ‘multinational’ material organization of the production and reproduction of daily life and the symbolic organization of the production and reproduction
of culture and imagination seem equally implicated. The boundary-maintaining images of base and superstructure, public and private, or material and ideal never seemed more feeble.

I have used Rachel Grossman’s (1980) image of women in the integrated circuit to name the situation of women in a world so intimately restructured through the social relations of science and technology. I used the odd circumlocution, ‘the social relations of science and technology’, to indicate that we are not dealing with a technological determinism, but with a historical system depending upon structured relations among people. But the phrase should also indicate that science and technology provide fresh sources of power, that we need fresh sources of analysis and political action (Latour 1984). Some of the rearrangements of race, sex and class rooted in high-tech-facilitated social relations can make socialist-feminism more relevant to effective progressive politics.

The ‘homework economy’ outside ‘the home’

The ‘New Industrial Revolution’ is producing a new worldwide working class, as well as new sexualities and ethnicities. The extreme mobility of capital and the emerging international division of labour are intertwined with the emergence of new collectivities, and the weakening of familiar groupings. These developments are neither gender-or race-neutral. White men in advanced industrial societies have become newly vulnerable to permanent job loss, and women are not disappearing from the job rolls at the same rates as men. It is not simply that women in Third World countries are the preferred labour force for the science-based multinationals in the export-processing sectors, particularly in electronics. The picture is more systematic and involves reproduction, sexuality, culture, consumption and production. In the prototypical Silicon Valley, many women’s lives have been structured around employment in electronics-dependent jobs, and their intimate realities include serial heterosexual monogamy, negotiating childcare, distance from extended kin or most other forms of traditional community, a high likelihood of loneliness and extreme economic vulnerability as they age. The ethnic and racial diversity of women in Silicon Valley structures a microcosm of conflicting differences in culture, family, religion, education and language.

Richard Gordon has called this new situation the ‘homework economy’. Although he includes the phenomenon of literal homework emerging in connection with electronics assembly, Gordon intends ‘homework economy’ to name a restructuring of work that broadly has the characteristics formerly ascribed to female jobs, jobs literally done only by women. Work is being redefined as both literally female and feminized, whether performed by men or women. To be feminized means to be made extremely vulnerable; able to be disassembled, reassembled, exploited as a reserve labour force; seen less as workers than as servers; subjected to time arrangements on and off the paid job that make a mockery of a limited work day; leading an existence that always borders on being obscene, out of place, and reducible to sex. Deskilling is an old strategy newly applicable to formerly privileged workers. However, the homework economy does not refer only to large-scale deskilling, nor does it deny that new areas of high skill are emerging, even for women and men previously excluded from skilled employment. Rather, the concept indicates that factory, home and market are integrated on a new
scale and that the places of women are crucial — and need to be analysed for differences among women and for meanings for relations between men and women in various situations.

The homework economy as a world capitalist organizational structure is made possible by (not caused by) the new technologies. The success of the attack on relatively privileged, mostly white, men’s unionized jobs is tied to the power of the new communications technologies to integrate and control labour despite extensive dispersion and decentralization. The consequences of the new technologies are felt by women both in the loss of the family (male) wage (if they ever had access to this white privilege) and in the character of their own jobs, which are becoming capital-intensive; for example, office work and nursing.

The new economic and technological arrangements are also related to the collapsing welfare state and the ensuing intensification of demands on women to sustain daily life for themselves as well as for men, children and old people. The feminization of poverty — generated by dismantling the welfare state, by the homework economy where stable jobs become the exception, and sustained by the expectation that women’s wages will not be matched by a male income for the support of children — has become an urgent focus. The causes of various women-headed households are a function of race, class or sexuality; but their increasing generality is a ground for coalitions of women on many issues. That women regularly sustain daily life partly as a function of their enforced status as mothers is hardly new; the kind of integration with the overall capitalist and progressively war-based economy is new. The particular pressure, for example, on US black women, who have achieved an escape from (barely) paid domestic service and who now hold clerical and similar jobs in large numbers, has large implications for continued enforced black poverty with employment. Teenage women in industrializing areas of the Third World increasingly find themselves the sole or major source of a cash wage for their families, while access to land is ever more problematic. These developments must have major consequences in the psychodynamics and politics of gender and race.

Within the framework of three major stages of capitalism (commercial/early industrial, monopoly, multinational) — tied to nationalism, imperialism and multinationalism, and related to Jameson’s three dominant aesthetic periods of realism, modernism and postmodernism — I would argue that specific forms of families dialectically relate to forms of capital and to its political and cultural concomitants. Although lived problematically and unequally, ideal forms of these families might be schematized as (1) the patriarchal nuclear family, structured by the dichotomy between public and private and accompanied by the white bourgeois ideology of separate spheres and nineteenth-century Anglo-American bourgeois feminism; (2) the modern family mediated (or enforced) by the welfare state and institutions like the family wage, with a flowering of a-feminist heterosexual ideologies, including their radical versions represented in Greenwich Village around the First World War; and (3) the ‘family’ of the homework economy with its oxymoronic structure of women-headed households and its explosion of feminisms and the paradoxical intensification and erosion of gender itself. This is the context in which the projections for worldwide structural unemployment stemming from the new technologies are part of the picture of the homework economy. As robotics and related technologies put men out of work in ‘developed’ countries and exacerbate failure to generate male jobs in Third World ‘development’, and as the automated office becomes
the rule even in labour-surplus countries, the feminization of work intensifies. Black women in the United States have long known what it looks like to face the structural underemployment ('feminization') of black men, as well as their own highly vulnerable position in the wage economy. It is no longer a secret that sexuality, reproduction, family and community life are interwoven with this economic structure in myriad ways which have also differentiated the situations of white and black women. Many more women and men will contend with similar situations, which will make cross-gender and race alliances on issues of basic life support (with or without jobs) necessary, not just nice.

The new technologies also have a profound effect on hunger and on food production for subsistence worldwide. Rae Lessor Blumberg (1983) estimates that women produce about 50 per cent of the world's subsistence food. Women are excluded generally from benefiting from the increased high-tech commodification of food and energy crops, their days are made more arduous because their responsibilities to provide food do not diminish, and their reproductive situations are made more complex. Green Revolution technologies interact with other high-tech industrial production to alter gender divisions of labour and differential gender migration patterns.

The new technologies seem deeply involved in the forms of 'privatization' that Ros Petchesky (1981) has analysed, in which militarization, right-wing family ideologies and policies, and intensified definitions of corporate (and state) property as private synergistically interact. The new communications technologies are fundamental to the eradication of 'public life' for everyone. This facilitates the mushrooming of a permanent high-tech military establishment at the cultural and economic expense of most people, but especially of women. Technologies like video games and highly miniaturized televisions seem crucial to production of modern forms of 'private life'. The culture of video games is heavily oriented to individual competition and extraterrestrial warfare. High-tech, gendered imaginations are produced here, imaginations that can contemplate destruction of the planet and a science fiction escape from its consequences. More than our imaginations is militarized; and the other realities of electronic and nuclear warfare are inescapable. These are the technologies that promise ultimate mobility and perfect exchange — and incidentally enable tourism, that perfect practice of mobility and exchange, to emerge as one of the world's largest single industries.

The new technologies affect the social relations of both sexuality and of reproduction, and not always in the same ways. The close ties of sexuality and instrumentality, of views of the body as a kind of private satisfaction- and utility-maximizing machine, are described nicely in sociobiological origin stories that stress a genetic calculus and explain the inevitable dialectic of domination of male and female gender roles. These sociobiological stories depend on a high-tech view of the body as a biotic component or cybernetic communications system. Among the many transformations of reproductive situations is the medical one, where women's bodies have boundaries newly permeable to both 'visualization' and 'intervention'. Of course, who controls the interpretation of bodily boundaries in medical hermeneutics is a major feminist issue. The speculum served as an icon of women's claiming their bodies in the 1970s; that handcraft tool is inadequate to express our needed body politics in the negotiation of reality in the practices of cyborg reproduction. Self-help is not enough. The technologies of visualization recall the important cultural practice of hunting with the camera and the deeply predatory nature of a photographic consciousness. Sex, sexuality and repro-
are central actors in high-tech myth systems structuring our imaginations of personal and social possibility.

Another critical aspect of the social relations of the new technologies is the reformulation of expectations, culture, work and reproduction for the large scientific and technical work-force. A major social and political danger is the formation of a strongly bimodal social structure, with the masses of women and men of all ethnic groups, but especially people of colour, confined to a homework economy, illiteracy of several varieties, and general redundancy and impotence, controlled by high-tech repressive apparatuses ranging from entertainment to surveillance and disappearance. An adequate socialist-feminist politics should address women in the privileged occupational categories, and particularly in the production of science and technology that constructs scientific-technical discourses, processes and objects.21

This issue is only one aspect of enquiry into the possibility of a feminist science, but it is important. What kind of constitutive role in the production of knowledge, imagination and practice can new groups doing science have? How can these groups be allied with progressive social and political movements? What kind of political accountability can be constructed to tie women together across the scientific-technical hierarchies separating us? Might there be ways of developing feminist science/technology politics in alliance with anti-military science facility conversion action groups? Many scientific and technical workers in Silicon Valley, the high-tech cowboys included, do not want to work on military science.22 Can these personal preferences and cultural tendencies be welded into progressive politics among this professional middle class in which women, including women of colour, are coming to be fairly numerous?

Women in the integrated circuit

Let me summarize the picture of women's historical locations in advanced industrial societies, as these positions have been restructured partly through the social relations of science and technology. If it was ever possible ideologically to characterize women's lives by the distinction of public and private domains, it is now a totally misleading ideology, even to show how both terms of these dichotomies construct each other in practice and in theory. I prefer a network ideological image, suggesting the profusion of spaces and identities and the permeability of boundaries in the personal body and in the body politic. 'Networking' is both a feminist practice and a multinational corporate strategy — weaving is for oppositional cyborgs.

So let me return to the earlier image of the informatics of domination and trace one vision of women's 'place' in the integrated circuit, touching only a few idealized social locations seen primarily from the point of view of advanced capitalist societies: Home, Market, Paid Work Place, State, School, Clinic-Hospital and Church. Each of these idealized spaces is logically and practically implied in every other locus, perhaps analogous to a holographic photograph. I want to suggest the impact of the social relations mediated and enforced by the new technologies in order to help formulate needed analysis and practical work. However, there is no 'place' for women in these networks, only geometries of difference and contradiction crucial to women's cyborg identities. If we learn how to read these webs of power and social life, we might learn new couplings, new coalitions. There is no way to read the following list from
a standpoint of 'identification', of a unitary self. The issue is dispersion. The task is to
survive in the diaspora.

Home: Women-headed households, serial monogamy, flight of men, old women
alone, technology of domestic work, paid homework, re-emergence of home sweat-
shops, home-based businesses and telecommuting, electronic cottage, urban
homelessness, migration, module architecture, reinforced (simulated) nuclear
family, intense domestic violence.

Market: Women's continuing consumption work, newly targeted to buy the profu-
sion of new production from the new technologies (especially as the competitive
race among industrialized and industrializing nations to avoid dangerous mass unem-
ployment necessitates finding ever bigger new markets for ever less clearly needed
commodities); bimodal buying power, coupled with advertising target of the
numerous affluent groups and neglect of the previous mass markets; growing impor-
tance of informal markets in labour and commodities parallel to high-tech, affluent
market structures; surveillance systems through electronic funds transfer; intensi-
fied market abstraction (commodification) of experience, resulting in ineffective
utopian or equivalent cynical theories of community; extreme mobility (abstrac-
tion) of marketing/financing systems; interpenetration of sexual and labour
markets; intensified sexualization of abstracted and alienated consumption.

Paid Work Place: Continued intense sexual and racial division of labour, but consid-
erable growth of membership in privileged occupational categories for many
white women and people of colour; impact of new technologies on women's work
in clerical, service, manufacturing (especially textiles), agriculture, electronics;
international restructuring of the working classes; development of new time
arrangements to facilitate the homework economy (flexi-time, part-time, over-
time, no time); homework and out work; increased pressures for two-tiered wage
structures; significant numbers of people in cash-dependent populations worldwide
with no experience or no further hope of stable employment; most labour
'marginal' or 'feminized'.

State: Continued erosion of the welfare state; decentralizations with increased
surveillance and control; citizenship by telematics; imperialism and political power
broadly in the form of information rich/information poor differentiation; increased
high-tech militarization increasingly opposed by many social groups; reduction of
civil service jobs as a result of the growing capital intensification of office work,
with implications for occupational mobility for women of colour; growing priva-
tization of material and ideological life and culture; close integration of privatization
and militarization, the high-tech forms of bourgeois capitalist personal and public
life; invisibility of different social groups to each other, linked to psychological
mechanisms of belief in abstract enemies.

School: Deepening coupling of high-tech capital needs and public education at all
levels, differentiated by race, class, and gender; managerial classes involved in
educational reform and refunding at the cost of remaining progressive educational
democratic structures for children and teachers; education for mass ignorance
and repression in technocratic and militarized culture; growing anti-science mystery
cults in dissenting and radical political movements; continued relative scientific illiteracy among white women and people of colour; growing industrial direction of education (especially higher education) by science-based multinationals (particularly in electronics- and biotechnology-dependent companies); highly educated, numerous elites in a progressively bimodal society.

Clinic-hospital: Intensified machine-body relations; renegotiations of public metaphors which channel personal experience of the body, particularly in relation to reproduction, immune system functions, and 'stress' phenomena; intensification of reproductive politics in response to world historical implications of women's unrealized, potential control of their relation to reproduction; emergence of new, historically specific diseases; struggles over meanings and means of health in environments pervaded by high technology products and processes; continuing feminization of health work; intensified struggle over state responsibility for health; continued ideological role of popular health movements as a major form of American politics.

Church: Electronic fundamentalist 'super-saver' preachers solemnizing the union of electronic capital and automated fetish gods; intensified importance of churches in resisting the militarized state; central struggle over women's meanings and authority in religion; continued relevance of spirituality, intertwined with sex and health, in political struggle.

The only way to characterize the informatics of domination is as a massive intensification of insecurity and cultural impoverishment, with common failure of subsistence networks for the most vulnerable. Since much of this picture interweaves with the social relations of science and technology, the urgency of a socialist-feminist politics addressed to science and technology is plain. There is much now being done, and the grounds for political work are rich. For example, the efforts to develop forms of collective struggle for women in paid work, like SHU's District 925 (Service Employees International Union's office workers' organization in the US) should be a high priority for all of us. These efforts are profoundly tied to technical restructuring of labour processes and reformations of working classes. These efforts also are providing understanding of a more comprehensive kind of labour organization, involving community, sexuality and family issues never privileged in the largely white male industrial unions.

The structural rearrangements related to the social relations of science and technology evoke strong ambivalence. But it is not necessary to be ultimately depressed by the implications of late twentieth-century women's relation to all aspect of work, culture, production of knowledge, sexuality and reproduction. For excellent reasons, most Marxisms see domination best and have trouble understanding what can only look like false consciousness and people's complicity in their own domination in late capitalism. It is crucial to remember that what is lost, perhaps especially from women's points of view, is often virulent forms of oppression, nostalgically naturalized in the face of current violation. Ambivalence towards the disrupted unities mediated by high-tech culture requires not sorting consciousness into categories of 'clear-sighted critique grounding a solid political epistemology' versus 'manipulated false consciousness, but subtle understanding of emerging pleasures, experiences, and powers with serious potential for changing the rules of the game.'
There are grounds for hope in the emerging bases for new kinds of unity across race, gender and class, as these elementary units of socialist-feminist analysis themselves suffer protean transformations. Intensifications of hardship experienced worldwide in connection with the social relations of science and technology are severe. But what people are experiencing is not transparently clear, and we lack sufficiently subtle connections for collectively building effective theories of experience. Present efforts – Marxist, psychoanalytic, feminist, anthropological - to clarify even 'our' experience are rudimentary.

I am conscious of the odd perspective provided by my historical position – a PhD in biology for an Irish Catholic girl was made possible by Sputnik's impact on US national science-education policy. I have a body and mind as much constructed by the post-Second World War arms race and cold war as by the women's movements. There are more grounds for hope in focusing on the contradictory effects of politics designed to produce loyal American technocrats, which also produced large numbers of dissidents, than in focusing on the present defeats.

The permanent partiality of feminist points of view has consequences for our expectations of forms of political organization and participation. We do not need a totality in order to work well. The feminist dream of a common language, like all dreams for a perfectly true language, of perfectly faithful naming of experience, is a totalizing and imperialist one. In that sense, dialectics too is a dream language, longing to resolve contradiction. Perhaps, ironically, we can learn from our fusions with animals and machines how not to be Man, the embodiment of Western logos. From the point of view of pleasure in these potent and taboo fusions, made inevitable by the social relations of science and technology, there might indeed be a feminist science.

**Cyborgs: a myth of political identity**

I want to conclude with a myth about identity and boundaries which might inform late twentieth-century political imaginations. I am indebted in this story to writers like Joanna Russ, Samuel R. Delany, John Varley, James Tiptree, Jr, Octavia Butler, Monique Wittig and Vonda McIntyre. These are our story-tellers exploring what it means to be embodied in high-tech worlds. They are theorists for cyborgs. Exploring conceptions of bodily boundaries and social order, the anthropologist Mary Douglas (1966, 1970) should be credited with helping us to consciousness about how fundamental body imagery is to world view, and so to political language. French feminists like Luce Irigaray and Monique Wittig, for all their differences, know how to write the body; how to weave eroticism, cosmology, and politics from imagery of embodiment, and especially for Wittig, from imagery of fragmentation and reconstitution of bodies.

American radical feminists like Susan Griffin, Audre Lorde and Adrienne Rich have profoundly affected our political imaginations – and perhaps restricted too much what we allow as a friendly body and political language. They insist on the organic, opposing it to the technological. But their symbolic systems and the related positions of ecofeminism and feminist paganism, replete with organicisms, can only be understood in Sandoval's terms as oppositional ideologies fitting the late twentieth century. They would simply bewilder anyone not preoccupied with the machines and consciousness of late capitalism. In that sense they are part of the cyborg world. But there are also great riches for feminists in explicitly embracing the possibilities inherent in the breakdown
of clean distinctions between organism and machine and similar distinctions structuring the Western self. It is the simultaneity of breakdowns that cracks the matrices of domination and opens geometric possibilities. What might be learned from personal and political 'technological' pollution? I look briefly at two overlapping groups of texts for their insight into the construction of a potentially helpful cyborg myth: constructions of women of colour and monstrous selves in feminist science fiction.

Earlier I suggested that 'women of colour' might be understood as a cyborg identity, a potent subjectivity synthesized from fusions of outsider identities and in the complex political-historical layerings of her 'biomythography', Zami (Lorde 1982; King 1987a, 1987b). There are material and cultural grids mapping this potential, Audre Lorde (1984) captures the tone in the title of her Sister Outsider. In my political myth, Sister Outsider is the offshore woman, whom US workers, female and feminized, are supposed to regard as the enemy preventing their solidarity, threatening their security. Onshore, inside the boundary of the US, Sister Outsider is a potential amidst the races and ethnic identities of women manipulated for division, competition and exploitation in the same industries. 'Women of colour' are the preferred labour force for the science-based industries, the real women for whom the worldwide sexual market, labour market and politics of reproduction kaleidoscope into daily life. Young Korean women hired in the sex industry and in electronics assembly are recruited from high schools, educated for the integrated circuit. Literacy, especially in English, distinguishes the 'cheap' female labour so attractive to the multinationals.

Contrary to orientalist stereotypes of the 'oral primitive', literacy is a special mark of women of colour, acquired by US black women as well as men through a history of risking death to learn and to teach reading and writing. Writing has a special significance for all colonized groups. Writing has been crucial to the Western myth of the distinction between oral and written cultures, primitive and civilized mentalities, and more recently to the erosion of that distinction in 'postmodernist' theories attacking the phallogocentrism of the West, with its worship of the monotheistic, phallic, authoritative and singular work, the unique and perfect name.26 Contests for the meanings of writing are a major form of contemporary political struggle. Releasing the play of writing is deadly serious. The poetry and stories of US women of colour are repeatedly about writing, about access to the power to signify; but this time that power must be neither phallic nor innocent. Cyborg writing must not be about the Fall, the imagination of a once-upon-a-time wholeness before language, before writing, before Man. Cyborg writing is about the power to survive, not on the basis of original innocence, but on the basis of seizing the tools to mark the world that marked them as other.

The tools are often stories, retold stories, versions that reverse and displace the hierarchical dualisms of naturalized identities. In retelling origin stories, cyborg authors subvert the central myths of origin of Western culture. We have all been colonized by those origin myths, with their longing for fulfilment in apocalypse. The phallogocentric origin stories most crucial for feminist cyborgs are built into the literal technologies — technologies that write the world, biotechnology and microelectronics — that have recently textualized our bodies as code problems on the grid of C't. Feminist cyborg stories have the task of recording communication and intelligence to subvert command and control.

Figuratively and literally, language politics pervade the struggles of women of colour; and stories about language have a special power in the rich contemporary writing by
US women of colour. For example, retellings of the story of the indigenous woman Malinche, mother of the mestizo 'bastard' race of the new world, master of languages, and mistress of Cortés, carry special meaning for Chicanita constructions of identity. Cherrie Moraga (1983) in *Loving in the War Years* explores the themes of identity when one never possessed the original language, never told the original story, never resided in the harmony of legitimate heterosexuality in the garden of culture, and so cannot base identity on a myth or a fall from innocence and right to natural names, mother's or father's. Moraga's writing, her superb literacy, is presented in her poetry as the same kind of violation as Malinche's mastery of the conqueror's language — a violation, an illegitimate production, that allows survival. Moraga's language is not 'whole'; it is self-consciously spliced, a chimera of English and Spanish, both conqueror's languages. But it is this chimeric monster, without claim to an original language before violation, that crafts the erotic, competent, potent identities of women of colour. Sister Outsider hints at the possibility of world survival, not because of her innocence, but because of her ability to live on the boundaries, to write without the founding myth of original wholeness, with its inescapable apocalypse of final return to a deathly oneness that Man has imagined to be the innocent and all-powerful Mother, freed at the End from another spiral of appropriation by her son. Writing marks Moraga's body, affirms it as the body of a woman of colour, against the possibility of passing into the unmarked category of the Anglo father or into the orientalist myth of 'original illiteracy' of a mother that never was. Malinche was mother here, not Eve before eating the forbidden fruit. Writing affirms Sister Outsider, not the Woman-before-the-Fall-into-Writing needed by the phallocentric Family of Man.

Writing is pre-eminently the technology of cyborgs, etched surfaces of the late twentieth century. Cyborg politics is the struggle for language and the struggle against perfect communication, against the one code that translates all meaning perfectly, the central dogma of phallocentrism. That is why cyborg politics insist on noise and advocate pollution, rejoicing in the illegitimate fusions of animal and machine. These are the couplings which make Man and Woman so problematic, subverting the structure of desire, the force imagined to generate language and gender, and so subverting the structure and modes of reproduction of 'Western' identity, of nature and culture, of mirror and eye, slave and master, body and mind. 'We' did not originally choose to be cyborgs, but choice grounds a liberal politics and epistemology that imagines the reproduction of individuals before the wider replications of 'texts'.

From the perspective of cyborgs, freed of the need to ground politics in 'our' privileged position of the oppression that incorporates all other dominations, the innocence of the merely violated, the ground of those closer to nature, we can see powerful possibilities. Feminisms and Marxisms have run aground on Western epistemological imperatives to construct a revolutionary subject from the perspective of a hierarchy of oppressions and/or a latent position of moral superiority, innocence and greater closeness to nature. With no available original dream of a common language or original symbiosis promising protection from hostile 'masculine' separation, but written into the play of a text that has no finally privileged reading or salvation history, to recognize 'oneself' as fully implicated in the world, frees us of the need to root politics in identification, vanguard parties, purity and mothering. Stripped of identity, the bastard race teaches about the power of the margins and the importance of a mother like Malinche.
Women of colour have transformed her from the evil mother of masculinist fear into the originally literate mother who teaches survival.

This is not just literary deconstruction, but liminal transformation. Every story that begins with original innocence and privileges the return to wholeness imagines the drama of life to be individuation, separation, the birth of the self, the tragedy of autonomy, the fall into writing, alienation; that is, war, tempered by imaginary respite in the bosom of the Other. These plots are ruled by a reproductive politics – birth without flaw, perfection, abstraction. In this plot women are imagined either better or worse off, but all agree they have less selfhood, weaker individuation, more fusion to the oral, to Mother, less at stake in masculine autonomy. But there is another route to having less at stake in masculine autonomy, a route that does not pass through Woman, Primitive, Zero, the Mirror Stage and its imaginary. It passes through women and other present tense, illegitimate cyborgs, not of Woman born, who refuse the ideological resources of victimization so as to have a real life. These cyborgs are the people who refuse to disappear on cue, no matter how many times a ‘Western’ commentator remarks on the sad passing of another primitive, another organic group done in by ‘Western’ technology, by writing. These real-life cyborgs (for example, the Southeast Asian village women workers in Japanese and US electronics firms described by Ahwa Ong) are actively rewriting the texts of their bodies and societies. Survival is the stakes in this play of readings.

To recapitulate, certain dualisms have been persistent in Western traditions; they have all been systemic to the logics and practices of domination of women, people of colour, nature, workers, animals – in short, domination of all constituted as others, whose task is to mirror the self. Chief among these troubling dualisms are self/other, mind/body, culture/nature, male/female, civilized/primitive, reality/appearance, whole/part, agent/resource, maker/made, active/passive, right/wrong, truth/illusion, total/partial, God/man. The self is the One who is not dominated, who knows that by the service of the other, the other is the one who holds the future, who knows that by the experience of domination, which gives the lie to the autonomy of the self. To be One is to be autonomous, to be powerful, to be God; but to be One is to be an illusion, and so to be involved in a dialectic of apocalypse with the other. Yet to be other is to be multiple, without clear boundary, frayed, insubstantial. One is too few, but two are too many.

High-tech culture challenges these dualisms in intriguing ways. It is not clear who makes and who is made in the relation between human and machine. It is not clear what is mind and what body in machines that resolve into coding practices. In so far as we know ourselves in both formal discourse (for example, biology) and in daily practice (for example, the homework economy in the integrated circuit), we find ourselves to be cyborgs, hybrids, mosaics, chimeras. Biological organisms have become biotic systems, communications devices like others. There is no fundamental, ontological separation in our formal knowledge of machine and organism, of technical and organic. The replicant Rachel in the Ridley Scott film *Blade Runner* stands as the image of a cyborg culture’s fear, love and confusion.

One consequence is that our sense of connection to our tools is heightened. The trance state experienced by many computer users has become a staple of science fiction film and cultural jokes. Perhaps paraplegics and other severely handicapped people can have the most intense experiences of complex hybridization with other communication
devices. Anne McCaffrey’s pre-feminist *The Ship Who Sang* (1969) explored the consciousness of a cyborg, hybrid of girl’s brain and complex machinery, formed after the birth of a severely handicapped child. Gender, sexuality, embodiment, skill: all were reconstituted in the story. Why should our bodies end at the skin, or include at best other beings encapsulated by skin? From the seventeenth century till now, machines could be animated — given ghostly souls to make them speak or move or to account for their orderly development and mental capacities. Or organisms could be mechanized — reduced to body understood as resource of mind. These machine/organism relationships are obsolete, unnecessary. For us, in imagination and in other practice, machines can be prosthetic devices, intimate components, friendly selves. We don’t need organic holism to give impermeable wholeness, the total woman and her feminist variants (mutants?). Let me conclude this point by a very partial reading of the logic of the cyborg monsters of my second group of texts, feminist science fiction.

The cyborgs populating feminist science fiction make very problematic the statues of man or woman, human, artefact, member of a race, individual entity, or body. Katie King clarifies how pleasure in reading these fictions is not largely based on identification. Students facing Joanna Russ for the first time, students who have learned to take modernist writers like James Joyce or Virginia Woolf without flinching, do not know what to make of *The Adventures of Alyx* or *The Female Man*, where characters refuse the reader’s search for innocent wholeness while granting the wish for heroic quests, exuberant eroticism and serious politics. *The Female Man* is the story of four versions of one genotype, all of whom meet, but even taken together do not make a whole, resolve the dilemmas of violent moral action, or remove the growing scandal of gender. The feminist science fiction of Samuel R. Delany, especially *Tales of Nevràjón*, mocks stories of origin by redoing the neolithic revolution, replaying the founding moves of Western civilization to subvert their plausibility. James Tiptree, Jr, an author whose fiction was regarded as particularly manly until her ‘true’ gender was revealed, tells tales of reproduction based on non-mammalian technologies like alternation of generations of male brood pouches and male nurturing. John Varley constructs a supreme cyborg in his archfeminist exploration of Gaea, a mad goddess-planet-trickster-old woman-technological device on whose surface an extraordinary array of post-cyborg symbioses are spawned. Octavia Butler writes of an African sorceress pitting her powers of transformation against the genetic manipulations of her rival (*Wild Seed*), of time warps that bring a modern US black woman into slavery where her actions in relation to her white master-ancestor determine the possibility of her own birth (*Kindred*), and of the illegitimate insights into identity and community of an adopted cross-species child who came to know the enemy as self (*Survivor*).

Because it is particularly rich in boundary transgressions, Vonda McIntyre’s *Superluminal* can close this truncated catalogue of promising and dangerous monsters who help redefine the pleasures and politics of embodiment and feminist writing. In a fiction where no character is ‘simply’ human, human status is highly problematic. Orca, a genetically altered diver, can speak with killer whales and survive deep ocean conditions, but she longs to explore space as a pilot, necessitating bionic implants jeopardizing her kinship with the divers and cetaceans. Transformations are effected by virus vectors carrying a new developmental code, by transplant surgery, by implants of microelectronic devices, by analogue doubles, and other means. Laenea becomes a pilot by accepting a heart implant and a host of other alterations allowing survival in transit at
speeds exceeding that of light. All the characters explore the limits of language; the
dream of communicating experience; and the necessity of limitation, partiality and inti-
macy even in this world of protean transformation and connection. *Superluminal* stands
also for the defining contradictions of a cyborg world in another sense; it embodies
textually the intersection of feminist theory and colonial discourse in the science fiction
I have alluded to in this chapter. This is a conjunction with a long history that many
‘First World’ feminists have tried to repress, including myself in my readings of
*Superluminal* before being called to account by Zoe Sofoulis, whose different location in
the world system’s informatics of domination made her acutely alert to the imperialist
moment of all science fiction cultures, including women’s science fiction. From an
Australian feminist sensitivity, Sofoulis remembered more readily McIntyre’s role as
writer of the adventures of Captain Kirk and Spock in TV’s *Star Trek* series than her
rewriting the romance in *Superluminal*.

Monsters have always defined the limits of community in Western imaginations.
The Centaurs and Amazons of ancient Greece established the limits of the centred polis
of the Greek male human by their disruption of marriage and boundary pollutions of
the warrior with animality and woman. Unseparated twins and hermaphrodites were
the confused human material in early modern France who grounded discourse on the
natural and supernatural, medical and legal, portents and diseases – all crucial to estab-
lishing modern identity. The evolutionary and behavioural sciences of monkeys and
apes have marked the multiple boundaries of late twentieth-century industrial identities.
Cyborg monsters in feminist science fiction define quite different political possibilities
and limits from those proposed by the mundane fiction of *Man and Woman*.

There are several consequences to taking seriously the imagery of cyborgs as other
than our enemies. Our bodies, ourselves; bodies are maps of power and identity. Cyborgs
are no exception. A cyborg body is not innocent; it was not born in a garden; it does
not seek unitary identity and so generate antagonistic dualisms without end (or until the
world ends); it takes irony for granted. One is too few, and two is only one possibility.
Intense pleasure in skill, machine skill, ceases to be a sin, but an aspect of embodiment.
The machine is not an it to be animated, worshipped and dominated. The machine is
us, our processes, an aspect of our embodiment. We can be responsible for machines;
they do not dominate or threaten us. We are responsible for boundaries; we are they.
Up till now (once upon a time), female embodiment seemed to be given, organic, neces-
sary; and female embodiment seemed to mean skill in mothering and its metaphorical
extensions. Only by being out of place could we take intense pleasure in machines, and
then with excuses that this was organic activity after all, appropriate to females. Cyborgs
might consider more seriously the partial, fluid, sometimes aspect of sex and sexual
embodiment. Gender might not be global identity after all, even if it has profound
historical breadth and depth.

The ideologically charged question of what counts as daily activity, as experience,
can be approached by exploiting the cyborg image. Feminists have recently claimed that
women are given to dailiness, that women more than men somehow sustain daily life,
and so have a privileged epistemological position potentially. There is a compelling
aspect to this claim, one that makes visible unvalued female activity and names it as the
ground of life. But the ground of life? What about all the ignorance of women, all the
exclusions and failures of knowledge and skill? What about men’s access to daily com-
petence, to knowing how to build things, to take them apart, to play? What about other
embodiments? Cyborg gender is a local possibility taking a global vengeance. Race, gender and capital require a cyborg theory of wholes and parts. There is no drive in cyborgs to produce total theory, but there is an intimate experience of boundaries, their construction and deconstruction. There is a myth system waiting to become a political language to ground one way of looking at science and technology and challenging the informatics of domination in order to act potently.

Cyborg imagery can help express two crucial arguments in this essay: first, the production of universal, totalizing theory is a major mistake that misses most of reality, probably always, but certainly now; and second, taking responsibility for the social relations of science and technology means refusing an anti-science metaphysics, a demonology of technology, and so means embracing the skillful task of reconstituting the boundaries of daily life, in partial connection with others, in communication with all of our parts. It is not just that science and technology are possible means of great human satisfaction, as well as a matrix of complex dominations. Cyborg imagery can suggest a way out of the maze of dualisms in which we have explained our bodies and our tools to ourselves. This is a dream not of a common language, but of a powerful inchoate heteroglossia. It is an imagination of a feminist speaking in tongues to strike fear into the circuits of the supersavers of the new right. It means both building and destroying machines, identities, categories, relationships, space stories. Though both are bound in the spiral dance, I would rather be a cyborg than a goddess.


Notes


3. A provocative, comprehensive argument about the politics and theories of 'postmodernism' is made by Fredric Jameson (1984), who argues that postmodernism is not an option, a style among others, but a cultural dominant requiring radical reinvention of left politics from within; there is no longer any place from without that gives meaning to the comforting fiction of critical distance. Jameson also makes clear why one cannot be for or against postmodernism, an essentially moralist move. My position is that feminists (and others) need continuous cultural reinvention, postmodernist critique, and historical materialism; only a cyborg would have a chance. The old dominations of white capitalist patriarchy seem nostalgically innocent now: they normalized heterogeneity, into man and woman, white and black, for example. 'Advanced capitalism' and postmodernism release heterogeneity without a norm, and we are flattened, without subjectivity, which requires depth, even unfriendly and daunting depths. It is time to write the Death of the Clinic. The clinic's methods required bodies and works; we have texts and surfaces. Our dominations don't work by medicalization and normalization any more; they work by networking, communications redesign, stress management. Normalization gives way to automation, utter redundancy. Michel Foucault's Birth of the Clinic (1963), History of Sexuality...
(1976), and *Discipline and Punish* (1975) name a form of power at its moment of implosion. The discourse of biopolitics gives way to technoscientific, the language of the spliced substantive; no noun is left whole by the multinationals. These are their names, listed from one issue of *Science: Tech-Knowledge, Genetech, Allergen, Hybritech, Compupro, Genen-corp, Syntax, Allelix, Agrigenetics Corp., Syntro, Codon, Repligen, MicroAngelo from Scion Corp., Percom Data, Inter Systems, Cyborg Corp., Statecom Corp., Interee.* If we are imprisoned by language, then escape from that prison house requires language poetics, a kind of cultural restriction enzyme to cut the code; cyborg heteroglossia is one form of radical cultural politics. For cyborg poetry, see Perloff (1984); Fraser (1984). For feminist modernist/postmodernist 'cyborg' writing, see HOW(ever), 871 Corbett Ave, San Francisco, CA 94131.

4. Baudrillard (1983). Jameson (1984: 66) points out that Plato's definition of the simulacrum is the copy for which there is no original, i.e. the world of advanced capitalism, of pure exchange. See *Discurso* 9 (Spring/Summer 1987) for a special issue on technology (cybernetics, ecology and the postmodern imagination).

5. A practice at once both spiritual and political that linked guards and arrested anti-nuclear demonstrators in the Alameda County jail in California in the early 1980s.

6. For ethnographic accounts and political evaluations, see Epstein (1993), Sturgeon (1986). Without explicit irony, adopting the spaceship earth/whole earth logo of the planet photographed from space, set off by the slogan 'Love Your Mother', the May 1987 Mothers and Others Day action at the nuclear weapons testing facility in Nevada made the less those account of the tragic contradictions of our world. Demonstrators applied for official permits to be on the land from officers of the Western Shoshone tribe, whose territory was invaded by the US government when it built the nuclear weapons test ground in the 1950s. Arrested for trespassing, the demonstrators argued that the police and weapons facility personnel, without authorization from the proper officials, were the trespassers. One affinity group at the women's action called themselves the 'Surrogate Others'; and in solidarity with the creatures forced to tunnel in the same ground with the bomb, they enacted a cyborgian emergence from the constructed body of a large, non-heterosexual desert worm.


9. On orientalism in feminist works and elsewhere, see Lowe (1986); Mohanty (1984); Said (1978); *Bye Voices, the Other: Black Feminist Perspectives* (1984).

10. Katie King (1986, 1987a) has developed a theoretically sensitive treatment of the workings of feminist taxonomies as genealogies of power in feminist ideology and polemic. King examines Jaggar's (1982) problematic example of taxonomizing feminisms to make a little machine producing the desired final position. My caricature here of socialist and radical feminism is also an example.

11. The central role of object relations versions of psychoanalysis and related strong universalizing versions in discussing reproduction, caring work and mothering in many approaches to epistemology underlie their authors' resistance to what I am calling postmodernism. For me, both the universalizing moves and these versions of psychoanalysis make analysis of 'women's place in the integrated circuit' difficult and lead to systematic difficulties in accounting for or even seeing major aspects of the construction of gender and gendered social life. The feminist standpoint argument has been developed by: Flax (1983), Harding (1986), Harding and Hintikka (1983), Hartslock (1984, 85), O'Brien (1984), Rose (1983), Smith (1974, 1979). For rethinking theories of feminist materialism and feminist standpoints in response to criticism, see Harding (1986, pp. 163–96), Hartslock (1987) and H. Rose (1986).

12. I make an argumentative category error in 'modifying' MacKinnon's positions with the qualifier 'radical', thereby generating my own reductive critique of extremely heterogeneous writing.
which does explicitly use that label, by my taxonomically interested argument about writing which does not use the modifier and which brooks no limits and thereby adds to the various dreams of a common, in the sense of univocal, language for feminism. My category error was occasioned by an assignment to write from a particular taxonomic position which itself has a heterogeneous history, socialist-feminism, for Socialist Review. A critique indebted to MacKinnon, but without the reductionism and with an elegant feminist account of Foucault's paradoxical conservatism on sexual violence (rape), is de Lauretis (1985; see also 1986, pp. 1–19). A theoretically elegant feminist social-historical examination of family violence, that insists on women's, men's and children's complex agency without losing sight of the material structures of male domination, race and class, is Gordon (1988).

13. This chart was published in 1985. My previous efforts to understand biology as a cybernetic command-control discourse and organisms as 'natural-technical objects of knowledge' were Haraway (1979, 1983, 1984). The 1979 version of this dichotomous chart appears in Haraway (1991) ch. 3; for a 1989 version, see ch. 10. The differences indicate shifts in argument.

14. For progressive analyses and action on the biotechnology debates: GeneWatch, a Bulletin of the Committee for Responsible Genetics, 5 Doane St, 4th Floor, Boston, MA 02109; Genetic Screening Study Group (formerly the Sociobiology Study Group of Science for the People), Cambridge, MA; Wright (1982, 1986); Yoxen (1983).


16. For the 'homework economy outside the home' and related arguments: Burr (1982); Collins (1982); Gordon (1983); Gordon and Kimball (1985); Gregory and Nusbaum (1982); Microelectronics Group (1980); Piven and Coward (1982); Reskin and Hartmann (1986); Stacey (1987); S. Rose (1986); Stallard et al. (1983); Women and Poverty (1984), which includes a useful organization and resource list.

17. The conjunction of the Green Revolution’s social relations with biotechnologies like plant genetic engineering makes the pressures on land in the Third World increasingly intense. AID’s estimates (New York Times, 14 October 1984) used at the 1984 World Food Day are that in Africa, women produce about 90 per cent of rural food supplies, about 60–80 per cent in Asia, and provide 40 per cent of agricultural labour in the Near East and Latin America. Blumberg charges that world organizations’ agricultural politics, as well as those of multinationals and national governments in the Third World, generally ignore fundamental issues in the sexual division of labour. The present tragedy of famine in Africa might owe as much to male supremacy as to capitalism, colonialism and rain patterns. More accurately, capitalism and racism are usually structurally male dominant. See also Bird (1984); Blumberg (1981); Busch and Lacy (1983); Hacker (1984); Hacker and Bovit (1981); International fund for Agricultural Development (1985); Sachs (1983); Wilfred (1982).

18. See also Enloe (1983a, b).

19. For a feminist version of this logic, see Hrdy (1981). For an analysis of scientific women’s story-telling practices, especially in relation to sociobiology in evolutionary debates around child abuse and infanticide, see Haraway (1991), ch. 5.


21. For guidance for thinking about the political/cultural/racial implications of the history of women doing science in the US see: Haas and Perucci (1984); Hacker (1981); Haraway (1989b); Keller (1983); National Science Foundation (1988); Rossiter (1982); Schiebinger (1987).


28. The convention of ideologically taming militarized high technology by publicizing its applications to speech and motion problems of the disabled/differently abled takes on a special irony in monolingual, patriarchal, and frequently anti-Semitic culture when computer-generated speech allows a boy with no voice to chant the Hatorah at his bar mitzvah. See Susman (1986). Making the always context-relative social definitions of 'ability' particularly clear, military high-tech has a way of making human beings disabled by definition, a perverse aspect of much automated battlefield and Star Wars R & D. See Wellford (1 July 1986).

29. James Clifford (1988) argues persuasively for recognition of continuous cultural reinvention, the stubborn non-disappearance of those 'marked' by Western imperializing practices.


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The
Cybercultures
Reader

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Prologue

You are alone in the room, except for two computer terminals flickering in the dim light. You use the terminals to communicate with two entities in another room, whom you cannot see. Relying solely on their responses to your questions, you must decide which is the man, which the woman. Or, in another version of the famous “imitation game” proposed by Alan Turing in his classic 1950 paper “Computer Machinery and Intelligence,” you use the responses to decide which is the human, which the machine. One of the entities wants to help you guess correctly. His/her/its best strategy, Turing suggested, may be to answer your questions truthfully. The other entity wants to mislead you. He/she/it will try to reproduce through the words that appear on your terminal the characteristics of the other entity. Your job is to pose questions that can distinguish verbal performance from embodied reality. If you cannot tell the intelligent machine from the intelligent human, your failure proves, Turing argued, that machines can think.

Here, at the inaugural moment of the computer age, the erasure of embodiment is performed so that “intelligence” becomes a property of the formal manipulation of symbols rather than enaction in the human life-world. The Turing test was to set the agenda for artificial intelligence for the next three decades. In the push to achieve machines that can think, researchers performed again and again the erasure of embodiment at the heart of the Turing test. All that mattered was the formal generation and manipulation of informational patterns. Aiding this process was a definition of information, formalized by Claude Shannon and Norbert Wiener, that conceptualized information as an entity distinct from the substrates carrying it. From this formulation, it was a small step to think of information as a kind of bodiless fluid that could flow between different substrates without loss of meaning or form. Writing nearly four decades after Turing, Hans
Moravec proposed that human identity is essentially an informational pattern rather than an embodied enaction. The proposition can be demonstrated, he suggested, by downloading human consciousness into a computer, and he imagined a scenario designed to show that this was in principle possible. The Moravec test, if I may call it that, is the logical successor to the Turing test. Whereas the Turing test was designed to show that machines can perform the thinking previously considered to be an exclusive capacity of the human mind, the Moravec test was designed to show that machines can become the repository of human consciousness—that machines can, for all practical purposes, become human beings. You are the cyborg, and the cyborg is you.

In the progression from Turing to Moravec, the part of the Turing test that historically has been foregrounded is the distinction between thinking human and thinking machine. Often forgotten is the first example Turing offered of distinguishing between a man and a woman. If your failure to distinguish correctly between human and machine proves that machines can think, what does it prove if you fail to distinguish woman from man? Why does gender appear in this primal scene of humans meeting their evolutionary successors, intelligent machines? What do gendered bodies have to do with the erasure of embodiment and the subsequent merging of machine and human intelligence in the figure of the cyborg?

In his thoughtful and perceptive intellectual biography of Turing, Andrew Hodges suggests that Turing’s predilection was always to deal with the world as if it were a formal puzzle. To a remarkable extent, Hodges says, Turing was blind to the distinction between saying and doing. Turing fundamentally did not understand that “questions involving sex, society, politics or secrets would demonstrate how what it was possible for people to say might be limited not by puzzle-solving intelligence but by the restrictions on what might be done” (pp. 423–24). In a fine insight, Hodges suggests that “the discrete state machine, communicating by teleprinter alone, was like an ideal for [Turing’s] own life, in which he would be left alone in a room of his own, to deal with the outside world solely by rational argument. It was the embodiment of a perfect J. S. Mill liberal, concentrating upon the free will and free speech of the individual” (p. 425). Turing’s later embroilment with the police and court system over the question of his homosexuality played out, in a different key, the assumptions embodied in the Turing test. His conviction and the court-ordered hormone treatments for his homosexuality tragically demonstrated the importance of doing over saying in the coercive order of a homophobic society with the power to enforce its will upon the bodies of its citizens.
The perceptiveness of Hodges's biography notwithstanding, he gives a strange interpretation of Turing's inclusion of gender in the imitation game. Gender, according to Hodges, "was in fact a red herring, and one of the few passages of the paper that was not expressed with perfect lucidity. The whole point of this game was that a successful imitation of a woman's responses by a man would not prove anything. Gender depended on facts which were not reducible to sequences of symbols" (p. 415). In the paper itself, however, nowhere does Turing suggest that gender is meant as a counterexample; instead, he makes the two cases rhetorically parallel, indicating through symmetry, if nothing else, that the gender and the human/machine examples are meant to prove the same thing. Is this simply bad writing, as Hodges argues, an inability to express an intended opposition between the construction of gender and the construction of thought? Or, on the contrary, does the writing express a parallelism too explosive and subversive for Hodges to acknowledge?

If so, now we have two mysteries instead of one. Why does Turing include gender, and why does Hodges want to read this inclusion as indicating that, so far as gender is concerned, verbal performance cannot be equated with embodied reality? One way to frame these mysteries is to see them as attempts to transgress and reinforce the boundaries of the subject, respectively. By including gender, Turing implied that renegotiating the boundary between human and machine would involve more than transforming the question of "who can think" into "what can think." It would also necessarily bring into question other characteristics of the liberal subject, for it made the crucial move of distinguishing between the enacted body, present in the flesh on one side of the computer screen, and the represented body, produced through the verbal and semiotic markers constituting it in an electronic environment. This construction necessarily makes the subject into a cyborg, for the enacted and represented bodies are brought into conjunction through the technology that connects them. If you distinguish correctly which is the man and which the woman, you in effect reunite the enacted and the represented bodies into a single gender identity. The very existence of the test, however, implies that you may also make the wrong choice. Thus the test functions to create the possibility of a disjunction between the enacted and the represented bodies, regardless which choice you make. What the Turing test "proves" is that the overlay between the enacted and the represented bodies is no longer a natural inevitability but a contingent production, mediated by a technology that has become so entwined with the production of identity that it can no longer meaningfully be separated from the human subject. To pose the question
of “what can think” inevitably also changes, in a reverse feedback loop, the terms of “who can think.”

On this view, Hodges’s reading of the gender test as nonsignifying with respect to identity can be seen as an attempt to safeguard the boundaries of the subject from precisely this kind of transformation, to insist that the existence of thinking machines will not necessarily affect what being human means. That Hodges’s reading is a misreading indicates he is willing to practice violence upon the text to wrench meaning away from the direction toward which the Turing test points, back to safer ground where embodiment secures the univocality of gender. I think he is wrong about embodiment’s securing the univocality of gender and wrong about its securing human identity, but right about the importance of putting embodiment back into the picture. What embodiment secures is not the distinction between male and female or between humans who can think and machines which cannot. Rather, embodiment makes clear that thought is a much broader cognitive function depending for its specificities on the embodied form enacting it. This realization, with all its exfoliating implications, is so broad in its effects and so deep in its consequences that it is transforming the liberal subject, regarded as the model of the human since the Enlightenment, into the posthuman.

Think of the Turing test as a magic trick. Like all good magic tricks, the test relies on getting you to accept at an early stage assumptions that will determine how you interpret what you see later. The important intervention comes not when you try to determine which is the man, the woman, or the machine. Rather, the important intervention comes much earlier, when the test puts you into a cybernetic circuit that splices your will, desire, and perception into a distributed cognitive system in which represented bodies are joined with enacted bodies through mutating and flexible machine interfaces. As you gaze at the flickering signifiers scrolling down the computer screens, no matter what identifications you assign to the embodied entities that you cannot see, you have already become posthuman.
We need first to understand that the human form—including human desire and all its external representations—may be changing radically, and thus must be re-visioned. We need to understand that five hundred years of humanism may be coming to an end as humanism transforms itself into something that we must helplessly call post-humanism.

Ihab Hassan, "Prometheus as Performer: Towards a Posthumanist Culture?"

This book began with a roboticist’s dream that struck me as a nightmare. I was reading Hans Moravec’s *Mind Children: The Future of Robot and Human Intelligence*, enjoying the ingenious variety of his robots, when I happened upon the passage where he argues it will soon be possible to download human consciousness into a computer. To illustrate, he invents a fantasy scenario in which a robot surgeon purees the human brain in a kind of cranial liposuction, reading the information in each molecular layer as it is stripped away and transferring the information into a computer. At the end of the operation, the cranial cavity is empty, and the patient, now inhabiting the metallic body of the computer, wakens to find his consciousness exactly the same as it was before.

How, I asked myself, was it possible for someone of Moravec’s obvious intelligence to believe that mind could be separated from body? Even assuming such a separation was possible, how could anyone think that consciousness in an entirely different medium would remain unchanged, as if it had no connection with embodiment? Shocked into awareness, I began noticing he was far from alone. As early as the 1950s, Norbert Wiener proposed it was theoretically possible to telegraph a human being, a suggestion underlaid by the same assumptions informing Moravec’s scenario. The producers of *Star Trek* operate from similar premises when they imagine that the body can be dematerialized into an informational pattern and re-materialized, without change, at a remote location. Nor is the idea confined to what Beth Loffreda has called “pulp science.” Much of the discourse on molecular biology treats information as the essential code the body expresses, a practice that has certain affinities with Moravec’s ideas. In fact, a defining characteristic of the present cultural moment is the belief that information can circulate unchanged among different material substrates. It
is not for nothing that “Beam me up, Scotty,” has become a cultural icon for the global informational society.

Following this thread, I was led into a maze of developments that turned into a six-year odyssey of researching archives in the history of cybernetics, interviewing scientists in computational biology and artificial life, reading cultural and literary texts concerned with information technologies, visiting laboratories engaged in research on virtual reality, and grappling with technical articles in cybernetics, information theory, autopoiesis, computer simulation, and cognitive science. Slowly this unruly mass of material began taking shape as three interrelated stories. The first centers on how information lost its body, that is, how it came to be conceptualized as an entity separate from the material forms in which it is thought to be embedded. The second story concerns how the cyborg was created as a technological artifact and cultural icon in the years following World War II. The third, deeply implicated with the first two, is the unfolding story of how a historically specific construction called the human is giving way to a different construction called the posthuman.

Interrelations between the three stories are extensive. Central to the construction of the cyborg are informational pathways connecting the organic body to its prosthetic extensions. This presumes a conception of information as a (disembodied) entity that can flow between carbon-based organic components and silicon-based electronic components to make protein and silicon operate as a single system. When information loses its body, equating humans and computers is especially easy, for the materiality in which the thinking mind is instantiated appears incidental to its essential nature. Moreover, the idea of the feedback loop implies that the boundaries of the autonomous subject are up for grabs, since feedback loops can flow not only within the subject but also between the subject and the environment. From Norbert Wiener on, the flow of information through feedback loops has been associated with the deconstruction of the liberal humanist subject, the version of the “human” with which I will be concerned. Although the “posthuman” differs in its articulations, a common theme is the union of the human with the intelligent machine.

What is the posthuman? Think of it as a point of view characterized by the following assumptions. (I do not mean this list to be exclusive or definitive. Rather, it names elements found at a variety of sites. It is meant to be suggestive rather than prescriptive.) First, the posthuman view privileges informational pattern over material instantiation, so that embodiment in a biological substrate is seen as an accident of history rather than an inevitability of life. Second, the posthuman view considers consciousness, re-
garded as the seat of human identity in the Western tradition long before Descartes thought he was a mind thinking, as an epiphenomenon, as an evolutionary upstart trying to claim that it is the whole show when in actuality it is only a minor sideshow. Third, the posthuman view thinks of the body as the original prosthesis we all learn to manipulate, so that extending or replacing the body with other prostheses becomes a continuation of a process that began before we were born. Fourth, and most important, by these and other means, the posthuman view configures human being so that it can be seamlessly articulated with intelligent machines. In the posthuman, there are no essential differences or absolute demarcations between bodily existence and computer simulation, cybernetic mechanism and biological organism, robot teleology and human goals.

To elucidate the significant shift in underlying assumptions about subjectivity signaled by the posthuman, we can recall one of the definitive texts characterizing the liberal humanist subject: C. B. Macpherson’s analysis of possessive individualism. “Its possessive quality is found in its conception of the individual as essentially the proprietor of his own person or capacities, owing nothing to society for them... The human essence is freedom from the wills of others, and freedom is a function of possession.” The italicized phrases mark convenient points of departure for measuring the distance between the human and the posthuman. “Owing nothing to society” comes from arguments Hobbes and Locke constructed about humans in a “state of nature” before market relations arose. Because ownership of oneself is thought to predate market relations and owe nothing to them, it forms a foundation upon which those relations can be built, as when one sells one’s labor for wages. As Macpherson points out, however, this imagined “state of nature” is a retrospective creation of a market society. The liberal self is produced by market relations and does not in fact predate them. This paradox (as Macpherson calls it) is resolved in the posthuman by doing away with the “natural” self. The posthuman subject is an amalgam, a collection of heterogeneous components, a material-informational entity whose boundaries undergo continuous construction and reconstruction. Consider the six-million-dollar man, a paradigmatic citizen of the posthuman regime. As his name implies, the parts of the self are indeed owned, but they are owned precisely because they were purchased, not because ownership is a natural condition preexisting market relations. Similarly, the presumption that there is an agency, desire, or will belonging to the self and clearly distinguished from the “wills of others” is undercut in the posthuman, for the posthuman’s collective heterogeneous quality implies a distributed cognition located in disparate parts that may be in only tenuous
communication with one another. We have only to recall Robocop’s memory flashes that interfere with his programmed directives to understand how the distributed cognition of the posthuman complicates individual agency. If “human essence is freedom from the wills of others,” the posthuman is “post” not because it is necessarily unfree but because there is no a priori way to identify a self-will that can be clearly distinguished from an other-will. Although these examples foreground the cybernetic aspect of the posthuman, it is important to recognize that the construction of the posthuman does not require the subject to be a literal cyborg. Whether or not interventions have been made on the body, new models of subjectivity emerging from such fields as cognitive science and artificial life imply that even a biologically unaltered *Homo sapiens* counts as posthuman. The defining characteristics involve the construction of subjectivity, not the presence of nonbiological components.

What to make of this shift from the human to the posthuman, which both evokes terror and excites pleasure? The liberal humanist subject has, of course, been cogently criticized from a number of perspectives. Feminist theorists have pointed out that it has historically been constructed as a white European male, presuming a universality that has worked to suppress and disenfranchise women’s voices; postcolonial theorists have taken issue not only with the universality of the (white male) liberal subject but also with the very idea of a unified, consistent identity, focusing instead on hybridity; and postmodern theorists such as Gilles Deleuze and Felix Guattari have linked it with capitalism, arguing for the liberatory potential of a dispersed subjectivity distributed among diverse desiring machines they call “body without organs.” Although the deconstruction of the liberal humanist subject in cybernetics has some affinities with these perspectives, it proceeded primarily along lines that sought to understand human being as a set of informational processes. Because information had lost its body, this construction implied that embodiment is not essential to human being. Embodiment has been systematically downplayed or erased in the cybernetic construction of the posthuman in ways that have not occurred in other critiques of the liberal humanist subject, especially in feminist and postcolonial theories.

Indeed, one could argue that the erasure of embodiment is a feature common to both the liberal humanist subject and the cybernetic posthuman. Identified with the rational mind, the liberal subject possessed a body but was not usually represented as being a body. Only because the body is not identified with the self is it possible to claim for the liberal subject its notorious universality, a claim that depends on erasing markers of bodily
difference, including sex, race, and ethnicity. Gillian Brown, in her influential study of the relation between humanism and anorexia, shows that the anorectic's struggle to "decrement" the body is possible precisely because the body is understood as an object for control and mastery rather than as an intrinsic part of the self. Quoting an anorectic's remark—"You make out of your body your very own kingdom where you are the tyrant, the absolute dictator"—Brown states, "Anorexia is thus a fight for self-control, a flight from the slavery food threatens; self-sustaining self-possession independent of bodily desires is the anorectic's crucial goal." In taking the self-possession implied by liberal humanism to the extreme, the anorectic creates a physical image that, in its skeletal emaciation, serves as material testimony that the locus of the liberal humanist subject lies in the mind, not the body. Although in many ways the posthuman deconstructs the liberal humanist subject, it thus shares with its predecessor an emphasis on cognition rather than embodiment. William Gibson makes the point vividly in *Neuromancer* when the narrator characterizes the posthuman body as "data made flesh." To the extent that the posthuman constructs embodiment as the instantiation of thought/information, it continues the liberal tradition rather than disrupts it.

In tracing these continuities and discontinuities between a "natural" self and a cybernetic posthuman, I am not trying to recuperate the liberal subject. Although I think that serious consideration needs to be given to how certain characteristics associated with the liberal subject, especially agency and choice, can be articulated within a posthuman context, I do not mourn the passing of a concept so deeply entwined with projects of domination and oppression. Rather, I view the present moment as a critical juncture when interventions might be made to keep disembodiment from being rewritten, once again, into prevailing concepts of subjectivity. I see the deconstruction of the liberal humanist subject as an opportunity to put back into the picture the flesh that continues to be erased in contemporary discussions about cybernetic subjects. Hence my focus on how information lost its body, for this story is central to creating what Arthur Kroker has called the "flesh-eating 90s." If my nightmare is a culture inhabited by posthumans who regard their bodies as fashion accessories rather than the ground of being, my dream is a version of the posthuman that embraces the possibilities of information technologies without being seduced by fantasies of unlimited power and disembodied immortality, that recognizes and celebrates finitude as a condition of human being, and that understands human life is embedded in a material world of great complexity, one on which we depend for our continued survival.
Perhaps it will now be clear that I mean my title, *How We Became Posthuman*, to connote multiple ironies, which do not prevent it from also being taken seriously. Taken straight, this title points to models of subjectivity sufficiently different from the liberal subject that if one assigns the term “human” to this subject, it makes sense to call the successor “posthuman.” Some of the historical processes leading to this transformation are documented here, and in this sense the book makes good on its title. Yet my argument will repeatedly demonstrate that these changes were never complete transformations or sharp breaks; without exception, they reinscribed traditional ideas and assumptions even as they articulated something new. The changes announced by the title thus mean something more complex than “That was then, this is now.” Rather, “human” and “posthuman” coexist in shifting configurations that vary with historically specific contexts. Given these complexities, the past tense in the title—“became”—is intended both to offer the reader the pleasurable shock of a double take and to reference ironically apocalyptic visions such as Moravec’s prediction of a “postbiological” future for the human race.

Amplifying the ambiguities of the past tense are the ambiguities of the plural. In one sense, “we” refers to the readers of this book—readers who, by becoming aware of these new models of subjectivity (if they are not already familiar with them), may begin thinking of their actions in ways that have more in common with the posthuman than the human. Speaking for myself, I now find myself saying things like, “Well, my sleep agent wants to rest, but my food agent says I should go to the store.” Each person who thinks this way begins to envision herself or himself as a posthuman collectivity, an “I” transformed into the “we” of autonomous agents operating together to make a self. The infectious power of this way of thinking gives “we” a performative dimension. People become posthuman because they think they are posthuman. In another sense “we,” like “became,” is meant ironically, positioning itself in opposition to the techno-ecstasies found in various magazines, such as *Mondo 2000*, which customarily speak of the transformation into the posthuman as if it were a universal human condition when in fact it affects only a small fraction of the world’s population—a point to which I will return.

The larger trajectory of my narrative arcs from the initial moments when cybernetics was formulated as a discipline, through a period of reformulation known as “second-order cybernetics,” to contemporary debates swirling around an emerging discipline known as “artificial life.” Although the progression is chronological, this book is not meant to be a history of cybernetics. Many figures not discussed here played important roles in that
history, and I have not attempted to detail their contributions. Rather, my selection of theories and researchers has been dictated by a desire to show the complex interplays between embodied forms of subjectivity and arguments for disembodiment throughout the cybernetic tradition. In broad outline, these interplays occurred in three distinct waves of development. The first, from 1945 to 1960, took homeostasis as a central concept; the second, going roughly from 1960 to 1980, revolved around reflexivity; and the third, stretching from 1980 to the present, highlights virtuality. Let me turn now to a brief sketch of these three periods.

During the foundational era of cybernetics, Norbert Wiener, John von Neumann, Claude Shannon, Warren McCulloch, and dozens of other distinguished researchers met at annual conferences sponsored by the Josiah Macy Foundation to formulate the central concepts that, in their high expectations, would coalesce into a theory of communication and control applying equally to animals, humans, and machines. Retrospectively called the Macy Conferences on Cybernetics, these meetings, held from 1943 to 1954, were instrumental in forging a new paradigm. To succeed, they needed a theory of information (Shannon’s bailiwick), a model of neural functioning that showed how neurons worked as information-processing systems (McCulloch’s lifework), computers that processed binary code and that could conceivably reproduce themselves, thus reinforcing the analogy with biological systems (von Neumann’s specialty), and a visionary who could articulate the larger implications of the cybernetic paradigm and make clear its cosmic significance (Wiener’s contribution). The result of this breathtaking enterprise was nothing less than a new way of looking at human beings. Henceforth, humans were to be seen primarily as information-processing entities who are essentially similar to intelligent machines.

The revolutionary implications of this paradigm notwithstanding, Wiener did not intend to dismantle the liberal humanist subject. He was less interested in seeing humans as machines than he was in fashioning human and machine alike in the image of an autonomous, self-directed individual. In aligning cybernetics with liberal humanism, he was following a strain of thought that, since the Enlightenment, had argued that human beings could be trusted with freedom because they and the social structures they devised operated as self-regulating mechanisms. For Wiener, cybernetics was a means to extend liberal humanism, not subvert it. The point was less to show that man was a machine than to demonstrate that a machine could function like a man.

Yet the cybernetic perspective had a certain inexorable logic that, especially when fed by wartime hysteria, also worked to undermine the very lib-
eral subjectivity that Wiener wanted to preserve. These tensions were kept under control during the Macy period partly through a strong emphasis on homeostasis.14 Traditionally, homeostasis had been understood as the ability of living organisms to maintain steady states when they are buffeted by fickle environments. When the temperature soars, sweat pours out of the human body so that its internal temperature can remain relatively stable. During the Macy period, the idea of homeostasis was extended to machines. Like animals, machines can maintain homeostasis using feedback loops. Feedback loops had long been exploited to increase the stability of mechanical systems, reaching a high level of development during the mid-to-late nineteenth century with the growing sophistication of steam engines and their accompanying control devices, such as governors. It was not until the 1930s and 1940s, however, that the feedback loop was explicitly theorized as a flow of information. Cybernetics was born when nineteenth-century control theory joined with the nascent theory of information.15 Coined from the Greek word for “steersman,” cybernetics signaled that three powerful actors—information, control, and communication—were now operating jointly to bring about an unprecedented synthesis of the organic and the mechanical.

Although the informational feedback loop was initially linked with homeostasis, it quickly led to the more threatening and subversive idea of reflexivity. A few years ago I co-taught, with a philosopher and a physicist, a course on reflexivity. As we discussed reflexivity in the writings of Aristotle, Fichte, Kierkegaard, Gödel, Turing, Borges, and Calvino, aided by the insightful analyses of Roger Penrose and Douglas Hofstadter, I was struck not only by the concept’s extraordinarily rich history but also by its tendency to mutate, so that virtually any formulation is sure to leave out some relevant instances. Instructed by the experience, I offer the following tentative definition, which I hope will prove adequate for our purposes here. Reflexivity is the movement whereby that which has been used to generate a system is made, through a changed perspective, to become part of the system it generates. When Kurt Gödel invented a method of coding that allowed statements of number theory also to function as statements about number theory, he entangled that which generates the system with the system. When M. C. Escher drew two hands drawing each other, he took that which is presumed to generate the picture—the sketching hand—and made it part of the picture it draws. When Jorge Luis Borges in “The Circular Ruins” imagines a narrator who creates a student through his dreaming only to discover that he himself is being dreamed by another, the system generating a reality is shown to be part of the reality it makes. As these examples illustrate, reflexivity has subversive effects because it confuses and entangles
the boundaries we impose on the world in order to make sense of that world. Reflexivity tends notoriously toward infinite regress. The dreamer creates the student, but the dreamer in turn is dreamed by another, who in his turn is dreamed by someone else, and so on to infinity.

This definition of reflexivity has much in common with some of the most influential and provocative recent work in critical theory, cultural studies, and the social studies of science. Typically, these works make the reflexive move of showing that an attribute previously considered to have emerged from a set of preexisting conditions is in fact used to generate the conditions. In Nancy Armstrong's *Desire and Domestic Fiction: A Political History of the Novel*, for example, bourgeois femininity is shown to be constructed through the domestic fictions that represent it as already in place.\(^\text{16}\) In Michael Warner's *The Letters of the Republic: Publication and the Public Sphere in Eighteenth-Century America*, the founding document of the United States, the Constitution, is shown to produce the very people whose existence it presupposes.\(^\text{17}\) In Bruno Latour's *Science in Action: How to Follow Scientists and Engineers through Society*, scientific experiments are shown to produce the nature whose existence they predicate as their condition of possibility.\(^\text{18}\) It is only a slight exaggeration to say that contemporary critical theory is produced by the reflexivity that it also produces (an observation that is, of course, also reflexive).

Reflexivity entered cybernetics primarily through discussions about the observer. By and large, first-wave cybernetics followed traditional scientific protocols in considering observers to be outside the system they observe. Yet cybernetics also had implications that subverted this premise. The objectivist view sees information flowing from the system to the observers, but feedback can also loop through the observers, drawing them in to become part of the system being observed. Although participants remarked on this aspect of the cybernetic paradigm throughout the Macy transcripts, they lacked a single word to describe it. To my knowledge, the word "reflexivity" does not appear in the transcripts. This meant they had no handle with which to grasp this slippery concept, no signifier that would help to constitute as well as to describe the changed perspective that reflexivity entails. Discussions of the idea remained diffuse. Most participants did not go beyond remarking on the shifting boundaries between observer and system that cybernetics puts into play. With some exceptions, deeper formulations of the problem failed to coalesce during the Macy discussions.

The most notable exception turned out to hurt more than it helped. Lawrence Kubie, a hard-line Freudian psychoanalyst, introduced a reflexive perspective when he argued that every utterance is doubly encoded,
acting both as a statement about the outside world and as a mirror reflecting
the speaker's psyche. If reflexivity was already a subversive concept, this in-
terpretation made it doubly so, for it threatened to dissolve the premise of
scientific objectivity shared by the physical scientists in the Macy group.
Their reactions to Kubie's presentations show them shying away from re-
flexivity, preferring to shift the conversation onto more comfortable ground.
Nevertheless, the idea hung in the air, and a few key thinkers—especially
Margaret Mead, Gregory Bateson, and Heinz von Foerster—resolved to
pursue it after the Macy Conferences ran out of steam.

The second wave of cybernetics grew out of attempts to incorporate re-
flexivity into the cybernetic paradigm at a fundamental level. The key issue
was how systems are constituted as such, and the key problem was how to
redefine homeostatic systems so that the observer can be taken into
account. The second wave was initiated by, among others, Heinz von
Foerster, the Austrian émigré who became coeditor of the Macy tran-
scripts. This phase can be dated from 1960, when von Foerster wrote the
first of the essays that were later collected in his influential book Observing
Systems. As von Foerster's punning title recognizes, the observer of sys-
tems can himself be constituted as a system to be observed. Von Foerster
called the models he presented in these essays "second-order cybernetics" be-
cause they extended cybernetic principles to the cyberneticians them-

In a sense, autopoiesis turns the cybernetic paradigm inside out. Its cen-
tral premise—that systems are informationally closed—radically alters
the idea of the informational feedback loop, for the loop no longer func-
tions to connect a system to its environment. In the autopoietic view, no
information crosses the boundary separating the system from its environ-
ment. We do not see a world “out there” that exists apart from us. Rather, we see only what our systemic organization allows us to see. The environment merely triggers changes determined by the system’s own structural properties. Thus the center of interest for autopoiesis shifts from the cybernetics of the observed system to the cybernetics of the observer. Autopoiesis also changes the explanation of what circulates through the system to make it work as a system. The emphasis now is on the mutually constitutive interactions between the components of a system rather than on message, signal, or information. Indeed, one could say either that information does not exist in this paradigm or that it has sunk so deeply into the system as to become indistinguishable from the organizational properties defining the system as such.

The third wave swelled into existence when self-organization began to be understood not merely as the (re)production of internal organization but as the springboard to emergence. In the rapidly emerging field of artificial life, computer programs are designed to allow “creatures” (that is, discrete packets of computer codes) to evolve spontaneously in directions the programmer may not have anticipated. The intent is to evolve the capacity to evolve. Some researchers have argued that such self-evolving programs are not merely models of life but are themselves alive. What assumptions make this claim plausible? If one sees the universe as composed essentially of information, it makes sense that these “creatures” are life forms because they have the form of life, that is, an informational code. As a result, the theoretical bases used to categorize all life undergo a significant shift. As we shall see in chapters 9 and 10, when these theories are applied to human beings, *Homo sapiens* are so transfigured in conception and purpose that they can appropriately be called posthuman.

The emergence of the posthuman as an informational-material entity is paralleled and reinforced by a corresponding reinterpretation of the deep structures of the physical world. Some theorists, notably Edward Fredkin and Stephen Wolfram, claim that reality is a program run on a cosmic computer. In this view, a universal informational code underlies the structure of matter, energy, spacetime—indeed, of everything that exists. The code is instantiated in cellular automata, elementary units that can occupy two states: on or off. Although the jury is still out on the cellular automata model, it may indeed prove to be a robust way to understand reality. Even now, a research team headed by Fredkin is working on showing how quantum mechanics can be derived from an underlying cellular automata model.

What happens to the embodied lifeworld of humans in this paradigm? In itself, the cellular automata model is not necessarily incompatible with
recognizing that humans are embodied beings, for embodiment can flow from cellular automata as easily as from atoms. No one suggests that because atoms are mostly empty space, we can shuck the electron shells and do away with occupying space altogether. Yet the cultural contexts and technological histories in which cellular automata theories are embedded encourage a comparable fantasy—that because we are essentially information, we can do away with the body. Central to this argument is a conceptualization that sees information and materiality as distinct entities. This separation allows the construction of a hierarchy in which information is given the dominant position and materiality runs a distant second. As though we had learned nothing from Derrida about supplementarity, embodiment continues to be discussed as if it were a supplement to be purged from the dominant term of information, an accident of evolution we are now in a position to correct.

It is this materiality/information separation that I want to contest—not the cellular automata model, information theory, or a host of related theories in themselves. My strategy is to complicate the leap from embodied reality to abstract information by pointing to moments when the assumptions involved in this move were contested by other researchers in the field and so became especially visible. The point of highlighting such moments is to make clear how much had to be erased to arrive at such abstractions as bodiless information. Abstraction is of course an essential component in all theorizing, for no theory can account for the infinite multiplicity of our interactions with the real. But when we make moves that erase the world’s multiplicity, we risk losing sight of the variegated leaves, fractal branchings, and particular bark textures that make up the forest. In the pages that follow, I will identify two moves in particular that played important roles in constructing the information/materiality hierarchy. Irreverently, I think of them as the Platonic backhand and forehand.

The Platonic backhand works by inferring from the world’s noisy multiplicity a simplified abstraction. So far so good: this is what theorizing should do. The problem comes when the move circles around to constitute the abstraction as the originary form from which the world’s multiplicity derives. Then complexity appears as a “fuzzing up” of an essential reality rather than as a manifestation of the world’s holistic nature. Whereas the Platonic backhand has a history dating back to the Greeks, the Platonic forehand is more recent. To reach fully developed form, it required the assistance of powerful computers. This move starts from simplified abstractions and, using simulation techniques such as genetic algorithms, evolves a multiplicity sufficiently complex that it can be seen as a world of its own. The two moves thus make their play in
opposite directions. The backhand goes from noisy multiplicity to reductive simplicity, whereas the forehand swings from simplicity to multiplicity. They share a common ideology—privileging the abstract as the Real and downplaying the importance of material instantiation. When they work together, they lay the groundwork for a new variation on an ancient game, in which disembodied information becomes the ultimate Platonic Form. If we can capture the Form of ones and zeros in a nonbiological medium—say, on a computer disk—why do we need the body’s superfluous flesh?

Whether the enabling assumptions for this conception of information occur in information theory, cybernetics, or popular science books such as *Mind Children*, their appeal is clear. Information viewed as pattern and not tied to a particular instantiation is information free to travel across time and space. Hackers are not the only ones who believe that information wants to be free. The great dream and promise of information is that it can be free from the material constraints that govern the mortal world. Marvin Minsky precisely expressed this dream when, in a recent lecture, he suggested it will soon be possible to extract human memories from the brain and import them, intact and unchanged, to computer disks. The clear implication is that if we can become the information we have constructed, we can achieve effective immortality.

In the face of such a powerful dream, it can be a shock to remember that for information to exist, it must always be instantiated in a medium, whether that medium is the page from the *Bell Laboratories Journal* on which Shannon’s equations are printed, the computer-generated topological maps used by the Human Genome Project, or the cathode ray tube on which virtual worlds are imaged. The point is not only that abstracting information from a material base is an imaginary act but also, and more fundamentally, that conceiving of information as a thing separate from the medium instantiating it is a prior imaginary act that constructs a holistic phenomenon as an information/matter duality.

The chapters that follow will show what had to be elided, suppressed, and forgotten to make information lose its body. This book is a “rememory” in the sense of Toni Morrison’s *Beloved*: putting back together parts that have lost touch with one another and reaching out toward a complexity too unruly to fit into disembodied ones and zeros.

Seriation, Skeuomorphs, and Conceptual Constellations

The foregoing leads to a strategic definition of “virtuality.” Virtuality is the cultural perception that material objects are interpenetrated by informa-
tion patterns. The definition plays off the duality at the heart of the condition of virtuality—materiality on the one hand, information on the other. Normally virtuality is associated with computer simulations that put the body into a feedback loop with a computer-generated image. For example, in virtual Ping-Pong, one swings a paddle wired into a computer, which calculates from the paddle’s momentum and position where the ball would go. Instead of hitting a real ball, the player makes the appropriate motions with the paddle and watches the image of the ball on a computer monitor. Thus the game takes place partly in real life (RL) and partly in virtual reality (VR). Virtual reality technologies are fascinating because they make visually immediate the perception that a world of information exists parallel to the “real” world, the former intersecting the latter at many points and in many ways. Hence the definition’s strategic quality, strategic because it seeks to connect virtual technologies with the sense, pervasive in the late twentieth century, that all material objects are interpenetrated by flows of information, from DNA code to the global reach of the World Wide Web.

Seeing the world as an interplay between informational patterns and material objects is a historically specific construction that emerged in the wake of World War II. By 1948, the distinction had coalesced sufficiently for Wiener to articulate it as a criterion that any adequate theory of materiality would be forced to meet. “Information is information, not matter or energy. No materialism which does not admit this can survive at the present day.” Wiener knew as well as anyone else that to succeed, this conception of information required artifacts that could embody it and make it real. When I say virtuality is a cultural perception, I do not mean that it is merely a psychological phenomenon. It is instantiated in an array of powerful technologies. The perception of virtuality facilitates the development of virtual technologies, and the technologies reinforce the perception.

The feedback loops that run between technologies and perceptions, artifacts and ideas, have important implications for how historical change occurs. The development of cybernetics followed neither a Kuhnian model of incommensurable paradigms nor a Foucauldian model of sharp epistemic breaks. In the history of cybernetics, ideas were rarely made up out of whole cloth. Rather, they were fabricated in a pattern of overlapping replication and innovation, a pattern that I call “seriation” (a term appropriated from archaeological anthropology). A brief explanation may clarify this concept. Within archaeological anthropology, changes in artifacts are customarily mapped through seriation charts. One constructs a seriation chart by parsing an artifact as a set of attributes that change over time. Suppose a researcher wants to construct a seriation chart for lamps. A key attribute is
the element that gives off light. The first lamps, dating from thousands of years ago, used wicks for this element. Later, with the discovery of electricity, wicks gave way to filaments. The figures that customarily emerge from this kind of analysis are shaped like a tiger’s iris—narrow at the top when an attribute first begins to be introduced, with a bulge in the middle during the heyday of the attribute, and tapered off at the bottom as the shift to a new model is completed. On a seriation chart for lamps, a line drawn at 1890 would show the figure for wicks waxing large with the figure for filaments intersected at the narrow tip of the top end. Fifty years later, the wick figure would be tapering off, and the filament figure would be widening into its middle section. Considered as a set, the figures depicting changes in the attributes of an artifact reveal patterns of overlapping innovation and replication. Some attributes change from one model to the next, but others remain the same.

As figure 1 illustrates, the conceptual shifts that took place during the development of cybernetics display a seriated pattern reminiscent of material changes in artifacts. Conceptual fields evolve similarly to material culture, in part because concept and artifact engage each other in continuous feedback loops. An artifact materially expresses the concept it embodies, but the process of its construction is far from passive. A glitch has to be fixed, a material exhibits unexpected properties, an emergent behavior surfaces—any of these challenges can give rise to a new concept, which results in another generation of artifact, which leads to the development of still other concepts. The reasoning suggests that we should be able to trace the development of a conceptual field by using a seriation chart analogous to the seriation charts used for artifacts.

In the course of the Macy Conferences, certain ideas came to be associated with each other. Through a cumulative process that continued across several years of discussions, these ideas were seen as mutually entailing each other until, like love and marriage, they were viewed by the participants as naturally going together. Such a constellation is the conceptual entity corresponding to an artifact, possessing an internal coherence that defines it as an operational unit. Its formation marks the beginning of a period; its disassembly and reconstruction signal the transition to a different period. Indeed, periods are recognizable as such largely because constellations possess this coherence. Rarely is a constellation discarded wholesale. Rather, some of the ideas composing it are discarded, others are modified, and new ones are introduced. Like the attributes composing an artifact, the ideas in a constellation change in a patchwork pattern of old and new.
<table>
<thead>
<tr>
<th>Period</th>
<th>Player</th>
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<th>Reflexivity</th>
<th>Virtuality</th>
<th>Artifacts</th>
<th>Skeuomorphs</th>
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<td>quantification</td>
<td>reflexive language-autopoiesis structural coupling system-environment</td>
<td>electronic rat, homeostat, electric tortoise</td>
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<td>von Foerster, Maturana, Varela</td>
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<td>1985</td>
<td>Varela, Brooks, Moravec</td>
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<td>emergent behavior functionalities computational universe</td>
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**FIGURE 1** The three waves of cybernetics
Here I want to introduce another term from archaeological anthropology. A *skeuomorph* is a design feature that is no longer functional in itself but that refers back to a feature that was functional at an earlier time. The dashboard of my Toyota Camry, for example, is covered by vinyl molded to simulate stitching. The simulated stitching alludes back to a fabric that was in fact stitched, although the vinyl “stitching” is formed by an injection mold. Skeuomorphs visibly testify to the social or psychological necessity for innovation to be tempered by replication. Like anachronisms, their pejorative first cousins, skeuomorphs are not unusual. On the contrary, they are so deeply characteristic of the evolution of concepts and artifacts that it takes a great deal of conscious effort to avoid them. At SIGGRAPH, the annual computer trade show where dealers come to hawk their wares, hard and soft, there are almost as many skeuomorphs as morphs.

The complex psychological functions a skeuomorph performs can be illustrated by an installation exhibited at SIGGRAPH '93. Called the “Catholic Turing Test,” the simulation invited the viewer to make a confession by choosing selections from the video screen; it even had a bench on which the viewer could kneel. On one level, the installation alluded to the triumph of science over religion, for the role of divinely authorized interrogation and absolution had been taken over by a machine algorithm. On another level, the installation pointed to the intransigence of conditioned behavior, for the machine’s form and function were determined by its religious predecessor. Like a Janus figure, the skeuomorph looks to past and future, simultaneously reinforcing and undermining both. It calls into a play a psychodynamic that finds the new more acceptable when it recalls the old that it is in the process of displacing and finds the traditional more comfortable when it is presented in a context that reminds us we can escape from it into the new.

In the history of cybernetics, skeuomorphs acted as threshold devices, smoothing the transition between one conceptual constellation and another. Homeostasis, a foundational concept during the first wave, functioned during the second wave as a skeuomorph. Although homeostasis remained an important concept in biology, by about 1960 it had ceased to be an initiating premise in cybernetics. Instead, it performed the work of a gesture or an allusion used to authenticate new elements in the emerging constellation of reflexivity. At the same time, it also exerted an inertial pull on the new elements, limiting how radically they could transform the constellation.

A similar phenomenon appears in the transition from the second to the third wave. Reflexivity, the key concept of the second wave, is displaced in
the third wave by emergence. Like homeostasis, reflexivity does not altogether disappear but lingers on as an allusion that authenticates new elements. It performs a more complex role than mere nostalgia, however, for it also leaves its imprint on the new constellation of virtuality. The complex story formed by these seriated changes is told in chapters 3, 6, and 9, which discuss cybernetics, autopoiesis, and artificial life, respectively.

I have already suggested that living in a condition of virtuality implies we participate in the cultural perception that information and materiality are conceptually distinct and that information is in some sense more essential, more important, and more fundamental than materiality. The preamble to "A Magna Carta for the Knowledge Age," a document coauthored by Alvin Toffler at the behest of Newt Gingrich, concisely sums up the matter by proclaiming, "The central event of the 20th century is the overthrow of matter." To see how this view began to acquire momentum, let us briefly flash back to 1948 when Claude Shannon, a brilliant theorist working at Bell Laboratories, defined a mathematical quantity he called information and proved several important theorems concerning it.

Information Theory and Everyday Life

Shannon's theory defines information as a probability function with no dimensions, no materiality, and no necessary connection with meaning. It is a pattern, not a presence. (Chapter 3 talks about the development of information theory in more detail, and the relevant equations can be found there.) The theory makes a strong distinction between message and signal. Lacan to the contrary, a message does not always arrive at its destination. In information theoretic terms, no message is ever sent. What is sent is a signal. Only when the message is encoded in a signal for transmission through a medium—for example, when ink is printed on paper or when electrical pulses are sent racing along telegraph wires—does it assume material form. The very definition of "information," then, encodes the distinction between materiality and information that was also becoming important in molecular biology during this period.

Why did Shannon define information as a pattern? The transcripts of the Macy Conferences indicate that the choice was driven by the twin engines of reliable quantification and theoretical generality. As we shall see in chapter 3, Shannon's formulation was not the only proposal on the table. Donald MacKay, a British researcher, argued for an alternative definition that linked information with change in a receiver's mindset and thus with meaning. To be workable, MacKay's definition required that psychologi-
cal states be quantifiable and measurable—an accomplishment that only now appears distantly possible with such imaging technologies as positron-emission tomography and that certainly was not in reach in the immediate post–World War II years. It is no mystery why Shannon’s definition rather than MacKay’s became the industry standard.

Shannon’s approach had other advantages that turned out to incur large (and mounting) costs when his premise interacted with certain predispositions already at work within the culture. Abstracting information from a material base meant that information could become free-floating, unaffected by changes in context. The technical leverage this move gained was considerable, for by formalizing information into a mathematical function, Shannon was able to develop theorems, powerful in their generality, that hold true regardless of the medium in which the information is instantiated. Not everyone agreed this move was a good idea, however, despite its theoretical power. As Carolyn Marvin notes, a decontextualized construction of information has important ideological implications, including an Anglo-American ethnocentrism that regards digital information as more important than more context-bound analog information. Even in Shannon’s day, malcontents grumbled that divorcing information from context and thus from meaning had made the theory so narrowly formalized that it was not useful as a general theory of communication. Shannon himself frequently cautioned that the theory was meant to apply only to certain technical situations, not to communication in general. In other circumstances, the theory might have become a dead end, a victim of its own excessive formalization and decontextualization. But not in the post–World War II era. The time was ripe for theories that reified information into a free-floating, decontextualized, quantifiable entity that could serve as the master key unlocking secrets of life and death.

Technical artifacts help to make an information theoretic view a part of everyday life. From ATMs to the Internet, from the morphing programs used in Terminator II to the sophisticated visualization programs used to guide microsurgeries, information is increasingly perceived as interpenetrating material forms. Especially for users who may not know the material processes involved, the impression is created that pattern is predominant over presence. From here it is a small step to perceiving information as more mobile, more important, more essential than material forms. When this impression becomes part of your cultural mindset, you have entered the condition of virtuality.

U.S. culture at present is in a highly heterogeneous state regarding the condition of virtuality. Some high-tech preserves (elite research centers
such as Xerox Palo Alto Research Center and Bell Laboratories, most major research universities, and hundreds of corporations) have so thoroughly incorporated virtual technologies into their infrastructures that information is as much as part of the researchers’ mindscapes as is electric lighting or synthetic plastics. The thirty million Americans who are plugged into the Internet increasingly engage in virtual experiences enacting a division between the material body that exits on one side of the screen and the computer simulacra that seem to create a space inside the screen. Yet for millions more, virtuality is not even a cloud on the horizon of their everyday worlds. Within a global context, the experience of virtuality becomes more exotic by several orders of magnitude. It is a useful corrective to remember that 70 percent of the world’s population has never made a telephone call.

Nevertheless, I think it is a mistake to underestimate the importance of virtuality, for it yields an influence altogether disproportionate to the number of people immersed in it. It is no accident that the condition of virtuality is most pervasive and advanced where the centers of power are most concentrated. Theorists at the Pentagon, for example, see it as the theater in which future wars will be fought. They argue that coming conflicts will be decided not so much by overwhelming force as by “neocortical warfare,” waged through the techno-sciences of information. If we want to contest what these technologies signify, we need histories that show the erasures that went into creating the condition of virtuality, as well as visions arguing for the importance of embodiment. Once we understand the complex interplays that went into creating the condition of virtuality, we can demystify our progress toward virtuality and see it as the result of historically specific negotiations rather than of the irresistible force of technological determinism. At the same time, we can acquire resources with which to rethink the assumptions underlying virtuality, and we can recover a sense of the virtual that fully recognizes the importance of the embodied processes constituting the lifeworld of human beings. In the phrase “virtual bodies,” I intend to allude to the historical separation between information and materiality and also to recall the embodied processes that resist this division.

Virtuality and Contemporary Literature

I have already suggested that one way to think about the organization of this book is chronologically, since it follows the three waves of seriated changes in cybernetics. In this organization of the textual body, each of the three chronologically arranged divisions has an anchoring chapter discussing the scientific theories: on the Macy Conferences (chapter 3); on autopoiesis
Toward Embodied Virtuality

(Chapter 6); and on artificial life (Chapter 9), respectively. Each section also has a chapter showing specific applications of the theories: the work of Norbert Wiener (Chapter 4); tape-recording technologies (Chapter 8); and human-computer interactions (Chapter 10). Also included in each of the three divisions are chapters on literary texts contemporaneous with the development of the scientific theories and cybernetic technologies (Chapters 5, 7, and 10). I have selected literary texts that were clearly influenced by the development of cybernetics. Nevertheless, I want to resist the idea that influence flows from science into literature. The cross-currents are considerably more complex than a one-way model of influence would allow. In the *Neuromancer* trilogy, for example, William Gibson's vision of cyberspace had a considerable effect on the development of three-dimensional virtual reality imaging software.39

A second way to think about the organization of *How We Became Posthuman* is narratively. In this arrangement, the three divisions proceed not so much through chronological progression as through the narrative strands about the (lost) body of information, the cyborg body, and the posthuman body. Here the literary texts play a central role, for they display the passageways that enabled stories coming out of narrowly focused scientific theories to circulate more widely through the body politic. Many of the scientists understood very well that their negotiations involved premises broader than the formal scope of their theories strictly allowed. Because of the wedge that has been driven between science and values in U.S. culture, their statements on these wider implications necessarily occupied the position of ad hoc pronouncements rather than “scientific” arguments. Shaped by different conventions, the literary texts range across a spectrum of issues that the scientific texts only fitfully illuminate, including the ethical and cultural implications of cybernetic technologies.40

Literary texts are not, of course, merely passive conduits. They actively shape what the technologies mean and what the scientific theories signify in cultural contexts. They also embody assumptions similar to those that permeated the scientific theories at critical points. These assumptions included the idea that stability is a desirable social goal, that human beings and human social organizations are self-organizing structures, and that form is more essential than matter. The scientific theories used these assumptions as enabling presuppositions that helped to guide inquiry and shape research agendas. As the chapters on the scientific developments will show, culture circulates through science no less than science circulates through culture. The heart that keeps this circulatory system flowing is narrative—narratives about culture, narratives within culture, narratives
about science, narratives within science. In my account of the scientific developments, I have sought to emphasize the role that narrative plays in articulating the posthuman as a technical-cultural concept. For example, chapter 4, on Wiener's scientific work, is interlaced with analyses of the narratives he tells to resolve conflicts between cybernetics and liberal humanism, and chapter 9, on artificial life, is organized by looking at this area of research as a narrative field.

What does this emphasis on narrative have to do with virtual bodies? Following Jean-François Lyotard, many theorists of postmodernity accept that the postmodern condition implies an incredulity toward metanarrative. As we have seen, one way to construct virtuality is the way that Moravec and Minsky do—as a metanarrative about the transformation of the human into a disembodied posthuman. I think we should be skeptical about this metanarrative. To contest it, I want to use the resources of narrative itself, particularly its resistance to various forms of abstraction and disembodiment. With its chronological thrust, polymorphous digressions, located actions, and personified agents, narrative is a more embodied form of discourse than is analytically driven systems theory. By turning the technological determinism of bodiless information, the cyborg, and the posthuman into narratives about the negotiations that took place between particular people at particular times and places, I hope to replace a teleology of disembodiment with historically contingent stories about contests between competing factions, contests whose outcomes were far from obvious. Many factors affected the outcomes, from the needs of emerging technologies for reliable quantification to the personalities of the people involved. Though overdetermined, the disembodiment of information was not inevitable, any more than it is inevitable we continue to accept the idea that we are essentially informational patterns.

In this regard, the literary texts do more than explore the cultural implications of scientific theories and technological artifacts. Embedding ideas and artifacts in the situated specificities of narrative, the literary texts give these ideas and artifacts a local habitation and a name through discursive formulations whose effects are specific to that textual body. In exploring these effects, I want to demonstrate, on multiple levels and in many ways, that abstract pattern can never fully capture the embodied actuality, unless it is as prolix and noisy as the body itself. Shifting the emphasis from technological determinism to competing, contingent, embodied narratives about the scientific developments is one way to liberate the resources of narrative so that they work against the grain of abstraction running through the teleology of disembodiment. Another way is to read literary texts along-
side scientific theories. In articulating the connections that run through these two discursive realms, I want to entangle abstract form and material particularity such that the reader will find it increasingly difficult to maintain the perception that they are separate and discrete entities. If, for cultural and historical reasons, I cannot start from a holistic perspective, I hope to mix things up enough so that the emphasis falls not on the separation of matter and information but on their inextricably complex compoundings and entwinings. For this project, the literary texts with their fashionings of embodied particularities are crucial.

The first literary text I discuss in detail is Bernard Wolfe’s *Limbo*. Written in the 1950s, *Limbo* has become something of an underground classic. It imagines a postwar society in which an ideology, Immob, has developed; the ideology equates aggression with the ability to move. “Pacifism equals passivity,” Immob slogans declare. True believers volunteer to banish their mobility (and presumably their aggression) by having amputations, which have come to be regarded as signifiers of social power and influence. These amputees get bored with lying around, however, so a vigorous cybernetics industry has grown up to replace their missing limbs. As this brief summary suggests, *Limbo* is deeply influenced by cybernetics. But the technical achievements of cybernetics are not at the center of the text. Rather, they serve as a springboard to explore a variety of social, political, and psychological issues, ranging from the perceived threat that women’s active sexuality poses for Immob men to global East-West tensions that explode into another world war at the end of the text. Although it is unusually didactic, *Limbo* does more than discuss cybernetics; it engages a full range of rhetorical and narrative devices that work both with and against its explicit pronouncements. The narrator seems only partially able to control his verbally extravagant narrative. There are, I will argue, deep connections between the narrator’s struggle to maintain control of the narrative and the threat to “natural” body boundaries posed by the cybernetic paradigm. *Limbo* interrogates a dynamic that also appears in Norbert Wiener’s work—the intense anxiety that erupts when the perceived boundaries of the body are breached. In addition, it illustrates how the body of the text gets implicated in the processes used to represent bodies within the text.

Several Philip K. Dick novels written from 1962 to 1966 (including *We Can Build You*, *Do Androids Dream of Electric Sheep?*, *Dr. Bloodmoney*, and *Ubik*) provide another set of texts through which the multiple implications of the posthuman can be explored. Chronologically and thematically, Dick’s novels of simulation cross the scientific theory of autopoiesis. Like Maturana, Varela, and other scientific researchers in the
second wave of cybernetics, Dick is intensely concerned with epistemological questions and their relation to the cybernetic paradigm. The problem of where to locate the observer—in or out of the system being observed?—is conflated in his fiction with how to determine whether a creature is android or human. For Dick, the android is deeply bound up with the gender politics of his male protagonists' relations with female characters, who ambiguously figure either as sympathetic, life-giving “dark-haired girls” or emotionally cold, life-threatening schizoid women. Already fascinated with epistemological questions that reveal how shaky our constructions of reality can be, Dick is drawn to cybernetic themes because he understands that cybernetics radically destabilizes the ontological foundations of what counts as human. The gender politics he writes into his novels illustrate the potent connections between cybernetics and contemporary understandings of race, gender, and sexuality.

The chapter on contemporary speculative fictions constructs a semiotics of virtuality by showing how the central concepts of information and materiality can be mapped onto a multilayered semiotic square. The tutor texts for this analysis, which include *Snow Crash*, *Blood Music*, *Galatea 2.2*, and *Terminal Games*, indicate the range of what counts as the posthuman in the age of virtuality, from neural nets to hackers, biologically modified humans, and entities who live only in computer simulations. In following the construction of the posthuman in these texts, I will argue that older ideas are reinscribed as well as contested. As was the case for the scientific models, change occurs in a seriated pattern of overlapping innovation and replication.

I hope that this book will demonstrate, once again, how crucial it is to recognize interrelations between different kinds of cultural productions, specifically literature and science. The stories I tell here—how information lost its body, how the cyborg was created as a cultural icon and technological artifact, and how humans became posthumans—and the waves of historical change I chart would not have the same resonance or breadth if they had been pursued only through literary texts or only through scientific discourses. The scientific texts often reveal, as literature cannot, the foundational assumptions that gave theoretical scope and artifactual efficacy to a particular approach. The literary texts often reveal, as scientific work cannot, the complex cultural, social, and representational issues tied up with conceptual shifts and technological innovations. From my point of view, literature and science as an area of specialization is more than a subset of cultural studies or a minor activity in a literature department. It is a way of understanding ourselves as embodied creatures living within and through embodied worlds and embodied words.
CONCLUSION: WHAT DOES IT MEAN TO BE POSTHUMAN?

What, finally, are we to make of the posthuman? At the beginning of this book, I suggested that the prospect of becoming posthuman both evokes terror and excites pleasure. At the end of the book, perhaps I can summarize the implications of the posthuman by interrogating the sources of this terror and pleasure. The terror is relatively easy to understand. "Post," with its dual connotation of superseding the human and coming after it, hints that the days of "the human" may be numbered. Some researchers (notably Hans Moravec but also my UCLA colleague Michael Dyer and many others) believe that this is true not only in a general intellectual sense that displaces one definition of "human" with another but also in a more disturbingly literal sense that envisions humans displaced as the dominant form of life on the planet by intelligent machines. Humans can either go gently into that good night, joining the dinosaurs as a species that once ruled the earth but is now obsolete, or hang on for a while longer by becoming machines themselves. In either case, Moravec and like-minded thinkers believe, the age of the human is drawing to a close. The view echoes the deeply pessimistic sentiments of Warren McCulloch in his old age. As noted earlier, he remarked: "Man to my mind is about the nastiest, most destructive of all the animals. I don't see any reason, if he can evolve machines that can have more fun than he himself can, why they shouldn't take over, enslave us, quite happily. They might have a lot more fun. Invent better games than we ever did." Is it any wonder that faced with such dismal scenarios, most people have understandably negative reactions? If this is what the posthuman means, why shouldn't it be resisted?

Fortunately, these views do not exhaust the meanings of the posthuman. As I have repeatedly argued, human being is first of all embodied being, and the complexities of this embodiment mean that human awareness...
unfolds in ways very different from those of intelligence embodied in cybernetic machines. Although Moravec’s dream of downloading human consciousness into a computer would likely come in for some hard knocks in literature departments (which tend to be skeptical of any kind of transcendence but especially of transcendence through technology), literary studies share with Moravec a major blind spot when it comes to the significance of embodiment. This blind spot is most evident, perhaps, when literary and cultural critics confront the fields of evolutionary biology. From an evolutionary biologist’s point of view, modern humans, for all their technological prowess, represent an eye blink in the history of life, a species far too recent to have significant evolutionary impact on human biological behaviors and structures. In my view, arguments like those that Jared Diamond advances in *Guns, Germs, and Steel: The Fates of Human Societies* and *Why Sex Is Fun: The Evolution of Human Sexuality* should be taken seriously. The body is the net result of thousands of years of sedimented evolutionary history, and it is naive to think that this history does not affect human behaviors at every level of thought and action.

Of course, the reflexivity that looms large in cybernetics also inhabits evolutionary biology. The models proposed by evolutionary biologists have encoded within them cultural attitudes and assumptions formed by the same history they propose to analyze; as with cybernetics, observer and system are reflexively bound up with one another. To take only one example, the computer module model advanced by Jerome H. Barkow, Leda Cosmides, and John Tooby in *The Adapted Mind: Evolutionary Psychology and the Generation of Culture* to explain human evolutionary psychology testifies at least as much to the importance of information technologies in shaping contemporary worldviews as it does to human brain function. Nevertheless, these reflexive complexities do not negate the importance of the sedimented history incarnated within the body. Interpreted through metaphors resonant with cultural meanings, the body itself is a congealed metaphor, a physical structure whose constraints and possibilities have been formed by an evolutionary history that intelligent machines do not share. Humans may enter into symbiotic relationships with intelligent machines (already the case, for example, in computer-assisted surgery); they may be displaced by intelligent machines (already in effect, for example, at Japanese and American assembly plants that use robotic arms for labor); but there is a limit to how seamlessly humans can be articulated with intelligent machines, which remain distinctively different from humans in their embodiments. The terror, then, though it does not disappear in this view, tends away from the apocalyptic and toward a more
moderate view of seriated social, technological, political, and cultural changes.

What about the pleasures? For some people, including me, the posthuman evokes the exhilarating prospect of getting out of some of the old boxes and opening up new ways of thinking about what being human means. In positing a shift from presence/absence to pattern/randomness, I have sought to show how these categories can be transformed from the inside to arrive at new kinds of cultural configurations, which may soon render such dualities obsolete if they have not already. This process of transformation is fueled by tensions between the assumptions encoded in pattern/randomness as opposed to presence/absence. In Jacques Derrida's performance of presence/absence, presence is allied with Logos, God, teleology—in general, with an originary plenitude that can act to ground signification and give order and meaning to the trajectory of history. The work of Eric Havelock, among others, demonstrates how in Plato's Republic this view of originary presence authorized a stable, coherent self that could witness and testify to a stable, coherent reality. Through these and other means, the metaphysics of presence front-loaded meaning into the system. Meaning was guaranteed because a stable origin existed. It is now a familiar story how deconstruction exposed the inability of systems to posit their own origins, thus ungrounding signification and rendering meaning indeterminate. As the presence/absence hierarchy was destabilized and as absence was privileged over presence, lack displaced plenitude, and desire usurped certitude. Important as these moves have been in late-twentieth-century thought, they still took place within the compass of the presence/absence dialectic. One feels lack only if presence is posited or assumed; one is driven by desire only if the object of desire is conceptualized as something to be possessed. Just as the metaphysics of presence required an originary plenitude to articulate a stable self, deconstruction required a metaphysics of presence to articulate the destabilization of that self.

By contrast, pattern/randomness is underlaid by a very different set of assumptions. In this dialectic, meaning is not front-loaded into the system, and the origin does not act to ground signification. As we have seen for multagent simulations, complexity evolves from highly recursive processes being applied to simple rules. Rather than proceeding along a trajectory toward a known end, such systems evolve toward an open future marked by contingency and unpredictability. Meaning is not guaranteed by a coherent origin; rather, it is made possible (but not inevitable) by the blind force of evolution finding workable solutions within given parameters. Although pattern has traditionally been the privileged term (for example, among the
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electrical engineers developing information theory), randomness has increas-
ingly been seen to play a fruitful role in the evolution of complex sys-
tems. For Chris Langton and Stuart Kauffman, chaos accelerates the
evolution of biological and artificial life;8 for Francisco Varela, randomness
is the froth of noise from which coherent microstates evolve and to which
living systems owe their capacity for fast, flexible response;9 for Henri
Atlan, noise is the body's murmuring from which emerges complex com-
munication between different levels in a biological system.10 Although
these models differ in their specifics, they agree in seeing randomness not
simply as the lack of pattern but as the creative ground from which pattern
can emerge.

Indeed, it is not too much to say that in these and similar models, ran-
doness rather than pattern is invested with plenitude. If pattern is the re-
alization of a certain set of possibilities, randomness is the much, much
larger set of everything else, from phenomena that cannot be rendered co-
herent by a given system's organization to those the system cannot perceive
at all. In Gregory Bateson's cybernetic epistemology, randomness is what
exists outside the confines of the box in which a system is located; it is the
larger and unknowable complexity for which the perceptual processes of
an organism are a metaphor.11 Significance is achieved by evolutionary
processes that ensure the surviving systems are the ones whose organi-
izations instantiate metaphors for this complexity, unthinkable in itself.
When Varela and his coauthors argue in Embodied Mind that there is no
stable, coherent self but only autonomous agents running programs, they
envision pattern as a limitation that drops away as human awareness ex-
pands beyond consciousness and encounters the emptiness that, in an-
other guise, could equally well be called the chaos from which all forms
emerge.12

What do these developments mean for the posthuman? When the self is
envisioned as grounded in presence, identified with originary guarantees
and teleological trajectories, associated with solid foundations and logical
coherence, the posthuman is likely to be seen as antihuman because it en-
visions the conscious mind as a small subsystem running its program of self-
construction and self-assurance while remaining ignorant of the actual
dynamics of complex systems. But the posthuman does not really mean the
end of humanity. It signals instead the end of a certain conception of the hu-
man, a conception that may have applied, at best, to that fraction of hu-
manity who had the wealth, power, and leisure to conceptualize themselves
as autonomous beings exercising their will through individual agency and
choice.13 What is lethal is not the posthuman as such but the grafting of the
posthuman onto a liberal humanist view of the self. When Moravec imagines “you” choosing to download yourself into a computer, thereby obtaining through technological mastery the ultimate privilege of immortality, he is not abandoning the autonomous liberal subject but is expanding its per- ogatives into the realm of the posthuman. Yet the posthuman need not be recuperated back into liberal humanism, nor need it be construed as anti- human. Located within the dialectic of pattern/randomness and grounded in embodied actuality rather than disembodied information, the posthuman offers resources for rethinking the articulation of humans with intelligent machines.

To explore these resources, let us return to Bateson’s idea that those organisms that survive will tend to be the ones whose internal structures are good metaphors for the complexities without. What kind of environments will be created by the expanding power and sophistication of intelligent machines? As Richard Lanham has pointed out, in the information-rich environments created by ubiquitous computing, the limiting factor is not the speed of computers, or the rates of transmission through fiber-optic cables, or the amount of data that can be generated and stored. Rather, the scarce commodity is human attention. It makes sense, then, that technological innovation will focus on compensating for this bottleneck. An obvious solution is to design intelligent machines to attend to the choices and tasks that do not have to be done by humans. For example, there are already intelligent-agent programs to sort email, discarding unwanted messages and prioritizing the rest. The programs work along lines similar to neural nets. They tabulate the choices the human operators make, and they feed back this information in recursive loops to readjust the weights given to various kinds of email addresses. After an initial learning period, the sorting programs take over more and more of the email management, freeing humans to give their attention to other matters.

If we extrapolate from these relatively simple programs to an environment that, as Charles Ostman likes to put it, supplies synthetic sentience on demand, human consciousness would ride on top of a highly articulated and complex computational ecology in which many decisions, invisible to human attention, would be made by intelligent machines. Over two decades ago, Joseph Weizenbaum foresaw just such an ecology and passionately argued that judgment is a uniquely human function and must not be turned over to computers. With the rapid development of neural nets and expert programs, it is no longer so clear that sophisticated judgments cannot be made by machines and, in some instances, made more accurately than by humans. But the issue, in Weizenbaum's view, involves more
than whether or not the programs work. Rather, the issue is an ethical imperative that humans keep control; to do otherwise is to abdicate their responsibilities as autonomous independent beings. What Weizenbaum’s argument makes clear is the connection between the assumptions undergirding the liberal humanist subject and the ethical position that humans, not machines, must be in control. Such an argument assumes a vision of the human in which conscious agency is the essence of human identity. Sacrifice this, and we humans are hopelessly compromised, contaminated with mechanic alienness in the very heart of our humanity.\(^\text{17}\) Hence there is an urgency, even panic, in Weizenbaum’s insistence that judgment is a uniquely human function. At stake for him is nothing less than what it means to be human.

In the posthuman view, by contrast, conscious agency has never been “in control.” In fact, the very illusion of control bespeaks a fundamental ignorance about the nature of the emergent processes through which consciousness, the organism, and the environment are constituted. Mastery through the exercise of autonomous will is merely the story consciousness tells itself to explain results that actually come about through chaotic dynamics and emergent structures. If, as Donna Haraway, Sandra Harding, Evelyn Fox Keller, Carolyn Merchant, and other feminist critics of science have argued, there is a relation among the desire for mastery, an objectivist account of science, and the imperialist project of subduing nature, then the posthuman offers resources for the construction of another kind of account.\(^\text{18}\) In this account, emergence replaces teleology; reflexive epistemology replaces objectivism; distributed cognition replaces autonomous will; embodiment replaces a body seen as a support system for the mind; and a dynamic partnership between humans and intelligent machines replaces the liberal humanist subject’s manifest destiny to dominate and control nature. Of course, this is not necessarily what the posthuman \textit{will} mean—only what it \textit{can} mean if certain strands among its complex seriations are highlighted and combined to create a vision of the human that uses the posthuman as leverage to avoid reinscribing, and thus repeating, some of the mistakes of the past.

Just as the posthuman need not be antihuman, so it also need not be apocalyptic. Edwin Hutchins addresses the idea of distributed cognition through his nuanced study of the navigational systems of oceangoing ships.\(^\text{19}\) His meticulous research shows that the cognitive system responsible for locating the ship in space and navigating it successfully resides not in humans alone but in the complex interactions within an environment that includes both human and nonhuman actors. His study allows him to give an
excellent response to John Searle’s famous “Chinese room.” By imagining a situation in which communication in Chinese can take place without the actors knowing what their actions mean, Searle challenged the idea that machines can think. Suppose, Searle said, that he is stuck inside a room, he who knows not a word of Chinese. Texts written in Chinese are slid through a slot in the door. He has in the room with him baskets of Chinese characters and a rulebook correlating the symbols written on the texts with other symbols in the basket. Using the rulebook, he assembles strings of characters and pushes them out the door. Although his Chinese interlocutors take these strings to be clever responses to their inquiries, Searle has not the least idea of the meaning of the texts he has produced. Therefore, it would be a mistake to say that machines can think, he argues, for like him, they produce comprehensible results without comprehending anything themselves. In Hutchins’s neat interpretation, Searle’s argument is valuable precisely because it makes clear that it is not Searle but the entire room that knows Chinese. In this distributed cognitive system, the Chinese room knows more than do any of its components, including Searle. The situation of modern humans is akin to that of Searle in the Chinese room, for every day we participate in systems whose total cognitive capacity exceeds our individual knowledge, including such devices as cars with electronic ignition systems, microwaves with computer chips that precisely adjust power levels, fax machines that warble to other fax machines, and electronic watches that communicate with a timing radio wave to set themselves and correct their date. Modern humans are capable of more sophisticated cognition than cavemen not because moderns are smarter, Hutchins concludes, but because they have constructed smarter environments in which to work.

Hutchins would no doubt disagree with Weizenbaum’s view that judgment should be reserved for humans alone. Like cognition, decision-making is distributed between human and nonhuman agents, from the steam-powered steering system that suddenly failed on a navy vessel Hutchins was studying to the charts and pocket calculators that the navigators were then forced to use to calculate their position. He convincingly shows that these adaptations to changed circumstances were evolutionary and embodied rather than abstract and consciously designed (pp. 347-51). The solution to the problem caused by this sudden failure of the steering mechanism was “clearly discovered by the organization [of the system as a whole] before it was discovered by any of the participants” (p. 361). Seen in this perspective, the prospect of humans working in partnership with intelligent machines is not so much a usurpation of human right and responsi-
bility as it is a further development in the construction of distributed cognition environments, a construction that has been ongoing for thousands of years. Also changed in this perspective is the relation of human subjectivity to its environment. No longer is human will seen as the source from which emanates the mastery necessary to dominate and control the environment. Rather, the distributed cognition of the emergent human subject correlates with—in Bateson’s phrase, becomes a metaphor for—the distributed cognitive system as a whole, in which “thinking” is done by both human and nonhuman actors. “Thinking consists of bringing these structures into coordination so they can shape and be shaped by one another,” Hutchins wrote (p. 316). To conceptualize the human in these terms is not to imperil human survival but is precisely to enhance it, for the more we understand the flexible, adaptive structures that coordinate our environments and the metaphors that we ourselves are, the better we can fashion images of ourselves that accurately reflect the complex interplays that ultimately make the entire world one system.

This view of the posthuman also offers resources for thinking in more sophisticated ways about virtual technologies. As long as the human subject is envisioned as an autonomous self with unambiguous boundaries, the human-computer interface can only be parsed as a division between the soli- dity of real life on one side and the illusion of virtual reality on the other, thus obscuring the far-reaching changes initiated by the development of virtual technologies. Only if one thinks of the subject as an autonomous self independent of the environment is one likely to experience the panic performed by Norbert Wiener’s Cybernetics and Bernard Wolfe’s Limbo. This view of the self authorizes the fear that if the boundaries are breached at all, there will be nothing to stop the self’s complete dissolution. By contrast, when the human is seen as part of a distributed system, the full expression of human capability can be seen precisely to depend on the splice rather than being imperiled by it. Writing in another context, Hutchins arrives at an insight profoundly applicable to virtual technologies: “What used to look like internalization [of thought and subjectivity] now appears as a gradual propagation of organized functional properties across a set of malleable media” (p. 312). This vision is a potent antidote to the view that parses virtuality as a division between an inert body that is left behind and a disembodied subjectivity that inhabits a virtual realm, the construction of virtuality performed by Case in William Gibson’s Neuromancer when he delights in the “bodiless exultation of cyberspace” and fears, above all, dropping back into the “meat” of the body. By contrast, in the model that Hutchins presents and that the posthuman helps to authorize, human
functionality expands because the parameters of the cognitive system it inhabits expand. In this model, it is not a question of leaving the body behind but rather of extending embodied awareness in highly specific, local, and material ways that would be impossible without electronic prosthesis.

As we have seen, cybernetics was born in a froth of noise when Norbert Wiener first thought of it as a way to maximize human potential in a world that is in essence chaotic and unpredictable. Like many other pioneers, Wiener helped to initiate a journey that would prove to have consequences more far-reaching and subversive than even his formidable powers of imagination could conceive. As Bateson, Varela, and others would later argue, the noise crashes within as well as without. The chaotic, unpredictable nature of complex dynamics implies that subjectivity is emergent rather than given, distributed rather than located solely in consciousness, emerging from and integrated into a chaotic world rather than occupying a position of mastery and control removed from it. Bruno Latour has argued that we have never been modern; the seriated history of cybernetics—emerging from networks at once materially real, socially regulated, and discursively constructed—suggests, for similar reasons, that we have always been posthuman. The purpose of this book has been to chronicle the journeys that have made this realization possible. If the three stories told here—how information lost its body, how the cyborg was constructed in the postwar years as technological artifact and cultural icon, and how the human became the posthuman—have at times seemed to present the posthuman as a transformation to be feared and abhorred rather than welcomed and embraced, that reaction has everything to do with how the posthuman is constructed and understood. The best possible time to contest for what the posthuman means is now, before the trains of thought it embodies have been laid down so firmly that it would take dynamite to change them. Although some current versions of the posthuman point toward the antihuman and the apocalyptic, we can craft others that will be conducive to the long-range survival of humans and of the other life-forms, biological and artificial, with whom we share the planet and ourselves.
Chapter One


5. Michel Foucault famously suggested that “man” is a historical construction whose era is about to end in *The Order of Things: An Archaeology of the Human Sciences* (New York: Vintage Books, 1973), a few years earlier than Ihab Hassan’s prescient announcement of posthumanism cited in the epigraph to this chapter. Since then, the more radical idea of the posthuman (as distinct from posthumanism) has appeared at a number of places. Among the important texts defining the posthuman in cultural studies are Allucquère Roseanne Stone, *The War of Desire and Technology at the Close of the Mechanical Age* (Cambridge: MIT Press, 1995); Judith Halberstam and Ira Livingston, eds., *Posthuman Bodies* (Bloomington: Indiana University Press, 1995); Scott Bukatman, *Terminal Identity: The Virtual Subject in Postmodern Science Fiction* (Durham: Duke University Press, 1993); and Anne Balsamo, *Technologies of the Gendered Body: Reading Cyborg Women* (Durham: Duke University Press, 1996). A number of scien-
tific works, detailed in chapters 3, 6, and 9, also figure importantly in delineating this list of characteristics.


12. Five of the Macy Conference transactions were published: Heinz von Foerster, ed., *Cybernetics: Circular Causal and Feedback Mechanisms in Biological and Social Systems*, vols. 6–10 (New York: Josiah Macy Jr. Foundation, 1949–55). From the seventh conference on, Margaret Mead and Hans Lukas Teuber are listed as “assistant editors.” The best study of the Macy Conferences is Steve J. Heims, *The Cybernetics Group* (Cambridge: MIT Press, 1991). In addition to discussing the conferences and doing extensive archival work, Heims also conducted interviews with many of the participants who have since died.


21. Niklas Luhmann has modified and extended Maturana’s epistemology in significant ways; see, for example, his *Essays on Self-Reference* (New York: Columbia Uni-


23. Marvin Minsky, “Why Computer Science Is the Most Important Thing That Has Happened to the Humanities in 5,000 Years” (public lecture, Nara, Japan, May 15, 1996). I am grateful to Nicholas Gessler for providing me with his transcript of the lecture.


27. Thomas S. Kuhn, The Structure of Scientific Revolutions, 2d ed. (Chicago: University of Chicago Press, 1970); Foucault, The Order of Things. Both Kuhn and Foucault substantially revised their theories in later years. The vision of historical change in Michel Foucault’s The History of Sexuality, translated by Robert Hurley (New York: Vintage Books, 1980), is much closer to seriation than are his earlier works.


29. “A Magna Carta for the Knowledge Age” can be found (along with skeptical commentaries, mine among them) at the FEED Web site, <http://www.emedia.net/feed>.


31. Doyle, On Beyond Living, makes the point that the construction of information as primary, with materiality as supplemental, is a rhetorical rather than an experimental
accomplishment. He argues that the discourse of molecular biology functions as "rhetorical software," for it operates as if it were running a program on the hardware of the laboratory apparatus to produce results that the research alone could not accomplish. See also Kay, "Cybernetics, Information, Life."


34. In response to a presentation by Alex Bavelas at the eighth Macy Conference, Shannon remarked that he did not see a "close connection" between the semantic questions that concerned Bavelas and his own emphasis on "finding the best encoding of symbols." Foerster, Mead, and Teuber, Cybernetics (Eighth Conference, 1951), 8:22.

35. Xerox PARC has been at the forefront of developing the idea of "ubiquitous computing," with computers embedded unobtrusively throughout the home and workplace environments. See Mark Weiser, "The Computer for the 21st Century," Scientific American 265 (September 1991): 94–104. For an account of how computers are transforming contemporary architecture and living patterns, see William J. Mitchell, City of Bits: Space, Place, and the Infobahn (Cambridge: MIT Press, 1995).

36. Sherry Turkle discusses the fascination of VR worlds in Life on the Screen: Identity in the Age of the Internet (New York: Simon and Schuster, 1995). Stone, The War of Desire and Technology, proposes that VR technologies undo the commonsense notion that one person inhabits one body. She suggests instead that we think of the subject "warranted by" the body rather than contained within it.


38. Don Ihde develops the full resonances of "lifeworld" from his grounding in phenomenology in Technology and the Lifeworld: From Garden to Earth (Bloomington: Indiana University Press, 1990), showing how the contemporary world is marked by a double attraction toward technology and toward the "natural" world simultaneously.


40. An important work linking postmodern fiction with cybernetic technologies is David Porush, The Soft Machine: Cybernetic Fiction (New York: Methuen, 1985). Porush defines cybernetic fiction as self-reflexive fictions that look to cybernetics both for their themes and for the literary machinery of their texts.


43. Philip K. Dick: We Can Build You (London: Grafton Books, 1986), first pub-


**Chapter Two**


11. Among the studies that explore these connections are Jay Bolter, *Writing Space: The Computer, Hypertext, and the History of Writing* (Hillsdale, N.J.: Lawrence Erl-


40. Steven Pinker makes this point in The Language Instinct (New York: W. Morrow, 1994). This model provides an interesting corrective to Maturana’s largely passive model of “languaging” between “observers.”

41. Steels, “The Artificial Life Roots.”


43. Marvin Minsky, “Why Computer Science Is the Most Important Thing That Has Happened to the Humanities in 5,000 Years” (public lecture, Nara, Japan, May 15, 1996). I am grateful to Nicholas Gessler for providing me with his transcript of the lecture.


Chapter Ten


2. For a discussion of the semiotic square, see Ronald Schleifer, Robert Con Davis, and Nancy Mergler, Culture and Cognition: The Boundaries of Literary and Scientific Inquiry (Ithaca: Cornell University Press, 1992). See also A. J. Greimas, Structural Semantics: An Attempt at a Method, translated by Daniele MacDowell, Ronald Schleifer, and Alan Velie (Lincoln: University of Nebraska Press, 1983). I do not claim for the semiotic square the inevitability with which Greimas, its inventor, invested it. Rather, for my purposes it is useful as a stimulus to thought and as a way to tease out relationships that might not otherwise be apparent.


12. Andrew Hodges, in his excellent biography *Alan Turing: The Enigma* (New York: Simon and Schuster, 1983), comments, "To Alan Turing, the multiplier was a rather tiresome technicality: the heart [of the Universal Turing Machine] lay in the logical control, which took the instructions from the memory, and put them into operation" (p. 320).


17. In the introduction to *Posthuman Bodies*, Halberstam and Livingston note: "You’re not human until you’re posthuman. You were never human" (p. 8).

18. Veronica Hollinger, in "Feminist Science Fiction: Breaking Up the Subject," *Extrapolation* 31 (1990): 229–39, makes a similar argument regarding the diversity of feminist science fiction. Some texts want to recuperate some aspects of the subject, whereas others aim for a more subversive and far-reaching deconstruction. Those who have never experienced a strong and unified subjectivity, Hollinger observes, might want to have a chance to articulate such subjectivity before they deconstruct it. Anne Balsamo, in "Feminism for the Incurably Informed," *South Atlantic Quarterly* 92 (1993): 681–712, takes issue with Hollinger’s conclusion, arguing that what is needed is not so much diversity among texts and readings as articulations that can escape from the dualism of anti/pro-humanism by offering a vision of “post-human existence where ‘technology’ and the ‘human’ are understood in contiguous rather than in oppositional terms” (p. 684).
Chapter Eleven

1. I am grateful to Marjorie Luesebrink for conversations that stimulated me to think further about the ideas in this conclusion.


13. In Neal Stephenson’s *Snow Crash* (New York: Bantam, 1992), his young white heroine, “Y.T.,” is kidnapped, dumped aboard the Raft, and assigned to mess detail. She then has an insight into how small the fraction of the world’s population is who ever believed they had a liberal humanist self. Once she gets over the shock and settles into a routine, she starts looking around her, watching the other fish-cutting dames, and realizes that this is just what life must be like for about 99 percent of the people in the world. “You’re in this place. There’s other people all around you, but they don’t understand you and you don’t understand them, but people do a lot of meaningless babble anyway. In order to stay alive, you have to spend all day every day doing stupid meaningless work. And the only way to get out of it is to quit, cut loose, take a flyer, and go off into the wicked
world, where you will be swallowed up and never heard from again” (pp. 303–4).


22. William Gibson, *Neuromancer* (New York: Ace Books, 1984). The narrator, after relating how Case has been exiled from cyberspace, comments: “For Case, who’d lived in the bodiless exultation of cyberspace, it was the Fall. . . . The body was meat. Case fell into the prison of his own flesh” (p. 6).


All Technology Is Assistive
Six design rules on “disability”

In 1941, the US Navy commissioned the husband-and-wife design team of Charles and Ray Eames to design a lightweight splint for wounded soldiers to get them out of the field more safely. Metal splints of that period weren’t secure enough to hold the leg still, causing unnecessary death from gangrene or shock, blood loss, and so on.
The Eameses had been working on techniques to mold and bend plywood, and they were able to come up with this splint design—conforming to the body without a lot of extra joints and parts. The wood design became a secure, lightweight, nest-able solution, and they produced more than 150,000 such splints for the Navy.

Over the next decade, the Eameses would go on to refine their wood-molding process to create both sculpture and functional design pieces, most notably, this celebrated chair:
Graham Pullin, in his book, *Design Meets Disability*, cites this story as an example of a seemingly specialized design problem—improving a battlefield medical aid for wounded soldiers—that inspired a whole aesthetic in modernist furnishings. The chairs launched a thousand imitators, and a new ethos of simple, organic lines in household objects.

It’s easy to assume that such innovation would more often happen in reverse: that a generalized design solution would “trickle down” to the narrow confines of adaptive and assistive aids. But, as Pullin points out, this example suggests that disability concerns are in fact an overlooked source of rich aesthetic ideas, with relevance and impact for design far beyond their immediate starting point.

More than that, I think this story demonstrates why everyone should pay more attention to matters of disability.

You might imagine that “disability studies” is just one more category of identity research that’s been created primarily for political advocacy, interesting only to those directly affected by issues of accessibility, accommodation, or special rights. But “disabled-ness” is another matter altogether. There are at least two big reasons why disability concerns are everyone’s concerns.
First, it’s a false divide to make a we/them: either able-minded, able-bodied, or disabled. After all, how cultures define, think about, and treat those who currently have marked disabilities is how all its future citizens may well be perceived if and when those who are able-bodied become less abled than they are now: by age, degeneration, or some sudden—or gradual—change in physical or mental capacities. All people, over the course of their lives, traffic between times of relative independence and dependence. So the questions cultures ask, the technologies they invent, and how those technologies broadcast a message about their users—weakness and strength, agency and passivity—are critical ones. And they’re not just questions for scientists and policy-makers; they’re aesthetic questions too.

Second, in many cultures—and certainly in the US—a pervasive, near-obsession with averages and statistical norms about bodies and capacities has become a naturalized form of describing both individuals and populations. But this way of measuring people and populations is historically very recent, and worth reconsidering.

Disability studies scholar Lennard Davis writes,
“. . . before the nineteenth century in Western culture, the concept of the ‘ideal’ was the regnant paradigm in relation to all bodies, so all bodies were less than ideal. The introduction of the concept of normality, however, created an imperative to be normal, as the eugenics movement proved by enshrining the bell curve (also known as the ‘normal curve’) as the umbrella under whose demanding peak we should all stand. With the introduction of the bell curve came the notion of ‘abnormal’ bodies. And the rest is history.”

_Bending Over Backwards: Disability, Dismodernism, and other Difficult Positions_

You all know the bell curve, of course.

![A chart of a classical bell curve, this one measuring “the severity of language disorders.” Standard scores, as usual, fall into the widest part of the curve.](image)

It’s the source of all talk about how individuals measure up, relative to others. In case you doubt this obsession, I invite you to witness the conversation among parents of young children: It’s all percentiles, and milestones, and being “ahead of the curve” with respect to each month of a child’s development. Exceptional normal-ness is what they prize above all else, and it’s these measurements that can reassure anxious caregivers, despite little correlation between these measures and a lifetime of wellness, healthy relationships, or sustaining work.
Again, Davis reminds us that this is a *recent* set of cultural ideas, so unquestioned now that these standards have a way of “enforcing normalcy.”

Of course, as Davis writes, “It’s too easy to say, ‘We’re all disabled.’” But a challenge remains: to interrupt cultural assumptions in powerful, creative ways—and to alter wider collective thinking about one’s own individual dependence, independence, and that of others.

So how might designers and artists engage these myths about what’s normal, and make more visible, critical, and expansive technologies?

A man in an office environment moves easily among computer screen, keyboard, headphones, and smart phone.
Well—it’s worth saying again: **All technology is assistive technology.** Honestly—what technology are you using that’s *not* assistive? Your smartphone? Your eyeglasses? Headphones? And those three examples alone are assisting you in multiple registers: They’re enabling or augmenting a sensory experience, say, or providing navigational information. But they’re also allowing you to decide whether to be available for approach in public, or not; to check out or in on a conversation or meeting in a bunch of subtle ways; to identify, by your choice of brand or look, with one culture group and not another.

Making a persistent, overt distinction about “assistive tech” embodies the second-tier do-gooderism and banality that still dominate design work targeted toward “special needs.” “Assistive technology” implies a separate species of tools designed exclusively for those people with a rather narrow set of diagnostic “impairments”—impairments, in other words, that have been culturally designated as needing special attention, as being particularly, grossly abnormal. But are you *sure* your phone isn’t a crutch, as it were, for a whole lot of unexamined needs?

The “Ekso,” a commercially available wearable exoskeleton, designed to encase the length of the body in a harness for support and augmented strength. It has enabled some wheelchair users to walk upright.
Undoing the distinctions between design for disability and design in general yields a couple of benefits: It brings new attention to technologies that are profound in their use and impact on physical and political accessibility. The advanced replacement limbs, all-terrain wheelchairs, and exoskeletons you can find now are evidence of this new attention.

It also brings a productive uncertainty and a powerful friction to the task of designing technologies of all kinds. Whether you’re designing for an established need or seeking an application for a technical novelty, you might take more time before confidently assigning it to a user, or to deciding, up front, with confidence, how it will be used. It might be for practical ends, or for play, or for something else you’ve not yet imagined.

Instead of labeling some technologies and not others as assistive, let’s start like this: We’re all getting all kinds of help from the things we make. All kinds of help, all the time, for our many material and social and educational and political needs. Private needs and public ones. No one is exempt. Then the questions get really interesting: What can a body do? What needs are you interested in? Who might use which thing for what? Where might the surprises be? How might a familiar thing morph into something else altogether?

In the name of good friction, then, I want to suggest some possible dispositions for designers and artists taking a look at ability and disability.

Invisibility is overrated.

The Victoria & Albert museum’s 2006 exhibit, Hearwear, commissioned designers to reconsider the traditional hearing aid, a long neglected prosthesis known for dubious “flesh toned” plastics and metal circuitry. The designers rejected the idea of these devices as objects of shame.
“The Beauty of Inner Space,” a design by Ross Lovegrove, has more in common with jewelry than medical gear. His proposal would have this aid amplify and mute sounds at the user’s discretion—highlighting sounds you want to hear and canceling out others. And the Svara hearing aid is a proposal to make amplification gestures blend seamlessly with other naturalistic movements: moving the necklace’s “pendant” up or down, for example, or tucking one’s hair behind the ears.

In other words, one strand of design might be devoted to making hearing aids as discreet as possible—to hide its function from view. But another round of questions becomes more interesting altogether: What might a hearing aid also do—or do instead—that’s never even been considered?

(See more hearing aids in the exhibition covered by Designboom.)
Rethink the default bodily experience.

Researchers at Georgia Tech re-imagined wheelchair navigation for quadriplegic users—with a tongue driver. It’s a wireless device that allows those who have high-level spinal cord injuries, and therefore little or no limb movement, to operate computers and their own electric wheelchairs.
Placing the controls in headsets, say the researchers, made them susceptible to getting jostled and needing frequent recalibration. Moving the entire system inside the mouth makes it stable and reliable, and the tongue’s receptors are sensitive enough that the user can move a cursor on a screen and direct a wheelchair in the way a joystick would have in the past. And the entire system can be programmed for many complex commands at once.

Instead of approximating a hand movement with joystick directionality, this system exploits a built-in sensitivity goldmine, protected from outside elements. Sometimes heightened functionality is about reconsidering typical adaptations entirely, inverting the expected sensory mechanism. One could easily picture this system in general use for tasks that typically require hand control—like gaming.

Consider fine gradations of qualitative change.

I’m as much a fan of the exoskeletons and bionic limbs as the next person. But there are far more subtle changes for bodies over the lifespan for the designer also to address. Some of the most interesting ideas pose ways to “edit” environments that already exist, to accommodate more bodies more of the time.

The Wanderest is just that kind of edit: a perch for pausing on the otherwise relentlessly forward-looking streetscape. As cities consider their usability for aging populations, this kind of accommodation might be as important as newer, “smarter” nursing home environments. Could small structures like these make streets more navigable, make independent living more attainable for a longer period?
So many medical technologies for treatment are just that: medicalized. They operate with the assumption that a change in ability is primarily a biological condition, without thought for the broader ways the built environment can expand and shift to welcome multiple kinds of bodies and experiences.

Uncouple medical technologies from their diagnostic contexts.

Temple Grandin is a research scientist in animal husbandry and now a well-known self-advocate for people with autism spectrum conditions. Grandin has revolutionized the cattle slaughter process, creating far more humane tools and practices for a huge percentage of slaughterhouses all across the U.S.
Grandin was a close observer of cattle on ranches growing up, and she noticed the common use of a “squeeze chute”—a tight chamber that would hold a cow still for inoculation. The deep pressure had a calming effect on the animals.

Watching this technology, Grandin intuited her own need for an adaptive “hugging machine” that would provide her with a proxy for human touch. For someone whose interpersonal interactions were often confusing, she found that this machine delivered a kind of affection and calming influence that she needed but wouldn’t get from a typical kind of human relationship.

Artist and MIT professor Wendy Jacob proposed a collaboration with Grandin to modify and replicate the hugging machine—in the form of these “squeeze chairs”—furniture that gives you a hug.
What happens when a tool used for therapeutic reasons also points outward from a diagnostic mode toward something more ambiguous, entering the realm of the poetic? Why shouldn't a critical object like this one possess more affect, be more responsive? When an object's uses and users get less clearly marked, new stories about that object and its users can suddenly emerge.

Design for one.
Michail Vanis, a young interaction designer working with a team of fellow students on “the future of work,” started to think about his grandmother Despina’s retirement from her job as a seamstress—a job she valued for its camaraderie of fellow workers at their sewing machines in a shared physical space.

After her retirement, it wasn’t that Despina needed a chair or adaptive machine to allow her to sew in her elder years; it was that she missed the togetherness of colleagues. So Vanis created Social Sewing, a complex of sewing machine avatars that activate when her now far-flung colleagues were also laboring in their post-work contexts.

This project is about productive, radical constraints: it narrows the design question to a single user, but it suggests a much wider frame for thinking about the “future of work” in all its crucial qualitative senses.
And this is perhaps the most important: Let the tools you make ask questions, not just solve problems.

The tricky part with popular prosthetic design—bespoke artificial limbs and such—is an overwhelmingly dominant trend toward making people with atypical bodies “pass” as “normal.” Plenty of well-meaning designers set out to re-design an object so that its wearer won’t “appear disabled,” with the presumption that a preconception of “normal” is always desirable.

Yes—of course—some users want discreet tools! But others roundly reject the notion that all bodies should conform to some standardized or performative ideal. This kind of variability and disagreement should also be a productive friction for the designer. Once freed from thinking in terms of creating tools for disability, designers can create personal objects that disrupt our notions of dependence and autonomy.

Jennifer Crupi, an artist and metalsmith, makes a kind of gestural jewelry:
Power Gesture, forces its wearer to assume the authoritative position of steepled fingers, held confidently and calmly in front of one’s chest. An assistive device to rehearse one’s self-presentation. The device forces the user’s fingertips on each hand to be aligned and pressed together, spread wide apart from each other.

The Guarded Gesture, externalizes the betrayal of emotions that’s so revealing in the crossed-arms stance. With these designs there’s a kind of comedy-with-teeth: Crupi makes a shrewd comment on the sciences of body language—and the ways humans say both what they want to express and what they wish to hide.

Questions of utility matter: Does it work efficiently? Is its power maximized? Is it user-friendly? Can it be mass produced, affordably? But questions outside utilitarian concerns also matter. Whether interrogative design, or critical
design, or “design for debate,” objects and their stories can suggest a para-
functionality that makes subtler needs and proxies become visible.

Let’s hope for objects that raise and suspend questions, and employ them
alongside objects designed to solve problems. Then we can have a complex
public conversation about needs and desires for interdependence. And about
tools that provide assistance to every human body.

... 

Thanks to Graham Pullin, Katherine Ott,
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How many times have you been asked this question: if you had to choose, which would you prefer to be: deaf or blind? The question illustrates the misconception that deafness is in some way the opposite of blindness—as though there’s some sort of binary representation of disability. When we look at accessible design for the deaf, it’s not surprising to see it addressed in a similar fashion: audio captioning is pretty much the equivalent of alt text on images for most designers.
Captioning by itself oversimplifies the matter and fails many Deaf people. To provide better user experiences for the Deaf, we need to stop thinking of deafness as simply the inverse of hearing—we need to understand deafness from both a cultural and linguistic perspective. Moreover, to enhance the online user experience for the deaf, we must understand how deafness influences web accessibility.

**Little “d” deaf and big “D” Deaf: the distinction**

You might have noticed that I’ve been interchanging little “d” deaf and big “D” Deaf in this article. It’s an important distinction—one that the Deaf community makes regularly.

Little “d” deaf describes anyone who is deaf or hard of hearing (HOH) but does not identify with the Deaf community. The Deaf community uses big “D” Deaf to distinguish themselves as being culturally Deaf.

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*The Deaf community is considered to be a linguistic and cultural minority group, similar to an ethnic community. Just as we capitalise the names of ethnic communities and cultures (e.g., Italian, Jewish) we capitalise the name of the Deaf community and culture. Since not all people who are physically deaf use Auslan and identify with the Deaf community, the d in deaf is not capitalized when we are referring to all deaf people or the physical condition of not hearing.*

*The Australian Deaf Community is a network of people who share a language and culture and a history of common experiences.*

—Australian Association of the Deaf

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**Collective deafness**

An interesting thing has happened on the web in the last 18 months—the web community has become more aware of deafness and how it influences accessible design practices.

The Open & Closed Project (http://openandclosed.org/) suggests two methods of presenting accessible media for the deaf and hard of hearing:

- **Captioning** is the *transcription* of speech and important sound effects.
- **Subtitling** is a written *translation* of dialogue.

Consider Wikipedia’s definitions of transcription and translation:

- **Transcription** (http://en.wikipedia.org/wiki/Transcription_(linguistics)) is the conversion into written, typewritten or printed form, of a spoken language source, such as the proceedings of a court hearing. It can also mean the conversion of a written source into another medium, such as scanning books and making digital versions.

- **Translation** (http://en.wikipedia.org/wiki/Translation) is the action of interpretation of the meaning of a text, and subsequent production of an equivalent text, also called a translation, that communicates the same message in another language.

Captioning and subtitling rely on written language to convey information.

As a transcription, captioning is simply the written form of spoken words and sound effects, including slang, colloquialisms, modifiers, and wordplay—which, as we’ll see below, can be very difficult for deaf, HOH, and Deaf people who struggle with English as a second language.

Subtitling, which is a translation, provides an opportunity to use words that are closer to the signs a Deaf person would use. However, it is important to note that typically, native sign languages have no natural written form.

It’s great that The OCP and Captioning Sucks! sites have drawn attention to deafness and accessible media, but it is important to understand that there is more we can do—particularly for the Deaf and hard of hearing audience.

Don’t get me wrong; research into captioning (http://web.archive.org/web/20080609205517/http://openandclosed.org/topics/captioning/) and subtitling (http://web.archive.org/web/20080609205524/http://openandclosed.org/topics/subtitling/) is an important thing that will, no doubt, improve access to information for many people—not just deaf, HOH, and Deaf people. Captioning and subtitling improves the user experience of
cinema, television, and the web for all kinds of people: anyone in a noisy environment, office workers in bee hive cubicles, migrants, teens addicted to earbuds, anyone with partial hearing, and even Deaf people.

But the Open & Closed Project doesn’t address the needs of the big “D” Deaf community as well as many people think it does. Maybe it isn’t supposed to. But it’s important to understand why captioning isn’t the most ideal method of supporting many Deaf people in accessing online content. Until the web community understands why, we won’t be able to address it adequately.

Because of limited awareness around Deafness and accessibility in the web community, it seems plausible to many of us that good captioning will fix it all. It won’t. Before we can enhance the user experience for all deaf people, we must understand that the needs of deaf, hard of hearing, and Deaf users are often very different.

**It’s a visual thing**

Native sign languages aren’t simply a gestural representation of spoken language; sign language is a visual-spatial language, without a natural written form. Grammar and syntax are very different from that of spoken languages, and rely heavily on facial expression to convey essential meaning and emphasis. While many Australian Deaf people, for example, use English as a second language, Auslan (Australian Sign Language) is their primary language. For this reason it’s important to recognize Deafness primarily as a culture, rather than a disability.

During a language class, a Deaf teacher once told me:

> We are not disabled and Deafness is not a disability; it’s the perception of many hearing (people) that we are disabled, and that is our disability.

Rather than thinking of Deaf users as disabled, simply understand that the dominant language in their country is not necessarily their primary language.

**Phonetics, slang, and wordplay present challenges**

What does phonetic based language mean to a Deaf person? The word “comfortable” is a great example of this. An old joke often shown to hearing sign language students is the mythical sign “come-for-table.” As you can see, pronounced quickly, it sounds like comfortable, but when signed it could literally mean “have you come for the table?” but never “comfortable.”
Consider also the phrase once in a blue moon, which means “occasionally” or “every now and then.” When taken literally, the meaning becomes ambiguous and even confusing. Think too about the way we use language in e-mails, text messages, and even advertising. Much of our shorthand and many of our colloquialisms are based on phonetics. For example, with CU l8tr, “C” sounds like “see,” but it doesn’t look like it. Jokes that rely on a play on words can have similar problems. Take, for example, one of my favorites:

Did you hear about the prawn that walked into a bar and pulled a mussel?

In hearing this joke, pulled a mussel could easily mean strained a muscle or dragged a mussel, but what it actually means here is “picked up” or “met.” So as you can see, it’s not hard for meaning to become confused.

Lost in transcription and translation

Let’s suppose we’re talking about providing accessible content for an English television sitcom with a Deaf audience.

Captioning is perfect for the post-lingual deaf or hard-of hearing audience; it presents content in an accessible format, in the primary language of the user. However, as captioning is a transcription, for the Deaf audience, content is presented in the user’s second language, one with which the user may have little or no fluency. While captioning provides better access to content for the Deaf than if there were none, it’s important to remember that there is a big difference in the needs of those who can’t hear (deaf) and those who speak another language altogether (Deaf).

In “What Really Matters in the Early Literacy Development of Deaf Children,” [1] Connie Mayer cites several studies that address the literacy gap present in the Deaf community:

Yet it remains the case that 50% of deaf students graduate from secondary school with a fourth grade reading level or less, [2] and 30% leave school functionally illiterate. [3]

The frequently reported low literacy levels among students with severe to profound hearing impairment are, in part, due to the discrepancy between their incomplete spoken language system and the demands of reading a speech-based system.” [4]
Keep in mind too that English, for example, has the highest number of synonyms of any language. Signed languages have very few in comparison. Sign language relies heavily on facial expressions and body language to provide meaning to language. So where we would say, “careful, the pie is extremely hot,” we might sign, “careful, the pie is very hot,” with a more pronounced facial expression on “very” to infer extreme heat. What this means is that the user with low to moderate fluency in English has to concentrate a lot harder, particularly when dialogue (captioning) is moving quickly.

Thus, captioning alone, as a transcription of spoken English, complete with its slang, colloquialisms, and wordplay, is not a perfect solution to the problem of creating accessible websites for the Deaf.

Alternatively, if we employ subtitling, we’re providing a written translation of a language for which there is no written form. (And therein lies the problem.) So how do we best provide a written translation for a language that has no written form? We provide sign language interpreting instead, as is sometimes seen on news broadcasts and current affairs programs. Where this isn’t possible, subtitles for the Deaf and hard of hearing, with notations on sound effects, would be most accessible.

There seems to be a perception by some people that subtitles for the Deaf use dumbed-down language. However, I’ve always perceived the language to be based on the English equivalent of the signs that would have been used had an interpreter been present. Of course this means that the grammar continues to follow an English pattern, but it seems to me that the subtitles are likely to be more accessible to a wider audience.

**So what’s the solution?**

Like with most things, there isn’t a single, fix-all solution to the issue. However, as socially-conscious designers, we’ve worked to understand the issues. Now, we can make an honest attempt at addressing them.

**WRITING FOR THE WEB**

Taking heed of all those *Writing for the Web 101* tips you’ve seen is a good place to start and will enhance site readability for a wide range of users, including the deaf. Sign language is a very direct language, where the main point is stated first and then expanded upon—much like the “inverted pyramid” or journalistic style of writing that we so often recommend for writing on the web. Some other considerations are:

- Use headings and subheadings.
• Write in a journalistic style: make your point and then explain it.
• Make one point per paragraph.
• Use short line lengths: seven to ten words per line.
• Use plain language whenever possible.
• Use bulleted lists.
• Write with an active voice.
• Avoid unnecessary jargon and slang, which can increase the user's cognitive load.
• Include a glossary for specialized vocabulary, e.g., medical or legal terminology, and provide definitions in simpler language.

Language learners, or anyone doing the usual page scan for highlights, will benefit—and users with cognitive and learning disabilities will find it helpful too. As with all web documents, the content should be marked up as standards-focused, semantic, and valid HTML.

**MULTIMEDIA**

Where possible, for web-based multimedia, the ideal solution is to incorporate sign language interpretation with the video as picture-in-picture, as this provides a synchronized presentation. However, this can be a very time consuming and costly process. And as sign language is specific to certain regions, it will be more appropriate in some situations than others. As an alternative, sign language interpreting can be recorded and provided in addition to the audio and transcript or captioning.

Alternately, a combination of captioning (to transcribe sound effects) and subtitling (written translation, with a focus on users with sign as a primary language) is most effective. Where this isn’t possible, a transcript of the dialogue will suffice; transcripts provide the user with an opportunity to print out the dialogue and read it at a comfortable pace.

Remember that the purpose of subtitling is to convey meaning, not to test the language skills of the audience. It is more important to convey the meaning and sentiment of audio content than to transcribe it verbatim.

**Take action now**
Transcribe all conference podcasts and make the content available in an accessible format. Organize an interpreter for your next presentation—record the translation and make it available online. Read one of the books listed below. Most importantly, whenever you have the chance, gain awareness of your local Deaf community. I’ll be surprised if that doesn’t make you want to learn a few signs yourself.

**Suggested Reading**


Harlan Lane—*When the Mind Hears* (Vintage, 1989) and *The Wild Boy of Aveyron* (Harvard University Press, 1979).


**References**


**About the Author**

Lisa Herrod
Lisa Herrod began her working life as a sign language interpreter before moving to the web in 1999. Owner of Scenario Seven, a user experience consultancy in Australia, her work now focuses on a taking an integrated, holistic approach to usability and accessibility. Lisa is co-lead of WaSP’s International Liaison Group.
As ever more education, employment, communication, entertainment, civic participation, and government functions move primarily or exclusively online, the high levels of inaccessibility on the Web and in Internet-enabled mobile technologies threaten to make people with disabilities into the second-class citizens of the information society. Unless the policy approach toward Internet accessibility for people with disabilities is reconceptualized for the current social and technological realities, people with disabilities will face exclusion from every core element of society.

In the United States, people with disabilities are the largest minority group. Some 54.4 million people, or 18.7% of the population, have a disability. This number will increase rapidly as the baby boom generation ages, because 53% of persons over 75 have a disability.

People with disabilities already face significant challenges in employment and education. Persons with disabilities face unemployment at more than three times higher levels than the rest of the population and suffer similar gaps in educational attainment. Yet 75% of people with disabilities who are not employed want to work. Only 30% of high-school graduates with disabilities enroll in college, as compared with 40% of the general population. One year after high-school graduation, only 10% of students with disabilities are enrolled in two-year colleges, and a paltry 5% are enrolled in four-year colleges.

Despite the fact that the United States has the world’s most comprehensive policy for Internet accessibility and that clear guidance for creating accessible technologies already exists, designers and developers of Web software and hardware technologies in industry, academia, and government often exploit holes in existing policy to ignore the needs of people with disabilities. As a result, most Internet-related technologies are born inaccessible, cutting out some or all users with disabilities.
People with disabilities use the Internet and related technologies at levels well below those of the rest of the population. The main reason for this is not a lack of interest or education, but that the Internet is inherently unfriendly to many different kinds of disabilities. These barriers to access and usage vary by type and extent of disability. Since the advent of the World Wide Web, study after study has demonstrated the inaccessibility of Web sites and other elements of the Internet. Recent studies of the accessibility of U.S. government Web sites, for example, have found that at least 90% of the sites have major access barriers, even though they are supposed to have been accessible for nearly a decade under the law. The levels of accessibility in commerce and educational settings are even worse. The failure of the current policy approach can be seen in the results of these studies.

Challenging interfaces
People of differing abilities obviously face different challenges in accessing the Internet. Persons with visual impairments can face challenges in the lack of compatibility of Web content with screen readers, which are software applications that provide computer-synthesized speech output of what appears on the screen, as well as equivalent text provided in the back-end code. Screen-reader users typically have problems when designers fail to put appropriate text tags on graphics, links, forms, or tables. For persons with motor impairments, such as limited or no use of fingers or hands, the barriers are created by cluttered layout, buttons and links that are too small, and other important navigability considerations (such as requiring the use of a pointing device) that can render entire sites and functions unusable. For persons with hearing impairments, the lack of textual equivalents of audio content can cut off large portions of the content of a site, and interactive Web chats and other conferencing features may be impossible. People with speech and communication impairments can also be excluded from interactive Web chats and other conferencing features. For persons with cognitive impairments, such as autism, dementia, or traumatic brain injury, issues of design, layout, and navigability are the difference between being able to use a site and not being able to use it. People with specific learning disabilities, depending on their nature, may face the same barriers as people with visual impairments or people with cognitive impairments. For people with seizure disorders, rates of flickering and flash can jeopardize their health.

Experiences with the Internet often vary by type of disability. The same Web site often offers opportunities for one group and excludes another. Consider Web-based distance education. A student who uses a wheelchair may find that being able to take courses online makes education much easier. But if the course Web site is not designed to be accessible for students with limited mobility in their hands, participation in the course may be limited or impossible. Similarly, a Web-enabled mobile device with a touch screen may seem like a miracle to a user with a hearing impairment and a nightmare to a user with a visual impairment, if it is not designed to provide alternative methods for interactions. Therefore, the Internet and related technologies present a com-
An accessible Internet holds enormous potential to heighten the inclusion of people with disabilities, facilitating telework, online education, participation in e-government, and formation of relationships that overcome barriers and challenges in the physical world.

plex set of problems for persons with disabilities, both as a larger population and as separate populations according to type of disability.

Although the range of potential barriers to persons with disabilities in the online environment is extensive, there are ways to develop and implement technologies so that persons with disabilities are included. There are known and achievable means to address the access barriers listed above. However, many developers of Web sites and related new technologies simply do not consider persons with disabilities when they create or update products. Yet the inaccessible Web sites and technologies that result from this disregard of accessibility run afoul of federal civil rights laws for persons with disabilities. Many of the issues of inclusion and exclusion online for persons with disabilities have been considered in law and policy, but the conceptions of disability under the law, exemptions from compliance, limited enforcement, and the inability of the law to keep pace with technological development all hinder the impact that the laws have had thus far.

Despite all of these barriers, the Internet has been justifiably viewed as having enormous potential for promoting social inclusion for persons with disabilities. In 2000, people with disabilities who were able to access and use the Internet were already reporting notably larger benefits from the Internet in some areas than was the general population. Adults with disabilities in 2000 were more likely to believe that the Internet improved the quality of their lives (48% to 27%), made them better informed about the world (52% to 39%), helped them meet people with similar interests and experiences (42% to 30%), and gave them more connections to the world (44% to 38%) than the general population. Currently, some Internet technologies are a significant benefit to people with specific types of disabilities, whereas others offer potential opportunities to all persons with disabilities.

Smartphones, although excluding many other persons with disabilities, have been a boon for those with hearing, speech, or other types of communication impairments, who can now use the phones to communicate face-to-face much more efficiently than they previously could. Similarly, with video chat, these same individuals can now carry on conversations over the phone in new ways. For the broader populations of people with disabilities, the Internet has a great deal of potential to create new means of communication and interaction through online communities devoted to particular types of disabilities. People who might never encounter someone with a similar disability in their physical environment can now interact directly with people with similar conditions worldwide. For people whose disabilities limit their ability to leave their homes, the Internet has the potential to provide a far greater world of interaction. People with disabilities even have the option to choose to live their online lives as people without disabilities, if they so wish.

Beyond the clear potential socialization and communication benefits, the Internet offers an enormous array of new ways to pursue education and employment. For people who might find it very difficult or even impossible to travel to a building for work or school, the Internet provides the ability to work or take classes from home. These potential benefits might be the greatest benefits in the long term for promoting social inclusion of persons with disabilities, given that the current levels of employment and education for persons with disabilities are catastrophically low as compared with the rest of the population.

Based on the importance of all of these types of engagement with the technology, the lack of equal access to the Internet will become an even more serious problem in the future. As more activities in the areas of communication, employment, education, and civic participation move primarily and then exclusively online, the effects of unequal access on persons with disabilities will multiply and mushroom. As more functions are available exclusively online (for example, if taxes can be filed only online and the tax Web site is inaccessible), individuals with disabilities are placed in an untenable situation. Inaccessible online education alone could seriously erode the ability of people with disabilities to have a place in society. Yet the virtual world is currently extend-
ing the comprehensive physical exclusions of the past.

The extreme irony of the situation is that an accessible Internet holds enormous potential to heighten the inclusion of people with disabilities, facilitating telework, online education, participation in e-government, and the formation of relationships that overcome barriers and challenges in the physical world. We must create a new approach to public policy that will better eliminate the virtual barriers that have been built, ensuring that people with disabilities are not marginalized by society.

The reasons for online inaccessibility

What does it mean to have an accessible interface? In the technology world, it means that your computer interface will work for people with disabilities, many of whom use an assistive technology to access software, operating systems, and Web sites. Commonly used assistive technologies include a screen reader, which provides computer-synthesized speech output of what appears on the screen; speech recognition, which allows for hands-free input; and various alternative keyboards and pointing devices.

Guidelines from nongovernmental organizations provide concrete technical specifications explaining how to build accessible interfaces. Most Web accessibility regulations around the world, including those in the United States, are based on the Web Content Accessibility Guidelines, a set of standards from the World Wide Web Consortium.

Despite the existence of assistive devices and accessibility guidelines, if a Web site is not designed in a manner that it is flexible enough to work with various assistive devices, there is nothing that the user can do that will lead to successful use of the site. It’s not a matter of a user with a disability upgrading to a new version of software or purchasing a new hardware device. If a Web site isn’t designed for accessibility, no action on the user’s side will make interaction successful.

Yet the technical solutions are easy. They don’t involve any type of advanced coding. They generally involve adding appropriate markup, such as using good descriptive text to describe graphics, table columns, forms, and links. These solutions are the responsibility of Web site developers, designers, and Webmasters. No additional technical expertise is needed, just an awareness of the need to provide appropriate labels.

At first glance, an accessible Web site won’t look any different from an inaccessible one. An accessible Web page is simply a well-coded Web page, or as one federal web manager told us, “the same coding techniques that make a Web page accessible also help with search engine optimization, because all of that markup helps search engines find and

John Dugdale, Houston Magnolia, Toned silver gelatin print, 20 x 16 inches, 1996.
properly classify your Web page.”

When a Web site is designed to be accessible from the beginning, there are no additional costs involved. If a Web site has already been designed, the amount of time and money required to retrofit it for accessibility depend on the size and technical nature of the site. Obviously, adding more textual labels will take a greater amount of time, depending on the number of static Web pages that must be edited. If a Web site uses a content management system, often the page templates can be edited very quickly, so that the page layout itself is accessible. Then, it’s only up to the content developers to make sure that they have labeled their pictures and provided closed-captioning or a transcript on multimedia. If a Web site is designed using inherently accessible technology such as HTML, the time and costs to make the site accessible should be limited. If a site is designed using an inherently inaccessible technology, such as a site built entirely in Flash, more time and expense will be required to make it accessible.

Although all people with disabilities may be affected by inaccessible Web sites, those who are blind or have low vision are often the most affected. Computer interfaces are still primarily visual, and when the nonvisual equivalents are not coded properly, blind or low-vision individuals may have access to none of the content. Individuals with hearing impairments can access most content, except for the audio, when developers don’t provide transcripts or captioning. Individuals with motor impairments, who may be unable to use standard keyboards or mice, may have trouble interacting with Web sites that provide content that is reachable only via pointing devices. Many of the design features that help blind users also help people with motor impairments, because making a Web site user-friendly for the blind means making sure that all content can be accessed via a keyboard, which is also what is needed by people with motor impairments. There is still relatively little research on Web accessibility for people with cognitive impairments, with the small body of literature indicating differing types of effects based on different cognitive impairments. Reflecting this lower level of attention, U.S. regulations have not included guidelines that meaningfully address cognitive impairments.

**Government obstacles**

Today, people with disabilities cannot access much of the information on federal Web sites that is available to those without disabilities. For example, in October 2010, some content on the Web site at ready.gov, which provides emergency readiness information, was inaccessible, meaning that blind people could not access the information about hurri-
cane preparedness and were not even aware that the information is there. Web sites that offer information about government loans and jobs are also inaccessible. Many federal Web sites state that users with disabilities should contact them if they have any problems accessing content, but then the online contact forms are themselves inaccessible.

These accessibility problems exist despite the fact that the federal government has pursued a robust legal program to promote equal online access through Section 508 of the Rehabilitation Act, the Americans with Disabilities Act (ADA), the E-government Act, the Telecommunications Act of 1996, and other related laws. These laws create the most comprehensive legislative approach to accessibility in the world. U.S. law focuses on the civil rights aspects of disability, which emphasize the ways in which society can better allow individuals with disabilities to function. Following the lead of the federal government, many states have also passed accessibility laws, such as Maryland’s Information Technology Nonvisual Access law and California’s Information Technology Accessibility Policy.

However, compliance with and enforcement of these laws have not been very effective. A recent study found that more than 90% of federal home pages were not in compliance with Section 508. Although the Justice Department has responsibility for collecting data from federal agencies on compliance every two years, it has not collected any data since 2003. The section508.gov Web site, which is managed by the General Services Administration, was redesigned in the summer of 2010, but the new version is not in compliance with Section 508. For instance, the feedback form has form fields that are not labeled properly, so that although the form looks normal to a user who can see, a user who is blind cannot determine what each form field is supposed to represent.

Each federal agency has someone in charge of compliance with 508, and the names are available on the section508.gov Web site. But that apparently has had no impact on actual compliance. Federal Web sites are not required to have an accessibility policy statement, and when they do, the statements often provide no more information than “we are compliant with Section 508” and even offer misleading information. Many states have regulations similar to Section 508 that address state government Web sites, but compliance and enforcement are often nonexistent at the state level.

In addition to the fact that no government agency is in charge of accessibility, there are several other barriers to compliance and enforcement with accessibility laws. People with disabilities have the responsibility to monitor accessibility and bring complaints and claims against agencies and companies that violate accessibility laws. This approach puts the burden on people with disabilities to enforce their own rights in a way that no other minority or traditionally disadvantaged group is asked to do. Even when people with disabilities are able to successfully make accessibility claims, they usually do not succeed. Under all of the disability laws, public and private entities can claim that the requested accommodation is not financially or practically reasonable and therefore is an “undue burden” under the law, meaning that the entity does not need to provide the accommodation because it represents too much effort in terms of time or cost. A final major problem is that the laws focus on the technologies, not the users of the technologies or the reasons why people use the technologies. Without a clear focus on the information and communication needs of the users with disabilities, the laws will permanently be far behind the current technologies.

The legal situation for private Web sites is even less clear. The courts in their interpretations of accessibility laws have sometimes created additional barriers to accessibility enforcement, often because of a limited understanding of the Internet and of accessibility. This problem is amply demonstrated by a federal district court opinion relating to the ADA—National Federation of the Blind v. Target, 2006—that found that the Target Web site, because it was closely integrated with physical stores, could be seen as being legally required to be accessible because of this nexus. However, the same opinion explicitly limited the holding to companies with an online presence that is closely integrated with a physical presence. As such, the current case law says that Target must have an accessible Web site, but Amazon.com, Priceline.com, and Overstock.com may not need to worry about accessibility. It also implies that a company can have both physical and online presences—with the online presence being inaccessible—so long as the Web site is not tightly integrated with the physical presence. Although technology companies have started to include accessibility features more consistently in mainline operating systems and devices, such as Microsoft Windows 7 and the Apple iPad, those are designed to be used by millions of users, and they have the benefit of the large number of accessibility and usability experts at Microsoft and Apple. For instance, text-to-speech and screen magnification come preinstalled so that there is no need to purchase any additional assistive technology. Web sites, on the other hand, tend to be developed by millions of different companies and organizations, often without accessibility experts involved and, surprisingly, without even basic knowledge of accessibility.
JOHN DUGDALE, Vespers, Cyanotype, 8 x 10 inches, 1999.
Promising developments
In short, although the United States has a robust slate of laws related to online accessibility, the laws have not had the effect of making the Internet widely accessible to persons with disabilities in the United States. A large part of the explanation is that the existence of laws and regulations is not sufficient. There must also be established mechanisms to develop guidelines, monitor compliance, promote innovation, and provide meaningful enforcement powers to ensure compliance. In the United States, no such agency exists. In fact, issues related to online accessibility are spread across agencies, and often no group has monitoring or enforcement roles with the laws and regulations, which include the undue-burden loopholes to avoid compliance.

However, there has been a recent surge in federal government focus on accessibility:

In March 2010, the Access Board released a draft for public comment of the first major revision of Section 508 and the accessibility provisions of the Telecommunications Act. The intent is that new guidelines, which are slated to be adopted in late 2010 or early 2011, will cover telephones, cell phones, mobile devices, PDAs, computer software and hardware, Web sites, electronic documents, and media players. If the new guidelines are implemented as suggested, the principles of accessibility will be strengthened considerably, although they continue to focus primarily on sensory and motor impairments. As mentioned earlier, this focus on sensory and motor impairments is primarily due to the concrete nature of the accommodations needed, along with the 30-year track record of existing research on how to successfully design computer interfaces for people with sensory and motor impairment, as compared to a shorter history with fewer concrete guidelines on how to design for people with cognitive impairments.

In June 2010, the Departments of Education and Justice took the unusual step of issuing a joint statement to educational institutions to say that the use of inaccessible e-book readers and similar devices by elementary, secondary, and postsecondary institutions was a violation of both the ADA and Section 508. Because many e-book texts and readers are not inherently accessible to readers with visual impairments, the movement by some universities to require the use of e-books was neglecting the needs of students and faculty with visual impairments. This means that educational institutions must consider the accessibility of not just the Internet and computers, but of newer mobile, Internet-enabled technological devices as well. There is no prohibition against using accessible e-book readers or other mobile devices, just the obligation for educational institutions to en-
Computer interfaces are still primarily visual, and when the nonvisual equivalents are not coded properly, blind or low-vision individuals may have access to none of the content.

sure that any of these that they adopt are not going to exclude students and faculty with disabilities.

In July 2010, a memo from the Office of Management and Budget and the federal chief information officer announced that although the Justice Department has not collected data on compliance since 2003, it would, in conjunction with the Government Services Administration, begin to collect data on compliance again as soon as fall 2010.

In July 2010, the Department of Justice also began pursuing a series of revisions to the ADA to account for changes in technology and society since the passage of the law. These updates include accessibility of movie theaters, furniture design, self-service machines used for retail transactions, access to 911, and Web site accessibility. The latter is the most significant proposal, because it would clearly extend the coverage of the ADA to the Web sites of all entities covered by the ADA: local and state governments and places of public accommodation. In such a case, the requirements of the ADA would apply widely to entertainment and commerce online, resolving the disagreements in the courts about the applicability of the ADA to e-commerce. All of these strengthened regulations, however, will be of value only if they are actually complied with, monitored, and enforced.

Finally, in October 2010, President Obama signed the Twenty-First Century Communications and Video Accessibility Act of 2010 into law, which includes provisions to expand the use of closed captioning and video description for online content; facilitate accessible advanced communications equipment and services such as text messaging and e-mail; promote access to Internet services that are built into mobile telephone devices such as smartphones; and require devices of any size to be capable of displaying closed captioning, delivering available video description, and making emergency information accessible. As with previous technology guidelines, however, these new standards include the ability to opt out if an undue burden exists.

Promoting greater accessibility

Despite the laws and enforcement activities by federal and state governments, the goals and intended outcomes of accessibility deserve greater consideration than they receive. Clearly, the most important goal is increased access to the information, communication, and services that are increasingly central to education, employment, civic participation, and government. Additionally, accessibility laws and regulations have the potential to provide incentives for the creation of new technologies, to make existing technologies usable by a wide range of users beyond people with disabilities, to involve people with disabilities in the development of regulations and technologies, to foster the creation of better-quality tools for developers, to make evaluation easier, and to educate the general populace about the importance of equal access for people with disabilities. For instance, eBay has recently been working on making both its buying and selling experience accessible, opening up the door for users with disabilities as consumers, sellers, and entrepreneurs.

During 2010, the U.S. government moved to strengthen regulations and policies related to Web accessibility; however, this is not enough. Evaluating compliance, improving enforcement, and increasing the availability of information about compliance are all necessary to promote and improve Web accessibility. There are a number of potential actions that can be taken to promote accessibility within industry and government.

The key concept to keep in mind is that the technical solutions for Web accessibility already exist. Coding standards for accessibility already exist, as do evaluation methods and testing tools. Because the technical knowledge already exists, the key challenges are knowledge dissemination, compliance, and enforcement. The first four actions below can be readily implemented, whereas the last two would require a sizeable reconceptualization of the approaches to accessibility monitoring and enforcement:

Creation of a chief accessibility officer within the federal government, dealing specifically with information and communications technology accessibility. Microsoft has such an officer, which has led to improvement in the accessibility of its interfaces. Although the White House currently has a
JOHN DUGDALE, Never Forget Who You Are, Albumen print, 8 x 10 inches, 2002.
special advisor on disability policy, this person deals with every issue related to disability policy, not specifically with computer interfaces.

Compilation of best practices related to processes for monitoring and enforcement of Section 508 within agencies. Although the www.section508.gov Web site currently has a link for good practices, it does not provide information except for technical specs, and many of the links are broken. Agencies need to have guidance on how to monitor and enforce compliance within their organizations. For instance, the monitoring processes used by recovery.gov, soon to be published in the textbook Interaction Design, are the types of best practices that need to be documented from other agencies.

Increased openness and transparency requirements explaining how agencies can ensure that their Web sites are compliant with Section 508. For instance, although many federal Web sites have an accessibility statement simply noting that their site is Section 508-compliant, there is limited information about what features make the site compliant, how the site was evaluated for compliance, and how the site maintains compliance. There currently are no requirements for federal Web sites to provide any information on site accessibility. Providing this roadmap to users with disabilities would be helpful.

Frequent, publicly posted evaluations of site accessibility across the government would be helpful in bringing the problem to light. For instance, the progress dashboard on the open government page at the White House (http://www.whitehouse.gov/open/around) describes how agencies are making progress toward the goals required by the Open Government Initiative. But it would be helpful to have similar data posted about agency progress toward accessible Web sites.

Altering laws to reduce the ability of covered entities to avoid compliance through undue-burden clauses. As noted above, these clauses have been widely used by corporations and government agencies to opt out of compliance with accessibility guidelines. Undue burden was originally conceived as a tool to be used in limited circumstances in which significant expense or effort would lead to the additional inclusion of only a small number of users or in which the expense or effort were simply beyond the resources of the organization. In practice, however, it is regularly used by companies and government agencies as a way to avoid many accessibility considerations, regardless of level of effort or expense. So long as these clauses exist, many accessibility guidelines will lack any meaningful force.

Finally, creation of a government enforcement agency devoted to accessibility monitoring and enforcement, which could be headed by the new chief information officer. Rather than continuing a decentralized approach, such an agency could create regulations, monitor and enforce compliance, support research, and better include persons with disabilities in the development of accessibility regulations. A dedicated agency could also educate the public and government employees on the importance of accessibility as an issue of inclusion and civil rights.

Without changes such as these, people with disabilities will not be able to fully participate in online opportunities in education, employment, communication, and government. Simply put, people with disabilities need accessibility to be included as equal members of the information society. Public policy has promoted the rights of persons with disabilities in the United States for four decades, and as technology evolves, so must legal guarantees of rights for persons with disabilities.

Recommended Readings


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As any linguist will tell you, all language claims are political. When people in the street argue that their language is distinct from another language, that someone speaks the national language correctly or incorrectly, or that this language is simply a dialect or creole of that language, they are making fundamentally political statements, not descriptive or scientific ones. Languages are part and parcel of the national borders (both physical and ethnic) of the “imagined nations” that separate us (cf. Anderson 1991)—“imagined” not because there might be tangible cultural and ethnic boundaries between two nations, but because the differences that seem so clearly defined on a map become a swirling mix of pointillistic variation on the ground. Although “French” people might carry French passports and speak French, when they try to precisely delineate what constitutes being French or French-ness (as being opposed to being Belgian or Swiss or part of the EU), they are committing political acts, not scientific ones.

The Declaration of Deaf Culture reproduced in the introduction was written by two of the leaders of D-Pro, the group that advocates a Deaf culture perspective. For many Americans, especially those who are liberal and educated, the declaration is framed so completely within the American discourse on ethnic and linguistic diversity that its political nature is largely invisible. Unfortunately for D-Pro, many Japanese disagree with the declaration, calling it “radical” and disputing the existence of a separate “Deaf culture.” That many of those in disagreement with D-Pro are in fact deaf themselves adds some mystery to the situation.
Part of the cognitive power of D-Pro's declaration is its deft use of a seemingly linguistic argument, namely that Japanese Sign Language (JSL) is an independent, autochthonous, natural language; that it is the native language of deaf persons in Japan; and, furthermore, that JSL's lexicon, morphology, syntax, and pragmatics differ from spoken Japanese because they are separate language systems. Since this premise is apparently grounded in linguistic fact (that is, the language claim appears neutrally based in science), we are less apt to deconstruct it in the same way we might other, more political aspects of D-Pro's position, such as its stance against cochlear implants, for example.

The goal of this chapter is to explore, analyze, and ultimately deconstruct this entity known as Japanese Sign Language (Nihon Shawa). However, as Japanese sign language scholar Kanda Kazuyuki has written, the linguistic situation in Japan is far from simple:

It is commonly thought that deaf people are able to understand each other using sign. That is certainly true; however, deaf people in Japan use a variety of different languages based on individual differences, and we cannot say that they all use the same method of communication. For example, a deaf person may be very fluent in Japanese Sign but may be unable to communicate in spoken Japanese. Another deaf person may use both speech and sign simultaneously. And yet another deaf person may use speech as well as converse using pen and paper (i.e., swapping notes). The source of that difference lies in each individual's particular language environment, especially the type of deaf education they received. (Kanda 1989:30)

While most people involved in the deaf community in Japan do not normally divide Japanese sign into “JSL” and “Manually Coded Japanese,” at least two terms have emerged to describe the wide variation: here is dentōteki shawa (traditional signing) and Nihongo-tai-shawa (literally “signing that corresponds to the Japanese language”). No one really warns to the phrase dentōteki-shawa (Traditional Signing) because it

1. “Natural language” is used here in the linguistic sense, as opposed to an artificial language such as Esperanto, Gestuno, or Manually Coded English (developed as a pedagogic aid).

2. Here, Kanda adds a footnote regarding his use of the term “Japanese Sign,” as many scholars were differentiating between variant forms of sign extant in Japan, especially in regard to the younger generation who were signing while speaking at the same time: I'm aware of the phrase Traditional Sign (dentōteki-shawa); however that was coined in opposition to Simultaneous Signing (shinjōteki-shawa). I believe that the term Japanese Sign (as in Nihon shawa) is the most appropriate one when referring to the still-changing rm of sign (being used today)” (Kanda 1989:43).
Sign Language Variation

A common misconception among many hearing people is that sign languages are universal or mutually intelligible among signers from different countries. Nothing could be further from the truth. Sign languages vary as much as other natural languages, or even more, as there has traditionally been less state activism in unifying sign language dialects within nations. Sign languages with different lineages such as American Sign Language and Japanese Sign Language are of course mutually unintelligible; a JSL signer would be unable to immediately understand what an ASL signer is saying in conversation.

Although the United Kingdom and the United States share a spoken language called English, British Sign Language and American Sign Language are mutually unintelligible. Even when fingerspelling English loan words, the deaf people in the two countries use different systems—the British use a two-handed system while the Americans borrow the one-handed fingerspelling style used in France, Spain, and other continental European countries.

Because sign languages often form around schools for the deaf, students at different schools for the deaf in the same city may even use different forms. The anthropologist Barbara Le Master (2003) provides an excellent example in Ireland, where two Catholic schools for the deaf in the same city developed different signing forms. Because the schools were segregated by gender, the language variation also carried over to the adult population, with men signing differently from women. Other scholars have found variance among older Black and white signers in the U.S. South where schools for the deaf were segregated by race until the middle of the twentieth century (Aramburu 1995; Hairston and Smith 1985).

Even within the same language community, there can be wide variation. Signers can have “accents” or idiolects—that is, they may sign particular words using slightly different (or totally different) forms; their grammar may follow different use patterns; pacing may be rapid and clipped or slow and drawling; their gesturing may be broader or larger, or smaller and more compact. These accents can vary across gender boundaries (one sweeping generalization being, for example, that deaf

3. In a sense, thinking mono-linguistically about Japanese signing reduces all of the interesting differences that drive this book: among them age, cohorts, power, regionality, and access to formal education.

4. Another common myth is that sign languages are invented by “someone.” That same someone is often referred to when people argue: “Why couldn’t they make it [sign language] universal?”
women in the United States tend to sign more compactly than men do, age, or geographic region. Astute native signers can often look at another signer and tell what region he or she is from, or even what school for the deaf he or she might have attended. Hearing people who learn sign in adulthood often have particular accents that mark them as non-deaf, but hearing children of deaf adults (so-called CODAs) can sign so fluently that they are considered culturally Deaf. Deaf children of deaf parents sign differently from their peers born of hearing parents, and these “deaf of deaf” are often the center of American deaf communities.

Donald Grushkin writes poignantly about the dilemma faced by the “hard of hearing” in the United States, who find themselves alienated from both hearing and deaf communities. Being hard of hearing is less a statement of audiologic ability than one about language choice and community identity. Signing ASL without voicing places you with the American cultural Deaf community; using oral speech and speechreading places you within the hearing community. True biculturalism/bilingualism is difficult. Grushkin writes of the “Deaf militancy . . . [that] asserts that some aspects of being hard of hearing are proof of nonmembership within the Deaf culture” (2003:114).

The Demographics of Deafness

Genetic deafness can be found in all countries and all times although it has rarely been the predominant cause of deafness. In remote villages or islands, an isolated gene pool can cause the normally recessive gene to express at a higher rate than usual. Nora Groce analyzed the case of the population on Martha’s Vineyard in the late nineteenth and early twentieth century in the United States (Groce 1985). More recently, a team of medical researchers has found an isolated village in Indonesia with similar characteristics (Winata et al. 1995; Morell et al. 1995; Friedman et al. 1995).

Except in such anomalous cases, it is estimated that only about 10 percent of deaf children are born to deaf parents. This also means that 90

percent of the deaf community are born to hearing parents and usually have limited access to sign language until they enter the school system. Thus, schools for the deaf play an essential role in identity construction. Just being physically deaf does not imply that you will sign or that you will identify as part of the deaf community. Biology is truly not destiny here.

Just how many physically deaf persons are there in Japan? According to the latest government report (Cabinet Office 2003), there were 346,000 registered people in 2002 with hearing impairments sufficient to receive social welfare benefits. Japan has different classes of registered disabilities. Class 5, the lowest level, involves hearing loss of 80 dB in both ears, while a Class 1 or 2 severe disability is complete hearing loss in both ears with concomitant communication impairment. The total population of Japan in 2003 was 126,139,000; thus, “hearing-impaired” persons represent 0.27 percent of the populace. The way the government structures this part of the welfare system, elderly persons who lose their hearing primarily for age-related reasons do not generally register as hearing impaired.

During my field period, everyone I met who had a severe enough hearing impairment to cause communication issues with hearing people carried the government disability ID (shōgaisha tectō). Registering as hearing impaired with the local welfare office and receiving the ID card makes you eligible to receive a large range of social benefits including a significant disability pension (over $1,700 per month for people with severe disabilities in Tokyo); discounted medical equipment; free municipal transportation; discounted travel on national and municipal railways and national highways; and discounts on a broad variety of public and private services. Even the most adamantly culturally Deaf leader of D-Pro, when I interviewed her in 1997, admitted that she was registered, carried the tectō, and received the monthly pension.

The opposite is not true. Just because you carry the tectō disability ID card does not mean that you sign or that you are part of the deaf community. It only means that you are classified as having a significant hearing impairment or other disability. Compared with governmental or organizational statistics, the number of “native” signers is much less clear. This is because we cannot precisely define the boundaries of Japanese

5. We could stereotype a “hearing accent” in both Japanese Sign and ASL as including: following the spoken grammar form rather than making use of the gestural/spatial potential; clumsier transitions between signs; greater focus on discrete words, adjectives, and adverbs rather than sign classifiers and gestural/facial markings of size, speed, or distance; chronological discontinuities in storytelling; less repetition and less use of chaining.

6. Even if the school is strictly oral and forbids sign language, the children almost always use some form of signing when communicating with each other. In oral schools, this is seen as a matter of grave concern.
Sign, and whether those who are hard of hearing or late-deafened, for example, can be said to be using it. As of 2001, approximately 20,000 hearing people passed the JFD affiliate-run sign training courses and there were over 6,000 registered interpreters for the deaf in Japan.

The number of members in the Japanese Federation of the Deaf (which allows only people who are deaf to join) was 25,518 in 2003 (JFD 2004:113). While we can make the assumption that nearly all members of the JFD can sign, not everyone in the JFD signs the same way; some sign while at the same time simultaneously speaking in Japanese, using a temporal/sequential grammar; others turn their “voices off” and sign without voicing, using a signing form that makes heavy use of spatial/simultaneous grammar forms. There is no precise division between these two forms, and for the most part they are mutually intelligible. I will resist, for the most part, the tendency to label the latter form “true JSL” (hontō no Nihon shawa) and the other just “Signed Japanese” (Nihongo-tai shawa) as this is precisely the topic of later chapters. The most I can say is that more than 25,000 and perhaps less than 400,000 people use sign communication in some form in their daily life activities in Japan.

Sign Linguistics and the History of ASL

The American scholar William Stokoe is often referred to as the founding father of sign linguistics (it must be stressed, not sign language). A professor at Gallaudet University in the 1950s and 60s, he noticed an apparent structure to the sign communication among his deaf students. At that time, signing was thought to be merely a form of mimicry or a derivative/broken form of English. Stokoe brought linguistic analysis to bear on signing and, to his astonishment (and that of the rest of the hearing world), discovered that sign communication was a natural language system with a very different structure from spoken English. He gave it the appellation “American Sign Language” to make it clear to other linguists that a language system was involved (Stokoe 1960).

Stokoe set up the basics of sign linguistics. He noticed that in sign languages there were parallel analogues to phonemes, morphemes, lexemes, grammar, and pragmatics. For example, in ASL there are basic handshapes (phonemes) that make up component, meaningful parts of words (morphemes) such as the word ending -PERSON used to sign things such as TEACHER or WAITER. Stokoe discovered that morphemes also have a spatial dimension; for example, the temple area of the head signifies MALE while the cheek area signifies FEMALE in ASL morphology. Other researchers continued his analysis of the syntax and pragmatics of sign languages. It quickly became apparent that this was a totally new and unexplored area of linguistics.

ASL is an amalgam of French Sign Language (brought by the Deaf educator Laurent Clerc), modified French initial sign forms (what we would call today Manually Coded French/English), and the native, local, and home sign language systems used by deaf children in the United States before Thomas Gallaudet founded the first school for the deaf in Hartford, Connecticut, in 1817. The graduates of Gallaudet's school went on to become educators of the deaf themselves, spreading across the country. This development is often cited as the reason why ASL is relatively uniform across the United States, and indeed we do see relatively little regional variation. However, we have to remind ourselves that this is a constructed story line that centers a pure and unchanging ASL in the narrative. Owen Wrigley puts it as follows in the preface to his Politics of deafness:

Rather than search for the origins of Deaf culture and the fall from grace of sign language, which is the hagiographic frame of Harlan Lane's dominant study, Foucault would have us recognize that “History teaches how to laugh at the solemnities of the origin.” He calls on Nietzsche in reminding us that the “lofty origins is no more than a meta physical extension which arises from the belief that things are most precious and essential at the moment of their birth.” (Wrigley 1996, xvii)

Wrigley is referring to the American deaf studies historian Harlan Lane's singular focus on the contributions of particular American and European educators and leaders: Thomas Gallaudet, Laurent Clerc, Abbé de l'Epee, Abbé Siccard, and others. Traced this way, American deaf history gains a particularly singular teleological course: from l'Epee, to Siccard, to Clerc, to Gallaudet, in a manner reminiscent of the Catholic lives of the saints. This hagiographic method ignores the widespread political, social, and linguistic variation in the community as well as the contributions of many other people who were not in leadership positions.
We can read elements of the contemporary cultural Deaf movement in the United States as resistance to this hagiography of elite, well-educated men. The recent blooming of the cultural Deaf movement has centered the “deaf-of-deaf”—the deaf children of deaf parents—as the core elements of Deaf culture, the bearers of the purest and most beautiful ASL, the sign poets, the storytellers, the leaders, and the political activists. In this counternarrative, the deaf-of-deaf served as the protectors of Deaf culture in the United States during the long period when it was pushed underground, between the Milan Congress of 1888 and the rediscovery of Deaf culture and ASL in the late 1960s (cf. Lane, Hoffmeister, and Bahan 1996; Preston 1994). ASL and cultural Deaf values are passed down, mother to child. This version foregrounds the contributions of working-class deaf people against Lane’s hagiographic frame that centers on the educated and privileged. Read this way, the story of the purity of the ASL lineage is also one of class struggle (Monaghan 2004).

The language mythology of a singular ASL is sustained in part by the American construction of cultural Deafness that excludes the hard of hearing, orally deaf (that is, deaf people whose primary form of communication is speech and speechreading), and late-deafened. These deaf persons, while they may use ASL-related sign communication forms, are specifically excluded from inclusion as “Deaf” or the recognition of their signing as “ASL”—for example, Heather Whitesone, a former Miss America who is orally deaf (she does not sign except on stage), and I. King Jordan, the first deaf president of Gallaudet University (installed after the DPN movement in 1988), are both late-deafened. Neither is considered real “Deaf” by the “Deaf militants,” to borrow Crushkin’s (2003) phrase, nor are they said to sign ASL. Instead they are somewhat dismissively said to use “pidgin sign English” (PSE) or “Manually Coded English” (MCE). It is easy to claim language and ethnic/cultural homogeneity when one is willing to exclude outliers.

In Japan, there has been no similar veneration of the deaf-of-deaf until very recently with the D-Pro generation. None of the leaders within the JFD, famous sign poets, or rakugo storytellers have been deaf of deaf until the last decade. As the story of the deaf community in Japan develops, we will see that the struggle between the JFD and D-Pro is not only generational but also linguistically bound with similar but different aspects of class distinction.9

The Origins of Japanese Signing

Unlike the American case, no one is quite sure where Japanese signing came from.10 Japanese Sign is unrelated to sign language forms used in the United States, Europe, or China. There are some similarities between Korean and Taiwanese Sign Languages and Japanese Sign, but this has been attributed to the colonial period rather than pre-modern languages of transport.11 There are no founding language fathers such as Thomas Gallaudet or Laurent Clerc within the Japanese deaf community. There are some important contributors, such as the founder of the first school for the deaf in Japan, Furukawa Tashiro. But they are not credited with creating Japanese Sign or even standardizing it. For the most part, signing in Japan is best described (and is seen by deaf persons there) as an autochthonous language. The title of the JFD’s series of sign books sums up this perspective nicely: wasaki-tachi no shura or Our signs.

What we can deduce is that before the Meiji period began, a hundred and forty years ago, there was very little sense of a unified Japanese sign language (Kanda 1989:371).12 Natural sign languages typically form around schools for the deaf, as these provide the ideal conditions of communities of deaf children. Sociolinguistic research done in Nicaragua (Senghas and Kegl 1994; Senghas 2003), for example, has shown that a

9. Judy Kegl writes in the production notes for BBC TV’s Silent Children, New Language (BBC TV 1997) that there were no deaf-of-deaf and very little genetic deafness in Nicaragua until the advent of schools for the deaf. This is because deaf individuals were segregated in their houses and not allowed to marry—very similar to the situation in Japan until the advent of compulsory education.
10. Okamoto (2000) has an innovative foundation theory based on a correlation between sign handshapes and Kanji. This has not yet been broadly accepted by other sign scholars. The cultural critic Donald Richie writing informally in a 1956 essay published in his 1992 collection, A Lateral View, notes how culturally embedded Japanese gestures are, then gives as examples a series of gestures familiar to any Japanese signer (thumb referring to men, little fingers as women, and others). Japanese culture is certainly rich in its gestural vocabulary, especially within its many niche segments (fishermen, sushi chefs, gangsters, and the like). I am not aware of any studies that have yet explored these specialized gestural systems and their impact or influence on Japanese signing.
11. For more information, see JFD (1994). This report notes that although the older generation uses a sign form that is still reminiscent of Japanese signing, the authors cannot see that same influence in the new generation of younger signers.
natural sign language (that is, one complete with its own syntax and morphology) appeared within a few decades of the founding of a school for the deaf. Before that time, there were only home signs, incomplete sign language systems used in the homes of families with deaf children.

Unless there is a genetic disposition toward deafness within a closely bounded community, the natural level of hearing impairment within a population (often less than 0.5 percent) is not a sufficiently critical mass for a language community to form in rural areas. The process of modernization, with its shift toward great population densities, greater incidence of epidemic influxes, and improved infant mortality (the diseases that used to kill children now are survivable, though sometimes with deafness as a result) bring larger numbers of deaf children together and help create deaf communities. Thus industrialization and urbanization are necessary components for a deaf social identity to develop.

The first school for the deaf in Japan was founded in 1875 in Kyoto by the aforementioned Furukawa Tashiro. Prior to founding the school, Furukawa saw deaf children signing outside the window of the prison cell where he was temporarily detained for forging documents related to a peasant protest. This was one of his inspirations for using signing in the classroom when he founded his school. His observation provides some evidence for the early existence of signing in Kyoto. Unfortunately, soon after it opened in 1875, the Kyoto School switched to an oral form owing to the global effects of what is called the Milan Conference (1880), an international meeting in which hearing teachers at schools for the deaf unilaterally decided that oralism was to be the main method of deaf education. Deaf teachers were not invited to attend (Van Cleve and Crouch 1989).

Looking at elderly deaf who grew up in Japan before the Pacific War, we see only limited evidence of a unified national sign language system prior to the 1940s. Teachers of the deaf had founded a few regional schools, but only a small portion of the deaf population was able to attend. For example, Nakano-san, whom we will meet in chapter 4, went to school only for a year. She is fairly typical. As a result, she and many other deaf persons born before the war tend to use a sign language composed of an amalgam of home signs, local signs, greater use of classifiers, and otherwise nonstandard sign forms. Their sign grammar departs even further from spoken Japanese than current signing. As a result,

very few people (mostly deaf adults who are in daily contact with these individuals) can communicate smoothly with them.

That the older deaf people do not use a standard signing is not surprising, because there was little social or political pressure for a single national sign language before the war. The Japanese government was not a unifying factor, as it did not recognize the use of sign in schoolrooms until the 1950s. The Japanese Federation of the Deaf, which encouraged social activities among local and regional deaf groups, had much more impact on language unification in the postwar period. It is through these social activities as well as movement of people from rural to urban areas that the various types of signing in Japan begin to consolidate.

After the end of the Pacific War the American Occupation Forces mandated compulsory education for all Japanese, including the deaf and blind. Schools for the deaf sprang up all over Japan, at least one in each prefecture. While signing was officially not permitted in these schools, ancillary effects happened. First was the conglomeration of children who had never met other deaf children before. It has been well documented in sign linguistics that natural (sign) languages emerge in this type of situation. After the first cohort graduated, they created alumni groups, centering deaf community life around the schools.

The Japanese Federation of the Deaf drew much of its strength from these alumni associations. Although it was not very politically active until the 1960s, the nascent JFD served a crucial socializing role. The annual Deaf Meeting was a huge attraction (and continues to be so), drawing members from all across Japan. The location of the meeting rotates among the 47 prefectural organizations and usually draws 2,000-4,000 people. For many, it is a time to reconnect with friends, travel, and see Japan. This central purpose has not changed over its fifty-year history.

Nevertheless, there was no central institution that served to homogenize Japanese signs for most of the modern period. There was no Gallaudet University churning out deaf teachers and professionals, serving as the ivory tower from which new knowledge and new signs could disseminate; nor was signing broadcast widely on TV until the 1990s.

13. Jill Morford (1990) has an excellent review essay on home signs and language acquisition.

14. The Ministry of Education still does not recognize sign language as a valid form of educational communication in elementary schools. It has not developed any special curricula for schools for the deaf at any grade level. The ministry has, however, "accepted" that use of sign language may be necessary at the middle and high school levels.

15. The first national deaf meeting was held in 1906; the first deaf association was formed in 1913 as the Tokyo Deaf Club. The Japanese Association of the Deaf formed in 1916. A large cadre of the original members came from the alumni groups of the Kyoto and Tokyo Schools for the Deaf, the two oldest schools in Japan.
only homogenizing forces were the school systems, which could standardize signing only at the local level, and the admixture of individuals at JFD meetings. This changed starting in the 1960s, as the JFD became more interested in codifying the lexicon, teaching interpreters, and otherwise standardizing the vocabulary of Japanese Sign.

But even now, Japanese Sign is a relatively diverse language system. Despite the JFD’s best efforts, the lexicon is not standardized. Even relatively basic words such as STUDENT and NAME differ from Sapporo to Tokyo to Kyoto and among signers. There are at least three main variant ways to sign “Deaf”: one brings the open palm from the ear to the mouth; a second uses the index finger (much like the ASL “DEAF”), and the third has the dominant palm cover the ear while the non-dominant palm covers the mouth. There are also synonyms in use such as mimi ga kikoeru (“ears can’t hear”), which has the dominant palm waving toward the ear.

The hand of hearing or nancha is given a particularly descriptive sign: an open palm splits the face in two. This is similar to the sign for half, referring to Japanese with mixed ancestry. Although deaf politics are constructed differently in the United States and Japan, the liminal position of the non-signing hard of hearing is the same.

In addition to the variations in the actual signs used, there are also visible regional differences in grammar and syntax. Although the various strains of sign remain mutually intelligible, I have noticed that two signers from different regions will often drop down into a register that more closely approximates spoken Japanese grammar concomitant with verbal mouthing, in order to facilitate the use of speechreading to aid the sign communication.

For example, Tochigi Prefecture just north of Tokyo is often cited as having a very different sign language than the rest of Japan. The lexicon used there is relatively consistent with other regions, but the grammar system is different. Twenty years ago, Tanokami Takashi, a hearing teacher at the Tochigi Prefectural School for the Deaf (the only school for the deaf in Tochigi) introduced daichi, simultaneous signing while speaking. He borrowed this system from Britain in order to improve the understanding of spoken Japanese among the students at the Tochigi

16 For right-handed signers, the dominant hand is the right hand and the non-dominant hand is the left. The reverse is true for left-handed signers (although many will sign “right handed”). However, many signers will switch hands in various circumstances, for example, when text messaging with a cell phone or driving.

School. Several generations later, the Tochigi students, now adults, still sign with a strong Japanese grammatical influence.

Unlike signers in other areas, Tochigi deaf people in their forties and fifties use a sequential syntax (words have meaning because of their word-order placement), and they use sign words or fingerspelling conjunctions, prepositions, and topic particles (“ha” in “kore ha pen desu: this topic is a pen.”) Signers from outside Tochigi, in contrast, tend to drop both prepositions and pronouns, either relying on the pragmatics of the conversation to carry the meaning or using a spatial/gestural indexical relationship (pointing to an object, and signing “PEN” to indicate that this is a pen).

Other Japanese deaf persons complain that they cannot understand Tochigi dialect signers. This perhaps has more to do with politics than with reality. The signing used in Tochigi is indeed different in that it follows Japanese spoken grammar and syntactical structures more closely than other dialect forms, but within the grand scheme of dialects of Japanese Sign it certainly does not seem different enough to render it mutually unintelligible. Instead, Tochigi Prefecture is engaged in complex lan-
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Language politics. Tokyo residents see Tochigi as a rural backwater, and the Tochigi dialect of spoken Japanese is considered country bumpkinish. This metropolitan snobishness carries over to Tochigi signing, which is considered awkward and strange.17

Language codification requires political power. In the case of the deaf this would mean either the establishment of schools that all use the same sign language, or the development of deaf cultural institutions that have the power to define the bounds of sign language. Neither of these exists yet in Japan. Only in the last ten years has a unified sign dictionary emerged (Yonekawa 1997), and preliminary attempts are just being made at codifying the syntax (Matsumoto 2001).18 There is a wide variance of vocabularies in local dialects as well as different syntactic systems in use, ranging from those in perfect alignment with spoken Japanese to those that use a spatial-temporal grammar.

Unfortunately, the main Japanese Sign lexicon remains relatively small. The aforementioned comprehensive sign dictionary published by the JFD in 1997 has only 4,500 individual signs. One major reason for this remains that signing is not widely used in classrooms. While many high schools for the deaf use sign informally, there is no formal usage at the secondary school level. Signing is not used at the college level either, and there is no central institution such as Gallaudet University where seminars are conducted at the undergraduate and graduate level, a situation in which new signs and specialized vocabularies are created by necessity.

One method of compensating has been the use of Kanji signs, signs representing Chinese characters for technical terms. For example, anthropology (jiritsu) is signed using its three component Kanji signs: HUMAN-VARIATION-STUDY. However, unless the listener is conversant in spoken Japanese, can speechread the pronunciation, or has encountered the term before, this string of Kanji signs is incomprehensible.

In her (1995) ethnography Do you see what I mean?, Brenda Parnell

17. Non-deaf (hearing) Japanese play the same language games. Much is made of Japan's cultural homogeneity, which ostensibly includes language. Yet at the same time, language is used to reinforce difference and centrality, for example, during NHK (public television) documentaries about the northern regions of Japan. The dialogue of residents is often open-captioned (subtitled) because their speech differs from standard (Tokyo) dialect. The U.S. equivalent of this would be PBS subtitling. Remarkable, however, is the Southerner because Northerners would not understand. In the 1966 movie Tatsubugai, a novel (mis)translated, to comic effect.

18. In contrast, the Gallaudet "Green Book" series (Baker-Shenk and Cokely 1980) has long served as a technical description of ASL and a teacher's guide to teaching the grammar.

poses questions about the narrowness of Western concepts of language by expanding the definition of language to include gestural and performative aspects. In Japan, the question of Japanese signing's language status has been ignored by all except D-Pro, who are using it toward the particular political goal of redefining deafness into cultural Deafness. They are doing this by codifying Japanese Sign Language grammars and attempts at a "pure JSL," which de-center the late-deafened and hard-of-hearing college-educated elites who dominate the leadership of the JFD.

The JFD's official position has been that "Japanese Sign (Nihon shota) is . . . the type of signing used by deaf persons living in various parts of Japan" (JFD 1998b:2). In other words, if you are a deaf person living in Japan and you sign, you are using Japanese Sign by definition. There has been resistance in the JFD leadership and membership to narrowing this tautological definition any further. In a pivotal essay, in contrast to a specific definition of Japanese Sign as only those forms of signing that do not involve synchronous mouthing, JFD leader Matsumoto Masayuki writes:

Establishing a definition for the term Japanese Sign (Nihon shota) is difficult because of the linguistic and social problems relating to the question of what the Japanese language (Nihongo) itself is. If you characterize the Japanese language as "the forms of language (kotoba) used in Japan (both past and present)," then Japanese Sign could also be conceived as part of the Japanese language (with the spoken language consisting of one form and signing another form of the Japanese language as a whole). . . .

Defining Japanese Sign as "only the type of signing that does not involve mouth movements," is based on the same principle as establishing the Tokyo dialect as the common language (standard Japanese [hajugung]), in contrast with other regional dialects . . . It all boils down to how you want to define the term "Japanese Sign." (1997b:4)

Here, Matsumoto underscores the JFD policy of blurring the difference both between the Japanese language and Japanese Sign and between the variations of Japanese Sign that are closer to or further from spoken Japanese grammar (in that they use mouth movements or not). In line with this, the main focus of the JFD's linguistic efforts in the 1980s and 1990s was to codify the lexicon and to introduce new vocabulary words to match new or existing terms in spoken Japanese. Almost no effort was made in syntactic analysis until the end of the twentieth century.

The avoidance of syntax is deliberate; syntax, more than anything else, is divisive. It divides both Japanese Sign from spoken Japanese and tra-
ditional signing from manually coded Japanese. It splits the deaf community from the hearing, and the hard of hearing from the deaf of deaf. That is why the JFD avoided focusing on grammar and syntax in order to build their mass movement and why D-Pro seized on it as central to their notion of cultural Deafness and pure JSL in order to differentiate themselves from the previous generation.

To get to the roots of this emerging language war between the JFD and D-Pro, we must start at the very beginning. The next several chapters examine the history of the deaf in Japan and explore the lives of five deaf women through their own words. Then we will return to the issue of Japanese Sign Language.
The staff of the Japanese Federation of the Deaf (JFD) was unwinding at the end of a long workday. The headquarters of the largest association of the deaf in Japan had about fifteen employees crammed into the eighth floor of a small office building in central Tokyo. The majority of the senior staff was deaf, while about half of the junior and part-time staff members and interns (including myself) were hearing. The chief of the Tokyo office, Ohno, Yoshiko, had been a longtime activist in the JFD's women's division. In her sixties, she was known, loved, and feared for her forthrightness and spunk. Although she herself was deaf, Ohno, often vocalized while she signed to make it easier for her hearing employees to understand what she was saying.

One of the JFD members from the outer metropolitan area had dropped by with some snacks, and we were enjoying them while he told us stories about what was going on in his local association. He had recently gone to a lecture organized by a new deaf organization called D-Pro, which had a core group of young activists. In a series of talks and publications, D-Pro was insisting on a separatist deaf identity with a unique sign language and cultural orientation different from mainstream (hearing) Japanese. They were promulgating a notion of a pure Japanese Sign Language (JS) - an exclusionary position counter to the one espoused by the JFD, which was arguing at the time that Japanese Sign was any sign form used by any deaf person in Japan.

Under the D-Pro model (and the American cultural Deaf model, which D-Pro drew from), deafness was a quasi-ethnic status. The pure deaf were those who were born to deaf parents and for whom signing was their first language. The next purest were those who were born deaf and attended schools for the deaf at
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an early age. Those who were late-deafened or had not gone to schools for the deaf were not truly deaf in this model, but only "hard of hearing." At the lecture, the D-Pro speaker apparently disparaged the JFD as a "hard-of-hearing organization (manchōsha dantai)" and the signing used by JFD members as an impure form of sign mixed with spoken Japanese.

Ohtsuki-san listened to this narrative with visibly growing irritation. Finally, in anger at D-Pro's attempt to disqualify both her identity and her signing, she blurted out in sign, "THAT'S SIGN FASCISM!"

As usual, Ohtsuki-san spoke out loud at the same time she signed this, so according to D-Pro, even in her moment of ultimate exasperation she was not signing pure JSL; further proving she was not really deaf, but one of those "hard-of-hearing" masqueraders.

This book is the story of three generations of deaf people in Japan and how the shifting political, social, and educational environment of the last century shaped their lives. The development of schools for the deaf and the birth of politically active organizations of the deaf during this period profoundly affected the types of friendships, social networking, jobs, political outlooks, and marriages possible for each cohort.

My central thesis is that the social and institutional history of postwar deaf communities in Japan enabled an unusual form of personal and mass organizational identity politics to emerge in the 1970s and 1980s. Articulating signing as a different mode of communication and not a fundamentally different language from spoken Japanese, the center-left Japanese Federation of the Deaf co-opted discourse surrounding social welfare policies in Japan for the benefit of its members. However, just as certain historical forces created a generational cohort that accepted this assimilationist message, subsequent changes in deaf education and etiology have caused a new, more radical separatist generation to emerge in the late 1990s.

We cannot assume that identities based on biological categories such as disability are any more stable than those based on ethnic categories. All such categories are socially constructed and historically specific. For example, unlike many of the ethnic minorities in Japan (Ainu, resident Koreans, and Chinese, for example), the JFD argues for a fundamental Japanese-ness. In this regard, they are similar to kikokushijo (returnee Japanese, the group to which I belong); some mikkeijin (Brazilian-Japanese); and the more assimilationist front of the Burakumin former outcaste movement. But all of this must be set against the context of generational changes within the deaf community. The younger generation represented by D-Pro argues that they are profoundly non-Japanese in language and culture and instead are members of a global Deaf culture and community. In this way, they are similar to factions of the Ainu native movement who argue that they are part of a global First People's struggle and are not ethnically Japanese.

This book takes us through the various shifts in the deaf community over the past hundred years. While there has been great interest in the history of minority social movements, much of it has unwittingly become hagiography (literally, the lives of saints), as authors tend to focus on the elite leadership of the groups and not the general membership. I have tried to avoid this by balancing the history of deaf schools, political organizations, and movement leaders with the life stories of five rural deaf women whose experiences span almost the entire twentieth century.

The first woman is "Nakano Shizuyo," who was born in 1913 in the northern edge of Kyoto Prefecture. We explore her story in chapter 4. Because her family was poor, Nakano-san was able to attend only a year of informal education at a local "temple school." Her parents forbade her from marrying, she never had any children, and she was largely secluded from the outside world until her forties, when Japan was in the process of recovering economically from the Pacific War. At about the same time, the nascent JFD was gaining prominence as the representative organization of the deaf in Japan. It was at this point that Nakano-san began to see more of the world outside of her small village through her local deaf association, an affiliate of the JFD.

Regional associations of the deaf such as the one she belonged to in northern Kyoto Prefecture sprang up in the 1950s and provided many essential community functions. By hosting drinking parties, hikes, picnics, barbeques, hot spring tours, and other social events, the local associations created a separate, parallel version of mainstream Japanese society for their members. Participating in this parallel society helped sustain the feeling within the deaf community that while they might be socially isolated from the mainstream, they were still Japanese at heart.

It is in this complex postwar environment that the second cohort of postwar deaf women emerged. Three life stories from this generation are presented in chapter 6. The first, Sano Hiroe, was born in 1926. As compulsory education for the deaf was only instituted in 1948, Sano-san had
a bare years of schooling, but even then her life course was much different from that of Nakano-san. Sano-san was able to work freely outside the home, marry a deaf man, and have children. These are experiences she shares with the other women in this group, such as Horikawa Hiro (born in 1946), who went on to lead the Women's Section of her local prefectural association of the deaf. The youngest woman in this cohort, Funata Hatsuko (born in 1951), attended school for twelve full years, but her hopes for college were dashed when her high school counselor told her that no college would accept a deaf applicant and that she should become a hairdresser instead. Struggling against social discrimination such as this, she managed to get a factory job, marry, and raise a son.

The director of the Tokyo office of the JFD who blurted out, "that's sign fascism," is a scandal out of this middle generation, as is most of the senior staff and leadership at the JFD. The movement she grew up in profoundly shaped the worldview of the director, Ohtsuki-san. Her deaf politics are inclusive—to her anyone who is hearing-impaired is deaf—and her sign language politics are equally encompassing. She has no tolerance for those who would criticize other deaf persons because their signing is too much like spoken Japanese. That is because in her mind being deaf and being Japanese are not contradictions.

This brings us to the youngest and most recent cohort of deaf people. Starting in the 1970s, deaf children in Japan were encouraged to mainstream, attending their regular local schools rather than residential schools for the deaf. They were taught to speakread and speak orally rather than to sign. This resulted in a generation of children who grew up not identifying as deaf and not using sign as their primary communication method. Ironically, in college many of these students became attracted to the notion of a cultural deaf identity and vibrant deaf culture espoused by American Deaf activists. The more radical ones formed groups such as D-Pro and sought to wrest control of Japanese Sign Language away from the JFD.

The subject of my final biographical chapter grew up in this mixed environment. Born in 1980, Yamashita Mayumi went to a kindergarten for the deaf, but was mainstreamed from first grade until she graduated from high school. Although like many in her generation, she did not have a strong sense of herself as deaf and could not sign, she ended up choosing to go to the only college for the deaf in Japan. There she learned how to sign and gradually became more aware of her identity as a deaf person. After graduation, she returned to the deaf community, this time as a teacher at a school for the deaf in Tokyo.

Postwar Deaf Political Activism

Up through the end of the 1970s, deaf people in Japan had few legal rights and little social recognition. They were classified as legal minors or mentally deficient. They were unable to obtain driver's licenses, sign contracts, or write wills. Many deaf men and women worked in factories or as beauticians, printers, shoe-shines, or dental technicians, or were simply unemployed. Schools for the deaf in Japan taught a difficult regimen of speechreading and oral speech methods and vocational skills. Very few graduates were able to attend college. Even by the mid-eighties, deaf persons were rarely seen signing in public. The dominant social/legal attitude toward the deaf dictated that—like other minorities in Japan—deaf people should try as hard as possible to assimilate even if societal discrimination in employment and marriage made such homogenization difficult.

The 1980s was a decade of much political mobilization behind the scenes. The United Nations declared 1981 as the first International Year of Disabled Persons. Many nations, including Japan, enacted legislation in response to this. After that, the UN realized that a single year for disabled persons would not yield the results they wanted, so they declared 1983–1993 as the International Decade for Disabled Persons. This prompted further political mobilization from the disability lobby in Japan, responses by politicians, and legislative activity. For the most part, however, the largely political and legal changes that occurred in the 1980s were not visible to those who were not part of the politically active disability community.

Through this period, the Japanese Federation of the Deaf was the leading national political and social organization for the deaf in Japan. It mobilized the protests, lobbied the politicians, organized the petition drives, oversaw the interpreter-training programs, published sign dictionaries, and even built a nursing home for elderly deaf residents. Infused with a new leadership who had come of age in the postwar period, the JFD adopted a collaborative approach to working with the Japanese government.

Called "participatory welfare" (sanka fukushi) by one JFD leader, their strategy involved working with the government in providing resources to the deaf community through grants and contracts. Their politics deemphasized the linguistic differences between Japanese Sign and spoken Japanese and highlighted the social responsibility of well-bodied Japanese to help their own (that is, disabled Japanese) through increased social welfare services and local volunteerism. These inclusive and as-
simultaneous politics derived from the experiences of the middle generation of deaf described above.

The past decade and a half alone has seen much change. In 1989, after the death of Emperor Hirohito and the end of the Showa era (1926–1989), the Japanese scholar Kanda Kazuyuki presciently wrote, “this year, the first year of the Heisei era, has the potential to be the first year of rapid [deaf] social change (1989:30).” That prediction turned out to be true. During the 1990s, the public television network NHK regularly broadcast a Japanese sign–interpreted news hour and hosted a weekly educational program named Signing for Everyone. There have been at least three hit mini-series on television with deaf characters. Instructional sign courses and seminars became very popular with housewives eager to become volunteer sign interpreters.

Comic books that taught signing became trendy among (hearing) Japanese students. Companies began slowly hiring deaf people in nonmanual labor positions and holding workshops for their hearing co-workers to ease the transition. The World Federation of the Deaf held a massive international congress of the deaf in Tokyo in 1991. These visible changes were accompanied by other social and legal shifts. In 1993, a major revision of disability law in Japan was passed. Several schools for the deaf began openly experimenting with signing in the classrooms. By the end of the 1990s and the beginning of the new millennium, the deaf community was in the public spotlight.

The JFD was a major force behind this transformation, and we need to understand how they pushed for it. Political arguments for social change can take several different forms: human rights (rights that accrue to us on the basis of being human); civil rights (rights that accrue to us on the basis of being a citizen of a particular nation); ethnic diversity rights (recognition of the linguistic or cultural needs of minorities); and so forth.

The model that the postwar JFD leaders promulgated was a mixture of civil and disability rights. First, they stressed that deaf people in Japan were quintessentially Japanese with all of the linguistic, ethnic, and cultural markers of mainstream Japanese. They argued that because of a physical impairment as well as the social discrimination, Japanese deaf persons were not able to achieve full parity with the mainstream in education, employment, or social integration. Thus, it was the responsibility of other Japanese, via the government, to ameliorate the difference through social welfare benefits, hiring quotas, and awareness education.

In many ways, we can view the JFD-led deaf movement as one of the new successful minority social and political movements in Japan. In the mid-1990s, however, a new generation of deaf activists emerged who relied on a very different model of social change, based on American minority identity politics and linguistic separatism.

Minority politics in the United States is unique because of the availability of the powerful and articulate frame of ethnic multiculturalism. In America, new groups such as “Somali-Americans” or “Hmong-Americans” are immediately recognized as being part of the same domain as Hispanic-Americans, African-Americans, and Japanese-Americans. Members of new immigrant groups are understood as being entitled to bilingual language support in the classroom, minority civil rights, or protection under anti-discrimination laws without having to argue for this status. In Japan by contrast, it has been very difficult to argue for a “Korean-Japanese” identity since there is no general recognition of the existence of ethnic minorities.1 In sociological terms, there is no frame for ethnic minorities in Japan. Within recent years, various social scientists in anthropology, political science, and sociology have begun to look at the intersection of language, identity, and politics in contemporary social and political movements and the role that these framing narratives play.2

Once frames such as ethnic multiculturalism are established, it is easy to extend them to include other nonethnic categories. For example, the American gay/lesbian movement has articulated itself as part of the multiculturalism frame. The rainbow flag of the gay and lesbian movement mirrors the rainbow colors of ethnic diversity. Gay bashing is a federal offense under the Hate Crimes Statistic Act of 1990, along with other violent crimes motivated by race, religion, national origin, and ethnicity. In other cultural contexts, it is not obvious that being attracted to people of the same sex or gender has anything in common with being a member of a minority ethnic group. Nor should it be. These types of frames are created and extended by social activists, not discovered.

The deaf political movement in America has leveraged the multiculturalism frame to great effect. Founded in 1864, Gallaudet University in Washington, DC, is the world’s first and only four-year college for the deaf, but up until 1988 it had never been led by a deaf president. Students during the 1988 Deaf President Now protests at Gallaudet argued that they

1. Legacies of Japan’s colonial expansion in East Asia during the Pacific War, ethnic Koreans in Japan are referred to as zainichi Koreans, or resident Koreans. Volumes have been written on this; see Ryang (1997) or Fukukawa (2000).

2. Erving Goffman’s original formulation of a frame as an “interpretive scheme that simplifies and condenses the ‘world out there’ by selectively punctuating and encoding objects, situations, events, experiences, and sequences of actions within one’s present or past environment” (Snow and Benford 1992:137) has been extended into the field of mass social movements by a number of scholars (Gillin 1990; Melucci 1980; McAdam 1994; Morris and Mueller 1993; Larraza, Johnston, and Gusfield 1994).
Sign Language, a language that is distinct from the Japanese language. The previous perspective was that “Deaf people” equaled “People who can’t hear”—a biomedical disease model that focuses on impairment. This is changing to a new perspective of “Deaf people” equal “People who use Japanese Sign Language as their daily/normal language”—namely, a social-cultural one. (Kimura and Ichida 1995:354)

This manifesto highlights the differences between Deaf culture and hearing culture in Japan. It stresses the importance of language within the Japanese deaf community and the development of a separate “Deaf culture” (kō bunka), drawing on ethnic minority positions espoused by American Deaf activists (cf. Padden 1980; Padden and Humphries 1988).

D-Pro’s Declaration borrows American deaf studies scholar Harlan Lane’s concept of the Deaf as a colonized people without a country. The capital D in Deaf here symbolizes a strong cultural minority identity and primary relationship with signing. But while the plight of deaf students in Japanese schools is comparable to those of other linguistic minorities in Japan, no mention was made in the D-Pro Declaration of resident Koreans, Chinese, Okinawans, or Ainu. Instead, an early article in their newsletter D compared deaf discrimination to the oppression of lefthanded individuals (May 1, 1992).

Here, the leaders of D-Pro had a problem. As mentioned before, a broadly successful, identity-based “new social movement” (Melucci 1980: 1994) using an ethnic minority frame is nonexistent in Japan or at least invisible. There are certainly many minority groups: the Burakumin, a former outcaste group; the Koreans who were brought over as forced laborers during the colonial period (1920–1945); the Ryukyuan/Okinawan who were forcibly annexed by Japan; and the Ainu, who are the aboriginal residents of northern Japan whose lands were occupied and colonized by the Japanese beginning in the eighteenth century. But there is no extant notion of an active “Burakumin culture”; there is no emergent Korean-Japanese culture discussed positively in the mainstream press; Okinawan nationalism is largely ignored by mainland media; and the Ainu native culture

4. Following standard notation in American Deaf studies (Woodward 1972; Padden 1980), “Deaf” (with a capital D) indicates people who identify with “Deaf culture” and “Deaf politics” and who use sign language as their primary language; lower-case “deaf” indicates individuals who are audiologically deaf. Neither implies the other, and so one can be “deaf” without being “Deaf”, for example, elderly people who become late-deafened are not usually considered Deaf.

5. This has changed slightly in the past few years with the emergence of a new generation of resident Koreans. The “Korea boom” (hanyūshū) in Japan with the popularity of dramas such as The Winter Sonata starring Bae Yong Jun—who is known in Japan as Yon-sama or “Lord Yong”—may yet prove to be more than just another short-lived fad.
(while still alive) has been encased behind museum glass in the popular consciousness. This underscores the powerlessness of the ethnic minority frame in Japan, not the lack of minority groups in general.

Former Japanese prime minister Yasuhiro Nakasone famously declared in September 1986 that the United States was a “less intelligent society” with its “blacks, Puerto Ricans, and Mexicans” compared to mono-ethnic Japan (Wetherall 1993:3). Although Nakasone was not the brightest politician Japan ever produced, most Japanese on the street would blink uncomprehendingly if asked about Japan’s ethnic minorities (shishō minzoku). The absence of a prevalent ethnic model has existed in large part because the Japanese government has actively subdued ethnic identities since the turn of the nineteenth century in the name of national unity. For example, early in Japan’s colonial phase, the Ainu had been forced, under such laws as the Hokkaido Former Aborigines Protection Act (1899), to adopt Japanese names and to abandon the Ainu language and customs. This same pattern emerges for Okinawans and resident Koreans as well. This suppression of minorities was not unique to Japan; in many ways Japan borrowed both the concept and implementation details from the United States and European colonial powers.

This unrelenting pressure to assimilate resulted in many second- and third-generation Koreans, Okinawans, and Ainu no longer identifying as such or even aware of their ancestry. In a 1995 nationwide poll, 99 percent of respondents (regardless of nationality) considered themselves to be of Japanese ethnicity.6

If D-Pro framed itself as an ethnic and linguistic minority and used that as the basis for political rights, they would have difficulty leveraging the relatively weak local concepts of ethnic diversity and multiculturalism. The leaders seem to recognize this. In the Declaration they

6. Source: NHK Broadcasting Culture Research Department, January 6, 1999. “The data utilized in this publication/presentation was originally collected by NHK Broadcasting Culture Research Department. The data was obtained from the Japan Public Opinion Location Library, JPOLL, Roper Center for Public Opinion Research, University of Connecticut. Neither the original collectors of the data, nor the Roper Center, bear any responsibility for the analyses or interpretations presented here.”

write: “perhaps some people will find some resistance to the term ‘ethnic group’; instead we could say that the Deaf are a ‘linguistic minority.’”

The authors lead their readers away from the problematic discourse on native ethnic minorities in Japan and instead tried to draw authority from the American multicultural frame.

The Physicality of Deafness and Deaf Identity

Although deaf politics in Japan are embedded within larger disability politics, this book mainly focuses on the deaf community and only intermittently talks about broader disabilities. For although JFD leaders in Japan often use the mantra of disability rights in making claims to the State, actual interaction between the deaf leadership and other disability groups (with the exception of those who are deaf-blind, deaf-wheelchair users or otherwise multiply disabled) has been limited until recently.

The same communication barriers that separate the deaf community from the non-signing mainstream also separate them from the non-signing disability community.7

Deafness has been called a hidden disability because you cannot tell from looking at someone that she is deaf unless she is wearing a hearing aid. The main social handicap caused by deafness is communication with hearing people since so much of mainstream cultural, social, and business life is conveyed through speech. The blind-deaf writer Helen Keller is said to have once remarked that while blindness cuts you off from the world, deafness cuts you off from other human beings, by which she meant the majority who do not know how to sign. Being deaf is a hybrid and intersectional identity. You are who you are—Japanese, a Christian, a painter, photographer, architect—but the language barrier places you out of the mainstream of all those categories.

With deafness, as with physical gender,8 many people believe that there is a clear physicality that underlies deaf identity—a biology of deafness. Many people think there is an essential quality to deafness, for example that all deaf everywhere in the world must surely understand each other using a universal sign. They see a deaf person as physically

7. This has changed with the creation of the Japan Disability Forum in October 2004, which integrates activists across multiple disabilities including deafness.

8. See Anne Fausto-Sterling’s (1993) article “The five sexes: why male and female are not enough” for a critique of the prevalent view that there are two and only two sexes bound into our biology.
deficient, or at least tangibly different from a hearing person. In this book, I argue instead that while the causes of deafness may be similar across cultures and times (illness, genes, and so on), the sociohistorical construction of what it means to be deaf varies considerably.

Although all deaf communities have discovered manual signs as a primary means of communication (perhaps pointing to the neurological, inherent adaptability of the brain), the forms of signing and relationship with spoken language within these communities are highly variant, and the politics of deafness are also multitudinous. British Sign Language is distinct from and mutually unintelligible with American Sign Language, which is distinct from Japanese Sign Language. Meetings at the World Federation of the Deaf are just as much a Tower of Babel as those at the United Nations.  

At the Gallaudet Deaf Prez Now demonstrations in the United States, deaf student protesters carried placards stating, “Deaf can do everything but hear.” Perhaps that is the most (and least) one could say about deafness and identity. The diverse identities created by the product of a physical impairment, social institutions, family, history, and individuality all contradict an essentialized, unitary, and mandatory nature to deaf existence.

In many ways, because deaf communities across the globe have each created their own sense of (deaf) identity, (sign) language, and (visual) culture, it is easy to imagine them as types of ethnic minorities. However, deafness is very different from other ethnic identities (such as being Black or Hispanic) in that very few deaf children are born to deaf parents, only 10 percent in most estimates. That means that rather than through their families, the majority of deaf people arrive at their identity as deaf through social institutions such as schools for the deaf in childhood or deaf associations as adults. Because the deaf community represents a unique type of non-family-based, noneconomic, cultural, and linguistic minority, we need to approach the study of deaf identity through different channels from those for traditional ethnic minorities. In the next chapters, we will first look at the demographics of deafness and linguistics of signing before exploring the early history of deafness in Japan.

9. In 1973, the World Federation of the Deaf constructed Gestuno as an international communication tool. But like Esperanto, Gestuno is criticized for being both artificial and Eurocentric in both derivation and use.

"Kenneth Olsen, the engineer who founded and still runs Digital Equipment Corp., confessed at the annual meeting that he can't figure out how to heat a cup of coffee in the company's microwave oven."

You Would Need an Engineering Degree to Figure This Out

"You would need an engineering degree from MIT to work this," someone once told me, shaking his head in puzzlement over his brand new digital watch. Well, I have an engineering degree from MIT. (Kenneth Olsen has two of them, and he can't figure out a microwave oven.) Give me a few hours and I can figure out the watch. But why should it take hours? I have talked with many people who can't use all the features of their washing machines or cameras, who can't figure out how to work a sewing machine or a video cassette recorder, who habitually turn on the wrong stove burner.

Why do we put up with the frustrations of everyday objects, with objects that we can't figure out how to use, with those neat plastic-wrapped packages that seem impossible to open, with doors that trap people, with washing machines and dryers that have become too con-
fusing to use, with audio-stereo-television-video-cassette-recorders that claim in their advertisements to do everything, but that make it almost impossible to do anything?

The human mind is exquisitely tailored to make sense of the world. Give it the slightest clue and off it goes, providing explanation, rationalization, understanding. Consider the objects—books, radios, kitchen appliances, office machines, and light switches—that make up our everyday lives. Well-designed objects are easy to interpret and understand. They contain visible clues to their operation. Poorly designed objects can be difficult and frustrating to use. They provide no clues—or sometimes false clues. They trap the user and thwart the normal process of interpretation and understanding. Alas, poor design predominates. The result is a world filled with frustration, with objects that cannot be understood, with devices that lead to error. This book is an attempt to change things.

The Frustrations of Everyday Life

If I were placed in the cockpit of a modern jet airliner, my inability to perform gracefully and smoothly would neither surprise nor bother me. But I shouldn't have trouble with doors and switches, water faucets and stoves. "Doors?" I can hear the reader saying, "you have trouble opening doors?" Yes. I push doors that are meant to be pulled, pull doors that should be pushed, and walk into doors that should be slid. Moreover, I see others having the same troubles—unnecessary troubles. There are psychological principles that can be followed to make these things understandable and usable.

Consider the door. There is not much you can do to a door; you can open it or shut it. Suppose you are in an office building, walking down a corridor. You come to a door. In which direction does it open? Should you pull or push, on the left or the right? Maybe the door slides. If so, in which direction? I have seen doors that slide up into the ceiling. A door poses only two essential questions: In which direction does it move? On which side should one work it? The answers should be given by the design, without any need for words or symbols, certainly without any need for trial and error.

A friend told me of the time he got trapped in the doorway of a post office in a European city. The entrance was an imposing row of perhaps six glass swinging doors, followed immediately by a second, identical row. That's a standard design: it helps reduce the airflow and thus maintain the indoor temperature of the building.

My friend pushed on the side of one of the leftmost pair of outer doors. It swung inward, and he entered the building. Then, before he could get to the next row of doors, he was distracted and turned around for an instant. He didn't realize it at the time, but he had moved slightly to the right. So when he came to the next door and pushed it, nothing happened. "Hmm," he thought, "must be locked." So he pushed the side of the adjacent door. Nothing. Puzzled, my friend decided to go outside again. He turned around and pushed against the side of a door. Nothing. He pushed the adjacent door. Nothing. The door he had just entered no longer worked. He turned around once more and tried the inside doors again. Nothing. Concern, then mild panic. He was trapped! Just then, a group of people on the other side of the entranceway (to my friend's right) passed easily through both sets of doors. My friend hurried over to follow their path.

How could such a thing happen? A swinging door has two sides. One contains the supporting pillar and the hinge, the other is unsupported. To open the door, you must push on the unsupported edge. If you push on the hinge side, nothing happens. In this case, the designer aimed for beauty, not utility. No distracting lines, no visible pillars, no visible hinges. So how can the ordinary user know which side to push
1.2 A Row of Swinging Glass Doors in a Boston Hotel. A similar problem to the doors from that European post office. On which side of the door should you push? When I asked people who had just used the doors, most couldn't say. You only a few of the people I watched had trouble with the doors. The design of the doors incorporated a subtle clue into the design. Notice that the horizontal bars are not centered; they are a bit closer together on the side you should push on. This design detail helps you almost always work, but not entirely for everyone. mud to the doors right on the first try.

While distorted, my friend had moved toward the invisible pillar. Supporting pillars, so he was pushing the doors on the hinged side. No wonder nothing happened. Pretty doors. Elegant. Probably won a design prize.

The door story illustrates one of the most important principles of design: visibility. The correct part must be visible, and they must convey the correct message. With doors that push, there is no need to provide signals about the direction. The correct part is the edge of the door. With doors that pull, the edge of the door is not visible, but the pull handle is visible, and it is the correct message.
forward, a long push and it would reverse. (Pity the conscientious student who kept pushing it hard—and long—to make sure that the switch was making contact.) What an elegant design. Why, it managed to do two functions with only one button! But how was a first-time user of the projector to know this?

As another example, consider the beautiful Amphithéâtre Louis-Laird in the Paris Sorbonne, which is filled with magnificent paintings of great figures in French intellectual history. (The mural on the ceiling shows lots of naked women floating about a man who is valiantly trying to read a book. The painting is right side up only for the lecturer—it is upside down for all the people in the audience.) The room is a delight to lecture in, at least until you ask for the projection screen to be lowered. “Ah,” says the professor in charge, who gestures to the technician, who runs out of the room, up a short flight of stairs, and out of sight behind a solid wall. The screen comes down and stops. “No, no,” shouts the professor, “a little bit more.” The screen comes down again, this time too much. “No, no, no!” the professor jumps up and down and gestures wildly. It’s a lovely room, with lovely paintings. But why can’t the person who is trying to lower or raise the screen see what he is doing?

New telephone systems have proven to be another excellent example of incomprehensible design. No matter where I travel, I can count upon finding a particularly bad example.

When I visited Basic Books, the publishers of this book, I noticed a new telephone system. I asked people how they liked it. The question unleashed a torrent of abuse. “It doesn’t have a hold function,” one woman complained bitterly—the same complaint people at my university made about their rather different system. In older days, business phones always had a button labeled “hold.” You could push the button and hang up the phone without losing the call on your line. Then you could talk to a colleague, or pick up another telephone call, or even pick up the call at another phone with the same telephone number. A light on the hold button indicated when the function was in use. It was an invaluable tool for business. Why didn’t the new phones at Basic Books or in my university have a hold function, if it is so essential? Well, they did, even the very instrument the woman was complaining about. But there was no easy way to discover the fact, nor to learn how to use it.

I was visiting the University of Michigan and I asked about the new system there. “Yech!” was the response, “and it doesn’t even have a hold function!” Here we go again. What is going on? The answer is simple: first, look at the instructions for hold. At the University of Michigan the phone company provided a little plate that fits over the keypad and reminds users of the functions and how to use them. I carefully unhooked one of the plates from the telephone and made a photocopy (figure 1.4). Can you understand how to use it? I can’t. There is a “call hold” operation, but it doesn’t make sense to me, not for the application that I just described.

The telephone hold situation illustrates a number of different problems. One of them is simply poor instructions, especially a failure to relate the new functions to the similarly named functions that people already know about. Second, and more serious, is the lack of visibility of the operation of the system. The new telephones, for all their added sophistication, lack both the hold button and the flashing light of the old ones. The hold is signified by an arbitrary action: dialing an arbitrary sequence of digits (+8, or *99, or what have you; it varies from one phone system to another). Third, there is no visible outcome of the operation.

Devices in the home have developed some related problems: functions and more functions, controls and more controls. I do not think that simple home appliances—stoves, washing machines, audio and television sets—should look like Hollywood’s idea of a spaceship control room. They already do, much to the consternation of the consumer who, often as not, has lost (or cannot understand) the instruction
manual, so—faced with the bewildering array of controls and displays—simply memorizes one or two fixed settings to approximate what is desired. The whole purpose of the design is lost.

In England I visited a home with a fancy new Italian washer-drier combination, with super-duper multi-symbol controls, all to do everything you ever wanted to do with the washing and drying of clothes. The husband (an engineering psychologist) said he refused to go near it. The wife (a physician) said she had simply memorized one setting and tried to ignore the rest.

Someone went to a lot of trouble to create that design. I read the instruction manual. That machine took into account everything about today's wide variety of synthetic and natural fabrics. The designers worked hard; they really cared. But obviously they had never thought of trying it out, or of watching anyone use it.

If the design was so bad, if the controls were so unusable, why did the couple purchase it? If people keep buying poorly designed products, manufacturers and designers will think they are doing the right thing and continue as usual.

The user needs help. Just the right things have to be visible: to indicate what parts operate and how, to indicate how the user is to interact with the device. Visibility indicates the mapping between intended actions and actual operations. Visibility indicates crucial distinctions—so that you can tell salt and pepper shakers apart, for example. And visibility of the effects of the operations tells you if the lights have turned on properly, if the projection screen has lowered to the correct height, or if the refrigerator temperature is adjusted correctly. It is lack of visibility that makes so many computer-controlled devices so difficult to operate. And it is an excess of visibility that makes the gadget-ridden, feature-laden modern audio set or video cassette recorder (VCR) so intimidating.

The Psychology of Everyday Things

This book is about the psychology of everyday things. POET emphasizes the understanding of everyday things, things with knobs and dials, controls and switches, lights and meters. The instances we have just examined demonstrate several principles, including the importance of visibility, appropriate clues, and feedback of one's actions. These principles constitute a form of psychology—the psychology of how people interact with things. A British designer once noted that the kinds of materials used in the construction of passenger shelters affected the way vandals responded. He suggested that there might be a psychology of materials.

AFFORDANCES

"In one case, the reinforced glass used to panel shelters (for railroad passengers) erected by British Rail was smashed by vandals as fast as it was renewed. When the reinforced glass was replaced by plywood boarding, however, little further damage occurred, although no extra force would have been required to produce it. Thus British Rail managed to elevate the desire for defacement to those who could write, albeit in somewhat limited terms. Nobody has, as yet, considered whether there is a kind of psychology of materials. But on the evidence, there could well be!"

There already exists the start of a psychology of materials and of things, the study of affordances of objects. When used in this sense, the term affordance refers to the perceived and actual properties of the thing, primarily those fundamental properties that determine just how the thing could possibly be used (see figures 1.5 and 1.6). A chair affords ("is for") support and, therefore, affords sitting. A chair can also be carried. Glass is for seeing through, and for breaking. Wood is normally used for solidity, opacity, support, or carving. Flat, porous, smooth surfaces are for writing on. So wood is also for writing on. Hence the problem for British Rail: when the shelters had glass, vandals smashed it; when they had plywood, vandals wrote on and carved it. The planners were trapped by the affordances of their materials.

Affordances provide strong clues to the operations of things. Plates are for pushing. Knobs are for turning. Slots are for inserting things into. Balls are for throwing or bouncing. When affordances are taken advantage of, the user knows what to do just by looking: no picture, label, or instruction is required. Complex things may require explanation, but simple things should not. When simple things need pictures, labels, or instructions, the design has failed.

A psychology of causality is also at work as we use everyday things.
Something that happens right after an action appears to be caused by that action. Touch a computer terminal just when it fails, and you are apt to believe that you caused the failure, even though the failure and your action were related only by coincidence. Such false causality is the basis for much superstition. Many of the peculiar behaviors of people using computer systems or complex household appliances result from such false coincidences. When an action has no apparent result, you may conclude that the action was ineffective. So you repeat it. In earlier days, when computer word processors did not always show the results of their operations, people would sometimes attempt to change their manuscript, but the lack of visible effect from each action would make them think that their commands had not been executed, so they would repeat the commands, sometimes over and over, to their later astonishment and regret. It is a poor design that allows either kind of false causality to occur.

TWENTY THOUSAND EVERYDAY THINGS

There are an amazing number of everyday things, perhaps twenty thousand of them. Are there really that many? Start by looking about you. There are light fixtures, bulbs, and sockets; wall plates and screws; clocks, watches, and watchbands. There are writing devices (I count twelve in front of me, each different in function, color, or style). There are clothes, with different functions, openings, and flaps. Notice the variety of materials and pieces. Notice the variety of fasteners—buttons, zippers, snaps, laces. Look at all the furniture and food utensils: all those details, each serving some function for manufacturability, usage, or appearance. Consider the work area: paper clips, scissors, pads of paper, magazines, books, bookmarks. In the room I'm working in, I counted more than a hundred specialized objects before I tired. Each is simple, but each requires its own method of operation, each has to be learned, each does its own specialized task, and each has to be designed separately. Furthermore, many of the objects are made of many parts. A desk stapler has sixteen parts, a household iron fifteen, the simple bathtub-shower combination twenty-three. You can't believe these simple objects have so many parts? Here are the eleven basic parts to a sink: drain, flange (around the drain), pop-up stopper, basin, soap dish, overflow vent, spout, lift rod, fittings, hot-water handle, and cold-water handle. We can count even more if we start taking the faucets, fittings, and lift rods apart.
The book *What's What: A Visual Glossary of the Physical World* has more than fifteen hundred drawings and pictures and illustrates twenty-three thousand items or parts of items. Irving Biederman, a psychologist who studies visual perception, estimates that there are probably 30,000 readily discriminable objects for the adult. Whatever the exact number, it is clear that the difficulties of everyday life are amplified by the sheer profusion of items. Suppose that each everyday thing takes only one minute to learn; learning 20,000 of them occupies 20,000 minutes—333 hours or about 8 forty-hour work weeks. Furthermore, we often encounter new objects unexpectedly, when we are really concerned with something else. We are confused and distracted, and what ought to be a simple, effortless, everyday thing interferes with the important task of the moment.

How do people cope? Part of the answer lies in the way the mind works—in the psychology of human thought and cognition. Part lies in the information available from the appearance of the objects—the psychology of everyday things. And part comes from the ability of the designer to make the operation clear, to project a good image of the operation, and to take advantage of other things people might be expected to know. Here is where the designer's knowledge of the psychology of people coupled with knowledge of how things work becomes crucial.

**CONCEPTUAL MODELS**

Consider the rather strange bicycle illustrated in figure 1.7. You know it won't work because you form a conceptual model of the device and mentally simulate its operation. You can do the simulation because the parts are visible and the implications clear.

Other clues to how things work come from their visible structure—in particular from affordances, constraints, and mappings. Consider a pair of scissors: even if you have never seen or used them before, you can see that the number of possible actions is limited. The holes are clearly there to put something into, and the only logical things that will fit are fingers. The holes are affordances: they allow the fingers to be inserted. The sizes of the holes provide constraints to limit the possible fingers: the big hole suggests several fingers, the small hole only one. The mapping between holes and fingers—the set of possible operations—is suggested and constrained by the holes. Moreover, the operation is not sensitive to finger placement: if you use the wrong fingers,


the scissors still work. You can figure out the scissors because their operating parts are visible and the implications clear. The conceptual model is made obvious, and there is effective use of affordances and constraints.

As a counterexample, consider the digital watch, one with two to four push buttons on the front or side. What are those push buttons for? How would you set the time? There is no way to tell—no evident relationship between the operating controls and the functions, no constraints, no apparent mappings. With the scissors, moving the handle makes the blades move. The watch and the Leitz slide projector provide no visible relationship between the buttons and the possible actions, no discernible relationship between the actions and the end result.

**Principles of Design for Understandability and Usability**

We have now encountered the fundamental principles of designing for people: (1) provide a good conceptual model and (2) make things visible.

**PROVIDE A GOOD CONCEPTUAL MODEL**

A good conceptual model allows us to predict the effects of our actions. Without a good model we operate by rote, blindly; we do operations as we were told to do them; we can't fully appreciate why, what effects to expect, or what to do if things go wrong. As long as things work properly, we can manage. When things go wrong, however, or when
we come upon a novel situation, then we need a deeper understanding, a good model.

For everyday things, conceptual models need not be very complex. After all, scissors, pens, and light switches are pretty simple devices. There is no need to understand the underlying physics or chemistry of each device we own, simply the relationship between the controls and the outcomes. When the model presented to us is inadequate or wrong (or, worse, nonexistent), we can have difficulties. Let me tell you about my refrigerator.

My house has an ordinary, two-compartment refrigerator—nothing very fancy about it. The problem is that I can’t set the temperature properly. There are only two things to do: adjust the temperature of the freezer compartment and adjust the temperature of the fresh food compartment. And there are two controls, one labeled “freezer,” the other “fresh food.” What’s the problem?

You try it. Figure 1.8 shows the instruction plate from inside the refrigerator. Now, suppose the freezer is too cold, the fresh food section just right. You want to make the freezer warmer, keeping the fresh food constant. Go on, read the instructions, figure them out.

1.8 My Refrigerator. Two compartments—fresh food and freezer—and two controls (in the fresh food unit). The illustration shows the controls and instructions. Your task: Suppose the freezer is too cold, the fresh food section just right. How would you adjust the controls so as to make the freezer warmer and keep the fresh food the same? (From Norman, 1986.)
Oh, perhaps I'd better warn you. The two controls are not independent. The freezer control affects the fresh food temperature, and the fresh food control affects the freezer. And don’t forget to wait twenty-four hours to check on whether you made the right adjustment, if you can remember what you did.

Control of the refrigerator is made difficult because the manufacturer provides a false conceptual model. There are two compartments and two controls. The setup clearly and unambiguously provides a simple model for the user: each control is responsible for the temperature of the compartment that carries its name. Wrong. In fact, there is only one thermostat and only one cooling mechanism. One control adjusts the thermostat setting, the other the relative proportion of cold air sent to each of the two compartments of the refrigerator. This is why the two controls interact. With the conceptual model provided by the manufacturer, adjusting the temperatures is almost impossible and always frustrating. Given the correct model, life would be much easier (figure 1.0).

Why did the manufacturer present the wrong conceptual model?

1.10 Conceptual Models. The design model is the designer's conceptual model. The user's model is the mental model developed through interaction with the system. The system image results from the physical structure that has been built (including documentation, instructions, and labels). The designer expects the user's model to be identical to the design model. But the designer doesn't talk directly with the user—all communication takes place through the system image. If the system image does not make the design model clear and consistent, then the user will end up with the wrong mental model. (From Norman, 1988.)

Perhaps the designers thought the correct model was too complex, that the model they were giving was easier to understand. But with the wrong conceptual model, it is impossible to set the controls. And even though I am convinced I now know the correct model, I still cannot accurately adjust the temperatures because the refrigerator design makes it impossible for me to discover which control is for the thermostat, which control is for the relative proportion of cold air, and in which compartment the thermostat is located. The lack of immediate feedback for the actions does not help: with a delay of twenty-four hours, who can remember what was tried?

The topic of conceptual models will reappear in the book. They are part of an important concept in design: mental models. The models people have of themselves, others, the environment, and the things with which they interact. People form mental models through experience, training, and instruction. The mental model of a device is formed largely by interpreting its perceived actions and its visible structure. I call the visible part of the device the system image (figure 1.10). When the system image is incoherent or inappropriate, as in the case of the refrigerator, then the user cannot easily use the device. If it is incomplete or contradictory, there will be trouble.

MAKE THINGS VISIBLE

The problems caused by inadequate attention to visibility are all neatly demonstrated with one simple appliance: the modern telephone.

I stand at the blackboard in my office, talking with a student, when my telephone rings. Once, twice it rings. I pause, trying to complete my sentence before answering. The ringing stops. “I'm sorry,” says the student. “Not your fault,” I say. “But it's no problem, the call now transfers to my secretary's phone. She'll answer it.” As we listen we hear her phone start to ring. Once, twice. I look at my watch. Six o'clock: it's late, the office staff has left for the day. I rush out of my office to my secretary's phone, but as I get there, it stops ringing. “Ah,” I think, “it's being transferred to another phone.” Sure enough, the phone in the adjacent office now starts ringing. I rush to that office, but it is locked. Back to my office to get the key, out to the locked door, fumble with the lock, into the office, and to the now quiet phone. I hear a telephone down the hall start to ring. Could that still be my call,
making its way mysteriously, with a predetermined lurching path, through the phones of the building? Or is it just another telephone call coincidentally arriving at this time?

In fact, I could have retrieved the call from my office, had I acted quickly enough. The manual states: “Within your pre-programmed pick-up group, dial 14 to connect to incoming call. Otherwise, to answer any ringing extension, dial ringing extension number, listen for busy tone. Dial 8 to connect to incoming call.” Huh? What do those instructions mean? What is a “pre-programmed pick-up group,” and why do I ever want to know? What is the extension number of the ringing phone? Can I remember all those instructions when I need them? No.

Telephone chase is the new game in the modern office, as the automatic features of telephones go awry—features designed without proper thought, and certainly without testing them with their intended users. There are several other games, too. One game is announced by the plea, “How do I answer this call?” The question is properly whined in front of a ringing, flashing telephone, receiver in hand. Then there is the paradoxical game entitled “This telephone doesn’t have a hold function.” The accusation is directed at a telephone that actually does have a hold function. And, finally, there is “What do you mean I called you, you called me?”

Many of the modern telephone systems have a new feature that automatically keeps trying to dial a number for you. This feature resides under names such as automatic recaling or automatic callback. I am supposed to use this feature whenever I call someone who doesn’t answer or whose line is busy. When the person next hangs up the phone, my phone will dial it again. Several automatic callbacks can be active at a time. Here’s how it works. I place a phone call. There’s no answer, so I activate the automatic callback feature. Several hours later my telephone rings. I pick it up and say “Hello,” only to hear a ringing sound and then someone else saying “Hello.”

“Hello,” I answer, “who is this?”

“Who is this?” I hear in reply, “you called me.”

“No,” I say, “you called me, my phone just rang.”

Slowly I realize that perhaps this is my delayed call. Now, let me see, who was I trying to call several hours ago? Did I have several callbacks in place? Why was I making the call?

The modern telephone did not happen by accident: it was carefully designed. Someone—one or a team of people—invented a list of features thought desirable, invented what seemed to them to be plausible ways of controlling the features, and then put it all together. My university, focusing on cost and perhaps dazzled by the features, bought the system, spending millions of dollars on a telephone installation that has proved vastly unpopular and even unworkable. Why did the university buy the system? The purchase took several years of committee work and studies and presentations by competing telephone companies, and piles of documentation and specification. I myself took part, looking at the interaction between the telephone system and the computer networks, ensuring that the two would be compatible and reasonable in price. To my knowledge, nobody ever thought of trying out the telephones in advance. Nobody suggested installing them in a sample office to see whether users’ needs would be met or whether users could understand how to operate the phone. The result: disaster. The main culprit—lack of visibility—was coupled with a secondary culprit—a poor conceptual model. Any money saved on the installation and purchase is quickly disappearing in training costs, missed calls, and frustration. Yet from what I have seen, the competing phone systems would not have been any better.

I recently spent six months at the Applied Psychology Unit in Cambridge, England. Just before I arrived the British Telecom Company had installed a new telephone system. It had lots and lots of features. The telephone instrument itself was unremarkable (figure 1.11). It was the standard twelve-button, push-button phone, except that it had an extra key labeled “R” off on the side. (I never did find out what that key did.)

The telephone system was a standing joke. Nobody could use all the features. One person even started a small research project to record people’s confusions. Another person wrote a small “expert system” computer program, one of the new toys of the field of artificial intelligence; the program can reason through complex situations. If you wanted to use the phone system, perhaps to make a conference call among three people, you asked the expert system and it would explain how to do it. So, you’re on the line with someone and you need to add a third person to the call. First turn on your computer. Then load the expert system. After three or four minutes (needed for loading the program), type in what you want to accomplish. Eventually the computer will tell you what to do—if you can remember why you want to
do it, and if the person on the other end of the line is still around. But, as it happens, using the expert system is a lot easier than reading and understanding the manual provided with the telephone (figure 1.12).

Why is that telephone system so hard to understand? Nothing in it is conceptually difficult. Each of the operations is actually quite simple. A few digits to dial, that's all. The telephone doesn't even look complicated. There are only fifteen controls: the usual twelve buttons—ten labeled 0 through 9, #, and *—plus the handset itself, the handset button, and the mysterious "R" button. All except the "R" are the everyday parts of a normal modern telephone. Why was the system so difficult?

A designer who works for a telephone company told me the following story:

"I was involved in designing the faceplate of some of those new multifunction phones, some of which have buttons labeled "R." The "R" button is kind of a vestigial feature. It is very hard to remove features of a newly designed product that had existed in an earlier version. It's kind of like physical evolution. If a feature is in the genome, and if that feature is not associated with any negativity (i.e., no customers gripe about it), then the feature hangs on for generations.

"It is interesting that things like the "R" button are largely determined through examples. Somebody asks, 'What is the "R" button used for?' and the answer is to give an example: 'You can push "R" to access loudspeaker paging.' If nobody can think of an example, the feature is dropped. Designers are pretty bright people, however. They can come up with a plausible-sounding example for almost anything. Hence, you get features, many many features, and these features hang on for a long time. The end result is complex interfaces for essentially simple things."

As I pondered this problem, I decided it would make sense to compare the phone system with something that was of equal or greater complexity but easier to use. So let us temporarily leave the difficult telephone system and take a look at my automobile. I bought a car in Europe. When I picked up the new car at the factory, a man from the company sat in the car with me and went over each control, explaining its function. When he had gone through the controls once, I said fine, thanked him, and drove away. That was all the instruction it took. There are 112 controls inside the car. This isn't quite as bad as it
sounds. Twenty-five of them are on the radio. Another 7 are the temperature control system, and 11 work the windows and sunroof. The trip computer has 14 buttons, each matched with a specific function. So four devices—the radio, temperature controls, windows, and trip computer—have together 57 controls, or just over 50 percent of the ones available.

Why is the automobile, with all its varied functions and numerous controls, so much easier to learn and to use than the telephone system, with its much smaller set of functions and controls? What is good about the design of the car? Things are visible. There are good mappings, natural relationships, between the controls and the things controlled. Single controls often have single functions. There is good feedback. The system is understandable. In general, the relationships among the user’s intentions, the required actions, and the results are sensible, nonarbitrary, and meaningful.

What is bad about the design of the telephone? There is no visible structure. Mappings are arbitrary; there is no rhyme or reason to the relationship between the actions the user must perform and the results to be accomplished. The controls have multiple functions. There isn’t good feedback, so the user is never sure whether the desired result has been obtained. The system, in general, is not understandable; its capabilities aren’t apparent. In general, the relationships among the user’s intentions, the required actions, and the results are completely arbitrary.

Whenever the number of possible actions exceeds the number of controls, there is apt to be difficulty. The telephone system has twenty-four functions, yet only fifteen controls—none of them labeled for specific action. In contrast, the trip computer for the car performs seventeen functions with fourteen controls. With minor exceptions, there is one control for each function. In fact, the controls with more than one function are indeed harder to remember and use. When the number of controls equals the number of functions, each control can be specialized, each can be labeled. The possible functions are visible, for each corresponds with a control. If the user forgets the functions, the controls serve as reminders. When, as on the telephone, there are more functions than controls, labeling becomes difficult or impossible. There is nothing to remind the user. Functions are invisible, hidden from sight. No wonder the operation becomes mysterious and difficult. The controls for the car are visible and, through their location and mode of operation, bear an intelligent relationship to their action. Visi-

bility acts as a good reminder of what can be done and allows the control to specify how the action is to be performed. The good relationship between the placement of the control and what it does makes it easy to find the appropriate control for a task. As a result, there is little to remember.

THE PRINCIPLE OF MAPPING

Mapping is a technical term meaning the relationship between two things, in this case between the controls and their movements and the results in the world. Consider the mapping relationships involved in steering a car. To turn the car to the right, one turns the steering wheel clockwise (so that its top moves to the right). The user must identify two mappings here: one of the 112 controls affects the steering, and the steering wheel must be turned in one of two directions. Both are somewhat arbitrary. But the wheel and the clockwise direction are natural choices: visible, closely related to the desired outcome, and providing immediate feedback. The mapping is easily learned and always remembered.

Natural mapping, by which I mean taking advantage of physical analogies and cultural standards, leads to immediate understanding. For example, a designer can use spatial analogy: to move an object up, move the control up. To control an array of lights, arrange the controls in the same pattern as the lights. Some natural mappings are cultural or biological, as in the universal standard that a rising level represents more, a diminishing level, less. Similarly, a louder sound can mean a greater amount. Amount and loudness (and weight, line length, and brightness) are additive dimensions: add more to show incremental increases. Note that the logically plausible relationship between musical pitch and amount does not work: Would a higher pitch mean less or more of something? Pitch (and taste, color, and location) are substitutive dimensions: substitute one value for another to make a change. There is no natural concept of more or less in the comparison of different pitches, or hues, or taste qualities. Other natural mappings follow from the principles of perception and allow for the natural grouping or patterning of controls and feedback (see figure 1.13).

Mapping problems are abundant, one of the fundamental causes of difficulties. Consider the telephone. Suppose you wish to activate the callback on “no reply” function. To initiate this feature on one tele-
A device is easy to use when there is visibility to the set of possible actions, where the controls and displays exploit natural mappings. The principles are simple but rarely incorporated into design. Good design takes care, planning, thought. It takes conscious attention to the needs of the user. And sometimes the designer gets it right:

Once, when I was at a conference at Gmunden, Austria, a group of us went off to see the sights. I sat directly behind the driver of the brand new, sleek, high-technology German tour bus. I gazed in wonder at the hundreds of controls scattered all over the front of the bus.

"How can you ever learn all those controls?" I asked the driver (with the aid of a German-speaking colleague). The driver was clearly puzzled by the question.

"What do you mean?" he replied. "Each control is just where it ought to be. There is no difficulty."

A good principle, that. Controls are where they ought to be. One function, one control. Harder to do, of course, than to say, but essentially this is the principle of natural mappings: the relationship between controls and actions should be apparent to the user. I return to this topic later in the book, for the problem of determining the "naturalness" of mappings is difficult, but crucial.

I've already described how my car's controls are generally easy to use. Actually, the car has lots of problems. The approach to usability used in the car seems to be to make sure that you can reach everything and see everything. That's good, but not nearly good enough.

Here is a simple example: the controls for the loudspeakers—a simple control that determines whether the sound comes out of the front speakers, the rear, or a combination (figure 1.14). Rotate the wheel from left to right or right to left. Simple, except how do you know which way to rotate the control? Which direction moves the sound to the rear, which to the front? If you want sound to come out of the front speaker, you should be able to move the control to the front. To get it out of the back, move the control to the back. Then the form of the motion would mimic the function and make a natural mapping. But the way the control is actually mounted in the car, forward and backward get translated into left and right. Which direction is which? There is no natural relationship. What's worse, the control isn't even labeled. Even the instruction manual does not say how to use it.
than when they are not. In addition, there must be a close, natural relationship between the control and its function: a natural mapping.

THE PRINCIPLE OF FEEDBACK

Feedback—sending back to the user information about what action has actually been done, what result has been accomplished—is a well-known concept in the science of control and information theory. Imagine trying to talk to someone when you cannot even hear your own voice, or trying to draw a picture with a pencil that leaves no mark: there would be no feedback.

In the good old days of the telephone, before the American telephone system was divided among competing companies, before telephones were fancy and had so many features, telephones were designed with much more care and concern for the user. Designers at the Bell Telephone Laboratories worried a lot about feedback. The push buttons were designed to give an appropriate feel—tactile feedback. When a button was pushed, a tone was fed back to the earpiece so the user could tell that the button had been properly pushed. When the phone call was being connected, clicks, tones, and other noises gave the user feedback about the progress of the call. And the speaker's voice was always fed back to the earpiece in a carefully controlled amount, because the auditory feedback (called "sidetone") helped the person regulate how loudly to talk. All this has changed. We now have telephones that are much more powerful and often cheaper than those that existed just a few years ago—more function for less money. To be fair, these new designs are pushing hard on the paradox of technology: added functionality generally comes along at the price of added complexity. But that does not justify backward progress.

Why are the modern telephone systems so difficult to learn and to use? Basically, the problem is that the systems have more features and less feedback. Suppose all telephones had a small display screen, not unlike the ones on small, inexpensive calculators. The display could be used to present, upon the push of a button, a brief menu of all the features of the telephone, one by one. When the desired one was encountered, the user would push another button to indicate that it should be invoked. If further action was required, the display could tell the person what to do. The display could even be auditory, with speech instead of a visual display. Only two buttons need be added to the
Designing well is not easy. The manufacturer wants something that can be produced economically. The store wants something that will be attractive to its customers. The purchaser has several demands. In the store, the purchaser focuses on price and appearance, and perhaps on prestige value. At home, the same person will pay more attention to functionality and usability. The repair service cares about maintainability: how easy is the device to take apart, diagnose, and service? The needs of those concerned are different and often conflict. Nonetheless, the designer may be able to satisfy everyone.

A simple example of good design is the $3.5$-inch magnetic diskette for computers, a small circle of floppy magnetic material encased in hard plastic. Earlier types of floppy disks did not have this plastic case, which protects the magnetic material from abuse and damage. A sliding metal cover protects the delicate magnetic surface when the diskette is not in use and automatically opens when the diskette is inserted into the computer. The diskette has a square shape; there are apparently eight possible ways to insert it into the machine, only one of which is correct. What happens if we do it wrong? I try inserting the disk sideways. Ah, the designer thought of that. A little study shows that the case really isn’t square; it’s rectangular, so you can’t insert a longer side. I try backward. The diskette goes in only part of the way. Small protrusions, indentations, and cutouts prevent the diskette from being inserted backward or upside down: of the eight ways one might try to insert the diskette, only one is correct, and only that one will fit. An excellent design.

Take another example of good design. My felt-tipped marking pen has ribs along only one of its sides; otherwise all sides look identical. Careful examination shows that the tip of the marker is angled and makes the best line if the marker is held with the ribbed side up, a natural result if the forefinger rests upon the ribs. No harm results if I hold the marker another way, but the marker writes less well. The ribs are a subtle design cue—functional, yet visibly and aesthetically unobtrusive.

The world is permeated with small examples of good design, with the amazing details that make important differences in our lives. Each detail was added by some person, a designer, carefully thinking through the uses of the device, the ways that people abuse things, the kinds of errors that can get made, and the functions that people wish to have performed.

Then why is it that so many good design ideas don’t find their way into products in the marketplace? Or something good shows up for a short time, only to fall into oblivion? I once spoke with a designer about the frustrations of trying to get the best product out:

It usually takes five or six attempts to get a product right. This may be acceptable in an established product, but consider what it means in a new one. Suppose a company wants to make a product that will perhaps make a real difference. The problem is that if the product is truly revolutionary, it is unlikely that anyone will quite know how to design it right the first time; it will take several tries. But if a product is introduced into the marketplace and fails, well that is it. Perhaps it could be introduced a second time, or maybe even a third time, but after that it is dead: everyone believes it to be a failure.

I asked him to explain. “You mean,” I said, “that it takes five or six tries to get an idea right?”

“Yes,” he said, “at least that.”

“But,” I replied, “you also said that if a newly introduced product doesn’t catch on in the first two or three times; then it is dead?”

“Yup,” he said.

“Then new products are almost guaranteed to fail, no matter how good the idea.”

“Now you understand,” said the designer. “Consider the use of voice messages on complex devices such as cameras, soft-drink machines, and copiers. A failure. No longer even tried. Too bad. It really is a good idea, for it can be very useful when the hands or eyes are busy elsewhere. But those first few attempts were very badly done and the public scoffed—properly. Now, nobody dares try it again, even in those places where it is needed.”

Technology offers the potential to make life easier and more enjoyable; each new technology provides increased benefits. At the same time,
added complexities arise to increase our difficulty and frustration. The development of a technology tends to follow a U-shaped curve of complexity: starting high, dropping to a low, comfortable level; then climbing again. New kinds of devices are complex and difficult to use. As technicians become more competent and the industry matures, devices become simpler, more reliable, and more powerful. But then, after the industry has stabilized, newcomers figure out how to add increased power and capability, but always at the expense of added complexity and sometimes decreased reliability. We can see the curve of complexity in the history of the watch, radio, telephone, and television set. Take the radio. In the early days, radios were quite complex. To tune in a station required several adjustments, including one for the antenna, one for the radio frequency, one for intermediate frequencies, and controls for both sensitivity and loudness. Later radios were simpler and had controls only to turn it on, tune the station, and adjust the loudness. But the latest radios are again very complex, perhaps even more so than early ones. Now the radio is called a tuner, and it is littered with numerous controls, switches, slide bars, lights, displays, and meters. The modern sets are technologically superior, offering higher quality sound, better reception, and enhanced capability. But what good is the technology if it is too complex to use?

The design problem posed by technological advances is enormous. Consider the watch. A few decades ago, watches were simple. All you had to do was set the time and keep them wound. The standard control was the stem: a knob at the side of the watch. Turning the knob wound the spring that worked the watch. Pulling the knob out and turning it made the hands move. The operations were easy to learn and easy to do. There was a reasonable relation between the turning of the knob and the resulting turning of the hands. The design even took into account human error: the normal position of the stem was for winding the spring, so that an accidental turn would not reset the time.

In the modern digital watch the spring is gone, replaced by a motor run by long-lasting batteries. All that remains is the task of setting the watch. The stem is still a sensible solution, for you can go fast or slow, forward or backward, until the exact desired time is reached. But the stem is more complex (and therefore more expensive) than simple push-button switches. If the only change in the transition from the spring-wound analog watch to the battery-run digital watch were in how the time was set, there would be little difficulty. The problem is that new technology has allowed us to add more functions to the watch: the watch can give the day of the week, the month, and the year; it can act as a stop watch (which itself has several functions), a countdown timer, and an alarm clock (or two); it has the ability to show the time for different time zones; it can act as a counter and even as a calculator. But the added functions cause problems: How do you design a watch that has so many functions while trying to limit the size, cost, and complexity of the device? How many buttons does it take to make the watch workable and learnable, yet not too expensive? There are no easy answers. Whenever the number of functions and required operations exceeds the number of controls, the design becomes arbitrary, unnatural, and complicated. The same technology that simplifies life by providing more functions in each device also complicates life by making the device harder to learn, harder to use. This is the paradox of technology.

The paradox of technology should never be used as an excuse for poor design. It is true that as the number of options and capabilities of any device increases, so too must the number and complexity of the controls. But the principles of good design can make complexity manageable.

In one of my courses I gave as homework the assignment to design a multiple-function clock radio:

You have been employed by a manufacturing company to design their new product. The company is considering combining the following into one item:

- AM-FM radio
- Cassette player
- CD player
- Telephone
- Telephone answering machine
- Clock
- Alarm clock (the alarm can turn on a tone, radio, cassette, or CD)
- Desk or bed lamp

The company is trying to decide whether to include a small (two-inch screen) TV set and a switched electric outlet that can turn on a coffee maker or toaster.

Your job is (A) to recommend what to build, then (B) to design the control panel, and finally (C) to certify that it is actually both what customers want and easy to use.
State what you would do for the three parts of your job: A, B, and C. Explain how you would go about validating and justifying your recommendations.

Draw a rough sketch of a control panel for the items in the indented list, with a brief justification and analysis of the factors that went into the choice of design.

There are several things I looked for in the answer. (Figure 1.15 is an unacceptable solution.) First, how well did the answer address the

1.15 Possible Solution to My Homework Assignment. Completely unacceptable. (Thanks to Bill Gaver for devising and drawing this sample.)

real needs of the user? I expected my students to visit the homes of potential users to see how their current devices were being used and to determine how the combined multipurpose device would be used. Next, I evaluated whether all the controls were usable and understandable, allowing all the desired functions to be operated with minimum confusion or error. Clock radios are often used in the dark, with the user in bed and reaching overhead to grope for the desired control. Therefore the unit had to be usable in the dark by feel only. It was not supposed to be possible to make a serious mistake by accidentally hitting the wrong control. (Alas, many existing clock radios do not tolerate serious errors—for example, the user may reset the time by hitting the wrong button accidentally.) Finally, the design was expected to take into account real issues in cost, manufacturability, and aesthetics. The finished design had to pass muster with users. The point of the exercise was for the student to realize the paradox of technology: added complexity and difficulty cannot be avoided when functions are added, but with clever design, they can be minimized.
The social model of disability


1. Introduction

In many countries of the world, disabled people and their allies have organised over the last three decades to challenge the historical oppression and exclusion of disabled people (Driedger, 1989; Campbell and Oliver, 1996; Charlton, 1998). Key to these struggles has been the challenge to over-medicalised and individualist accounts of disability. While the problems of disabled people have been explained historically in terms of divine punishment, karma or moral failing, and post-Enlightenment in terms of biological deficit, the disability movement has focused attention onto social oppression, cultural discourse and environmental barriers.

The global politics of disability rights and deinstitutionalisation has launched a family of social explanations of disability. In North America, these have usually been framed using the terminology of minority groups and civil rights (Hahn, 1988). In the Nordic countries, the dominant conceptualisation has been the relational model (Gustavsson et al, 2005). In many countries, the idea of normalisation and social role valorisation has been inspirational, particularly amongst those working with people with learning difficulties (Wolfensburger, 1972). In Britain, it has been the social model of disability which has provided the structural analysis of disabled people’s social exclusion (Hasler, 1993).

The social model emerged from the intellectual and political arguments of the Union of Physically Impaired Against Segregation (UPIAS). This network had been formed after Paul Hunt, a former resident of the Lee Court Cheshire Home, wrote to The Guardian newspaper in 1971, proposing the creation of a consumer group of disabled residents of institutions. In forming the organisation and developing its ideology, Hunt worked closely with Vic Finkelstein, a South African psychologist, who had come to Britain in 1968 after being expelled for his anti-apartheid activities. UPIAS was a small, hardcore group of disabled people, inspired by Marxism, who rejected the liberal and reformist campaigns of more mainstream disability organisations such as the Disablement Income Group and the Disability Alliance. According to their policy statement (adopted December 1974), the aim of UPIAS was to replace...
segregated facilities with opportunities for people with impairments to participate fully in society, to live independently, to undertake productive work and to have full control over their own lives. The policy statement defined disabled people as an oppressed group and highlighted barriers:

“We find ourselves isolated and excluded by such things as flights of steps, inadequate public and personal transport, unsuitable housing, rigid work routines in factories and offices, and a lack of up-to-date aids and equipment.” (UPIAS Aims paragraph 1)

Even in Britain, the social model of disability was not the only political ideology on offer to the first generation of activists (Campbell and Oliver, 1996). Other disabled-led activist groups had emerged, including the Liberation Network of People with Disabilities. Their draft Liberation Policy, published in 1981, argued that while the basis of social divisions in society was economic, these divisions were sustained by psychological beliefs in inherent superiority or inferiority. Crucially, the Liberation Network argued that people with disabilities, unlike other groups, suffered inherent problems because of their disabilities. Their strategy for liberation included: developing connections with other disabled people and creating an inclusive disability community for mutual support; exploring social conditioning and positive self-awareness; the abolition of all segregation; seeking control over media representation; working out a just economic policy; encouraging the formation of groups of people with disabilities.

However, the organisation which dominated and set the tone for the subsequent development of the British disability movement, and of disability studies in Britain, was UPIAS. Where the Liberation Network was dialogic, inclusive and feminist, UPIAS was hard-line, male-dominated, and determined. The British Council of Organisations of Disabled People, set up as a coalition of disabled-led groups in 1981, adopted the UPIAS approach to disability. Vic Finkelstein and the other BCODP delegates to the first Disabled People’s International World Congress in Singapore later that year, worked hard to have their definitions of disability adopted on the global stage (Driedger, 1989). At the same time, Vic Finkelstein, John Swain and others were working with the Open University to create an academic course which would promote and develop disability politics (Finkelstein, 1998). Joining the team
was Mike Oliver, who quickly adopted the structural approach to understanding disability, and was to coin the term “social model of disability” in 1983.

2. What is the social model of disability?

While the first UPIAS Statement of Aims had talked of social problems as an added burden faced by people with impairment, the Fundamental Principles of Disability discussion document, recording their disagreements with the reformist Disability Alliance, went further:

"In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society.” (UPIAS, 1975)

Here and in the later development of UPIAS thinking are the key elements of the social model: the distinction between disability (social exclusion) and impairment (physical limitation) and the claim that disabled people are an oppressed group. Disability is now defined, not in functional terms, but as

“the disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities.” (op cit)

This redefinition of disability itself is what sets the British social model apart from all other socio-political approaches to disability, and what paradoxically gives the social model both its strengths and its weaknesses.

Key to social model thinking is a series of dichotomies:

1. Impairment is distinguished from disability. The former is individual and private, the latter is structural and public. While doctors and professions allied to medicine seek to remedy impairment, the real priority is to accept impairment and to remove disability. Here there is an analogy with feminism, and the distinction between biological sex (male and female) and social gender (masculine and feminine) (Oakley, 1972). Like gender, disability is a culturally and historically specific phenomenon, not a universal and unchanging essence.
2. The social model is distinguished from the medical or individual model. Whereas the former defines disability as a social creation – a relationship between people with impairment and a disabling society – the latter defines disability in terms of individual deficit. Mike Oliver writes:

“Models are ways of translating ideas into practice and the idea underpinning the individual model was that of personal tragedy, while the idea underpinning the social model was that of externally imposed restriction.” (Oliver, 2004, 19)

Medical model thinking is enshrined in the liberal term “people with disabilities”, and in approaches which seek to count the numbers of people with impairment, or which reduce the complex problems of disabled people to issues of medical prevention, cure or rehabilitation. Social model thinking mandates barrier removal, anti-discrimination legislation, independent living and other responses to social oppression. From a disability rights perspective, social model approaches are progressive, medical model approaches are reactionary.

3. Disabled people are distinguished from non-disabled people. Disabled people are an oppressed group, and often non-disabled people and organisations – such as professionals and charities – are the causes or contributors to that oppression. Civil rights, rather than charity or pity, are the way to solve the disability problem. Organisations and services controlled and run by disabled people provide the most appropriate solutions. Research accountable to, and preferably done by, disabled people offers the best insights.

For more than ten years, a debate has raged in Britain about the value and applicability of the social model (Morris, 1991, Crow, 1992, French, 1993, Williams, 1999; Shakespeare and Watson 2002). In response to critiques, academics and activists maintain that the social model has been misunderstood, misapplied, or even wrongly viewed as a social theory. Many leading advocates of the social model approach maintain that the essential insights developed by UPIAS in the 1970s still remain accurate and valid three decades later.
3. Strengths of the social model

As demonstrated internationally, disability activism and civil rights are possible without adopting social model ideology. Yet the British social model is arguably the most powerful form which social approaches to disability have taken. The social model is simple, memorable and effective, each of which is a key requirement of a political slogan or ideology. The benefits of the social model have been shown in three main areas.

First, the social model, which has been called “the big idea” of the British disability movement (Hasler, 1993), has been effective politically in building the social movement of disabled people. It is easily explained and understood, and it generates a clear agenda for social change. The social model offers a straightforward way of distinguishing allies from enemies. At its most basic, this reduces to the terminology people use: “disabled people” signals a social model approach, whereas “people with disabilities” signals a mainstream approach.

Second, by identifying social barriers which should be removed, the social model has been effective instrumentally in the liberation of disabled people. Michael Oliver argues that the social model is a “practical tool, not a theory, an idea or a concept” (2004, 30). The social model demonstrates that the problems disabled people face are the result of social oppression and exclusion, not their individual deficits. This places the moral responsibility on society to remove the burdens which have been imposed, and to enable disabled people to participate. In Britain, campaigners used the social model philosophy to name the various forms of discrimination which disabled people (Barnes, 1991), and used this evidence as the argument by which to achieve the 1995 Disability Discrimination Act. In the subsequent decade, services, buildings and public transport have been required to be accessible to disabled people, and most statutory and voluntary organisations have adopted the social model approach.

Third, the social model has been effective psychologically in improving the self-esteem of disabled people and building a positive sense of collective identity. In traditional accounts of disability, people with impairments feel that they are at fault. Language such as “invalid” reinforce a sense of personal deficit and failure. The
focus is on the individual, and on her limitations of body and brain. Lack of self-esteem and self-confidence is a major obstacle to disabled people participating in society. The social model has the power to change the perception of disabled people. The problem of disability is relocated from the individual, to the barriers and attitudes which disable her. It is not the disabled person who is to blame, but society. She does not have to change, society does. Rather than feeling self-pity, she can feel anger and pride.

4. Weaknesses of the social model

The simplicity which is the hallmark of the social model is also its fatal flaw. The social model’s benefits as a slogan and political ideology are its drawbacks as an academic account of disability. Another problem is its authorship by a small group of activists, the majority of whom had spinal injury or other physical impairments and were white heterosexual men. Arguably, had UPIAS included people with learning difficulties, mental health problems, or with more complex physical impairments, or more representative of different experiences, it could not have produced such a narrow understanding of disability.

Among the weaknesses of the social model are:

1. The neglect of impairment as an important aspect of many disabled people’s lives. Feminists Jenny Morris (1991), Sally French (1993) and Liz Crow (1992) were pioneers in this criticism of the social model neglect of individual experience of impairment:

“As individuals, most of us simply cannot pretend with any conviction that our impairments are irrelevant because they influence every aspect of our lives. We must find a way to integrate them into our whole experience and identity for the sake of our physical and emotional well-being, and, subsequently, for our capacity to work against Disability”. [Crow, 1992, 7]

The social model so strongly disowns individual and medical approaches, that it risks implying that impairment is not a problem. Whereas other socio-political accounts of disability have developed the important insight that people with impaired are disabled
by society as well as by their bodies, the social model suggests that people are
disabled by society not by their bodies. Rather than simply opposing medicalisation, it
can be interpreted as rejecting medical prevention, rehabilitation or cure of
impairment, even if this is not what either UPIAS, Finkelstein, Oliver or Barnes
intended. For individuals with static impairments, which do not degenerate or cause
medical complications, it may be possible to regard disability as entirely socially
created. For those who have degenerative conditions which may cause premature
death, or which any condition which involves pain and discomfort, it is harder to
ignore the negative aspects of impairment. As Simon Williams has argued,

“… endorsement of disability solely as social oppression is really only an option, and
an erroneous one at that, for those spared the ravages of chronic illness.” (Williams,
1999, 812)

Carol Thomas (1999) has tried to develop the social model to include what she calls
“impairment effects”, in order to account for the limitations and difficulties of
medical conditions. Subsequently, she subsequently suggested that a relational
interpretation of the social model enables disabling aspects to be attributed to
impairment, as well as social oppression:

“once the term ‘disability’ is ring-fenced to mean forms of oppressive social reactions
visited upon people with impairments, there is no need to deny that impairment and
illness cause some restrictions of activity, or that in many situations both disability
and impairment effects interact to place limits on activity.” (2004, 29)

One curious consequence of the ingenious reformulation is that only people with
impairment who face oppression can be called disabled people. This relates to
another problem:

2. The social model assumes what it needs to prove: that disabled people are
oppressed. The sex/gender distinction defines gender as a social dimension, not as
oppression. Feminists claimed that gender relations involved oppression, but did not
define gender relations as oppression. However, the social model defines disability as
oppression. In other words, the question is not whether disabled people are oppressed
in a particular situation, but only the extent to which they are oppressed. A circularity
enters into disability research: it is logically impossible for a qualitative researcher to find disabled people who are not oppressed.

3. The analogy with feminist debates about sex and gender highlights another problem: the crude distinction between impairment (medical) and disability (social). Any researcher who does qualitative research with disabled people immediately discovers that in everyday life it is very hard to distinguish clearly between the impact of impairment, and the impact of social barriers (see for example Watson, 2002; Sherry, 2002). In practice, it is the interaction of individual bodies and social environments which produces disability. For example, steps only become an obstacle if someone has a mobility impairment: each element is necessary but not sufficient for the individual to be disabled. If a person with multiple sclerosis is depressed, how easy is it to make a causal separation between the effect of the impairment itself; her reaction to having an impairment; her reaction to being oppressed and excluded on the basis of having an impairment; other, unrelated reasons for her to be depressed? In practice, social and individual aspects are almost inextricable in the complexity of the lived experience of disability.

Moreover, feminists have now abandoned the sex/gender distinction, because it implies that sex is not a social concept. Judith Butler (1990) and others show that what we think of as sexual difference is always viewed through the lens of gender. Shelley Tremain (2002) has claimed similarly that the social model treats impairment is an unsocialised and universal concept, whereas, like sex, impairment is always already social.

4. The concept of the barrier-free utopia. The idea of the enabling environment, in which all socially imposed barriers are removed, is usually implicit rather than explicit in social model thinking, although it does form the title of a major academic collection (Swain et al, 1993). Vic Finkelstein (1981) also wrote a simple parable of a village designed for wheelchair users to illustrate the way that social model thinking turned the problem of disability on its head. Yet despite the value of approaches such as Universal Design, the concept of a world in which people with impairments were free of environmental barriers is hard to operationalise.
For example, many parts of the natural world will remain inaccessible to many disabled people: mountains, bogs, beaches are almost impossible for wheelchair users to traverse, while sunsets, birdsong and other aspects of nature are difficult for those lacking sight or hearing to experience. In urban settings, many barriers can be mitigated, although historic buildings often cannot easily be adapted. However, accommodations are sometimes incompatible because people with different impairments may require different solutions: blind people prefer steps and defined curbs and indented paving, while wheelchair users need ramps, dropped curbs, and smooth surfaces. Sometimes, people with the same impairment require different solutions: some visually impaired people access text in Braille, others in large print, audio tape or electronic files. Practicality and resource constraints make it unfeasible to overcome every barrier: for example, the New York subway and London Underground systems would require huge investment to make every line and station accessible to wheelchair users. A copyright library of five million books could never afford to provide all these texts in all the different formats which visually impaired users might potentially require. In these situations, it seems more practical to make other arrangements to overcome the problems: for example, Transport for London have an almost totally accessible fleet of buses, to compensate those who cannot use the tube, while libraries increasingly have arrangements to make particular books accessible on demand, given notice.

Moreover, physical and sensory impairments are in many senses the easiest to accommodate. What would it mean to create a barrier free utopia for people with learning difficulties? Reading and writing and other cognitive abilities are required for full participation in many areas of contemporary life in developed nations. What about people on the autistic spectrum, who may find social contact difficult to cope with: a barrier free utopia might be a place where they did not have to meet, communicate with, or have to interpret other people. With many solutions to the disability problem, the concept of addressing special needs seems more coherent than the concept of the barrier free utopia. Barrier free enclaves are possible, but not a barrier free world.

While environments and services can and should be adapted wherever possible, there remains disadvantage associated with having many impairments which no amount of
environmental change could entirely eliminate. People who rely on wheelchairs, or personal assistance, or other provision are more vulnerable and have fewer choices than the majority of able-bodied people. When Michael Oliver claims that

“An aeroplane is a mobility aid for non-flyers in exactly the same way as a wheelchair is a mobility aid for non-walkers.” (Oliver, 1996, 108)

his suggestion is amusing and thought provoking, but cannot be taken seriously. As Michael Bury has argued,

“It is difficult to imagine any modern industrial society (however organised) in which, for example, a severe loss of mobility or dexterity, or sensory impairments, would not be ‘disabling’ in the sense of restricting activity to some degree. The reduction of barriers to participation does not amount to abolishing disability as a whole.” (Bury, 1997, 137)

Drawing together these weaknesses, a final and important distinction needs to be made. The disability movement has often drawn analogies with other forms of identity politics, as I have done in this paper. The disability rights struggle has even been called the “Last Liberation Movement” (Driedger, 1989). Yet while disabled people do face discrimination and prejudice, like women, gay and lesbian people, and minority ethnic communities, and while the disability rights movement does resemble in its forms and activities many of these other movements, there is a central and important difference. There is nothing intrinsically problematic about being female or having a different sexual orientation, or a different skin pigmentation or body shape. These other experiences are about wrongful limitation of negative freedom. Remove the social discrimination, and women and people of colour and gay and lesbian people will be able to flourish and participate. But disabled people face both discrimination, but also intrinsic limitations. This claim has three implications. First, even if social barriers are removed as far as practically possible, it will remain disadvantageous to have many forms of impairment. Second, it is harder to celebrate disability than it is to celebrate Blackness, or Gay Pride, or being a woman. “Disability pride” is problematic, because disability is difficult to recuperate as a concept, as it refers either to limitation and incapacity, or else to oppression and exclusion, or else to both dimensions. Third, if disabled people are to be emancipated, then society will have to
provide extra resources to meet the needs and overcome the disadvantage which arises from impairment, not just work to minimise discrimination (Bickenbach et al, 1999).

5. Beyond the social model?

In this chapter, I have tried to offer a balanced assessment of the strengths and weaknesses of the British social model of disability. While acknowledging the benefits of the social model in launching the disability movement, promoting a positive disability identity, and mandating civil rights legislation and barrier removal, it is my belief that the social model has now become a barrier to further progress.

As a researcher, I find the social model unhelpful in understanding the complex interplay of individual and environmental factors in the lives of disabled people. In policy terms, it seems to me that the social model is a blunt instrument for explaining and combatting the social exclusion that disabled people face, and the complexity of our needs. Politically, the social model has generated a form of identity politics which has become inward looking and separatist.

A social approach to disability is indispensable. The medicalisation of disability is inappropriate and an obstacle to effective analysis and policy. But the social model is only one of the available options for theorising disability. More sophisticated and complex approaches are needed, perhaps building on the WHO initiative to create the International Classification of Functioning, Disability and Health. One strength of this approach is the recognition that disability is a complex phenomenon, requiring different levels of analysis and intervention, ranging from the medical to the socio-political. Another is the insight that disability is not a minority issue, affecting only those people defined as disabled people. As Irving Zola (1989) maintained, disability is a universal experience of humanity.
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“Why Should Our Bodies End at the Skin?”: Embodiment, Boundaries, and Somatechnics

MARGRIT SHILDRICK

Donna Haraway’s enduring question—“Why should our bodies end at the skin?” (Haraway 1990, 220)—is ever more relevant in the postmodern era, where issues of bodies, boundaries, and technologies increasingly challenge not only the normative performance of the human subject, but also the very understanding of what counts as human. Critical Disability Studies has taken up the problematic of technology, particularly in relation to the deployment of prostheses by people with disabilities. Yet rehabilitation to normative practice or appearance is no longer the point; instead, the lived experience of disability generates its own specific possibilities that both limit and extend the performativity of the embodied self. I look at what is at stake in the challenge to the Western logos that comes specifically from the capacities of the disabled body, understood not as a less than perfect form of the normative, but as figuring difference in a nonbinary sense. Feminist theory has long contested the isomorphism of the logos, but I go beyond simply setting out the grounds for revaluing multiple variant forms. The feminist turn to Jacques Derrida and Gilles Deleuze opens up the problematic to a celebratory positioning of difference and transcorporeality as the very conditions of life.

In the era of postmodernity, issues of bodies, boundaries, and technologies increasingly challenge not only the normative performance of the human subject, but also the very understanding of what counts as human. Donna Haraway’s evocative question—“Why should our bodies end at the skin, or include at best other beings encapsulated by skin?” (Haraway 1990, 220)—is decades old, but it is really only in recent years that the notion of the corporeal integrity essential to the modernist notion of human being has been critically theorized more widely. One area in which this is most apparent is in the emergence of Critical Disability Studies,1 which, among other things, has taken up the problematic of technology, particularly in relation to the deployment of various kinds of prostheses by people with disabilities. Historically,
such technologies have usually grounded some utilitarian compensation for a perceived bodily lack, but the emphasis now is firmly on enhancement and supplement (Shildrick 2013). For many disabled people, rehabilitation to normative practice or normative appearance is no longer the point; instead, the lived experience of disability—with its embodied absences, displacements, and prosthetic additions—generates, at the very least, its own specific possibilities that both limit and extend the performativity of the self. Such transformations not only comprehensively disorder the conventional limits of embodiment, but question the very attribution of human being. I want to look more precisely at the challenge to the Western logos that comes specifically from the capacities—I use the word advisedly—of the disabled body when it is understood not as a less than perfect form of the normative standard, but as figuring difference in a nonbinary sense. Feminist theory has long contested the isomorphism at the heart of the logos, but what I shall stress goes further than simply revaluing multiple variant forms. The turn to Jacques Derrida and Gilles Deleuze, the quintessential philosophers of difference, and their uptake by feminist scholars, pushes the problematic far beyond conventional meanings of the human and opens up a celebratory positioning of difference and transcorporeality as the very conditions of life.

Although the significance of corporeality has always been underdeveloped in Western philosophy, in the early twenty-first century, the invocation of quasi-Cartesian notions of the body as nothing more than the unchanging material base of continuing existence, and of no concern to the practices of the self, is outdated. Feminist thinking has long embraced the phenomenology associated with Maurice Merleau-Ponty (1962), which provides for an explanatory model of embodiment as an irreducible coming together of both mind and body that corresponds more adequately to the lived experience, not just of women as explored in the original feminist texts (Young 1990), but more generally across an array of intersectional differences. Merleau-Ponty’s account of embodiment as effectively coincident with the emergence of the subject relies on a sense of both the intercorporeality of our everyday engagements with others—although never mentioned as such, intercorporeality is strongly implied in the chiasmatic relation between bodies (Merleau-Ponty 1968)—and of the environment itself shaping intentional action. Whereas feminist scholars have often seen such ideas as supporting the existent feminist validation of the very human positivity of connection and relationality, a move that nonetheless maintains separate subjectivities, I will push the problematic toward a Deleuzian reading of connectivity that is better expressed through the term assemblage, where all distinctions are troubled, whether between self and other, or between the categories of human, animal, and machine. Although in their characterization of assemblages as desiring machines (Deleuze and Guattari 1984), Deleuze and Guattari were in part reacting against the humanist values of phenomenology, it is clear that Merleau-Ponty was already engaged to some extent with the affective significance of technology. He has little to say about physical or cognitive disability as such, except as an explanatory limit that throws light on normative embodiment, yet he does demonstrate the transformational nature of prostheses—famously in the example of the blind man’s cane becoming an
extension of his self-embodiment (Merleau-Ponty 1962, 165)—and shows that the lived body is not identical with the material entity bounded by the skin.

My reason for belaboring the intellectual continuity between Merleau-Ponty and Deleuze is that feminist philosophers—with a few exceptions such as Gail Weiss (1999)—and critical disability theorists rarely make the move from phenomenology to postmodernism, even though Haraway’s understanding of the technologized body might seem an obvious stepping stone. Phenomenology has become a powerful tool of analysis in CDS, but Deleuze is still treated with extreme caution. It is, I think, a missed opportunity based on a reluctance to take more seriously the shift in thinking between Merleau-Ponty’s early work, The Phenomenology of Perception (1962), which undoubtedly remains within the humanistic tradition, and his posthumously published work, The Visible and the Invisible (1968), which moves strongly toward a postmodernist contestation of the distinction between consciousness and its object (Evans and Lawlor 2000, 9). Within that final work, the notion of flesh ontology is central. What Merleau-Ponty points to is a dimension in excess of the interhuman connections that channel the co-construction of embodiment: the “flesh of the world” in which we are all immersed, and through which we are constituted. It throws into doubt the very sense of self and other as distinct entities and speaks to a folding over of flesh that creates the possibility of difference within a unified but undifferentiated medium (Shildrick 2013). In turning away from a knowing sovereign subject and insisting that we are all enveloped by the flesh of the world, Merleau-Ponty seeks to instantiate “other landscapes besides my own” (Merleau-Ponty 1968, 141) that are nonetheless mutually interwoven. As he understands it, the crucial notion of the reversibility between self and other that is developed in The Visible and the Invisible implies not a merging of subjectivities, but more a coming-together in difference, a matter of both convergence and divergence.

Phenomenology provides an explication that both falls far short of the Deleuzian model of assemblage and yet inaugurates some of its central features. It is important to remember, however, that Merleau-Ponty’s account was recovered posthumously in draft form and as such is open to materialist feminist reinterpretations that—as well as outlining its limitations—might usefully extend it. In critical disability theory, any account of disabled people who use prostheses could take off from phenomenology, before segueing into the more committed Deleuzian challenge to humanist principles. There is no need to supersede phenomenological accounts—which still prove highly challenging to the modernist framing of conventional disability studies—but rather a gain can be made in approaching the problematic with a determination to use multiple resources. The major thrust of conventional disability theory and activism itself has been to reclaim, if not full autonomy and independence for disabled people, then at least varying degrees of agency that enhance self-determination and control over one’s environment. As a result, that impetus is very much directed toward physical disabilities of a relatively moderate nature and leaves adrift those with very severe physical impairments, as well as many forms of cognitive disability. I am not arguing that this is the wrong approach—there are always effective stagings to consider—but that it is highly constrained and misses entirely the complexity and extensiveness of
the Deleuzian approach that I advocate. Turning to feminist theory, its great strength has been its openness to cross-cutting approaches, in philosophy as elsewhere. What matters is that both Merleau-Ponty and Deleuze enhance our understanding of a fundamental hybridity that speaks to the coming together of bodies in difference that are never comfortably subsumed into a new unified whole.

The issue, then, is whether there is something special about disabled embodiment that would readily respond not simply to a phenomenological analysis but to a Deleuzian one. Does the trope of hybridity hold any particular significance in the lived experience of people with disabilities? My immediate answer is that on the level of theory there is no distinction to be made between one body and another in terms of the manifold interconnections and transformatory entanglements—to use Karen Barad’s coinage (Barad 2003, 818)—that mark all forms of embodiment. In that sense there is nothing peculiar to the corporeality of disability that would justify seeing it as the conceptual other of the normative body. At the very least, the interface with technology is the common experience of us all. As Don Ihde notes: “We are our bodies—but in that very basic notion one also discovers that our bodies have an amazing plasticity and polymorphism that is often brought out precisely in our relations with technologies. We are bodies in technologies” (Ihde 2002, 137). Similarly, disability theorists David Mitchell and Sharon Snyder assert: “the prostheticized body is the rule, not the exception” (Mitchell and Snyder 2000, 7). The point is not that we are all alike, but precisely that we are all different and that conventional categories are simply a convenient way of simplifying the irreducible complexity of corporeal forms. To a greater or lesser extent, none of us is entitled to claim a singular body. When it comes to precisely that question of degree, however, there are good reasons for seeing the disabled body in its material specificities as a privileged exemplar of hybridity. Those with anomalous corporealities—whether physical, sensory, or cognitive—have been, both in the era of high biotechnologies and historically, more readily, though by no means exclusively, associated with various prosthetic devices. These may be either external to the body as with conventional “replacements” for missing limbs, supports for sensory functions, and behavior-controlling drugs, or they may be more obviously incorporated as with neuro-implants or transplanted organs. Whether the technologies use organic or nonorganic components, in all cases, such prostheses contest our faith in corporeal integrity even as they are intended to restore the clean and proper body. They not only demonstrate the inherent plasticity of the body, but, in the very process of incorporating non-self matter, point to the multiple possibilities of co-corporeality, where bodies are not just contiguous and mutually reliant but entwined with one another. Against a modernist convention of fully bounded bodies, separate and distinct from one another, such modes of corporeal transformation comprehensively undo the limits of the embodied self.

In previous work, I have addressed more fully the complex nature and meaning of prostheses as such (Shildrick 2009a; 2013), as well as their close association with the Deleuzian notion of assemblage (Deleuze and Guattari 1987). Suffice it to say that whereas traditional understandings have centered on their utility for a subject experiencing some form of lack or inability, more contemporary approaches stress that...
prostheses speak to the mode of supplementation, both in its ordinary and in its Derridean sense (Wills 1995; Jain 1999). Derrida said little directly about corporeality, still less about anomalous bodies, but his "logic of the supplement" (Derrida 1973; 1974) may provide vital insights into embodiment, boundaries, and technologies. Like the term *différance*, supplementarity exposes the fluidity of categorical boundaries and an inherent undecidability that signals the ultimate impossibility of completion. Indeed, he argues, the very possibility of (prosthetic) augmentation indicates an absence of self-sufficiency or originary wholeness (Derrida 1987). In Derrida's analysis, the supplement is necessary in constituting the object as such, and in turn its necessity exposes the undecidable nature of categorical distinctions between self/other, natural/artificial, and so on that are usually taken for granted. In other words, prostheses exceed their instrumentality, and construct the very thing that they purport to merely enhance. As Derrida puts it, “technology has not simply added itself, from the outside... this foreign or dangerous supplement is ‘originarily’ at work and in place in the supposedly ideal interiority of the ‘body and soul’” (Derrida 1995, 244). As such, the singularity and purity of the subject cannot hold. I will not pursue the Derridean approach further, but merely note that his claim that the supplement is always already “at work and in place” mirrors Deleuze’s implication that the assemblage—in all its dis-organization—is the inevitable condition of living.

The significance of prostheses is far in excess, then, of either therapeutic or rehabilitative intentions, and prostheses should not be read as solely material additions to the body. On the one hand functioning as utilitarian material artifacts, on the other, prostheses are rich in semiotic meaning and mark the site where the disordering ambiguity, and potential transgressions, of the interplay between the human, animal, and machine cannot be occluded. One is reminded of Haraway's cyborg—a heterogeneous machine–organism hybrid—whose "illegitimate fusions of animal and machine" render problematic “the structure of desire...(and) the structure and modes of reproduction of ‘Western’ identity” (Haraway 1990, 218). Any reading of the *Cyborg Manifesto* would indicate the impossibility of limiting the human/machine interface of even conventional biomedical prostheses to their intended function. Haraway clearly points the way forward to the uptake of Deleuze and Guattari when she figures the cyborg as “a kind of disassembled and reassembled, postmodern and collective self” (205), so it is a puzzle that, although her work is now beginning to inform critical disability theory (Campbell 2009; Goodley and Runswick-Cole 2011; Reeve 2012) and has long been seminal within feminist theory, the Deleuzian notion of assemblage has not provoked wider experimentation in the same fields.4 Ironically, Haraway has since moved on from the cyborg as such, and her affirmation of what seems to be a very Deleuzian form of desire—a dynamic, indeterminate, and productive circulating force, excessive to the embodied self, constituting what I would call an erotics of connection—is more exclusively linked with the organic side of life, and to our interconnections with other living beings (Haraway 2007; 2008). My own preference is to follow through on the wider conceptualization of the assemblage offered by Deleuze and Guattari, which can be read as encompassing not just technological aspects such as prostheses but an array of materials, locations, and spaces that
might all be called technics. The flourishing that is central to Haraway's ethical vision is equally strong in the Deleuzian affirmation of the productive force of all the multifarious elements—living and nonliving—that come together, temporarily and unpredictably, to constitute an assemblage.

The term technics is difficult to pin down and is used inconsistently across the literature, but I shall take it to denote the entangled and co-constitutive interrelations between technologies, “users,” and the sociocultural context. As already outlined, there is always a general sense of the symbiotic, co-constititutional nature of the human and its technologies that could be described in terms of the prosthesis or the supplement. Elizabeth Grosz, for example, notes that “from the moment in which the human appears as such, it appears alongside of both artifacts and technologies, poesis and techne” (Grosz 2005, 137). And she claims that human embodiment can only be understood in the modality of practice, a series of actions that entangle the ontological with an irreducible materiality in which both undergo “mutual metamorphosis” (148). This echoes the Deleuzian approach in that what is of consequence is not the “content” of any particular entity—organic or nonorganic—but the provisional instantiations that emerge from the interconnectivity of multiple forces. There are no solid bodies as such, only becoming-bodies. As Deleuze and Guattari put it:

tools only exist in relation to the interminglings they make possible or that make them possible. The stirrup entails a new man–horse symbiosis that at the same time entails new weapons and new instruments. Tools are inseparable from symbioses or amalgamations defining a Nature–Society machinic assemblage. . . . a society is defined by its amalgamations, not by its tools. (Deleuze and Guattari 1987, 90)

Moreover, it is not simply material entities that come together in technics, but a heterogeneous array of discursive elements and practices that encompass, without privileging any one modality, the affective, the political, the institutional, and the biological. All are linked together, cross over, and become more or less mutually—albeit provisionally—incorporated in unpredictable assemblages that figure both the affirmation of becoming OTHERWISE and the potential emergence of new organizations of power. In short, technics encompass an arena of action far in excess of two or more intersecting bodies, although what is always figured is the instantiation of particular bodies. The term somatechnics—now established with an eponymous journal—seems especially apt in its grasp of what is at stake. I will return to the underlying question of Deleuzian assemblages, but want first to address why such forms of thinking otherwise are of significance to critical disability theory.

It is instructive to think through technics in terms of some familiar prostheses, such as wheelchairs, artificial limbs, or cochlear implants, associated with disabled people. With regard to the former, the only acceptable terminology is to shun popular but careless terms like wheelchair-bound and refer to the subject as a wheelchair user. In terms of modernist paradigms of the sovereign subject as intentional agent, this is entirely justified, for no-one should be reduced to the dimensions of an inanimate object nor figured as passive. Yet what the conventional model of the
wheelchair user speaks to is the illusion of a naturally bounded and self-contained body that is somehow diminished, even as mobility is undoubtedly enhanced, by the reliance on an external technology. To counter such an image, the person with the disability must be represented as effectively in control and thus unified in mind if not in body. The recent 2012 Paralympics clearly exemplifies what is at stake. The range of prosthetic technologies on display was highly sophisticated with the emphasis firmly on enhancement rather than the more usual trope of making good an inherent lack, with the athletes themselves consistently represented as superheroes—supercrips in critical perspectives—not because they were highly skilled and hard-working sportspeople, but because their achievements were read within a narrative of exceptional inspiration and overcoming. I am not suggesting that such a narrative is unusual with regard to any high-achieving athlete, however embodied, but that in the stress on disabled people's mastery and self-determination against the odds—which could not be taken for granted—any critical appreciation of the significance of prostheses is obscured. Consider the very clear difference in calling a gold-medal winner “a machine” in relation to first the nondisabled sprinter Usain Bolt and then the equally successful wheelchair racer David Weir. Whereas for the former it might be seen as a compliment to his singular teleological focus and delivery, with the latter it could be construed as undermining and insulting, even dehumanizing. Disabled people are expected to transcend their very visible reliance on technologies. From a Deleuzian perspective, of course, there is no distinction to be made; however we are embodied, we are enmeshed within technics.

In contrast to humanist conventions, then, the close attention to the individual as the ontological and ethical area of concern fails to account for the extensiveness of the human–wheelchair amalgam as Deleuze and Guattari might read it. They are interested not so much in what a body is—the questions of identity and subjectivity that are so entrenched in the conventional model of disability studies—but in what that body is capable of, particularly when unconstrained by normative limits: “we know nothing about a body until we know what it can do, in other words, what its affects are, and how they can or cannot enter into composition with other affects, with the affects of another body” (Deleuze and Guattari 1987, 284). At a superficial level, this may appear to reflect the social-model focus on the material obstacles that operate in discriminatory societies, impeding action and effectively creating disability for those with impaired bodies. The argument is that if people with anomalous bodies were accommodated rather than thwarted in their quest for mobility or comprehension, for example, they would not be disabled, but rather enabled. But this is not what Deleuze and Guattari mean, at least not insofar as the argument centers on an intentional subject. For them, it is precisely the dis-organization of bodily being, the unpredictable additions and absences from a normative body schema that enables the putative subject—for she is not in a state of being, but becoming—to enter into the potentially productive relations of the assemblage. Referring to technics, as a somewhat cognate term, signals very much more than the symbiosis of artifact and user; it stands for the whole indeterminate plethora of interlinked practices, materials, events, discourses, and bodies that co-constitute the choreographies of action. The
resonances, not just with Deleuze, but with Haraway’s characterization of bodies as “material-semiotic generative nodes” (Haraway 1991, 200) will be readily apparent. The wheelchair user is not simply dependent on technology in a very transparent way but is brought into being through that usually unacknowledged context of variable, dynamic, and often conflicting energies and forces. As Deleuze and Guattari note: “On the one hand it is a machinic assemblage of bodies, of actions and passions, and intermingling of bodies reacting to one another; on the other hand, it is a collective assemblage of enunciation, of acts and statements, of incorporeal transformations attributed to bodies” (Deleuze and Guattari 1987, 88). And—as both Haraway and Deleuze acknowledge— “the protean embodiments of world” (Haraway 1991, 201) demand new configurations of ontology and ethics, which I understand as entailing the transformatory encounter with irreducible forms of otherness.

The Paralympic athlete, then, may appear as a successful, self-determined individual, but she is—quite literally—the provisional effect of the imbrication of multiple rhizomatic strands that are always in a process of change. In the Deleuzian sense, a rhizome is a decentralized proliferating system without origin, sequence, or destination that relies on multiple resources, mergings, connections, interruptions, and breaking points (Deleuze and Guattari 1987). The athlete’s body neither ends at the skin, nor expresses solely her incorporation of a specific external prosthesis. Indeed, the body can no longer be thought as natural, distinct, or universal, but only in terms of its permeability—the demarcation of inside and outside becomes increasingly meaningless—and of process. It is at most a relational artifact beyond singular identification; the athlete-as-event.7 The woman who stands tearfully smiling on the rostrum with her medal in hand has every reason to bask in the approbation given by the crowd, but she will know too what they can barely acknowledge: that her moment of triumph is just a freeze-frame in an assemblage that defies the imposition of parameters. At the back of her mind perhaps are her trainers; the utility of her prosthesis, if she uses one; the carefully controlled diet that she has followed to stay competitive; the gym sessions that maintain her strength; the loving family who gave her the opportunity to overcome her corporeal difference and become an athlete; the schoolmates who mocked or praised her achievements against their own; and the life she must return to once her Olympic moment has passed. Beyond that in consciousness, but in Deleuzian terms equally constitutive of the athlete-as-event, lie the rules and regulations governing Paralympian categories; the specific national benefits system that impedes or supports her embodied difference; the negotiation of transport between accommodation and the stadium; the health and safety inspections; the drug tests; the paid assistants who facilitate personal care; the beliefs and expectations of the spectators; finally, but by no means exclusively, the question: Who am I? There is no closure or completion. As Alecia Jackson and Lisa Mazzei remark, “an assemblage isn’t a thing—it’s the process of making and unmaking the thing” (Jackson and Mazzei 2012, 1). In the life of a disabled person, particularly one who is on show, as a Paralympian competitor might be, the elements of the assemblage are perhaps relatively easy to trace, though never to exhaustively map, but that is only a difference in degree—and hardly even that—rather than a difference in kind. Regardless of our
specific form of embodiment, each one of us is similarly enmeshed within such energetic amalgamations that signal endless difference.

I want to look more closely now at how the notion of assemblage derived from Deleuze and Guattari (1987) is characterized in order to respond to some challenging questions as to the relevance of their model for critical disability studies. I have been using the figure of the disabled athlete to exemplify the excessive supplementarity that disorders the comforting image of the sovereign subject of modernity, but at the same time it is clear that in her moment of glory, in her supreme mastery of her event, the athlete could just as well be taken as exemplary of the humanist agenda. The Deleuzian approach, note, is not directed toward some kind of utopian future, still less a utopian techno-posthumanism. For all that they understand assemblages as “desiring machines” (Deleuze and Guattari 1984), it is in the sense of somatechnics rather than technologies per se. In any case, the tension between the lines of flight that escape the mundane realities of normative forms of organization that exploit the productive potentials of assemblage, and the reimposition of societies of control—not least through technologies themselves—is unremitting. When Deleuze and Guattari bring together multiple, heterogeneous orders in an assemblage, they are concerned with the mutual interactions, not with privileging any particular element above others. What that means is that although the orders of the normative continue to play a part, their power is significantly reduced in comparison with their primacy in conventionally structured discourse. In assemblages, it is the connection between disparate components that produces meaning rather than the other way round, where the fixed meaning of an element would prescribe the nature of its possible connections. As Jasbir Puar notes, “assemblages foreground no constants but rather ‘variation to variation’ and hence the event-ness of identity” (Puar 2012, 58). In other words, there is no internal necessity to the assemblage, just a set of contingent relations that evolve and change over time. All this may appear highly abstract, but for Deleuze and Guattari the effects are wholly material and political. Assemblages matter to critical disability studies as they provide a way of thinking differently about embodiment, a way that avoids the hierarchies of value that mark modernist thought.

Once again, how does this throw light on the Paralympian athlete, and by derivation—for there are only differences—on other disabled bodies, and indeed all bodies? Surely the very success of the occasion and the public acclaim speaks to the recuperation of the anomalous body to normative structures. Does it not signal that we are after all in control of our bodies, compliant with the governing rules and conforming to the demands of Western selfhood? Such a possibility is not to be denied from a Deleuzian perspective as, similar to Foucault’s endless cycle of power and resistance, the specific event of any assemblage may participate in both molar and molecular politics. The term molar refers to the prevailing macro-orders of ideological, social, and psychic power that mandate particular forms of identity and subjectivity, without, however, ever finally cementing them into place. Such restrictive and oppressive identities speak to the organization and stratification of embodied practices—like a sporting event—and cannot be entirely surpassed, yet they are constantly confronted and displaced by the molecular politics of flows and intensities. The fluid and
transformatory capacity of our bodies does not preclude the potential for an assemblage to manifest molar effects, but those are never determinant: unanticipated and unpredictable connections will emerge that allow data to flow in new directions that signal a micropolitics of molecular becoming, of ever-evolving affiliations, and points of encounter and engagement in which issues of power and dependency refuse to settle. In a recent empirical study, for example, Alecia Jackson tracked the everyday experience of a young female cheerleader at a school in the United States, seeking to understand the movement between the rigid and programmed elements of her identity and her escape into free-flowing moments of becoming otherwise (Jackson 2010). The data could very well lend themselves to a Foucauldian analysis, but Jackson chose a Deleuzian approach. She writes:

Molar is something that is well-defined, massive, and governing—such as large structures or identity categories. For example, cheerleading can be considered a molar form in the southern USA; cheerleading exists within discursive and material fields saturated with patriarchy, masculinity, and historically laden ideals of dainty, feminine southern girlhood. (Jackson 2010, 581)

Like the young cheerleader, who casually and intermittently de-stabilizes the program by resisting the strictures of the clean, proper, and disciplined body, the disabled athlete too can take pride in her molar achievements but need not be defined by them. Because such identities are temporary effects of the ever-changing assemblage, for both there are possibilities of molecular escape.

The point for Deleuze and Guattari is that when assemblages are what they call “overcoded” with meaning, they fall into molar forms; they are territorialized. Nonetheless, in a process that is continually opened up and shut down, the possibility remains for assemblages to be deterritorialized. The key to such movements toward a molecular politics rests with the lines of flight that “flee from and potentially scatter assemblages of meanings, representations, practices and subjectivations, offering new ‘becomings’” (Youdell and Armstrong 2011, 145). Consider again the Paralympics. Although somewhat drowned out by the media assemblage around the spectacle, many of the disabled contestants from the UK dislocated the molar capture of their identities to disrupt the narrative of an inspirational selfhood emerging against the odds. Participating in new modes of assemblage, several were able to intervene in and contest the circulation of a very negative political discourse about disability that had been temporarily silenced by the hype of national admiration for Paralympians. In the face of what has emerged as a concerted—and internationally reflected—agenda to reposition people with disabilities as effectively undeserving of their various specific state benefits (Bambra and Smith 2010; Garthwaite 2011; Soldatic and Meekosha 2012), such people gave voice to other modalities of the contemporary experience of being disabled. In exceeding the constrained subjectivities of inspirational role models that set new and unrealistic standards for all disabled people, they spoke to new affectivities and becomings that brought into question the existing relations of power.8 One of the best-known and respected figures in disability politics, for
example, Tanni Grey-Thompson, herself a previous Paralympics gold-medal winner and now a life peer—both unmistakable molar identities—repositioned herself as a critic of state policy by pointing out just how far she would be rendered unable to function were it not for the many supporting networks that connected her to a multiplicity of components beyond her public roles and opened up enhanced possibilities for fully engaging her corporeal capacities (Crampton 2012). Her line of flight away from the authorized narrative ruptures public acceptance of the austerity measures that disproportionately affect disabled people, and introduces new dimensions of her own becoming that nevertheless remain connected back to her influence as a putative spokesperson. The molar and molecular, the macro and the micro, territorialization and deterritorialization work together within any assemblage to both dismantle boundaries and binaries and mobilize unexpected and productive connections between disparate orders of becoming.

Breaking free of molar identities and immersing oneself in the process of becoming is a potential open to all, but perhaps there is something about the state of what is labeled disability—in its inevitable bodily transgressions and modes of assemblage—that more readily lends itself to what is needed to enter into lines of flight. The prosthetic connections addressed earlier are often an everyday experience for disabled people, taking on all the aspects of human–human, human–animal, and human–machine entanglements that would delight any scholar of posthumanism or of assemblage theory. And, as such, people with disabilities may be better able to let go of the illusions of sovereign selfhood (Shildrick 2009b, 140). A growing body of work in CDS, which—unlike the more limited analyses of corporeality that have marked disability theory of the past—engages with a full range of physical, sensory, and cognitive disabilities, is emerging to address not just how postmodernist theories generate new understandings of embodiment, but to explore how to disrupt the whole epistemological project. In comparison to previous research—and this is particularly true of empirical projects—there is less stress on closure and completion, on clean and proper scholarship, and a new willingness, to a greater or lesser extent, to accept that the writer him or herself is part of the process of becoming. The work of Barbara Gibson, for example, on physical disabilities, which engages with Deleuze from a background in health therapies, demonstrates the power of what she calls “transgressive connectivity” and the intermeshed technics of the assemblage, though she still sustains a certain interval of “knowing-about” (Gibson 2006; Gibson, Carnevale, and King 2012). The same is true of Dan Goodley, writing about disabled babies (Goodley 2007), and Bjorn Nansen’s dextrous analysis of the mechanical ventilator in which he describes the symbiotic supplementation of human and machine and—using Elizabeth Grosz’s phrase—the “mutual metamorphosis” of both (Nansen 2007).

A more radical approach is apparent in the work of Deborah Youdell and Felicity Armstrong, who, coming from education studies, have conducted a provocative study of school children with what are classed as learning difficulties (Youdell and Armstrong 2011). Similarly, Michael Feely has analyzed what he calls the sexual surveillance assemblage of an institution for young people with cognitive disabilities that, he insists, constitutes an intermeshing of the service users, the keyworkers, the
managers, the local public, the technologies of surveillance, the specific spatial locations and buildings, and not least himself, both as a recognized “expert” in the field of disability and sexuality, and as an academic researcher (Feely 2013). I cite such projects because their unhesitant immersion in the notion of assemblage raises not only ontological and epistemological, but also ethical reconfigurations.

Once it is acknowledged that a human body is not a discrete entity ending at the skin, and that material technologies constantly disorder our boundaries, either through prosthetic extensions or through the internalization of mechanical parts, it is difficult to maintain that those whose bodies fail to conform to normative standards are less whole or complete than others. As Derrida so clearly shows, the very possibility of supplementation exposes the illusion of any originary integrity and autonomy that might ground hierarchies of value with respect to the embodiment of people with and without so-called anomalies. This is a significant insight in breaking down one of the props for the oppression of disabled people at all levels, but it is with the turn to Deleuze, and particularly to the productivity of the assemblage, that it becomes possible to think yet more positively. The Deleuzian assemblage, and the whole notion of what I am calling somatechnics, which includes very much more than clearly material components, opens up a scenario in which immersion in the indeterminacy and provisionality of multiple inter- and intraconnections is not simply the condition of living but the source of flourishing. As Deleuze makes clear, difference is the default condition, not the representative of some kind of material and ethical failing, and it allows him to think of ethics as the affirmation of multiple transformative possibilities rather than adherence to any fixed standard, be it of embodiment, practices, or affects. Where embodied anomaly has figured in modernist discourse as a lack of fully realized selfhood or has failed to satisfy the demands of the clean and proper body, those very same transgressions can be rethought as the potential for productive change. As the improper and irregular elements that circulate through and unsettle any system of being, they conduct the transformative forces of becoming. Against modernist societies that suppress difference and impose limits on what a body can do, Deleuze proposes that flourishing consists in going to the limits of what is possible, embracing fluidity and radical change, dispensing with fixed identities, and affirming a becoming whose form can neither be predicted nor settled in the future. It is an opening up to the unknown that goes beyond existing organization with its boundaries and blockages to pass through “multiple entryways” (Deleuze and Guattari 1987, 14) into potentially productive alternatives.

The ethical implications for disability could not be clearer: the damaging focus on self-contained individuality, itself dependent on normative standards of acceptability, is displaced by an encompassing connectivity that is untroubled by structure, form, or identity. The dependencies experienced as inherent by those who are disabled speak not to diminished capabilities but to the energies and flows that are the potent source of new becomings with others. I am not implying that all connections are equally positive, and some may stall, some assemblages will be reterritorialized in destructive ways, some bodies will not flourish, but none of these outcomes is fixed; it remains the case that things could be otherwise. As a strong feminist proponent of the
Deleuzian ethical schema, Rosi Braidotti insists on sustainable forms of transformation (Braidotti 2006; 2013). As she notes, ethics “requires adequate assemblages or interaction: one has to pursue or actively create the kind of encounters that are likely to favour an increase in active becomings” (Braidotti 2006, 217). That move is open to all, and no one form of embodiment is at greater risk of negative outcomes by virtue of existing dependencies; insofar as our entanglements are nondetermined, we all remain vulnerable. But that too is a source of new beginnings, for if, as I argue elsewhere, vulnerability is the shared condition of becoming, then we must question the stability of human being itself (Shildrick 2002, 133). Like Braidotti (2013) and others, I remain alert to some dangers of what is otherwise a hopeful post-anthropocentrism, eschewing equally the determinist hype of technological singularity, the desire for a nostalgic return to a lost Eden, and the depredations of neo-capitalist global markets that would commodify the very processes of assemblage itself. The way forward is never clear, but the ethical task does not reside in evaluating a projected scenario in advance, but in taking the risk that the processes will continue to affirm differences and maximize our diverse potentialities.

Feminist theory, no less than masculinist areas of inquiry, has not been especially engaged with disability theory until quite recently, but it does have a long history, dating in particular from Haraway’s early work, of rethinking the significance of human–animal relations, as well as a commitment to science and technology studies. In the recent development of new materialism, those transversal concerns have been brought together in a fuller exposition of the vitalism underlying life itself. The exploration of difference in all its modalities has been fundamental to the feminist project, and disability is now firmly embraced as one of those intersectional modalities that cannot be separated out for discrete study as though its significance were limited to those anomalously embodied. Although it always remains “a context-specific articulation of omnipresent difference” (Hickey-Moody and Wood 2008), disability—perhaps above other differences—can move us toward a clearer understanding of bodies, boundaries, and somatechnics. What is at stake is not just the decline of the priority given to some form of human embodiment over others, but the contestation of human exceptionalism as such and a turn to a kind of post-anthropocentrism that can celebrate an erotics and ethics of connection with an array of organic and inorganic others.

Notes

1. Critical disability studies (CDS) is distinguished from disability studies per se by its very different theoretical bases. Whereas the latter is driven largely by the social model of disability (SMD) and understands disability—though not biological impairment—as constructed by oppressive social and political structures and material practices, critical theory is more concerned with the attitudes and affects that drive discrimination in the first place. The discourse of CDS is usually more based in postconventional theories and is highly skeptical of identity politics and the rights-based nature of SMD approaches.
2. Despite the passions sometimes aroused by the supposed need to choose between using either “people with disabilities” or “disabled people” and the confusing national variations as to which is the more acceptable, I deliberately deploy both forms. There are good arguments for and against both of them, but none that is compelling.

3. Barad is explicit that her use of “entanglements” goes beyond its disciplinary origins in physics (Barad 2003; 2011).

4. Perhaps the apparent delimitation of transcendental empiricism has discouraged thinking with and beyond Deleuze, despite his own encouragement to use his work as a toolbox. Certainly he would not recognize some developments, including my own interpretation perhaps, but that is no reason to limit exploration.

5. As Guattari explains: “desire is everything that exists before the opposition between subject and object... It’s everything whereby the world and affects constitute us outside ourselves.... It’s everything that overflows from us” (Guattari 1996, 46).

6. In discussing the term assemblage as a translation of the Deleuzo–Guattarian use of the French term agencement, a term that signals arrangements and relations, Jasbir Puar notes: “Concepts do not prescribe relations, nor do they exist prior to them; rather, relations of force, connection, resonance, and patterning give rise to concepts” (Puar 2012, 57).

7. Consider the complexity of the athlete-assemblage in sight-impaired alpine skiing. Aside from all the interconnecting and temporally extensive elements—organic, technological, and environmental components, for example—that already comprise the event of a ski-run, the disabled competitor exemplifies the fluidity of what constitutes the assemblage. The sport relies on pairings, with each skier having a guide who skis in close proximity to the competitor, calling out instructions about what is required to negotiate the course. The calls themselves may be amplified by the use of radio mikes that keep the pair in coordinated contact, and the assemblage then widens its scope to include the spectators. Instead of cheering as the skiers approach the finish line, the crowd typically falls silent in order not to interfere with the audio communication between the pair. This is the somatechnics of the assemblage.

8. Affectivity, which I don’t have space to map more fully, is an important element in the work of Deleuze and Guattari (1984; 1987; 1994). Affectivities can be understood as sensations and intensities related to the forces of becoming that flow between bodies in processes of assemblage. They are not experienced directly as such nor do they belong to a particular subject. Rather, they are impersonal, experiential modalities that imply “an augmentation or diminution in that body’s capacity to act” (Massumi 1987, xvii).

9. In the UK, life peers—who sit in the upper legislative body—are political appointments.

10. Even as I write, I am aware of maintaining a critical distance not yet overcome in relation to a theoretically based endeavor, but we will learn eventually from those who have already embraced the materiality of the research assemblage and moved on. The doctoral thesis work of Michael Feely has particularly challenged me as a powerful example of how thinking heterogeneously has an impact both theoretically and methodologically, rendering that binary distinction meaningless.

11. Dis-organization is surely the meaning of the body-without-organs: the ending of the privilege of normative embodiment.
12. In her recent book, Braidotti takes a different view of shared vulnerability as the reactive bond between humans and other species (Braidotti 2013). I understand the dangers she sees in anthropomorphizing those others, but would maintain that any recognition that contests our privilege as a species should be welcomed.

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THE IDEOLOGY OF ABILITY

We seem caught as persons living finite lives between two sets of contradictory ideas about our status as human beings. The first contradiction targets our understanding of the body itself. On the one hand, bodies do not seem to matter to who we are. They contain or dress up the spirit, the soul, the mind, the self. I am, as Descartes explained, the thinking part. At best, the body is a vehicle, the means by which we convey who we are from place to place. At worst, the body is a fashion accessory. We are all playing at Dorian Gray, so confident that the self can be freed from the dead weight of the body, but we have forgotten somehow to read to the end of the novel. On the other hand, modern culture feels the urgent need to perfect the body. Whether medical scientists are working on a cure for the common cold or the elimination of all disease, a cure for cancer or the banishment of death, a cure for HIV/AIDS or control of the genetic code, their preposterous and yet rarely questioned goal is to give everyone a perfect body. We hardly ever consider how incongruous is this understanding of the body—that the body seems both inconsequential and perfectible.

A second but related contradiction targets the understanding of the human being in time. The briefest look at history reveals that human beings are fragile. Human life confronts the overwhelming reality of sickness, injury, disfigurement, enfeeblement, old age, and death. Natural disasters, accidents, warfare and violence, starvation, disease, and pollution of the natural environment attack human life on all fronts, and there are no survivors. This is not to say that life on this earth is wretched and happiness nonexistent. The point is simply that history reveals one unavoidable truth about human beings—whatever our destiny as a species, we are as individuals feeble and finite. And yet the vision of the future to which we often hold promises an existence that bears little or no resemblance to our history. The future obeys an entirely different imperative, one that commands our triumph over death and contradicts everything that history tells us about our lot in life. Many religions instruct that human beings will someday win eternal life. Science fiction fantasizes about aliens who have left behind their mortal sheath; they are superior to us, but we are evolving in their direction. Cybernetics treats human intelligence as software that can be moved from machine to machine. It promises a future where human beings might be downloaded into new hardware whenever their old hardware wears out. The
reason given for exploring human cloning is to defeat disease and aging. Apparently, in some future epoch, a quick trip to the spare-parts depot will cure what ails us; people will look better, feel healthier, and live three times longer. Finally, the human genome project, like eugenics before it, places its faith in a future understanding of human genetics that will perfect human characteristics and extend human life indefinitely.

However stark these contradictions, however false in their extremes, they seem credible in relation to each other. We are capable of believing at once that the body does not matter and that it should be perfected. We believe at once that history charts the radical finitude of human life but that the future promises radical infinitude. That we embrace these contradictions without interrogating them reveals that our thinking is steeped in ideology. Ideology does not permit the thought of contradiction necessary to question it; it sutures together opposites, turning them into apparent complements of each other, smoothing over contradictions, and making almost unrecognizable any perspective that would offer a critique of it. In fact, some cultural theorists claim to believe that ideology is as impenetrable as the Freudian unconscious—that there is no outside to ideology, that it can contain any negative, and that it sprouts contradictions without suffering them (see Goodheart 1996; Siebers 1999). I argue another position: ideology creates, by virtue of its exclusionary nature, social locations outside of itself and therefore capable of making epistemological claims about it. The arguments that follow here are based on the contention that oppressed social locations create identities and perspectives, embodiments and feelings, histories and experiences that stand outside of and offer valuable knowledge about the powerful ideologies that seem to enclose us.

This book pursues a critique of one of these powerful ideologies—one I call the ideology of ability. The ideology of ability is at its simplest the preference for able-bodiedness. At its most radical, it defines the baseline by which humanness is determined, setting the measure of body and mind that gives or denies human status to individual persons. It affects nearly all of our judgments, definitions, and values about human beings, but because it is discriminatory and exclusionary, it creates social locations outside of and critical of its purview, most notably in this case, the perspective of disability. Disability defines the invisible center around which our contradictory ideology about human ability revolves. For the ideology of ability makes us fear disability, requiring that we imagine our bodies are of no consequence while dreaming at the same time that we might perfect them. It describes disability as what we flee in the past and hope to defeat in the future. Disability identity stands in uneasy relationship to the ideology of ability, presenting a critical framework that disturbs and critiques it.

One project of this book is to define the ideology of ability and to make its workings legible and familiar, despite how imbricated it may be in our thinking and practices, and despite how little we notice its patterns, authority, contradictions, and influence as a result. A second and more important project is to bring disability out of the shadow of the ideology of ability, to increase awareness about disability, and to illuminate its kinds, values, and realities. Disability creates theories of embodiment more complex than the ideology of ability allows, and these many embodiments are each crucial to the understanding of humanity and its variations, whether physical, mental, social, or historical. These two projects unfold slowly over the course of my argument for the simple reason that both involve dramatic changes in thinking.
The level of literacy about disability is so low as to be nonexistent, and the ideology of ability is so much a part of every action, thought, judgment, and intention that its hold on us is difficult to root out. The sharp difference between disability and ability may be grasped superficially in the idea that disability is essentially a “medical matter,” while ability concerns natural gifts, talents, intelligence, creativity, physical prowess, imagination, dedication, the eagerness to strive, including the capacity and desire to strive—in brief, the essence of the human spirit. It is easy to write a short list about disability, but the list concerning ability goes on and on, almost without end, revealing the fact that we are always dreaming about it but rarely thinking critically about why and how we are dreaming.

I resort at the outset to the modern convention of the bullet point to introduce the ideology of ability as simply as possible. The bullet points follow without the thought of being exhaustive or avoiding contradiction and without the full commentary that they deserve. Some of the bullets are intended to look like definitions; others describe ability or disability as operators; others still gather stereotypes and prejudices. The point is to begin the accumulation of ideas, narratives, myths, and stereotypes about disability whose theory this book seeks to advance, to provide a few small descriptions on which to build further discussion of ability as an ideology, and to start readers questioning their own feelings about ability and disability:

- Ability is the ideological baseline by which humanness is determined. The lesser the ability, the lesser the human being.
- The ideology of ability simultaneously banishes disability and turns it into a principle of exclusion.
- Ability is the supreme indicator of value when judging human actions, conditions, thoughts, goals, intentions, and desires.
- If one is able-bodied, one is not really aware of the body. One feels the body only when something goes wrong with it.
- The able body has a great capacity for self-transformation. It can be trained to do almost anything; it adjusts to new situations. The disabled body is limited in what it can do and what it can be trained to do. It experiences new situations as obstacles.
- Disability is always individual, a property of one body, not a feature common to all human beings, while ability defines a feature essential to the human species.
- Disability can be overcome through will power or acts of the imagination. It is not real but imaginary.
- It is better to be dead than disabled.
- Nondisabled people have the right to choose when to be able-bodied. Disabled people must try to be as able-bodied as possible all the time.
- Overcoming a disability is an event to be celebrated. It is an ability in itself to be able to overcome disability.
- The value of a human life arises as a question only when a person is disabled. Disabled people are worth less than nondisabled people, and the difference is counted in dollars and cents.
- Disabilities are the gateway to special abilities. Turn disability to an advantage.
- Loss of ability translates into loss of sociability. People with disabilities are bitter, angry, self-pitying, or selfish. Because they cannot see beyond their own pain, they lose the ability to consider the feelings of other people. Disability makes narcissists of us all.
- People who wish to identify as disabled are psychologically damaged. If they could think of themselves as able-bodied, they would be healthier and happier.
To reverse the negative connotations of disability apparent in this list, it will be necessary to claim the value and variety of disability in ways that may seem strange to readers who have little experience with disability studies. But it is vital to show to what extent the ideology of ability collapses once we “claim disability” as a positive identity (Linton 1998). It is equally vital to understand that claiming disability, while a significant political act, is not only political but also a practice that improves quality of life for disabled people. As documented in the case of other minority identities, individuals who identify positively rather than negatively with their disability status lead more productive and happier lives. Feminism, the black and red power movements, as well as gay and disability pride—to name only a few positive identity formations—win tangible benefits for their members, freeing them not only from the violence, hatred, and prejudice directed toward them but also providing them with both shared experiences to guide life choices and a community in which to prosper.

Some readers with a heightened sense of paradox may object that claiming disability as a positive identity merely turns disability into ability and so remains within its ideological horizon. But disability identity does not flounder on this paradox. Rather, the paradox demonstrates how difficult it is to think beyond the ideological horizon of ability and how crucial it is to make the attempt. For thinking of disability as ability, we will see, changes the meaning and usage of ability.

MINORITY IDENTITY AS THEORY
Identity is out of fashion as a category in critical and cultural theory. While it has been associated by the Right and Left with self-victimization, group think, and political correctness, these associations are not the real reason for its fall from grace. The real reason is that identity is seen as a crutch for the person who needs extra help, who is in pain, who cannot think independently. I use the word “crutch” on purpose because the attack on identity is best understood in the context of disability.

According to Linda Martin Alcoff’s extensive and persuasive analysis in Visible Identities, the current rejection of identity has a particular philosophical lineage, one driven, I believe, by the ideology of ability (2006, 47–83). The line of descent begins with the Enlightenment theory of rational autonomy, which represents the inability to reason as the sign of inbuilt inferiority. Usually, the defense of reason attacked non-Europeans as intellectually defective, but because these racist theories relied on the idea of biological inferiority, they necessarily based themselves from the start on the exclusion of disability. “The norm of rational maturity,” Alcoff makes clear, “required a core self stripped of its identity. Groups too immature to practice this kind of abstract thought or to transcend their ascribed cultural identities were deemed incapable of full autonomy, and their lack of maturity was often ‘explained’ via racist theories of the innate inferiority of non-European peoples” (2006, 22).

The Enlightenment view then descends to two modern theories, each of which sees dependence on others as a form of weakness that leads to oppressive rather than cooperative behavior. The first theory belongs to Freud, for whom strong identity attachments relate to pathological psychology and figure as symptoms of ego dysfunction. In psychoanalysis, in effect, a lack lies at the heart of identity (2006, 74), and those unable to overcome this lack fall into patterns of dependence and aggression. Second, in Sartre’s existential ontology, identity is alienated from the real self. Identity represents for Sartre a social role, linked to bad faith and motivated by moral failing and intellectual weakness,
that tempts the self with inauthentic existence, that is, an existence insufficiently free from the influence of others (2006, 68).

Dossier No. 1  The Nation  November 6, 2006
Show Him the Money
By Katha Pollitt
I wanted to admire The Trouble with Diversity, Walter Benn Michaels’s much-discussed polemic against identity politics and economic inequality. Like him, I’m bothered by the extent to which symbolic politics has replaced class grievances on campus, and off it too: the obsessive cultivation of one’s roots, the fetishizing of difference, the nitpicky moral one-upmanship over language. Call an argument “lame” on one academic-feminist list I’m on and you’ll get—still!—an electronic earful about your insensitivity to the disabled...

These two strains of thinking, despite their differences, support the contemporary distrust of identity. Thus, for Michel Foucault and Judith Butler—to name two of the most influential theorists on the scene today—identity represents a “social necessity that is also a social pathology” (Alcoff 2006, 66); there supposedly exists no form of identity not linked ultimately to subjugation by others. In short, contemporary theorists banish identity when they associate it with lack, pathology, dependence, and intellectual weakness. Identity in their eyes is not merely a liability but a disability.

Notice, however, that identity is thought defective only in the case of minorities, whereas it plays no role in the critique of majority identifications, even among theorists who assail them. For example, no one attacks Americanness specifically because it is an identity. It may be criticized as an example of nationalism, but identity receives little or no mention in the critique. Identity is attacked most frequently in the analysis of minority identity—only people of color, Jews, Muslims, gay, lesbian, bisexual, and transgendered people, women, and people with disabilities seem to possess unhealthy identities. It is as if identity itself occupied a minority position in present critical and cultural theory—for those who reject identity appear to do so only because of its minority status, a status linked again and again to disability.

Moreover, the rejection of minority identity repeats in nearly every case the same psychological scenario. The minority identity, a product of damage inflicted systematically on a people by a dominant culture, is rearticulated by the suffering group as self-affirming, but because the identity was born of suffering, it is supposedly unable to shed its pain, and this pain soon comes to justify feelings of selfishness, resentment, bitterness, and self-pity—all of which combine to justify the oppression of other people. Thus, J. C. Lester (2006) complains that “the disabled are in danger of being changed,” because of disability studies, “from the proper object of decent voluntary help, where there is genuine need, into a privileged and growing interest group of oppressors of more ordinary people.” Nancy Fraser also points out that identity politics “encourages the reification of group identities” and promotes “conformism, intolerance, and patriarchalism” (2000, 113, 112). Even if this tired scenario were credible—and it is not because it derives from false ideas about disability—it is amazing that so-called politically minded people are worried that a few minority groups might somehow, some day, gain the power to retaliate for injustice, when the wealthy, powerful, and wicked are actively plundering the globe in every conceivable manner: the decimation of nonindustrial countries by the industrial nations, arms-trafficking, enforcement of poverty to maintain the circuit between cheap labor and robust consumerism, global warming,
sexual trafficking of women, industrial pollution by the chemical and oil companies, inflation of costs for drugs necessary to fight epidemics, and the cynical failure by the wealthiest nations to feed their own poor, not to mention starving people outside their borders.

My argument here takes issue with those who believe that identity politics either springs from disability or disables people for viable political action. I offer a defense of identity politics and a counterargument to the idea, embraced by the Right and Left, that identity politics cannot be justified because it is linked to pain and suffering. The idea that suffering produces weak identities both enforces the ideology of ability and demonstrates a profound misunderstanding of disability: disability is not a pathological condition, only analyzable via individual psychology, but a social location complexly embodied. Identities, narratives, and experiences based on disability have the status of theory because they represent locations and forms of embodiment from which the dominant ideologies of society become visible and open to criticism. One of my specific tactics throughout this book is to tap this theoretical power by juxtaposing my argument with dossier entries detailing disability identities, narratives, images, and experiences. The dossier is compiled for the most part from news stories of the kind that appear in major newspapers across the country every day, although I have avoided the feel-good human-interest stories dominating the news that recount how their disabled protagonists overcome their disabilities to lead “normal” lives. Rather, the dossier tends to contain testimony about the oppression of disabled people, sometimes framed in their own language, sometimes framed in the language of their oppressors. At first, the dossier entries may have no particular meaning to those untutored in disability studies, but my hope is that they will grow stranger and stranger as the reader progresses, until they begin to invoke feelings of horror and disgust at the blatant and persistent prejudices directed against disabled people. The dossier represents a deliberate act of identity politics, and I offer no apology for it because identity politics remains in my view the most practical course of action by which to address social injustices against minority peoples and to apply the new ideas, narratives, and experiences discovered by them to the future of progressive, democratic society.

Identity is neither a liability nor a disability. Nor is it an ontological property or a state of being. Identity is, properly defined, an epistemological construction that contains a broad array of theories about navigating social environments. Manuel Castells calls identity a collective meaning, necessarily internalized by individuals for the purpose of social action (1997, 7), while Charles Taylor argues, “My identity is defined by the commitments and identifications which provide the frame or horizon within which I can try to determine from case to case what is good, or valuable, or what ought to be done, or what I endorse or oppose” (1987, 27). Alcoff explains that “identity is not merely that which is given to an individual or group, but is also a way of inhabiting, interpreting, and working through, both collectively and individually, an objective social location and group history” (2006, 42). We do well to follow these writers and to consider identity a theory-laden construction, rather than a mere social construction, in which knowledge for social living adheres—though not always and necessarily the best knowledge. Thus, identity is not the structure that creates a person’s pristine individuality or inner essence but the structure by which that person identifies and becomes identified with a set of social narratives, ideas, myths, values, and types of knowledge of
varying reliability, usefulness, and verifiability. It represents the means by which the person, qua individual, comes to join a particular social body. It also represents the capacity to belong to a collective on the basis not merely of biological tendencies but symbolic ones—the very capacity that distinguishes human beings from other animals.

While all identities contain social knowledge, mainstream identities are less critical, though not less effective for being so, because they are normative. Minority identities acquire the ability to make epistemological claims about the society in which they hold liminal positions, owing precisely to their liminality. The early work of Abdul JanMohamed and David Lloyd, for example, privileges the power of the minor as critique: “The study—and production—of minority discourse requires, as an inevitable consequence of its mode of existence, the transgression of the very disciplinary boundaries by which culture appears as a sublimated form with universal validity. This makes it virtually the privileged domain of cultural critique” (1987, 9). The critique offered by minority identity is necessarily historical because it relies on the temporal contingency of its marginal position. Different groups occupy minority positions at different times, but this does not mean that their social location is any less objective relative to their times. Nor does it suggest that structures of oppression differ in the case of every minority identity. If history has taught us anything, it is that those in power have the ability to manipulate the same oppressive structures, dependent upon the same prejudicial representations, for the exclusion of different groups. The experiences of contemporary minority people, once brought to light, resound backward in history, like a reverse echo effect, to comment on the experiences of past minority peoples, while at the same time these past experiences contribute, one hopes, to an accumulation of knowledge about how oppression works.

Minority identity discovers its theoretical force by representing the experiences of oppression and struggle lived by minority peoples separately but also precisely as minorities, for attention to the similarities between different minority identities exposes their relation to oppression as well as increases the chance of political solidarity. According to the definition of Gary and Rosalind Dworkin, minority identity has recognizable features that repeat across the spectrum of oppressed people. “We propose,” Dworkin and Dworkin write, “that a minority group is a group characterized by four qualities: identifiability, differential power, differential and pejorative treatment, and group awareness” (1976, 17). These four features form the basis of my argument about minority identity as well, with one notable addition—that minority status also meet an ethical test judged both relative to society and universally. These features require, each one in turn, a brief discussion to grasp their collective simplicity and power and to arrive at a precise and universal definition of minority identity on which to base the elaboration of disability identity, to describe its relation to minority identity in general, and to defend identity politics as crucial to the future of minority peoples and their quest for social justice and inclusion.

1. Identifiability as a quality exists at the heart of identity itself because we must be able to distinguish a group before we can begin to imagine an identity. Often we conceive of identifiability as involving visible differences connected to the body, such as skin color, gender traits, gestures, affect, voice, and body shapes. These physical traits, however, are not universal with respect to different cultures, and there may be actions or cultural differences that also figure as the basis of identifiability. Note as well that identifiability exists in time,
and time shifts its meaning. As a group is identified, it acquires certain representations, and the growth of representations connected to the group may then change how identifiability works. For example, the existence of a group called disabled people produces a general idea of the people in the group—although the existence of the group does not depend on every disabled person fitting into it—and it then becomes easier, first, to identify people with it and, second, to shift the meaning of the group definition. Fat people are not generally considered disabled at this moment, but there are signs that they may be in the not too distant future (Kirkland 2006). Deaf and intersex people have resisted being described as disabled; their future relation to the identity of disabled people is not clear.

Two other obvious characteristics of identifiability need to be stressed. First, identifiability is tied powerfully to the representation of difference. In cases where an existing minority group is not easily identified and those in power want to isolate the group, techniques will be used to produce identifiability. For example, the Nazis required that Jews wear yellow armbands because they were not, despite Nazi racist mythology, identifiably different from Germans. Second, identity is social, and so is the quality of identifiability. There are many physical differences among human beings that simply do not count for identifiability. It is not the fact of physical difference that matters, then, but the representation attached to difference—what makes the difference identifiable. Representation is the difference that makes a difference. We might contend that there is no such thing as private identity in the same way that Wittgenstein claimed that private language does not exist. Identity must be representable and communicable to qualify as identifiable. Identity serves social purposes, and a form of identity not representable in society would be incomprehensible and ineffective for these purposes.

Of course, people may identify themselves. Especially in societies where groups are identified for differential and pejorative treatment, individuals belonging to these groups may internalize prejudices against themselves and do on their own the work of making themselves identifiable. Jim Crow laws in the American South counted on people policing themselves—not drinking at a white water fountain if they were black, for example. But the way in which individuals claim identifiability also changes as the history of the group changes. A group may be singled out for persecution, but as it grows more rebellious, it may work to preserve its identity, while transforming simultaneously the political values attached to it. The American military’s policy, “Don’t ask, don’t tell” in the case of gay soldiers, tries to stymie the tendency of individuals to claim a positive minority identity for political reasons.

2. Differential power is a strong indicator of the difference between majority and minority identity; in fact, it may be the most important indicator because minority status relies on differential power rather than on numbers. The numerical majority is not necessarily the most powerful group. There are more women than men, and men hold more political power and have higher salaries for the same jobs. Numerical advantage is significant, but a better indicator is the presence of social power in one group over another. Dworkin and Dworkin mention the American South in the 1950s and South Africa under apartheid as good examples of differential power located in a nonnumerical majority (12). Minorities hold less power than majority groups.

3. A central question is whether the existence of differential treatment already implies pejorative treatment. Allowing that differential treatment may exist for legitimate reasons—and it is not at all certain
that we should make this allowance—the addition of pejorative treatment as a quality of minority identity stresses the defining connection between oppression and minority status. Differential and pejorative treatment is what minority group members experience as a consequence of their minority position. It affects their economic standing, cultural prestige, educational opportunities, and civil rights, among other things. Discrimination as pejorative treatment often becomes the focus of identity politics, those concerted attempts by minorities to protest their inferior and unjust status by forming political action groups.

The emergence of identity politics, then, relies on a new epistemological claim. While it is not necessarily the case that a group will protest against discrimination, since there is a history of groups that accept inferior status and even fight to maintain it, the shift to a protest stance must involve claims different from those supporting the discriminatory behavior. A sense of inequity comes to pervade the consciousness of the minority identity, and individuals can find no reasonable justification for their differential treatment. Individuals in protest against unjust treatment begin to develop theories that oppose majority opinion not only about themselves but about the nature of the society that supports the pejorative behavior. They develop ways to represent the actions used to perpetuate the injustice against them, attacking stereotypes, use of violence and physical attack, and discrimination. Individuals begin to constitute themselves as a minority identity, moving from the form of consciousness called internal colonization to one characterized by a new group awareness.

4. Group awareness does not refer to group identifiability but to the perception of common goals pursued through cooperation, to the realization that differential and pejorative treatment is not justified by actual qualities of the minority group, and to the conviction that majority society is a disabling environment that must be transformed by recourse to social justice. In other words, awareness is not merely self-consciousness but an epistemology that adheres in group identity status. It is the identity that brings down injustice initially on the individual's head. This identity is constructed in such a way that it can be supported only by certain false claims and stereotypes. Resistance to these false claims is pursued and shared by members of the minority identity through counterarguments about, and criticism of, the existing state of knowledge. Thus, minority identity linked to group awareness achieves the status of a theoretical claim in itself, one in conflict with the mainstream and a valuable source of meaningful diversity. Opponents of identity politics often argue that identity politics preserves the identities created by oppression: these identities are born of suffering, and embracing them supposedly represents a form of self-victimization. This argument does not understand that new epistemological claims are central to identity politics. For example, societies that oppress women often assert that they are irrational, morally depraved, and physically weak. The minority identity “woman,” embraced by feminist identity politics, disputes these assertions and presents alternative, positive theories about women. Identity politics do not preserve the persecuted identities created by oppressors because the knowledge claims adhering in the new identities are completely different from those embraced by the persecuting groups.

Opponents of identity politics are not wrong, however, when they associate minority identity with suffering. They are wrong because they do not accept that pain and suffering may sometimes be resources for the epistemological insights of minority identity. This issue will arise whenever
we consider disability identity, since it is
the identity most associated with pain,
and a great deal of discrimination against
people with disabilities derives from the
irrational fear of pain. It is not uncommon
for disabled people to be told by complete
strangers that they would kill themselves
if they had such a disability. Doctors often
withhold treatment of minor illnesses from
disabled people because they believe they
are better off dead—the doctors want to
end the suffering of their patients, but these
disabled people do not necessarily think of
themselves as in pain, although they must
suffer discriminatory attitudes (Gill 2000;
Longmore 2003, 149–203). Nevertheless,
people with disabilities are not the only
people who suffer from prejudice. The
epistemological claims of minority identity
in general are often based on feelings of
injustice that are painful. Wounds received
in physical attacks may pale against the
suffering experienced in the idea that one
is being attacked because one is unjustly
thought inferior—and yet suffering may
have theoretical value for the person
in pain. While there is a long history of
describing pain and suffering as leading to
egotism and narcissism—a metapsychol-
ogy that plays, I argue in chapter 2, an ancil-
lar role in the evolution of the ideology of
ability—we might consider that the strong
focus given to the self in pain has episte-
mological value.1 Suffering is a signal to the
self at risk, and this signal applies equally
to physical and social situations. The body
signals with pain when a person is engaged
in an activity that may do that person phys-
ical harm. Similarly, consciousness feels
pain when the individual is in social dan-
ger. Suffering has a theoretical component
because it draws attention to situations
that jeopardize the future of the individ-
ual, and when individuals who suffer from
oppression gather together to share their
experiences, this theoretical component
may be directed toward political ends.

By suggesting that suffering is theory-
laden—that is, a sensation evaluative of
states of reality—I am trying to track how
and why minority identity makes episte-
mological claims about society. All identity
is social theory. Identities are the theories
that we use to fit into and travel through
the social world. Our identities have a con-
tent that makes knowledge claims about
the society in which they have evolved, and
we adjust our identities, when we can, to
different situations to improve our chances
of success. But because mainstream iden-
tities so robustly mimic existing social
norms, it is difficult to abstract their claims
about society. Identities in conflict with
society, however, have the ability to expose
its norms. Minority identity gains the sta-
tus of social critique once its content has
been sufficiently developed by groups that
unite to protest their unjust treatment by
the society in which they live.

5. In addition to the four qualities pro-
posed by Dworkin and Dworkin, groups
claiming minority identity need to meet an
ethical test. Minority identities make epis-
temological claims about the societies in
which they hold liminal positions, but not
all theories are equal in ethical content,
especially relative to minority identity,
since it begins as a product of oppression
and acquires the status of social critique.
While matters ethical are notoriously dif-
ficult to sort out, it is nevertheless worth
pausing briefly over how ethics relates to
minority identity because ethical content
may serve to check fraudulent claims of
minority status. For example, in South
Africa of recent date, the ideology of apart-
heid represented the majority position
because it held power, identified the nature
of minority identity, and dictated differen-
tial and pejorative treatment of those in
the minority. Today in South Africa, how-
ever, the apartheidists are no longer in the
majority. Applying the theory of Dworkin
and Dworkin, they might be construed as
having a minority identity: they are identifiable, they have differential power, they are treated pejoratively, and they possess group awareness—that is, they present a set of claims that actively and consciously criticize majority society. They also believe themselves to be persecuted, and no doubt they feel suffering about their marginal position.

Why are the apartheidists not deserving of minority status? The answer is that the theories contained in apartheidist identity do not pass an ethical test. The contrast between its ethical claims and those of the majority are sufficiently striking to recognize. The apartheidists propose a racist society as the norm to which all South African citizens should adhere. Relative to South African social beliefs and those of many other countries, apartheid ideology is unacceptable on ethical grounds because it is biased, violent, and oppressive. Consequently, the apartheidists fail to persuade us with their claims, and we judge them not a minority group subject to oppression but a fringe group trying to gain unlawful advantage over others.

To summarize, the definition embraced here—and used to theorize disability identity—does not understand minority identity as statistical, fixed in time, or exclusively biological but as a politicized identity possessing the ability to offer social critiques. There are those who attack minority identities precisely because they are politicized, as if only minorities made political arguments based on identity and politicized identity in itself were a species of defective attachment. But many other examples of politicized identity exist on the current scene—Democrats, Republicans, Socialists, the Christian Coalition, the American Nazi Party, and so on. In fact, any group that forms a coalition to make arguments on its own behalf and on the behalf of others in the public forum takes on a politicized identity. Arguments to outlaw minority political action groups merely because they encourage politicized identities would have to abolish other political groups as well.

**DISABILITY AND THE THEORY OF COMPLEX EMBODIMENT**

Feminist philosophers have long argued that all knowledge is situated, that it adheres in social locations, that it is embodied, with the consequence that they have been able to claim that people in marginal social positions enjoy an epistemological privilege that allows them to theorize society differently from those in dominant social locations (Haraway 1991, 183–201; Harding 1986). Knowledge is situated, first of all, because it is based on perspective. There is a difference between the knowledge present in a view of the earth from the moon and a view of the earth from the perspective of an ant. We speak blandly of finding different perspectives on things, but different perspectives do in fact give varying conceptions of objects, especially social objects. Nevertheless, situated knowledge does not rely only on changing perspectives. Situated knowledge adheres in embodiment. The disposition of the body determines perspectives, but it also spices these perspectives with phenomenological knowledge—lifeworld experience—that affects the interpretation of perspective.

To take a famous example from Iris Young, the fact that many women “throw like a girl” is not based on a physical difference. The female arm is as capable of throwing a baseball as the male arm. It is the representation of femininity in a given society that disables women, pressuring them to move their bodies in certain, similar ways, and once they become accustomed to moving in these certain, similar ways, it is difficult to retrain the body. “Women in sexist society are physically handicapped,” Young explains. “Insofar as we learn to live out our
existence in accordance with the definition that patriarchal culture assigns to us, we are physically inhibited, confined, positioned, and objectified” (2005, 171). It is possible to read the differential and pejorative treatment of women, as if it were a disability, on the surface of their skin, in muscle mass, in corporeal agility. This form of embodiment is also, however, a form of situated knowledge about the claims being made about and by women in a given society. To consider some positive examples, the particular embodiment of a woman means that she might, after experiencing childbirth, have a new and useful perception of physical pain. Women may also have, because of menstruation, a different knowledge of blood. Female gender identity is differently embodied because of women’s role in reproductive labor. The presence of the body does not boil down only to perspective but to profound ideas and significant theories about the world.

Embodiment is, of course, central to the field of disability studies. In fact, a focus on disability makes it easier to understand that embodiment and social location are one and the same. Arguments for the specificity of disability identity tend to stress the critical nature of embodiment, and the tacit or embodied knowledge associated with particular disabilities often justifies their value to larger society. For example, George Lane’s body, we will see in chapter 6, incorporates a set of theoretical claims about architecture that the Supreme Court interprets in its ruling against the State of Tennessee, finding that Lane’s inability to enter the Polk County Courthouse reveals a pattern of discrimination against people with disabilities found throughout the American court system. Chapter 5 explores disability passing not as avoidance of social responsibility or manipulation for selfish interests but as a form of embodied knowledge—forced into usage by prejudices against disability—about the relationship between the social environment and human ability. The young deaf woman who tries to pass for hearing will succeed only if she possesses significant knowledge about the informational potential, manners, physical gestures, conversational rituals, and cultural activities that define hearing in her society. Disabled people who pass for able-bodied are neither cowards, cheats, nor con artists but skillful interpreters of the world from whom we all might learn.

Dossier No. 2 New York Times Online November 15, 2006 Officials Clash over Mentally Ill in Florida Jails By Abby Goodnough MIAMI, Nov. 14—For years, circuit judges here have ordered state officials to obey Florida law and promptly transfer severely mentally ill inmates from jails to state hospitals. But with few hospital beds available, Gov. Jeb Bush’s administration began flouting those court orders in August. . . . “This type of arrogant activity cannot be tolerated in an orderly society,” Judge Crockett Farnell of Pinellas-Pasco Circuit Court wrote in an Oct. 11 ruling.

State law requires that inmates found incompetent to stand trial be moved from county jails to psychiatric hospitals within 15 days of the state’s receiving the commitment orders. Florida has broken that law for years, provoking some public defenders to seek court orders forcing swift compliance. . . . Two mentally ill inmates in the Escambia County Jail in Pensacola died over the last year and a half after being subdued by guards, according to news reports. And in the Pinellas County Jail in Clearwater, a schizophrenic inmate gouged out his eye after waiting weeks for a hospital bed, his lawyer said. . . . The problem is not unique to Florida, although it is especially severe in Miami-Dade County, which has one of the nation’s largest percentages of mentally ill residents, according to the National Alliance for the Mentally Ill, an advocacy group. . . . In Miami, an average of 25 to 40 acutely psychotic people live in a unit of the main
county jail that a lawyer for Human Rights Watch, Jennifer Daskal, described as squalid after visiting last month. . . . Ms. Daskal said that some of the unit’s 14 “suicide cells”—dim, bare and designed for one inmate—were holding two or three at a time, and that the inmates were kept in their cells 24 hours a day except to shower . . .

But embodiment also appears as a bone of contention in disability studies because it seems caught between competing models of disability. Briefly, the medical model defines disability as a property of the individual body that requires medical intervention. The medical model has a biological orientation, focusing almost exclusively on disability as embodiment. The social model opposes the medical model by defining disability relative to the social and built environment, arguing that disabling environments produce disability in bodies and require interventions at the level of social justice. Some scholars complain that the medical model pays too much attention to embodiment, while the social model leaves it out of the picture. Without returning to a medical model, which labels individuals as defective, the next step for disability studies is to develop a theory of complex embodiment that values disability as a form of human variation.

The theory of complex embodiment raises awareness of the effects of disabling environments on people’s lived experience of the body, but it emphasizes as well that some factors affecting disability, such as chronic pain, secondary health effects, and aging, derive from the body. These last disabilities are neither less significant than disabilities caused by the environment nor to be considered defects or deviations merely because they are resistant to change. Rather, they belong to the spectrum of human variation, conceived both as variability between individuals and as variability within an individual’s life cycle, and they need to be considered in tandem with social forces affecting disability. The theory of complex embodiment views the economy between social representations and the body not as unidirectional as in the social model, or nonexistent as in the medical model, but as reciprocal. Complex embodiment theorizes the body and its representations as mutually transformative. Social representations obviously affect the experience of the body, as Young makes clear in her seminal essay, but the body possesses the ability to determine its social representation as well, and some situations exist where representation exerts no control over the life of the body.

As a living entity, the body is vital and chaotic, possessing complexity in equal share to that claimed today by critical and cultural theorists for linguistic systems. The association of the body with human mortality and fragility, however, forces a general distrust of the knowledge embodied in it. It is easier to imagine the body as a garment, vehicle, or burden than as a complex system that defines our humanity, any knowledge that we might possess, and our individual and collective futures. Disability gives even greater urgency to the fears and limitations associated with the body, tempting us to believe that the body can be changed as easily as changing clothes. The ideology of ability stands ready to attack any desire to know and to accept the disabled body in its current state. The more likely response to disability is to try to erase any signs of change, to wish to return the body magically to a past era of supposed perfection, to insist that the body has no value as human variation if it is not flawless.

Ideology and prejudice, of course, abound in all circles of human existence, labeling some groups and individuals as inferior or less than human: people of color, women, the poor, people with different sexual orientations, and the disabled.
confront the intolerance of society on a daily basis. In nearly no other sphere of existence, however, do people risk waking up one morning having become the persons whom they hated the day before. Imagine the white racist suddenly transformed into a black man, the anti-Semite into a Jew, the misogynist into a woman, and one might begin to approach the change in mental landscape demanded by the onset of disability. We require the stuff of science fiction to describe these scenarios, most often for comic effect or paltry moralizing. But no recourse to fiction is required to imagine an able-bodied person becoming disabled. It happens every minute of every day.

The young soldier who loses his arm on an Iraqi battlefield wakes up in bed having become the kind of person whom he has always feared and whom society names as contemptible (Corbett 2004). Given these circumstances, how might we expect him to embrace and to value his new identity? He is living his worst nightmare. He cannot sleep. He hates what he has become. He distances himself from his wife and family. He begins to drink too much. He tries to use a functional prosthetic, but he loathes being seen with a hook. The natural prosthetic offered to him by Army doctors does not really work, and he prefers to master tasks with his one good arm. He cannot stand the stares of those around him, the looks of pity and contempt as he tries to perform simple tasks in public, and he begins to look upon himself with disdain.

The soldier has little chance, despite the promise of prosthetic science, to return to his former state. What he is going through is completely understandable, but he needs to come to a different conception of himself, one based not on the past but on the present and the future. His body will continue to change with age, and he may have greater disabling conditions in the future. He is no different in this regard from any other human being. Some disabilities can be approached by demanding changes in how people with disabilities are perceived, others—by changes in the built environment. Some can be treated through medical care. Other disabilities cannot be approached by changes in either the environment or the body. In almost every case, however, people with disabilities have a better chance of future happiness and health if they accept their disability as a positive identity and benefit from the knowledge embodied in it. The value of people with disabilities to themselves does not lie in finding a way to return through medical intervention to a former physical perfection, since that perfection is a myth, nor in trying to conceal from others and themselves that they are disabled. Rather, embodiment seen complexly understands disability as an epistemology that rejects the temptation to value the body as anything other than what it was and that embraces what the body has become and will become relative to the demands on it, whether environmental, representational, or corporeal.

**INTERSECTIONAL IDENTITY COMPLEXLY EMBODIED**

The ultimate purpose of complex embodiment as theory is to give disabled people greater knowledge of and control over their bodies in situations where increased knowledge and control are possible. But the theory has side benefits for at least two crucial debates raging on the current scene as well. First, complex embodiment makes a contribution to influential arguments about intersectionality—the idea that analyses of social oppression take account of overlapping identities based on race, gender, sexuality, class, and disability. While theorists of intersectionality have never argued for a simple additive model in which oppressed identities are stacked one upon another, a notion of disability embodiment helps to
resist the temptation of seeing some identities as more pathological than others, and it offers valuable advice about how to conceive the standpoint of others for the purpose of understanding the prejudices against them. This is not to suggest that the intersection of various identities produces the same results for all oppressed groups, since differences in the hierarchical organization of race, gender, sexuality, class, and disability do exist (Collins 2003, 212). Rather, it is to emphasize, first, that intersectionality as a theory references the tendency of identities to construct one another reciprocally (Collins 2003, 208); second, that identities are not merely standpoints where one may stand or try to stand but also complex embodiments; and, third, that the ideology of ability uses the language of pathology to justify labeling some identities as inferior to others.4

For example, theorists of intersectional identity might find useful the arguments in disability studies against disability simulation because they offer a view of complex embodiment that enlarges standpoint theory. The applied fields of occupational therapy and rehabilitation science sometimes recommend the use of disability simulations to raise the consciousness of therapists who treat people with disabilities. Instructors ask students to spend a day in a wheelchair or to try navigating classroom buildings blindfolded to get a better sense of the challenges faced by their patients. The idea is that students may stand for a time in the places occupied by disabled people and come to grasp their perspectives. Disability theorists have attacked the use of simulations for a variety of reasons, the most important being that they fail to give the student pretenders a sense of the embodied knowledge contained in disability identities. Disability simulations of this kind fail because they place students in a time-one position of disability, before knowledge about disability is acquired, usually resulting in emotions of loss, shock, and pity at how dreadful it is to be disabled. Students experience their body relative to their usual embodiment, and they become so preoccupied with sensations of bodily inadequacy that they cannot perceive the extent to which their “disability” results from social rather than physical causes. Notice that such games focus almost entirely on the phenomenology of the individual body. The pretender asks how his or her body would be changed, how his or her personhood would be changed, by disability. It is an act of individual imagination, then, not an act of cultural imagination. Moreover, simulations tempt students to play the game of “What is Worse?” as they experiment with different simulations. Is it worse to be blind or deaf, worse to lose a leg or an arm, worse to be paralyzed or deaf, mute, and blind? The result is a thoroughly negative and unrealistic impression of disability.

The critique of disability simulation has applications in several areas of intersectional theory. First, the practice of peeling off minority identities from people to determine their place in the hierarchy of oppression is revealed to degrade all minority identities by giving a one-dimensional view of them. It also fails to understand the ways in which different identities constitute one another. Identities may trump one another in the hierarchy of oppression, but intersectional identity, because embodied complexly, produces not competition between minority identities but “outsider” theories about the lived experience of oppression (see Collins 1998). Additionally, coming to an understanding of intersecting minority identities demands that one imagine social location not only as perspective but also as complex embodiment, and complex embodiment combines social and corporeal factors. Rather than blindfolding students for an hour, then, it is preferable to send them off wearing sunglasses and carrying a
white cane, in the company of a friend, to restaurants and department stores, where
they may observe firsthand the spectacle of discrimination against blind people as
passersby avoid and gawk at them, clerks refuse to wait on them or condescend to
ask the friend what the student is looking for, and waiters request, usually at the top
of their lungs and very slowly (since blind people must also be deaf and cognitively
disabled), what the student would like to eat.5

It is crucial to resist playing the game of “What Is Worse?” when conceiving of inter-
sectional identity, just as it is when imaginating different disabilities. Asking whether it
is worse to be a woman or a Latina, worse to be black or blind, worse to be gay or poor
registers each identity as a form of ability that has greater or lesser powers to over-
come social intolerance and prejudice. Although one may try to keep the focus
on society and the question of whether it oppresses one identity more than another,
the debate devolves all too soon and often to discussions of the comparative costs of
changing society and making accommoda-
tions, comparisons about quality of life,
and speculations about whether social dis-
advantages are intrinsic or extrinsic to the
group. The compelling issue for minority
identity does not turn on the question of
whether one group has the more arduous
existence but on the fact that every minor-
ity group faces social discrimination, vio-

lence, and intolerance that exert toxic and
unfair influence on the ability to live life to
the fullest (see Asch 2001, 406–7).

SOCIAL CONSTRUCTION

COMPLEXLY EMBODIED

Second, the theory of complex embodiment makes it possible to move forward
arguments raging currently about social construction, identity, and the body. Aside
from proposing a theory better suited to the experiences of disabled people, the goal is
to advance questions in identity and body theory unresponsive to the social construc-
tion model. Chapters 3, 4, and 6 [original volume] make an explicit adjustment in
social construction theory by focusing on the realism of identities and bodies. By
“realism” I understand neither a positivistic claim about reality unmediated by social
representations, nor a linguistic claim about reality unmediated by objects of
representation, but a theory that describes reality as a mediation, no less real for being
such, between representation and its social objects.6 Rather than viewing representa-
tion as a pale shadow of the world or the world as a shadow world of representation,
my claim is that both sides push back in the construction of reality. The hope is to
advance discourse theory to the next stage by defining construction in a radical way,
one that reveals constructions as possessing both social and physical form. While
identities are socially constructed, they are nevertheless meaningful and real pre-
cisely because they are complexly embodied. The complex embodiment apparent in
disability is an especially strong example to contemplate because the disabled body
compels one to give concrete form to the theory of social construction and to take its
metaphors literally.

Consider an introductory example of the way in which disability complexly embodied
extends the social construction argument in the direction of realism. In August 2000
a controversy about access at the Galehead hut in the Appalachian Mountains came to
a climax (Goldberg 2000). The Appalachian Mountain Club of New Hampshire had just
constructed a rustic thirty-eight bed lodge at an elevation of thirty-eight hundred feet.
The United States Forest Service required that the hut comply with the Americans
with Disabilities Act (ADA) and be accessible to people with disabilities, that it have
a wheelchair ramp and grab bars in larger
toilet stalls. The Appalachian Mountain Club had to pay an extra $30,000 to $50,000 for a building already costing $400,000 because the accessible features were late design changes. Its members ridiculed the idea that the building, which could be reached only by a super-rugged 4.6 mile trail, would ever be visited by wheelchair users, and the media tended to take their side.

At this point a group from Northeast Passage, a program at the University of New Hampshire that works with people with disabilities, decided to make a visit to the Galehead hut. Jill Gravink, the director of Northeast Passage, led a group of three hikers in wheelchairs and two on crutches on a twelve-hour climb to the lodge, at the end of which they rolled happily up the ramp to its front door. A local television reporter on the scene asked why, if people in wheelchairs could drag themselves up the trail, they could not drag themselves up the steps into the hut, implying that the ramp was a waste of money. Gravink responded, “Why bother putting steps on the hut at all? Why not drag yourself in through a window?”

The design environment, Gravink suggests pointedly, determines who is able-bodied at the Galehead lodge. The distinction between the disabled and non-disabled is socially constructed, and it is a rather fine distinction at that. Those who are willing and able to climb stairs are considered able-bodied, while those who are not willing and able to climb stairs are disabled. However, those who do climb stairs but are not willing and able to enter the building through a window are not considered disabled. It is taken for granted that nondisabled people may choose when to be able-bodied. In fact, the built environment is full of technologies that make life easier for those people who possess the physical power to perform tasks without these technologies. Stairs, elevators, escalators, washing machines, leaf and snow blowers, eggbeaters, chainsaws, and other tools help to relax physical standards for performing certain tasks. These tools are nevertheless viewed as natural extensions of the body, and no one thinks twice about using them. The moment that individuals are marked as disabled or diseased, however, the expectation is that they will maintain the maximum standard of physical performance at every moment, and the technologies designed to make their life easier are viewed as expensive additions, unnecessary accommodations, and a burden on society.

The example of the Galehead hut exposes the ideology of ability—the ideology that uses ability to determine human status, demands that people with disabilities always present as able-bodied as possible, and measures the value of disabled people in dollars and cents. It reveals how constructed are our attitudes about identity and the body. This is a familiar point, and usually social analysis comes to a conclusion here, no doubt because the idea of construction is more metaphorical than real. The implication seems to be that knowledge of an object as socially constructed is sufficient to undo any of its negative effects. How many books and essays have been written in the last ten years, whose authors are content with the conclusion that x, y, or z is socially constructed, as if the conclusion itself were a victory over oppression?

Far from being satisfied with this conclusion, my analysis here will always take it as a point of departure from which to move directly to the elucidation of embodied causes and effects. Oppression is driven not by individual, unconscious syndromes but by social ideologies that are embodied, and precisely because ideologies are embodied, their effects are readable, and must be read, in the construction and history of societies. When a Down syndrome citizen tries to enter a polling place and is turned away, a social construction is revealed and must be read. When wheelchair users are called
selfish if they complain about the inaccessibility of public toilets, a social construction is revealed and must be read (Shapiro 1994, 126–27). When handicapped entrances to buildings are located in the rear, next to garbage cans, a social construction is revealed and must be read. When a cosmetic surgeon removes the thumb on a little boy’s right hand because he was born with no thumb on his left hand, a social construction is revealed and must be read (Marks 1999, 67). What if we were to embrace the metaphor implied by social construction, if we required that the “construction” in social construction be understood as a building, as the Galehead hut for example, and that its blueprint be made available? Not only would this requirement stipulate that we elaborate claims about social construction in concrete terms, it would insist that we locate the construction in time and place as a form of complex embodiment.

Whenever anyone mentions the idea of social construction, we should ask on principle to see the blueprint—not to challenge the value of the idea but to put it to practical use—to map as many details about the construction as possible and to track its political, epistemological, and real effects in the world of human beings. To encourage this new requirement, I cite three familiar ideas about social construction, as currently theorized, from which flow—or at least should—three methodological principles. These three principles underlie the arguments to follow, suggesting how to look for blueprints and how to begin reading them:

- Knowledge is socially situated—which means that knowledge has an objective and verifiable relation to its social location.
- Identities are socially constructed—which means that identities contain complex theories about social reality.
- Some bodies are excluded by dominant social ideologies—which means that these bodies display the workings of ideology and expose it to critique and the demand for political change.

NOTES

1. The nature of pain and the methodology of its study are diverse because they involve the definition of emotion and consciousness. Aydede collects a strong sampling of contemporary views about pain; one of which, the perceptual theory, appeals to the idea that pain has the capacity to signal changes in states of reality (59–98).

2. Snyder and Mitchell express this view powerfully throughout Cultural Locations of Disability. For example: “As Darwin insisted in On the Origin of Species, variation serves the good of the species. The more variable a species is, the more flexible it is with respect to shifting environmental forces. Within this formulation, one that is central to disability studies, variations are features of biological elasticity rather than a discordant expression of a ‘natural’ process gone awry” (2006, 70).

3. The literature on intersectionality is now vast. Some key texts relating to disability include Barbee and Little; Beale; Butler and Parr; Fawcett; Hayman and Levi; Ikemoto; Jackson-Braboy and Williams; Martin; O’Toole (2004); and Tyjewski.

4. While not aware of disability studies per se, Johnny Williams provides an excellent intersectional analysis of stereotypical conflations of race and class, arguing that American society explains the social and economic failures of minority groups in terms of personal “inabilities,” while maintaining the belief that “social arrangements are fundamentally just” (221).

5. Catherine Kudlick proposed, on the DS-HUM listserv, an exercise similar to this one to replace traditional and biased disability simulations often used by classroom instructors. I am indebted to her discussion.

6. Philosophical realism has a number of varieties. The particular lineage of interest to me focuses on Hilary Putnam in philosophy and Richard Boyd in the philosophy of science. Satya P. Mohanty imports Boyd’s ideas into the humanities in general and critical theory in particular, putting the concept of realism in the service of minority studies in novel and convincing ways. Other important figures in philosophical realism working in the humanities include Linda Martin Alcoff, Michael Hames-Garcia, Paula M. L. Moya, and Sean Teuton.
REFERENCES


Cognitive Disabilities Part 1
We Still Know Too Little, and We Do Even Less

Introduction

Cognitive disabilities are the least understood and least discussed type of disability among web developers. As a result, developers rarely design web content to be accessible to people with cognitive disabilities. This is unlikely to change overnight, because the amount of research related to the accessibility of web content is relatively scarce. Without a large body of research, the information about designing for people with cognitive disabilities is more speculative, more vague, and more difficult to implement. To complicate matters, many cognitive disabilities are ill-defined domains for research. Such disabilities are sometimes difficult to diagnose and characterize because of the wide variance between the characteristics of people who have similar cognitive disabilities.

In light of the problematic nature of defining and categorizing cognitive disabilities it should come as no surprise that the cognitive disability sciences have not yet yielded a well-defined set of recommendations for web developers. This isn't to say that no recommendations exist. Some recommendations have been incorporated into the W3C's Web Content Accessibility Guidelines. Others have been suggested elsewhere. The problem is that the scarcity of supporting research for these recommendations casts a shadow of doubt on their accuracy and completeness.

The first purpose of this brief article is to encourage more research in the field of content design for people with cognitive disabilities.

The second purpose of this article is to encourage developers to consider users with cognitive disabilities more seriously. There are far more users with cognitive disabilities than all the other types of disabilities combined (when you include learning disabilities, reading disorders, attention deficit disorders, and other common conditions).

The third purpose of this article is to publish and ask for feedback on a tentative list of recommendations.

http://webaim.org/articles/cognitive/cognitive_too_little/
The list of recommendations that follows is neither definitive nor comprehensive. Not all of these recommendations are easy to implement, nor even necessary in all circumstances. Not all of these recommendations are equally applicable to all kinds of cognitive disabilities. To complicate matters, some of these recommendations may appear to conflict with other accessibility recommendations. These conflicts may be real or not, depending on how the recommendations are implemented. Finally, not everyone in the cognitive disability field is likely to agree on the validity or accuracy of these recommendations. **These recommendations are based on a combination of existing research, commonly-assumed best practices, and thoughtful speculation.**

This list of recommendations can be useful to developers in its current state, but the hope is that researchers and developers will treat these recommendations as hypotheses to be tested. **Please put these recommendations to the test!** WebAIM is very interested in hearing about any research related to these topics.

**Recommendations for Making Web Content Accessible to People with Cognitive Disabilities**

1. **Create transformable, rich, multi-modal content.**
   a. **Transformable**
      i. **Allow fonts to be enlarged.**
         The ability to enlarge fonts is dependent upon the capabilities of the user agent (browser), but relative units are recommended, rather than absolute units. For example, use "em" or "%" rather than "pt" or "cm".
      ii. **Use real text or vector-based text, rather than text within raster-based images, to allow for higher quality enlargement, without pixilation.**
         Real text is always the best, most transformable method of conveying text content. When text is used within graphics or rich media, vector-based formats (flash, SVG) enlarge better than raster-based formats (e.g. jpg, gif, bmp).
      iii. **Provide all content in a text format so that it can be read aloud by text-to-speech synthesizers.**
         Content can be in plain text, HTML, in alt text for images, or in any other format with true text that can be accessed by assistive technologies. It may be appropriate in some circumstances to provide the text version separate from the rich media version (e.g. text transcripts for videos).
   b. **Multi-modal**
i. Illustrate concepts with drawings, diagrams, photos, audio files, video clips, animations, and other non-textual media.
Communicate with the user through as many different sensory modalities and input modes as possible (sight, hearing, interaction, reading, etc.) to increase the chance that content will be understood.

ii. Provide synchronized captions and transcripts for the audio portion of time-based media.
Add captions to video files (e.g. using SMIL or SAMI) and provide a link to a text transcript.

iii. Provide audio descriptions of visual events in time-based media.
Narrate the visual actions in videos so that the video can be understood by listening to it, without watching it.

2. Focus the attention of the user.
   a. Sensory focus
      i. Use softer colors (e.g. pastels) for graphical elements, rather than sharply contrasting colors. (Note: this is not widely accepted)
      When using background colors to differentiate sections of the same page, choose softer colors, rather than high contrast colors.
      
      ii. Limit the types of font faces in a document.
      Use only one font, or a very small number of fonts in any single document.
      
      iii. Limit or eliminate the use of italics or ALL CAPS.
      Avoid italics and all caps to the extent possible, to improve readability.
      
      iv. Avoid background sounds that distract the user's attention (e.g. background music).
      Allow the user to focus on the main content without audio distractions.
      
      v. Use sounds to focus the user's attention (e.g. give instructions, alert the user to errors, etc.).
      Provide audible cues that help the user to focus on the main content.
      
      vi. Include "white space"—non-content space—around the content, between paragraphs, and between headings.
      Don't crowd the design visually.
      
      vii. Avoid complex or "busy" visual backgrounds.
      Don't create extraneous visual information that distracts from the main content.
   b. Content focus
      i. Place the important parts of a paragraph (key points) in the first sentence.
Don't hide important points in the middle of paragraphs.

ii. **Organize content into well-defined groups or chunks, using headings, bulleted lists, and other visual-semantic organizing schemes.**
    Make the document's structure as obvious as possible.

iii. **Highlight text as it's being read out loud (or allow users to activate this option).**
    This recommendation is most applicable to rich media, such as Flash and SVG, that does not have native captioning capabilities, and where captions are added through programming or scripting.

iv. **Emphasize important text—or the headings to sections of text—with bold font faces or larger text size.**
    Use bold and/or large text to visually emphasize important text. Note: the default style of HTML headings is bold and large, so there is no need to use extra tags or markup to achieve this affect in HTML.

c. **Interaction focus**
   i. **Provide multi-modal navigational cues (e.g. text + graphical/visual highlight + auditory instructions + animated demonstration).**
      Help users know what to do and how to interact with the content (e.g. create an audible voice that says "click the 'next' button to go to the next page", or a sound to accompany error messages, or visually highlight the "next" button, etc.)

   ii. **Give feedback on a user's actions (e.g. confirm correct choices, alert users to errors or possible errors).**

   iii. **Provide instructions for unfamiliar interfaces.**

3. **Design a consistent environment.**
   a. **Ensure that similar interface elements and similar interactions produce predictably similar results.**
   b. **Create a navigational scheme that is consistent across pages within a site or within related sections of a site.**

4. **Create simple, concise content.**
   a. **Use clear and simple language.**
      This recommendation is difficult to evaluate, but important.
   b. **Avoid tangential information.**
      Stick to the main topic.
   c. **Use correct grammar and spelling.**
      Use a spell-checker. Write well.
5. **Allow the user sufficient time to access and interact with content.**
   a. **Don't set short "expiration" times on content.**
      To the extent possible, avoid time-dependent JavaScript, HTML auto-refreshing, and other types of timed redirects.
   b. **If expiration times are necessary allow the user to request more time.**
      Allow users to set preferences and/or alert users when time is about to expire and give them the option to extend the timeline.

6. **Allow users to recover from accidental and erroneous interactions.**
   a. **Ask users to confirm choices.**
   b. **Use shorter, multi-step forms for complex interactions, rather than lengthy, all-in-one forms.**

Continue to part two of this articles - Conceptualizing Design Considerations
Cognitive Disabilities Part 2
Conceptualizing Design Considerations

Introduction

It is an unfortunate fact that the web accessibility community has struggled for some time to come to a consensus on guidelines that can be applied to web content for individuals with cognitive disabilities. Many authors propose specific, commonsense considerations while others wait for more definitive research. At WebAIM, we believe that promoting a dialogue on this important issue will be helpful in two ways. First, the collective thoughts of a number of individuals can be gathered and distilled. This may aid researchers in forming their questions as well as the ways in which they approach answering them. It may also aid web developers who want to design their content now in a way that does not exclude the largest population of individuals with disabilities. Second, ongoing interaction on the topic holds the promise to further refine important areas and subtle distinctions between issues that will be important.

In the article Cognitive Disabilities Part 1: We Still Know Too Little, and We Do Even Less, WebAIM published a list of tentative recommendations that could be included in design guidelines. Responses from the field will help refine these technical recommendations. Another way to look at conceptualizing design considerations is from a human factors approach. It is the experience of WebAIM staff members that developers often benefit from understanding design techniques from the user point of view. Placing accessibility issues in a macro structure, such as human factors, can facilitate the developer's ability to assimilate accessibility techniques into their practice. For example, it seems easier for a developer to consider that someone who is blind "does not see" than it is for the developer to remember all the technical specifications necessary to make a page accessible for someone who is blind. From that simple perspective, the developer can proceed with items that make sense to them. By remembering that the individual can't see the elements of the page, they are prompted to ask if equivalent alternatives exist for content (e.g., alternative text) and structure (e.g., associated form labels or associated column and row headers in data tables). Organizing technical specifications around the real problems of the user has been a WebAIM
Important

With this in mind, WebAIM seeks input on the best ways to organize design considerations for persons with cognitive disabilities from the user perspective. We invite you to comment on the contents of this brief article. We are interested in sharing the concept of the user perspective in the hopes that it can be refined, tested, and used by developers into the future.

Who are Individuals with Cognitive Disabilities?

Individuals with cognitive disabilities represent the largest single disability group worldwide. There are 4 times more individuals with cognitive disabilities than there are individuals who are blind. This is in part due to the fact that many distinct disabilities can affect an individual's ability to process, access, or remember information and learning experiences. Due to the array of similar challenges present for individuals with cognitive disabilities, many subgroups are typically placed into the overarching category of a "Cognitive Disability." This includes individuals who have learning disabilities (e.g., dyslexia and dysgraphia), attention disorders (e.g., ADHD and ADUD), developmental disabilities (e.g., Down's Syndrome, Fragile X, Autism, and Cerebral Palsy), and neurological impairments (e.g., Alzheimer's, traumatic brain injury, dementia, and stroke). One of the challenges present in this large disability group is that the needs of the individual users are quite diverse. It is common for individuals with cognitive disabilities to have deficits in one area but to exhibit typical skills, or even advanced skills, in other areas.

Patterns emerge, however, when you attempt to describe difficulties that an individual with a cognitive disability must overcome. The most common words used to describe the problems encountered by individuals in this group on the web include problems with:

- Perception and processing
- Memory
- Problem-solving
- Attention

**Perception and Processing**

Perception and processing refers to an individual’s ability to identify (i.e., perceive) and integrate information (e.g., visual or auditory information) into meaningful chunks. Some authors’ place reading and writing into this category, others place some reading or writing skills here and some in other areas.

The need for reading and writing skills on the web are fairly apparent. For users with cognitive disabilities they must have the ability to access, and comprehend, letters, written words and phrases, and provide or identify a written response when required. Problems may be present in decoding individual words, comprehending literal or abstract language, and constructing responses when required. These may be typed responses or responses identified from pull-down menus. If a developer were to understand the implications that a user will face in perceiving or processing words and sentences they might be interested in checking their work for technical considerations (e.g., using the clearest and simplest language appropriate for the content, pairing graphics with text, allowing fonts to be enlarged, providing text contrast, and adding white space to the page).

**Memory**

Memory refers to the ability of a user to recall what they have learned over time. We all have working (i.e., immediate) memory, short-term memory, and long-term memory. Meaningful information is typically moved up the chain from immediate to short-term into long-term memory stores. Some individuals with cognitive disabilities have difficulties with one, two, or all 3 of these memory types. The more meaningful your content can be to the needs of the user, the greater the chances that it will be moved into functional memory stores in the brain. Some users may have memory difficulties that impair their ability to remember how they got to content on and off the web site. These users would benefit from many technical considerations including:

1. Navigation that is consistent across the site and over time
2. The use of obvious breadcrumbs
3. Consistent use of style to denote hypertext links such as a blue underline

**Problem-solving**

Some individuals with cognitive disabilities have a difficult time solving problems as they
arise. In many instances, their resilience can be low and the resulting frustration is such that they choose to leave the site and not persist to solve the problem. One example of this would be the presence of a 404 error, a bad link, or a link that does not take them where they thought they were going. For some individuals, the problems associated with moving the mouse to a desired area on the screen (e.g., due to a visual processing problem), and clicking within a small area is more than they can bear. Designers would be wise to think about the ways in which their designs help to reduce or eliminate problems (e.g., by checking for valid links on a regular basis, making sure the forms work properly, avoiding pop-ups, and providing a mechanism to answer questions or providing support to the user if needed).

**Attention**

There are many individuals that have difficulty with focusing their attention to the task at hand. Distractions such as scrolling text and blinking icons can make the web environment difficult. Even for typical users the presence of blinking and scrolling items or multiple pop-ups can be irritating. Good design principles would limit these instances to only that which is necessary to convey the content.

**Sample Table**

The table below is one example of an attempt to organize specific design considerations across areas that present common problems for individuals with cognitive disabilities. This information could easily be organized in a variety of different ways. For example, it might make the most sense to organize by each area of challenge rather than across all areas in a table format. If this were done, technical considerations would need to be repeated several times as they appear in multiple problem areas. No attempt was made to make this list inclusive of all the technical considerations that would benefit individuals with cognitive disabilities. Sixteen considerations are listed. A comprehensive list would likely contain 4 times as many technical considerations. The point here, however, is to gain input on the utility of such organization for web developers.

<table>
<thead>
<tr>
<th>Design considerations that present common problems for individuals with cognitive disabilities.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Samples of some areas that possibly affect users with a cognitive disability</strong></td>
</tr>
<tr>
<td>Use the simplest language possible for the</td>
</tr>
<tr>
<td>Content (check reading levels with an automated tool).</td>
</tr>
<tr>
<td>Allow for text to be enlarged.</td>
</tr>
<tr>
<td>Pair icons or graphics with text so that contextual clues are available.</td>
</tr>
<tr>
<td>Avoid scrolling text as it increases pressure to read at set speeds.</td>
</tr>
<tr>
<td>Save your best contrast for items that carry content, allow non-content areas to be muted or displayed in pastels.</td>
</tr>
<tr>
<td>Insure that the user can view with their own styles and turn off color and images if desired.</td>
</tr>
<tr>
<td>Avoid time-based elements (auto refresh, redirects, shut outs) unless the user is prompted to ask for additional time.</td>
</tr>
<tr>
<td>Insure that any &quot;on-mouse&quot; command has a large clickable area.</td>
</tr>
<tr>
<td>Use consistent and predictable navigation that is consistent throughout the site.</td>
</tr>
<tr>
<td>Use consistent methods of indicating hyperlinks (e.g., blue underlined text) and make them descriptive (e.g., avoid &quot;click here&quot; and &quot;more&quot;).</td>
</tr>
<tr>
<td>Provide demonstrations or audio descriptions whenever possible.</td>
</tr>
<tr>
<td>Provide text transcripts for captioned media so that the user can revisit concepts within the narrative.</td>
</tr>
<tr>
<td>Use obvious breadcrumbs in your design.</td>
</tr>
<tr>
<td>Use descriptive headings and other organizational techniques (e.g., bullets) to chunk your material.</td>
</tr>
<tr>
<td>Ensure ample white space in your design rather than condense or clutter information</td>
</tr>
<tr>
<td>onto your pages.</td>
</tr>
<tr>
<td>------------------------------------------------------</td>
</tr>
<tr>
<td>Avoid animated or blinking icons unless necessary for content.</td>
</tr>
</tbody>
</table>

http://webaim.org/articles/cognitive/conceptualize/
Motivations to Create Accessible Web Content

There are at least three main kinds of reasons that might motivate people to create accessible web content:

1. To improve the lives of people with disabilities (human-centered motivations)
2. To capitalize on the a wider audience or consumer base (marketing or economic-centered motivations)
3. To avoid lawsuits and/or bad press (public relations and punishment-centered motivations)

All of these can be good reasons. Accessible web sites will accomplish all of these goals. The motivations are listed in order of most altruistic to least altruistic, but as long as the web site is accessible in the end, perhaps it does not matter what the developers' motivations were to begin with.

No matter which motivation works for a particular developer, one principle will always hold true: web accessibility is most easily achieved when people are at the center of the process. Even those who are simply trying to avoid lawsuits will sooner or later realize that the needs of the target audience—people with disabilities—must be carefully considered and addressed.

- Understanding the user's perspective and needs
- Moving beyond technical accessibility
- Focusing on the principles of accessibility

Understanding the User's Perspective and Needs

The techniques and guidelines of web accessibility were not invented to make life hard for web developers. They were invented to make life easier for people with disabilities. Like everyone else,
people with disabilities want and need to access the kinds of resources offered on the web. Many services and goods once available only by visiting brick-and-mortar offices and shops are now available online, from the comfort of one's home. Nothing could be more perfect in terms of making the world more accessible to people with disabilities.

The web is not a barrier to people with disabilities, it is the solution. The web has the potential to revolutionize the day-to-day lives of millions of people with disabilities by increasing their ability to independently access information, communication, entertainment, commerce, and other aspects of life that most people take for granted. However, for the web to reach its full potential for people with disabilities, web developers must commit to always designing with accessibility in mind. Failure to do so risks turning a revolutionary solution into yet another barrier in the lives of people with disabilities.

This is why web accessibility was invented. This is the perspective to keep in mind when developing web sites. After all, people with disabilities are people. They just want to make the most of life. An accessible Internet is not a magic bullet or panacea to every obstacle faced by people with disabilities, but it is at least a step in the right direction.

Moving Beyond Technical Accessibility

Techniques and guidelines are important because they represent an attempt to define and standardize what web accessibility means. They represent a consensus, or at least a majority opinion, about the best practices and methods for achieving web accessibility. The Web Content Accessibility Guidelines (WCAG) are the most widely-accepted set of recommendations, and were developed over several years of collaborative involvement by a panel of experts and interested individuals. The rigorous process is purposefully slow and methodical, in an attempt to consider a wide variety of viewpoints and issues. Still, none of the participants in this process would ever claim that the guidelines are the last word on accessibility, or that conformance to the guidelines will guarantee web content accessibility. The guidelines are an excellent foundation upon which to build accessible web content, but unless the developers understand the reasons behind the guidelines, they might apply the guidelines incorrectly or ineffectively.

For example, one of the best-known guidelines is to provide alternative text for images in the alt attribute of the <img> tag. If web developers learn only the guideline, but not the reason for the guideline, they may provide alternative text that is not helpful to users who need it. They may even create rather than solve accessibility barriers.
When developers focus on technical specifications, they may achieve technical accessibility, but they may not achieve usable accessibility. To make a comparison, a large office building may be technically accessible to a person who is blind—meaning that this person may be able to walk through all the hallways, use the elevators, open the doors, etc.—but without an explanation (or perhaps a tactile map) of how the building is arranged, where the elevators and doors are, and which offices are on which floors, the building will be quite difficult to navigate, especially at first. The person may try to find locations through a process of trial and error, but this is a very slow and cumbersome process. The building is accessible, but not very usable.

In a similar way, web developers can create web sites that are possible for people with disabilities to access, but only with great difficulty. The technical standards are important, but they may be insufficient on their own. Developers need to learn when and how to go beyond the technical standards when necessary.

**Focusing on the Principles of Accessibility**

Version 1.0 of the [Web Content Accessibility Guidelines](http://webaim.org/articles/pour/) focused heavily on the *techniques* for accomplishing accessibility, especially as related to HTML. WCAG 2.0 takes a different approach: it focuses more heavily on the *principles* of accessibility, and presents some techniques in separate documents. By focusing more on principles rather than techniques, version 2.0 of the guidelines is more flexible, and encourages developers to think through the process conceptually. The four main guiding principles of accessibility in WCAG 2.0 are:

- Perceivable
- Operable
- Understandable
- Robust

Conveniently, these principles spell out an acronym that is relatively easy to remember: POUR. The idea is to create a *POUR* web site, so to speak. The pun may be a bad one, but if it helps developers memorize the principles, then it has served its purpose. Each of these principles is discussed more in depth in the sections that follow. For now it is sufficient to say that putting the POUR principles helps put people at the center of the process, which, in the end, is the whole reason for even discussing the issues.
Constructing a POUR Website

Perceivable

Overview

All forms of communication require input into the brain via at least one of the senses of the body. The Internet is a medium of communication providing access to knowledge and processes through electronic means. The most relevant senses in this context are sight, hearing, and touch. (Other animals have learned elaborate communication systems through taste and smell, but we humans are comparatively deficient in that department. Besides, tastes and smells are harder to transmit electronically.)

Any discussion of web accessibility is based upon the assumption that people need to be able to perceive web content. They need to be able to input the information into their brain so that they can process it. If the information cannot get into the brain, it is inaccessible. As obvious as that statement may sound, it is a principle which is frequently ignored by developers. Too many sites contain web content that cannot even be perceived by some of the people who would like to access it.

Sight

People with full use of their vision are able to read text, view images, understand the visual cues afforded by web page layouts, understand the symbolic meaning of colors in certain cultural contexts (as with red and green street lights, or blue and pink baby clothing), and in general can use their eyes to make sense of information that is presented to them. This mode of perception—from the eye to the brain—is powerful, and Web developers should take full advantage of its communicative strengths. Visual perception is especially important to individuals who lack one of the other main communicative senses, such as people who are deaf. For such individuals, their remaining senses take on heightened importance.
However, there are people who cannot take full advantage of this mode of communication. Some people have no vision at all. Others have a limited amount of vision. For these individuals, other modes of communication are necessary. In some cases this means that information must be converted into a format which they can more easily perceive, such as an audio format. Assistive technologies can perform this conversion, but only if the content is designed with accessibility in mind.

See also Visual Disabilities.

Hearing

Oral conversations between people are a daily occurrence. People talk at home, in the office, on the phone, and, increasingly, on the Internet. The Internet enables people to engage in voice chats, to leave voice messages, to watch videos, to hear music, to listen to web radio broadcasts, and to participate in numerous other kinds of audio interactions with other people or with electronic content prepared by other people. The number and kinds of audio interactions will only increase as Web technologies mature and proliferate.

Technologies and methods exist for making audio information available to people who cannot hear it. These technologies and methods cannot help anybody though unless someone actually uses them to make the information accessible to people who cannot hear it.

See also Auditory Disabilities.

Touch

For most people, touch is not their main form of communication. For them, touch may have relevance for indirect expressions of solidarity, as in romantic relationships (physical intimacy), among friends (hugs, high-fives, handshakes), with children (rocking babies to sleep, holding children when they're scared), and other situations that communicate emotions but which do not directly communicate information per se.

For individuals who have neither sight nor hearing, touch is the most important form of communication of all. Interpersonal communication is possible through sign language, in which two people use their hands to feel each other's gestures, signed language, and body movements. The fingers can be used to perceive textual information printed in Braille formats. In fact, refreshable Braille devices can convert text into Braille output for use on the web.
For more information, read the Screen Readers section of the Blindness article.

**Transformability**

Since not everyone has the same abilities or equal use of the same senses, one of the main keys to accessibility is ensuring that information is transformable from one form into another, so that it can be perceived in multiple ways. Text can be transformed into audio and into Braille by the assistive technologies used by people with disabilities. Audio can be transformed into text, but this must be done before it reaches the user, because technologies to automatically convert audio to text are usually unreliable and not commonly available to users who might need them. Graphics, animations, and videos are similar to audio in the sense that developers must provide the text alternative to users.

Overall, text is the most easily and most universally transformable format. However, this does not mean that web accessibility means an end to all non-text elements. On the contrary, the non-text elements in many cases are crucial to accessibility, as explained in Text-only Versions.

The take-home message is that the information must be perceivable somehow. That is the first step to accessibility upon which all others are based, and without which accessibility cannot happen.

**Content vs. Style and Presentation**

The main content should be separable from the way it is styled or presented. Even though styling can enhance the user experience, and in some cases even improve comprehension, the main message should not depend on the mode of presentation. Semantic structure and meaning should be independent of the "look and feel." This is important because not all users will be able to perceive the presentational look and feel aspects of web content. When the presentation is disabled, the web content should still be able to communicate its message effectively.

See Creating Semantic Structure for more information.

In addition, background colors, graphics, and sounds should not interfere with the content. If the main content is presented in an audio format, background sounds should not obscure the message. Content presented in a visual format should likewise be distinguishable from extraneous stylistic visual elements. Text should be distinguishable from its background.
Constructing a POUR Website
Operable

Input Methods

Not everyone uses a standard keyboard and mouse to access the web. Some people use adaptive devices or alternative devices that accommodate their disabilities. Some people simply prefer to use the alternative technologies. While this may not seem like an important point at first, consider the fact that some web content can be operated only with a mouse. Mouse-dependent web content will be inaccessible to a person cannot use a standard mouse—due to tremors, insufficient fine motor control, or even a lack of hands altogether. A person in this situation is likely to use an adaptive technology of some sort, such as a mouth stick, to manipulate the keyboard. In some cases, the person may be able to use a trackball mouse (e.g. with a mouth stick), but others need to rely on the functionality of the keyboard. (See also the motor disabilities article.) People who do not have use of their vision usually rely on the functionality of the keyboard as well. They may be able to manipulate a mouse just fine, but it doesn't do them much good because they can't see where to click on the screen. The keyboard is much easier for a person who is blind to manipulate. (See also the visual disabilities article.)

Keyboard accessibility is one of the most important principles of Web accessibility because it cuts across disability types and technologies. Most of the alternative and adaptive devices used by people with disabilities emulate the keyboard in terms of functionality. Content that is accessible to the keyboard is operable by the devices that emulate keyboard functionality, no matter how radically different those devices are in appearance from standard keyboards.

(See also the keyboard accessibility section.)

Interaction Methods
Users should be able to find, navigate through, and interact with web content. Search features, site indexes, and site maps allow users to locate content within a Web site. (See also the site searches, site indexes, and site maps article.) With web pages or sections of Web content, users should be able to bypass extraneous or irrelevant pieces of content in order to focus on the content of interest to them. (See also the "skip navigation" links article.) They should be able discern the structure of the content by its headings, subsections, bulleted lists, and other elements of semantic markup. (See also the creating semantic structure article.) In other words, the content itself should be navigable or operable by multiple methods.

User Control Over Timing and Time Limits

Whenever possible, users should have an unlimited amount of time to complete tasks on the web. Motor disabilities can slow a person's muscle movements. Cognitive disabilities can slow a person's mental processes. Even visual or auditory disabilities can slow a person's response time if the information is not ideally accessible.

In some cases, security concerns become an issue, and time limits must be set on Web content. A common example is online banking. Allowing the user an unlimited amount of time to complete tasks would put that user's bank account information at risk, especially if the computer is in a shared or public environment. Another example is online tests administered by schools, colleges, or testing organizations that require time limits in order to maintain a controlled testing environment. These situations may legitimately require time limits on access or functionality, but accommodations can still be made for people with disabilities. One way would be to allow users to specify the amount of time that should pass before the time-out deadline. In other cases, as with online tests, it may be more appropriate to allow test administrators to specify custom time limits for different students. In all cases, users should be allowed sufficient time to complete the tasks they are supposed to complete, whether by allowing everyone an unlimited amount of time, allowing special accommodations for those who need them, or some other solution between those two extremes.

Users should also be able to manipulate and control media players, animations, and any other kind of time-dependent content. Media players should include ways of pausing, rewinding, and fast-forwarding content. Users should be able to stop animations, especially if they flicker or strobe, because this puts some users at risk for experiencing seizures. (See also the seizures disorders article.)

Error Recovery
No one likes to accidentally and permanently delete a file, pay for the wrong product, send an email to the wrong person, or make any mistake that can't be corrected. Users with disabilities are no exception. The difference is that some people have disabilities that make them a little more likely than people without disabilities to make a mistake. People with tremors may hit the wrong key or click on the wrong link. People with cognitive disabilities (or anyone else, for that matter) may misunderstand the purpose of a link and click the wrong one. People make spelling mistakes when typing search terms, their address, or any other kind of content.

Everyone appreciates the ability to recover from mistakes—to have a second chance. Web developers should program second chances into their Web functionality. Confirmation screens, error alerts, and warnings should all be an integral part of the design of interactive web content. Even beyond this, it is often helpful to provide users with instructions, especially if the interaction is complicated or if the site is rich with information that may be difficult to find. Oftentimes a few words of instruction can eliminate or at least decrease the number of errors committed by users.
Constructing a POUR Website
Understandable

Meaning

Let's say that web content is perceivable and operable by all kinds of users of all abilities, but it is understandable to none of them. Is the web content accessible? Of course not. Understandability can be just as big a barrier to accessibility as any of the more technical issues. Talking about understandability moves the discussion into the broader realm of usability. Usability became a hot topic in the late nineties and early 21st century. It still is a hot topic, but has moved from being a fringe fad to being a topic of mainstream conversation among web developers. Web accessibility never achieved "fad" status, but awareness of the topic has also increased over time. Unfortunately, too many people still separate usability and accessibility into two separate disciplines. Trying to separate principles into mutually exclusive categories of "usability" versus "accessibility" would be pointless. There is too much of an overlap between the two. After all, could an unusable site ever be considered an accessible site? Not if accessibility means anything.

Language

Most web content contains information communicated through language. The language should be as easy to understand as possible. The wording as well as the words should be simple and concise. How simple and concise? That depends on a number of factors, many of which depend upon the characteristics of the intended audience. Factors such as the audience's educational background, their familiarity with the subject matter, their background knowledge and life experiences, their culture, and so on. Authors do not always know the exact characteristics of their audience, so it is usually best to err on the side of caution by using simple language and explaining background information that readers may not know. Other factors are related to the content itself, such as the level of detail required to
understand it, reason for talking about about the subject matter, and so on.

(See also Writing Clearly and Simply.)

**Alternative or supplemental representations**

Providing alternative or supplemental representations of information can often increase understandability. Text can be supplemented with illustrations, videos, animations, audio, and content in other alternative formats. In fact, for some people with more severe cognitive disabilities or people with reading disabilities, these alternative formats may be necessary for comprehension. Providing summaries or abstracts of lengthy content can also make it more understandable.

**Functionality**

The functionality of web content must also be understandable. Users must be able to understand all navigation and other forms of interaction. On static web sites, the interaction may be limited to hypertext links. In more complex Web content, the interaction can be extremely complex, requiring the user to pass through multiple steps or stages, to make decisions along the way, input information, confirm information, and so on. Every point of interaction deserves attention in order to give users the best experience possible. If users don't understand any of the points of interaction, they may not be able to complete the necessary tasks on that web site.

Wherever possible, navigation should be consistent and predictable throughout the context of the web site. Interactive elements such as form controls should also be predictable and should be clearly labeled. Wherever necessary, users should be able to access instructions or receive guidance. If math calculations are involved, such as when subtotaling items in a shopping cart, the math should either be calculated automatically, or else users should be provided with guidance and/or tools on how to perform the calculations.
Constructing a POUR Website

Robust

Functionality Across Current and Future Technologies

Not everyone uses the same technologies now, nor will they in the future. People use different operating systems, different browsers, and different versions of browsers. Some people have advanced features enabled. Others have these features turned off. Some people are early adopters of new technologies. Others are slow to adapt to the rapidly-changing currents in the flow of technological advances.

Despite the differences between users and the technologies they use, they all expect the web to work. When they go to a site that uses methods not supported by their technologies, they get frustrated and may never return. In the past it was common to sites optimized for certain browsers or versions of browsers. Fortunately, most developers now try to develop their content so that it will work in many versions of many browsers. One of the most noticeable exceptions to this general trend is found in web sites owned by companies which develop their own browsers. They think that they can persuade people to use their company's browser if they create lesser versions of web content for all other brands of browsers. While this may be an effective marketing technique, it is not a good accessibility technique.

Users should be allowed to choose their own technologies to access web content. This allows the users to customize their technologies to meet their needs, including accessibility needs. Web content that requires a certain technology, such as a certain browser, may exclude some types of users who either don't want to use that technology or can't use it because of their disability. As a general rule, the more control the user has, the more likely the user will be able to access the content effectively.

Of course, there are limits to this logic. Netscape 1.0 was a revolutionary browser when it was
introduced, but has now gone the way of the dinosaurs because technological evolution has produced newer, better technologies. Modern web developers should not be forced to develop to the "lowest common denominator." Older or inferior technologies will never be able to support the full range of possibilities offered by newer, more capable technologies. In fact, the accessibility capabilities of the newer, more capable technologies is also superior. Developers can and should feel free to take advantage of technological advances in all areas, including in areas related to accessibility.

Developers can set a baseline of requirements. For example, they could decide to fully support browsers that are four years old or newer. Users of older browsers could still access the content, but perhaps it wouldn't be styled properly due to lack of support for Cascading Style Sheets. In the case of Adobe Acrobat files, developers may choose to support only versions 5 or greater, since all previous versions had virtually no support for screen reader users. Similar decisions could be made for different versions of media players. As long as the baseline is not too restrictive, limiting full support to a subset of technologies is a reasonable approach. And, again, to the extent possible, it is still best to let the user decide which technologies to use.

**Using Technologies According to Specification**

Modern browsers are much better than the older versions at displaying content properly. However, browsers cannot correct or compensate for all of the errors and inconsistencies that developers intro web content. The best way to ensure that content displays properly—and accessibly—is to create web content that validates against the technical standards for the technologies being used. Valid HTML is much more likely to work correctly across browsers and platforms than sloppy HTML. It is also more likely to work consistently in the different types of assistive technologies that people with disabilities use. Sloppy HTML may still work for some users on some technologies, but it is a gamble that puts accessibility at risk for all users.

Rather than focus on the limitations of old technologies, it is often better to focus on the possibilities offered by current and future technologies. In order to create content that is "future proof"—compatible with future technologies—it is necessary to use current technologies according to specification, so that future browsers and content viewers will know how to interpret the content.

In some cases it may take more time and effort to develop web content according to the specifications of the technologies being used, but in the long run it will produce more reliable results and will increase the chances that the content will be accessible to people with disabilities.
## Blindness

<table>
<thead>
<tr>
<th>Challenges</th>
<th>Solutions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Images, photos, graphics are unusable</td>
<td>• Provide text descriptions, in the <code>&lt;alt&gt;</code> attribute and, if necessary, longer explanations (either on the same page or with a link to another page).</td>
</tr>
<tr>
<td>Users often listen to the web pages</td>
<td>• Create links that allow users to skip over navigational menus, long lists of items, ASCII art, and other things that might be difficult or tedious to listen to.</td>
</tr>
<tr>
<td>Users often jump from link to link using the <code>Tab</code> key</td>
<td>• Make sure that links make sense out of context (&quot;click here&quot; is problematic).</td>
</tr>
<tr>
<td>Users generally do not use a mouse</td>
<td>• Don’t write scripts that require mouse usage. Supply keyboard alternatives (e.g. use <code>onFocus</code> instead of <code>onMouseover</code>).</td>
</tr>
<tr>
<td>It may be difficult for users to tell where they are when listening to data table cell contents</td>
<td>• Provide column and row headers (<code>&lt;th&gt;</code>) for data tables.</td>
</tr>
<tr>
<td></td>
<td>• Avoid spanned rows or columns in data tables, if at all possible.</td>
</tr>
<tr>
<td>Complex data tables and graphs that are usually interpreted visually are unusable</td>
<td>• Provide summaries and/or text descriptions, preferably on the same page, or link to another page as an alternative.</td>
</tr>
<tr>
<td>Frames cannot be &quot;seen&quot; all at once. They must be accessed separately, leading</td>
<td>• Don’t use frames unless you have to. If you use them, provide frame titles that communicate their purpose (e.g. &quot;navigational</td>
</tr>
</tbody>
</table>
### Color Blindness

<table>
<thead>
<tr>
<th>Challenges</th>
<th>Solutions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Colors of similar contrast are often indistinguishable</td>
<td>• Make sure that there is sufficient contrast</td>
</tr>
<tr>
<td></td>
<td>• Don't use color alone to convey meaning (supplement the color with text, for example).</td>
</tr>
</tbody>
</table>

### Low Vision

<table>
<thead>
<tr>
<th>Challenges</th>
<th>Solutions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Users often use screen enlargers</td>
<td>• To reduce that amount of horizontal scrolling, use relative rather than absolute units (e.g., use percentages for table widths, instead of pixels)</td>
</tr>
<tr>
<td>Text in graphics does not enlarge without special software, and looks pixilated when enlarged</td>
<td>• Limit or eliminate text within graphics.</td>
</tr>
<tr>
<td></td>
<td>• Use anti-aliasing to make text crisp and readable.</td>
</tr>
</tbody>
</table>
## Deafness

<table>
<thead>
<tr>
<th>Challenges</th>
<th>Solutions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Audio is unusable</td>
<td>• Provide transcripts for audio clips.</td>
</tr>
<tr>
<td></td>
<td>• Provide synchronous captioning for video clips.</td>
</tr>
</tbody>
</table>

## Motor Disabilities

<table>
<thead>
<tr>
<th>Challenges</th>
<th>Solutions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Users may not be able to use the mouse</td>
<td>• Make sure that all functions are available from the keyboard (try tabbing from link to link).</td>
</tr>
<tr>
<td></td>
<td>• Make sure that the tab order is logical.</td>
</tr>
<tr>
<td>Users may become fatigued when using &quot;puff-and-sip&quot; or similar adaptive</td>
<td>• Provide a method for skipping over long lists of redundant links or other lengthy content.</td>
</tr>
<tr>
<td>technologies.</td>
<td></td>
</tr>
<tr>
<td>Users may be using voice activated software</td>
<td>• Voice activated software generally cannot replicate mouse movement as effectively as it can replicate keyboard usage, so make sure that all functions are available from the keyboard.</td>
</tr>
</tbody>
</table>

## Cognitive Disabilities

<table>
<thead>
<tr>
<th>Challenges</th>
<th>Solutions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Users may become confused at complex layouts or inconsistent navigational</td>
<td>• Simplify the layout as much as possible.</td>
</tr>
<tr>
<td>schemes.</td>
<td>• Keep the navigational schemes as consistent as possible.</td>
</tr>
<tr>
<td>Users may have difficulty focusing on or comprehending lengthy sections of</td>
<td>• Where appropriate, group textual information under logical headings.</td>
</tr>
<tr>
<td>text</td>
<td>• Organize information in manageable &quot;chunks.&quot;</td>
</tr>
<tr>
<td>One method of input may not be sufficient</td>
<td>• Where appropriate, supplement text with illustrations or other</td>
</tr>
</tbody>
</table>
media, and vice versa.
Disability, Universal Design, and the Digital Humanities

GEORGE H. WILLIAMS

Over the last several decades, scholars have developed standards for how best to create, organize, present, and preserve digital information so that future generations of teachers, students, scholars, and librarians may still use it. What has remained neglected for the most part, however, are the needs of people with disabilities. As a result, many of the otherwise most valuable digital resources are useless for people who are—for example—deaf or hard of hearing, as well as for people who are blind, have low vision, or have difficulty distinguishing particular colors. While professionals working in educational technology and commercial web design have made significant progress in meeting the needs of such users, the humanities scholars creating digital projects all too often fail to take these needs into account. This situation would be much improved if more projects embraced the concept of universal design, the idea that we should always keep the largest possible audience in mind as we make design decisions, ensuring that our final product serves the needs of those with disabilities as well as those without.

It is imperative that digital humanities work take into account the important insights of disability studies in the humanities, an interdisciplinary field that considers disability “not so much a property of bodies as a product of cultural rules about what bodies should be or do,” in the words of Rosemarie Garland-Thomson, a prominent figure in the field (6). Digital knowledge tools that assume everyone approaches information with the same abilities and using the same methods risk excluding a large percentage of people. In fact, such tools actually do the work of disabling people by preventing them from using digital resources altogether. We must broaden our understanding of the ways in which people use digital resources. For example, visually impaired people take advantage of digital technologies for “accessibility,” technologies that (with their oral/aural and tactile interfaces) are fascinatingly different than the standard screen-keyboard-mouse combination, forcing us to rethink our embodied relationship to data. Learning to create scholarly digital archives that take into account these human differences is a necessary task no one has yet undertaken.

In what follows I consider the somewhat arbitrary concept of disability and assistive technology, argue why the digital humanities community should adopt a universal design approach, explain what a universal design approach would look like, and
then offer a few specific suggestions for collaborative projects that should be undertaken by digital humanists.

**Questioning Disability**

I first became interested in these issues as a graduate student working with Garland-Thomson when she was a faculty fellow at the Maryland Institute for Technology in the Humanities (MITH) in the fall of 2001. During this experience, I was forced to reevaluate my assumptions about using computers and designing web pages. Garland-Thomson worked with the staff at MITH to create an online academic resource site for disability studies, and we decided to design the website with maximum accessibility. To do so, we needed to think about the needs of people who are blind, have low vision, or have difficulty navigating because of the clutter that often accumulates on web pages. (We had no plans to include audio, so addressing the needs of people who are deaf or hard of hearing was not in our plan.) At the same time, we aimed for a visual design that would appeal to sighted users. We kept the layout simple and added certain features specifically for certain kinds of users. For example, because tech-savvy blind people often have their computer read websites out loud using what is known as screen-reading software, many find it tedious to listen to the identical detailed navigation menu on every page within a given site. To solve this problem, we inserted a tiny image—a transparent GIF exactly one pixel square, to be exact—at the beginning of each page with an alt attribute that read, “Skip to main content.” This image would be invisible to sighted users, but those listening to the page with screen-reading software—which reads aloud the alt attributes of images embedded in an HTML page—could use that GIF as their cue to jump past what they did not need to hear in order to get to the information that they did want to hear. We also made sure that every image tag had an alt attribute where necessary, although in general we kept images to a minimum. For advice on accessibility issues, we worked with a blind person who used screen-reading software to listen to the web, rather than reading it off of a visual display as a sighted person would do. She demonstrated this software for me, and I was surprised by how quickly the words were spoken by the synthesized voice that came from her laptop’s speakers. In fact, I could not understand anything at all that she was doing. To accommodate me, she adjusted the settings to slow down significantly the synthesized speech, at which point I could understand the words but still found myself unable to orient myself on a given page or within a given website. This scenario caused me to reevaluate my understanding of what it means to be disabled, as she clearly was using abilities that I did not—and still do not—have: I had not trained myself to be able to process auditory information as efficiently as she could.
Walter Ong famously wrote, “Technologies are artificial, but ...artificiality is natural to humans” (81). Ong’s concern is with writing as a fundamentally artificial process that has been so “internalized” by humans that it appears to be as natural to us as talking. Ong’s observation is part of a larger cultural critique that highlights the socially constructed nature of the ways we perceive technology and its role in our lives. To those of us who are more or less comfortable with the existing dominant model of using computers, anything different, like a fast screen reader, seems alien, and the potential shortcomings of our familiar model of some combination of keyboard, mouse, and visual display remain invisible to us. We classify some software and hardware tools as “assistive technology”—sometimes the term “adaptive technology” is used instead—because they have been designed specifically to assist those people with “special needs.” We might consider, however, that there is no “natural” way to interact with the 1’s and 0’s that make up the data we are interested in creating, transmitting, receiving, and using; there is only the model we have chosen to think of as natural. All technology is assistive, in the end.

Finally, we would do well to be aware of the range of “assistive”-technology software applications and hardware devices that do not work in the same ways as the devices used by nondisabled people. In addition to being compatible with desktop computers, laptops, smart phones, and tablet devices, the materials we create should also work well with such tools as refreshable braille displays, digital talking book devices, screen reader applications, and screen magnification software.

**Universal Design Defined**

The term “universal design” was invented by architect Ronald Mace, founder of North Carolina State University’s (NCSU) Center for Universal Design. According to the NCSU College of Design, the term “describe[s] the concept of designing all products and the built environment to be aesthetic and usable to the greatest extent possible by everyone, regardless of their age, ability, or status in life” (“Ronald L. Mace”). Wendy Chisolm and Matt May write that to embrace universal design principles is to “approach every problem ...with the ultimate goal of providing the greatest benefit to the greatest number of people possible” (2). Mace argues for the importance of distinguishing between universal design principles and accessibility principles. To embrace accessibility is to focus design efforts on people who are disabled, ensuring that all barriers have been removed. To embrace universal design, by contrast, is to focus “not specifically on people with disabilities, but all people” (Mace). Something created to assist a person with a disability—to make their environment more accessible in some way—might not be affordable or aesthetically pleasing even if it is usable and helpful. Some-
thing created using universal design principles, on the other hand, is designed “for a very broad definition of user that encourages attractive, marketable products that are more usable by everyone” (Mace). Devoting efforts to accessibility might improve the built environment for disabled people, but devoting efforts to universal design improves the built environment for all people. Mace cites the example of the automatic garage door opener as a consumer product created with universal design principles: it is affordable; it appeals to and is useful to people both with and without disabilities. Another frequently cited example of universal design is the sidewalk curb cut; initially created to allow people in wheelchairs to cross the street more easily, curb cuts became recognized as useful also to other people such as someone making a delivery with a dolly, a traveler pulling luggage on wheels, a parent pushing a child in a stroller, or a person walking beside their bicycle. Whether in a physical or a digital environment, designers are always making choices about accessibility. However, not all designers are aware of how their choices affect accessibility. Universal design is design that involves conscious decisions about accessibility for all, and it is a philosophy that should be adopted more widely by digital humanities scholars.

**Why Universal Design?**

Before I recommend how to adopt universal design principles, I need to explain the several reasons why we should do so. First, ensuring that digital resources created with federal funding are accessible is the law in many countries. In the United States, for example, the Federal Rehabilitation Act of 1973 was amended in 1998 with what is now referred to as Section 508 to require that all federal agencies “developing, procuring, maintaining, or using electronic and information technology” ensure that disabled people “have access to and use of information and data that is comparable to the access to and use of the information and data” by people who are not disabled (U.S. General Services Administration, “Section 508 of the Rehabilitation Act, as Amended by the Workforce Investment Act of 1998.”). American government agencies that fund digital humanities projects do not currently require proof of accessibility, but there is no reason to assume that this will always be the case. In addition to the United States, the list of nations with laws or policies requiring web accessibility includes Australia, Canada, Germany, Israel, India, Italy, Ireland, Japan, Korea, Portugal, and Spain (Chisolm and May, 14–15). At some point in the future, project directors seeking government funding could be turned down if they are unable to demonstrate in their grant proposals that the results of their work will be accessible. Rather than wait until such time at which the laws begin to be enforced, we should start now to follow the existing guidelines for accessibility and
to develop our own guidelines and tools for authoring and evaluating accessible resources. Not all digital humanities projects are created with government funding, of course, but enough of them are that this is a significant issue. Furthermore, instructors who wish to use digital humanities resources in their courses will need to ensure that those resources are accessible if they teach at an institution that receives any sort of government funding. Otherwise, they make themselves and their institution vulnerable to legal action.

Second, universal design is efficient. In order to adhere to the "alternative means of access" subsection of Section 508, American web designers used to create alternative, accessible versions of their content to parallel the original content. However, coding everything twice—first for nondisabled people and then again for disabled people—is time consuming and expensive. Fortunately, web standards have developed enough that this duplication of effort is no longer necessary. Instead, it is now possible to create just one version of a resource and to make design choices that ensure the resource suits the needs of all users, disabled and nondisabled alike. The ability to separate structure from presentation is particularly useful in this regard.

Third, applying universal design principles to digital resources will make those resources more likely to be compatible with multiple devices. To create an online resource that only works with a desktop or laptop computer is to exclude people who would prefer to access the resource with a smartphone, a tablet, or some other mobile device. The Web Accessibility Initiative of the World Wide Web Consortium points out that there is "significant overlap between making a website accessible for a mobile device and for people with disabilities" (Henry, "Web Content Accessibility"). Compatibility with mobile devices is important because an increasing number of people are using such devices to access the web. In the United States, for example, young adults between the ages of eighteen and thirty-three make up the largest segment of the population of web users at 35 percent (Zickuhr, 4), and 65 percent of those between the ages of eighteen and twenty-nine use a mobile device to go online (Smith, 5). Furthermore, those more likely to use a mobile device for online access include African Americans, Hispanics, and individuals from lower-income households (Smith, 10). If the digital humanities is to create resources accessible by a diverse array of people, then compatibility with mobile devices is a necessity.

Fourth and finally, it is the right thing to do. We recognize the importance of open access for scholarly materials, but "open access means more than simply making stuff available," as Jeremiah Boggs, humanities design architect at the University of Virginia’s Scholars’ Lab, has said. We would never use a proprietary format for preserving and sharing our work, in part because to do so would be to exclude those people who cannot afford or
do not have access to the necessary software to use that format. However, few of us think twice about whether or not the format we have chosen and the design choices we have made exclude disabled people. It might be tempting to assume that few, if any, disabled people are interested in or need to make use of our work, but by creating barriers to access we are ensuring that such people will never have the opportunity to participate in the digital humanities. According to a report from the Pew Research Center’s Internet and American Life Project, 81 percent of all adults report using the Internet, but only 54 percent of disabled adults do (Fox, “Americans,” 3). Of course, disabled adults are also more likely to be older, to have lower incomes, and to have less education than nondisabled adults, and all of these demographic factors are correlated with lower levels of Internet use (Fox, “What People”). However, inaccessible design choices remain a significant barrier to information for disabled people, and removing those barriers to information can only contribute to higher levels of education and perhaps higher levels of income as well. If our goals include the ability to share our work with as wide and diverse an audience as possible, then we should embrace universal design principles.

**Designing for Accessibility**

It is beyond the scope of this chapter to reiterate the specific guidelines for designing accessible web resources, especially when so many useful guidelines already exist. Digital humanists interested in learning more about these guidelines would do well to start with the Web Accessibility Initiative website hosted by the World Wide Web Consortium, where they will find a wide variety of specific recommendations as well as references to additional resources. Many helpful tutorials may be found on other sites, of course, but the Web Accessibility Initiative guidelines specifically and the World Wide Web Consortium guidelines more generally are widely considered to be web standards followed by those who create and maintain web-based resources. There are, however, specific projects that the digital humanities community should undertake in order to improve greatly the accessibility of the resources we create as well as the ease with which we make those resources accessible.

**Specific Project Ideas**

- accessibility tools for content management systems

Accessibility would be much easier for most content creators to achieve if a suite of free and open-source accessibility tools were developed for popular content management systems (CMS). A list of the most commonly used CMSes for digital humanities projects would include—but not be limited to—WordPress, Drupal, Omeka, MediaWiki, and Joomla. Each of these has a number of appealing features: they are relatively easy to in-
stall, often available as one-click-installation options through commercial web-hosting services; they are free and open-source projects; and their appearance and functions may be customized through the use of such add-ons as themes, plugins, modules, and extensions. A valuable project would be for the digital humanities community to develop a collection of add-ons that would integrate easily with these CMSes and improve the accessibility of the websites they deliver. Making available a ready-made set of accessibility tools for developers to add to their sites would allow individual projects to avoid the work of developing and evaluating their own accessibility features independently of one another. These tools could not only provide end users with a more accessible interface but also provide content creators with built-in accessibility evaluation functions, facilitating good design choices from the ground up rather than after a site has already been completed.

FORMAT TRANSLATION TOOLS

In July of 2010, the Center for History and New Media at George Mason University hosted a workshop involving twelve digital humanists who were tasked with creating a useful digital humanities tool in one week. The result was Anthologize, “a free, open-source plugin that transforms WordPress 3.0 into a platform for publishing electronic texts” (“About,” Anthologize). Anthologize imports texts from RSS feeds and then translates them into one of a handful of alternate formats: ePub, PDF, TEI (plus HTML), or RTF. Blind people who use the web are in need of a digital humanities project that either extends Anthologize or creates a similar tool so that RSS feeds may be converted easily and automatically into XML formats that work with digital talking book devices or with braille output devices.

A digital talking book is an XML document created to be compatible with any of a number of devices that will read the document aloud. The format includes metadata that facilitates navigation between different sections of the document, and it may include recordings of a person reading the document aloud, or it may be designed to be read aloud as synthesized speech by a device (“ANSI/NISO Z39.86”). Since 1996, the DAISY Consortium has been working to establish and promote an open standard for digital talking books (“About Us”). One of their most powerful products is the DAISY Pipeline, “a cross-platform, open source framework for DTB-related document transformations” (“DAISY Pipeline”). A well-structured document in a format like TEI or HTML is ideally suited to be automatically translated into the DAISY format through a software process that makes use of the DAISY Pipeline. A CMS add-on like Anthologize that accomplishes this task efficiently, automatically, and easily would be an extremely powerful tool in the hands of content creators, allowing them to easily make their texts available
as digital talking books, providing access to information for the many people who make use of digital talking books as their primary method of reading.

People literate in braille often prefer to read by that method rather than by listening to texts. Reading content through braille provides a deeper understanding of that content for many, yet producing well-formatted braille files is accomplished through one of two expensive methods. First, professionals who are certified braille translators may be hired to create well-formatted braille. Second, a number of commercial braille translation software applications may be used; the most reliable applications cost several hundred dollars and are cost prohibitive to low-income users and nonspecialized content creators. A CMS add-on like Anthologize could be such a translator if it incorporated Liblouis, a widely used open-source braille translation engine. Such an add-on would allow braille readers to access online texts through such devices as refreshable braille displays or braille embossers. Clearly, creating a free and easy-to-use online braille translator would make a tremendous difference in the lives of individuals who need braille translations of online content and in the ability of content creators to reach braille-literate audiences.

TOOLS FOR CROWDSOURCED CAPTIONS, SUBTITLES, AND TRANSCRIPTS

Online information presented in audio or video format is not accessible to deaf and hard-of-hearing end users without captions. These individuals benefit from online captioning as well as from written transcriptions presented as separate and independent documents. Creating captions and transcriptions makes such information subject to search and computer analysis in ways not currently possible with audio and video alone. Additionally, individuals without disabilities often find transcriptions easier to follow. The time and expense of captioning or transcribing is a significant obstacle to making accessible an online project featuring several hours of video or audio. Currently, a number of desktop software applications provide an interface designed to facilitate captioning videos or transcribing audio. However, none of them that I have found are free, and because they are not online tools none of them allow projects to take advantage of one of the web’s most powerful and relatively new practices: crowdsourcing.

“Crowdsourcing” is a term coined by Jeff Howe in 2006 to describe online projects that make use of free or extremely inexpensive labor provided by “enthusiasts” around the world who are interested in donating their time to a project that interests them. Several digital humanities projects have experimented with taking this approach to transcribing digital images of documents, with mixed results: nonexpert transcribers some-
times make a significant number of mistakes when transcribing material written in an unfamiliar hand (Cohen). However, a digital file in which the audio has been clearly recorded stands to result in a more accurate transcription, even by nonexpert transcribers. The Center for History and New Media is currently developing a promising online tool named Scripto, which “will allow users to contribute transcriptions to online documentary projects” (“About,” Scripto). Transcriptions of images of documents greatly enhance accessibility for people who are blind because screen readers will be able to read aloud the transcriptions while image-only documents are inaccessible. People who are deaf or hard of hearing, however, are in need of a digital humanities project that presents a user-friendly interface like Scripto for hearing people to caption videos or transcribe audio. Universal Subtitles, created by the Participatory Culture Foundation, is an admirable example of such an interface (“Frequently Asked Questions”). However, captions created with this interface are stored on the Universal Subtitles server, rather than in a project’s content management system. An extremely valuable digital humanities accessibility project would be one that facilitates crowdsourced transcriptions and captions but that works with a variety of different content management systems, saving the resulting text in the relevant database field of the CMS or in a shared, open repository.

**Conclusion: Reciprocal Benefits**

People with disabilities will benefit significantly if the digital humanities community pursues projects such as these and begins to take seriously the need to adopt universal design principles. However, by working to meet the needs of disabled people—and by working with disabled people through usability testing—the digital humanities community will also benefit significantly as it rethinks its assumptions about how digital devices could and should work with and for people. Graham Pullin, a senior lecturer in the University of Dundee School of Computing, has observed that the prevailing assumption in product design is that new developments in the mainstream slowly “trickle-down” to “specialist products for people with disabilities” (xiii). However, as Pullin points out, sometimes the effect works the other way, “when the issues around disability catalyze new design thinking and influence a broader design culture in return” (xiii). What I am arguing is that infusing the digital humanities with universal design principles will result in just this kind of reciprocal relationship.

Matthew Kirschenbaum has described “the current state of new media studies” as one “in which the graphical user interface is often uncritically accepted as the ground zero of the user’s experience” (34). In arguing that computer storage deserves more critical attention from scholars than it has tradi-
tionally received, Kirschenbaum adopts Nick Montfort’s term “screen essentialism” to describe the fallacy of assuming that all computer interaction occurs through the interface of the screen. Montfort points out that screen essentialism obscures the diversity of computing interfaces that have existed prior to the appearance of the modern electronic screen; in particular, as he describes, early computing programs relied on paper interfaces. Montfort’s point is historical, but screen essentialism also obscures the diversity of contemporary interfaces used by people with disabilities and, increasingly, by all people.

Blind computer users, for example, have no use for a screen, and they most often use an interface that is either tactile, in the form of refreshable braille devices, or audible, in the form of screen-reading software or digital books. We might also reconsider our “essentialist” thinking about the keyboard and the mouse and not just because of the technologies that we perceive to be specific to disabled people. Speech recognition technologies, while far from perfect, are already accurate enough to allow writers—if that is still the correct term—to compose documents without the need for typing. And the growth of touch screens, primarily but not exclusively available on mobile devices, bring the possibility of a mouse-less future ever closer. Both of these technologies are extremely useful for people who are disabled, but they are used for the most part by people who are not. To continue to create projects designed primarily for the screen-keyboard-mouse environment would be foolish: if a resource doesn’t work on a device that lacks one of those components, then that resource is already worthless to a significant number of computer users, disabled and nondisabled alike. As we observe contemporary computing devices proliferate and diversify, we need to plan for a future in which our current digital resources continue to be not only useful but usable.

Notes

1. I am grateful to Jennifer Guiliano for this suggestion.

2. My understanding of braille and braille technologies would not have been possible without advice and input from Tina Herzberg.

Bibliography


API and Atom Feed

Data about this text is available via read-only JSON API endpoints: sentences, annotations, comments, and index keywords.

Comments posted on this text can be followed by subscribing to this text’s Atom Feed.
Which sounds are significant? Towards a rhetoric of closed captioning

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Closed captioning, deaf, rhetoric, style, video

Abstract

This article offers a way of thinking about closed captioning that goes beyond quality (narrowly defined in current style guides in terms of visual design) to consider captioning as a rhetorical and interpretative practice that warrants further analysis and criticism from scholars in the humanities and social sciences. A rhetorical perspective recasts quality in terms of how genre, audience, context, and purpose shape the captioning act. Drawing on a range of Hollywood movies and television shows, this article addresses a set of topics that are central to an understanding of the effectiveness, significance, and reception of captions: overcaptioning, undercaptioning, subtitles vs. captions, the manipulation of time, non-speech information, series awareness, and the backchannel.

Distinguished guests, audience members, and to all of you watching at home tonight, or more realistically, Monday morning on a computer…

— Alec Baldwin, Saturday Night Live monologue (2010, May 15)

We do not want to be left behind as television moves to the Internet.
Video has exploded in popularity on the Web in recent years. More viewers are catching their favorite TV shows, like Saturday Night Live, on Monday mornings with laptops and mobile devices. Leave aside, for the moment, the millions of so-called "disposable" videos (Reid, 2008) that users are creating on-the-fly with their mobile phones and web cams, and then uploading to YouTube, Facebook, and other social networking sites (Bilton, 2010). What remains are thousands of hours of television shows and movies that broadcasters and retransmitters are increasingly making available online, usually for free (ad-supported). Very few of these TV shows and movies, when retransmitted on the Web, have closed captions. The episode of SNL featured in the epigraph to this essay (Baldwin, 2010) is required by law to be closed captioned when broadcast on TV. When the same episode is rebroadcast on the Web (via NBC’s official retransmitter, Hulu.com), it is, at this time, uncaptioned.

But that will soon be changing. A new law, The 21st Century Communications and Video Accessibility Act of 2010, will require "captioned television programs to be captioned when delivered over the Internet" (AAPD, 2010). To date, online discussions about web captioning have centered on questions of quantity: How do we increase the number of captioned videos on the Web? How do we encourage our representatives in Congress to support one of the pending pieces of accessibility legislation? How do we increase awareness among content providers like Netflix of the importance of offering captions on their streaming web videos? Despite the passage of new legislation requiring Internet captioning on some types of content, questions of quantity will continue to dominate the discussions of online captioning because TV content accounts for only a fraction of the video content available online.

Before we can talk about quality, so the thinking goes, we need to have something to talk about. But closed-captioning technology predates the Web by about twenty years. The history of captioning on TV goes back to the early 1970s (see Earley, 1978), and TV captions in the U.S. are by law plentiful today (FCC, 2010; Robson, 2004, pp. 39-42). We have had plenty to talk about for a long time. Despite the age of captioning technology, we still do not have a comprehensive approach to caption quality that goes beyond basic issues of typography, placement, and timing. Current practice, at least on television, is too often burdened by a legacy of styling captions in all capital letters with centered alignment, among other lingering and pressing problems. In other words, caption quality has been evaluated in terms of visual design for the most part—i.e., how legibility and readability interact with screen placement, timing, and caption style (e.g., scroll-up style vs. pop-on style).
What we do not have yet, and what I intend to offer in this essay, is a way of thinking about captions that goes beyond quality (narrowly defined in terms of visual design) to consider captioning as a rhetorical and interpretative practice that warrants further analysis and criticism from scholars in the humanities and social sciences. My argument is not simply that we do not have any guidelines on quality but rather that we have not explored quality rhetorically. A rhetorical perspective recasts quality in terms of how readers and viewers make meaning: What do captioners need to know about a text or plot in order to honor it? Which sounds are essential to the plot? Which sounds do not need to be captioned? How should genre, audience, context, and purpose shape the captioning act? What are the differences between making meaning through reading and making meaning through listening? Is it even possible, given the inherent differences between, and different affordances of, writing and sound, to provide the same information in writing as in sound? The concepts that structure these questions—effectiveness, meaning, purpose, context, genre, audience—are of abiding interest to rhetoricians.

Closed captions have gone unnoticed by mainstream scholars in rhetoric and related fields, despite the seemingly obvious ways in which captions can be analyzed as text by textual/rhetorical critics and as a mode by scholars in composition interested in multimodal composition. The invisibility of captioning is a result of the invisibility of disability and disabled people in our scholarship. Despite some important exceptions in the fields of rhetoric and composition (e.g. Brueggemann, 1999; Lewiecki-Wilson & Brueggemann, 2007; Wilson & Lewiecki-Wilson, 2001) and technical communication (e.g. Bayer & Pappas, 2006; Carter & Markel, 2001; O'Hara, 2004; Lippincott, 2004; Palmeri, 2006; Theofanos & Redish, 2003, 2005; Van Der Geest, 2006; Wilson, 2000), research studies in our fields tend to be populated with able-bodied "users" and "students" who are often assumed to be seeing, hearing, fleet-footed, multi-tasking, nimble-fingered digital natives. Our scholarly texts have not typically made room for, or even seemed to recognize the existence of, disabled subjects. The able-bodied subject is the unmarked norm (on "ableism," see Cherney, this volume; Linton, 2010). For example, Jonathan Alexander's (2008) guest editorial for a special issue of Computers and Composition on "media convergence" features a vibrant, exciting scene populated by young people expertly, ably, and nimbly remixing and repurposing multimedia content (p. 2). Since many online texts are inaccessible to students with disabilities—e.g. only 7% of web images "provide adequate alt text" for blind and low vision users (Chisholm & May, 2009, p. 24), very few audio podcasts include text transcripts (see Thatcher et al., 2006, p.153; Zdenek, 2009), and very few videos are closed captioned (as I will discuss below)—we must conclude that the students being described and imagined by Alexander are not disabled.
A representative, accurate account of how our students and users interact with multimedia texts, then, must include people with disabilities. A sampling of statistics about hearing and deafness in the U.S. begins to suggest just how many people may require or benefit from closed captioning:

- In the U.S., approximately 36 million adults—about 11% of the population—"report some degree of hearing loss" (NIDCD, 2010).
- The number of closed-caption users in the U.S. is estimated at 50 million (CaptionsOn, 2010)—i.e. about 1 in 6 Americans.
- The number of U.S. students with disabilities going to college "more than tripled" between 1978 and 1996 (OCR, 1999).
- "According to the Deafness Research Foundation, hearing loss is the No. 1 diagnosis for U.S. soldiers in Afghanistan and more than 65 percent of Afghan war veterans are suffering from hearing damage" (Hemstreet, 2010).
- The number of Americans 65 years of age and older—a population group more likely to benefit from accommodations such as closed captioning—is projected to rise from 13% in 2010 to 20% by 2050 (U.S. Census, 2008).
- "One third of all senior citizens have hearing problems" (CaptionsOn, 2010).

Thus when we focus on digital natives and so-called Millennials, we risk ignoring the needs of this fast-growing group of older Americans.

To take these numbers seriously requires a re-centering of our research studies around universal design and away from an able-bodied, youth-oriented norm. We do a disservice to all of our students and users when we assume that captions and other accommodations can only benefit people who are disabled (if we consider accessibility at all). As any hearing caption user (or universal design text) can tell you, closed captions are helpful in situations that create temporary or "situational disabilities" for able-bodied users (Chisholm & May, 2009, p. 12): watching TV in a noisy sports bar, helping your child learn to read, learning a second language, watching a movie with low production values, studying in a quiet area such as a library, marketing your Internet videos by making text captions available to search engines, and so on. (Search engines such as Google and video sharing sites such as YouTube are designed to index textual data such as video descriptions, tags, and closed captions [Ballek, 2010; Stelter, 2010; Sizemore, 2010]). From a universal design perspective, then, captions can potentially benefit all of us as we move through an increasingly noisy, increasingly less private, increasingly mobile world.

As closed captions online become both more important in a mobile world and more prevalent for certain types of content, we need to attend to the myriad ways in which captions create different, sometimes richer experiences for viewers than
non-captioned viewing experiences. By exploring captions rhetorically, we take them seriously as vital components of the video landscape (as opposed to incidental, invisible, imitative, or merely required by law). This perspective is admittedly informed by the Hollywood movies and TV shows I analyze below; a different set of texts, especially texts that are not structured by traditional narrative techniques, will most likely yield a different set of claims about rhetoric and closed captions. Regardless of the texts chosen for analysis, however, captioning for deaf and hard of hearing viewers will remain a rhetorically complex act, not simply a matter of copying dialogue from the script file to the caption track. The question of which sounds should be captioned, for example, can only be answered by attending to the rhetorical needs of the text itself. Descriptions of non-speech information, like descriptions of alternative text for Web images (Chisholm & May, 2009, p. 26), should always be situated in the context of a specific text or situation. Two closely related non-speech sounds (e.g. audible heavy breathing from two different characters) may need different captions or no captions at all. Likewise, two different sounds may need the same caption. Sounds are embedded in contexts that must be nourished. A rhetorical perspective is interested in the work that a particular sound does within the context of a particular scene or text. Captions must be responsive not to the objective qualities of sound but to the contexts in which sounds occur.

To support this perspective, I address a central question for closed captioning, one that rhetoricians are well-suited to address: Which sounds are significant? This question has not been discussed in detail, even though it structures the practice of captioning itself. It also provides a lens through which to address the rhetorician's abiding interest in genre, audience, context, meaning, and purpose. My materials are a small and varied collection of Hollywood movies and TV shows. My methods include comparing a small collection of captioning style guides with which a rhetorical perspective can then be contrasted. In the course of my analysis I discuss a set of topics that are central to an understanding of the effectiveness, significance, and reception of captions: overcaptioning, undercaptioning, subtitles vs. captions, the manipulation of time, non-speech information, series awareness, and the backchannel.

What I propose is a way of thinking about captions that goes beyond 1) a correspondence model in which captions are assumed to merely duplicate the sound track, and 2) a richness model in which the "real" action is assumed to be found on the sound track and captions are marked as inferior attempts to embody sound. An alternative model acknowledges the qualitative differences between sound and writing and draws attention to the need for a rhetorical understanding of captioning. For disability and deaf studies scholars, the stakes are obvious. Deaf and hard-of-hearing viewers need high quality captions and more studies that
explore and extend our understanding of caption quality. For composition and technical communication scholars, the stakes are just as high but perhaps not as obvious. When we assume that our students are not disabled, we build ableist pedagogies that fail to account for the rich variety of students who are increasingly populating our classrooms. A rhetorical understanding of captioning can also inform our theories of multimodal composition by helping us reflect on the rhetorical work of sound, the differences between writing and sound, and a concept of audience as more than a narrow group of hearing and seeing digital natives.

This essay is divided into five parts. After reviewing web captioning laws in the United States and offering a rough estimate of the number of web videos available with closed captions, I turn to an analysis of four captioning style guides that will set the stage for a rhetorical approach to closed captioning. This rhetorical approach goes beyond current discussions of quality and style—and at times runs counter to the style guides—to reflect how captions create different experiences for viewers. The concluding section imagines a scholarly landscape in which captions (and accessibility more broadly) are viewed as natural and necessary elements of our theories and pedagogies.

**U.S. web captioning laws**

On television, nearly all English language content is required by U.S. law to be transmitted with closed captions (FCC, 2010). On the Web, Section 508 of the Rehabilitation Act of 1973, as amended in 1998, requires federal agencies that "develop, procure, maintain, or use electronic and information technology" to make their products and services, including their websites, accessible (Section 508). §1194.22b of Section 508 mandates the use of synchronized alternatives (e.g., open or closed captions) for video content: "Equivalent alternatives for any multimedia presentation shall be synchronized with the presentation" (Section 508). In the private sector, businesses that have contracts or hope to have contracts with the federal government must ensure that the products they deliver to the government comply with Section 508. State universities that receive federal money, even indirectly (e.g., through federal student loan programs), are also responsible for adhering to Section 508. State agencies, including state universities, may have additional or different obligations. In my home state, for example, the Texas Administrative Code regulates, among other things, website accessibility for state agencies, including state institutions of higher education. The regulations for higher education websites in Texas follow Section 508 almost to the letter, with one major exception: §1194.22b of Section 508, which mandates synchronized alternatives such as captions for multimedia content, is compulsory in Texas Administrative Code only after an institution of higher education receives a request from a user for "alternative form(s) of accommodation" (Texas
Administrative Code, Rule §206.70). For example, an informational video on the website of a state university in Texas only needs to be accessible to deaf and hard-of-hearing users after a request for accommodation is made by a visitor to the site.

Other laws in the U.S., particularly the Americans with Disabilities Act (ADA), may also require closed captioning for the Web's private sector. For example, the judge presiding over the landmark National Federation of the Blind v. Target case ruled in 2006 that the ADA, which was signed into law before the advent of the Web, applies to private businesses regardless of whether goods and services are offered in brick-and-mortar stores or online: "Judge Marilyn Patel rejected Target's position that their site couldn't be sued under the ADA because the services of Target.com were separate from Target's brick-and-mortar stores" (Chisholm & May, 2009, p. 16). But because Target settled the case in 2008 "without admitting any wrongdoing," "the question of the ADA's applicability to the Web [is] somewhat unresolved" (p. 16). Regardless, the Department of Justice has declared that the ADA does indeed apply to the Internet. According to Thomas E. Perez, Assistant Attorney General in the DOJ's civil rights division, "It is and has been the position of the Department of Justice since the late 1990s that Title III of the ADA applies to websites. We intend to issue regulations under our Title III authority in this regard to help companies comply with their obligations to provide equal access" (quoted in Evans 2010).

Finally, a new law, The 21st Century Communications and Video Accessibility Act (2010), will require "captioned television programs to be captioned when delivered over the Internet" (AAPD, 2010). Signed into law by President Obama in October 2010 and roughly coinciding with the twentieth anniversary of the Americans with Disabilities Act, this law points to the growing seriousness with which the U.S. government is taking the issue of Web accessibility in the private sector. Currently, when TV shows and movies are redistributed on the Web by the original TV networks and authorized retransmitters like Hulu or Netflix, they are not likely to be accompanied with closed captions. Advocacy groups such as the Coalition of Organizations for Accessible Technology (COAT) lobbied for the passage of the bill because it will extend "closed captioning obligations to video programming provided by, or generally considered comparable to programming provided by, a television broadcast station, even when distributed over the Internet" (COAT 2009). The proposed legislation has met with resistance, most notably from the consumer electronics industry (Shapiro, 2010), but it was only a matter of time before the same regulations and agreements that govern television and DVD content—and ensure equal access to information and entertainment for millions of deaf and hard-of-hearing users in the U.S.—were extended to the Internet.

How much Web content is captioned?
How much TV and movie content is currently retransmitted on the Internet with closed captions? It's hard to say for sure; the situation on the Web is always in flux. What no one disputes is that very few television shows are closed captioned when re-presented on the Web. A recent, informal study by Jamie Berke in 2009 found that only five major content providers and retransmitters on the Web were offering closed-captioned content online. A whopping seventy-seven providers did not offer or support closed captions. Only ABC, CNET, Fox, Hulu, and NBC offered closed-captioned content online (Berke, 2009). Yet even Hulu's captioned collection is embarrassingly small—and appears to be getting smaller. An informal study I conducted over ten days in August 2009 found that Hulu's captioned content was hovering at around 4.5% for full episodes and 6.5% for movies (Zdenek, 2009). Five months later (on Jan. 31, 2010), I noted that Hulu's captioned full episodes had fallen to 2.7% (1355 episodes out of 50463 total) and captioned movies to 3.8% (36 movies out of 941 total). On my most recent check of the site on June 29, 2010, I found that the amount of captioned content had increased slightly but was still less than the percentage of captioned content from a year ago: 4.3% of episodes (2407 out of 55468) and 4.9% of movies (63 out of 1285) were available with captions. So while Hulu is sometimes held up as a model of accessibility by users of TV and video content on the Web, the fact is that Hulu's reputation is relative. The rest of the field is doing very little (and often nothing) to ensure the accessibility of their online content for deaf and hard-of-hearing viewers. At the same time, Hulu deserves praise for continuing to explore the potential of captions to serve the goals of universal design. For example, Hulu has taken steps to exploit the power of captioned media to provide a more fine-grained search experience. Search results can be targeted to specific instances within captioned shows. In addition, users are able to see visually on a "Heat Map" graph "the parts of the video that have been viewed the most; you can also click on the chart to navigate to any point within the captions" (Hulu). According to Eric Feng, the chief technical officer at Hulu, captions have "turned into a very important part of our user experience" (quoted in Stelter, 2010). These features leverage the power of captions to address the ongoing challenges of helping all users—regardless of ability—browse, search, find, and analyze large collections of video content.

The (un)captioned Web is in transition. Positive signs of change are everywhere. In June 2010 (when I composed the first draft of this essay), ESPN was partnering with VITAC to live caption World Cup soccer games on the Web, arguably "the first time that a cable network has added live captions to a streaming webcast simultaneous with TV captioning" (GlobalPittsburgh, 2010). Even Netflix, a company notorious among captioning advocates for seeming to be indifferent, even insensitive, to requests by users and organizations such as the National Association of the Deaf (NAD) to provide closed captioning on its web-based streaming movie service (e.g. see K_Yew, 2009; NAD, 2009), finally overcame the
technical hurdles that had been preventing the company from offering closed
captions on the Web (Netflix, 2009; 2010).). In February 2011, Netflix increased
the amount of captioned streaming content to 30% and "expect[s] to get to 80%
viewing coverage by the end of 2011" (Netflix, 2011). While Netflix users are still
not able to search for captioned streaming movies on the Netflix site, other services
such as FeedFliks.com allow users to do so. In contrast, users can easily search
iTunes for closed-captioned movies. But as of June 2010, according to my own
count, iTunes was only offering 318 closed-captioned movies (up from 53 in April
2008 [Buchanan, 2008]) out of "thousands" of downloadable movies (Apple, 2010),
thus making the captioned content on iTunes most likely comparable (percentage-
wise) to what is being offered with captions on Hulu—i.e., just a drop in the bucket.

1

Given the recent and continuing explosion of online video, the global saturation of
mobile devices (especially the iPhone and iPad), the increasing awareness of and
support for web accessibility among U.S. law makers, and the increasing
sophistication and bandwidth capacity of the U.S. Internet infrastructure, the
situation is sure to continue to evolve rapidly and unexpectedly.

**Captioning style guides**

Style guides for closed captioning are plentiful on the Web. They run the gamut
from informal suggestions posted to personal websites to formal documents written
by large captioning firms. Style guides cover roughly the same ground, even if they
do not agree on specific guidelines (on the problem of standardization, see Clark,
2004). My own analysis of the style guides is limited to what is publicly available on
the Web. I am keenly aware that captioning vendors and individual captioners
make use of a wide range of learning and training methods that are not typically
available to the outside researcher (e.g., in-house style manuals, formal training
sessions, informal conversations, etc.). However, my goal is not to provide a
comprehensive review of in-house captioning style guides but rather to sample
briefly a small number of authoritative, publicly available guides in order to suggest
something about the contours of these texts and the terrain they cover. This review
will allow me to situate a rhetorical approach to closed captioning alongside of, and
in some cases in opposition to, the information that is currently available on
captioning style. My review is based on the following style guides:

- **Captioning Key for Educational Media: Guidelines and Preferred Techniques**
  (DCMP, 2009). A major resource on captioning style, this guide is authored by
  the Described and Captioned Media Program (DCMP), which is funded by
  the U.S. Department of Education and administered by the National
  Association of the Deaf. The DCMP maintains a list of approved captioning
  vendors (including CaptionMax, National Captioning Institute, The Media
Access Group/WGBH, and VITAC). *Captioning Key* mandates style guidelines for vendors who produce captioned content for the DCMP/Department of Education. *Captioning Key*'s style guidelines are based on "captioning manuals...from major captioning vendors in the United States" (DCMP, 2009, p. 2).

- *The CBC Captioning Style Guide* (2003). The Canadian Broadcasting Centre released this in-house captioning style guide in response to an information request filed by Joe Clark, a well-known and longtime expert on closed captioning (see Clark, 2008).


- WGBH's "Suggested styles and conventions for closed captioning" (2002). Caption technology for television was developed at WGBH, a PBS station in Boston, in the early 1970s (Earley, 1978). The first captioning agency—The Caption Center—was established at WGBH in 1972 (Robson, 2004, p. 10). WGBH has arguably been thinking about captioning style longer than any other agency, thus making their style guidelines of particular value.

Standard topics in the style guides include: methods of captioning (prerecorded or live), styles of captions (pop on or roll up), accuracy, verbatim vs. edited captions, screen placement, line breaking, timing, typeface and type case, grammar and punctuation, and non-speech information (speaker IDs, music, sound descriptions). Style guides are light on theory; individual guidelines are typically offered up as truths in no need of justification. While readers should not necessarily expect style guides to provide a lengthy explanation of each best practice, the lack of good reasons is troubling for those practices that seem counter-intuitive, such as the requirement to style captions in upper case letters only, using centered alignment, in the shape of an inverted pyramid, in no more than two rows, with new sentences always starting on a new line, and with speaker IDs and sound descriptions set in mixed case.

Of these requirements, the all-caps guideline is undoubtedly going to be the most troubling and confusing to rhetoricians and document designers. While an all-caps style may have been necessary in the early days of TV captioning, it is unnecessary today and at odds with the most basic rules of good typography. With printed texts, lower case letters are "more legible than those in upper case" (Kostelnick & Roberts, 1998, p. 144). The same is true for electronic letters produced in the high resolution TV and web environments of today. Joe Clark (2008) refers to the preference for upper case caption styling in his review of *The CBC Captioning Style Guide* as "1980s nonsense." Uppercase styling is "a
mistake, an archaism. It only ever came about because the original decoders’ fonts were so lousy that all-upper-case captioning was deemed less illegible than mixed-case. CBC doesn't even know the reasons why it is using capital letters, or that such reasons are no longer in effect" (Clark, 2008). Whereas CBC offers no explanation for why offline captions need to be set in uppercase style ("All text shall be presented in upper case, except for...") [CBC, 2003, p. 9]), WGBH (2002) offers conflicting advice about type case. Examples in WGBH's captioning style guide are set in uppercase, with lowercase reserved for non-speech information and speaker IDs. But WGBH's style guideline for type case stipulates that "caption text is generally rendered in uppercase and lowercase, or sentence case, Roman font." Readers are thus presented with a WGBH guideline that WGBH itself does not follow, a guideline that seems better suited to a pre-Web, low resolution, analog world. Moreover, if an all-caps style is interpreted as screaming for viewers steeped in texting and instant messaging conventions, then how can uppercase captions convey whispering?

(whispering)

PLEASE OPEN THE DOOR!

In this example from WGBH's (2002) style guide, a screaming uppercase style comes into conflict with the intent to convey the opposite of screaming. Uppercase captions, in addition to being less legible than standard sentence case, are troubled by an association between all-caps and screaming. Is it even possible, in a post-Web world shaped by email and texting conventions, to whisper in all-caps?

A second issue likely to be of particular interest to rhetoricians is verbatim captioning—i.e., whether it is possible to caption every word of dialogue and every audible sound, and whether captioners should edit captions for certain readers (i.e., children), to meet maximum presentation rates, or to clean up a speaking style marked by presumably irrelevant verbal fillers like "um" and "uh." The first regularly captioned show on television—a nightly rebroadcast on PBS stations of The ABC News with open captions—was edited for content and for reading speed (Earley, 1978). The producers at WGBH who created the open captioned version of The ABC News decided to edit the audio content for two reasons:

Captioners at WGBH recognize two needs: (1) to reduce the amount of text in the average television program (roughly 180 words per minute) to allow time to read the captions and watch the program video, and (2) to adjust the language itself so that comprehension of the captions can be rapid and accurate. (Earley, 1978, p. 6)

Today, reading speed continues to guide decisions by captioners to edit content. According to WGBH, "[A]ny editing that occurs nowadays is usually for reading
speed only." The authors of *The Captioning Key* agree and have specified maximum presentation rates for captions (ranging from 130 words per minute [wpm] for children to "near verbatim" or 235 wpm for theatrical productions for adults [DCMP, 2009, p. 12]). Some deaf and hard-of-hearing viewers may benefit from slower caption presentation speeds: "Where reading speed data are available, they suggest that the reading speeds of deaf and hard-of-hearing viewers are typically slower than those for hearing viewers" (Burnham et al., 2008, p. 391). At the same time, deaf and hard-of-hearing viewers have made it clear that they prefer verbatim or near-verbatim captioning because they want the same access as hearing viewers. As a result, the original practice of adjusting the language of captions for comprehension is no longer advocated in the captioning manuals and in fact has even been referred to as censorship: "Extreme rewriting of narration for captions develops problems, such as 'watered-down' language and omitted concepts. Language should not be censored" (DCMP, 2009, p. 1). With the exception of CBC's (2003, p. 7) style guide, which erroneously defines verbatim captioning as "difficult" to achieve, the style guides embrace verbatim captioning as standard practice that only presentation rate has the power to alter. "Editing is performed only when a caption exceeds a specified rate limit" (DCMP, 2009, p. 12).

Verbatim captioning and editing for reading speed are complicated by non-speech information (NSI) and in particular the variety of approaches to captioning it. NSI—a third issue likely to be of interest to rhetoricians—includes sound descriptions, speaker IDs, manners of speaking, music lyrics, and any other information that might be needed to convey a full understanding of the sound track. Captioning NSI is a creative and at times complex rhetorical act that involves careful attention to the context and nature of the video text. The amount, quality, and variety of NSI can vary wildly from DVD to DVD. Movies and TV shows are teeming with sounds that either cannot be captioned due to space or rate constraints, or are not deemed significant enough to warrant being captioned. It is simply not possible to caption every sound in a movie or TV show. Discussions of NSI in the style guides dutifully list which categories of non-speech sounds need to be captioned and how, at a basic level, to caption them, but they do not offer suggestions for helping captioners identify sounds which are significant or how to develop and hone the captioner's rhetorical powers of description. The style guides seem to assume that it will be obvious which non-speech sounds need to be described. In some cases, they are right, as with the guideline to caption music lyrics verbatim (e.g., DCMP, 2009, p. 23). But given the diversity of approaches to captioning NSI, the lack of standardized guidelines across service providers for handling NSI, and the few cues in a movie or television script for describing NSI, it is more often the case that captioners must choose which NSI sounds need to be captioned and how to caption them so that they fit seamlessly into the signifying world of the text.
NSI is, to a large extent, invented by the captioner. A style guide may direct the captioner to "convey all the concomitant non-dialog information that the hearing audience takes for granted" (WGBH, 2002), but the guide will not explain what challenges are involved in making captioners aware of information they usually take for granted or how to caption that information. Should a character's breathy sound be described as a gasp, sigh, scoff, grunt, pant, groan, moan, or nothing at all? A style guide may warn the captioner "not to congest a show with unnecessary descriptive captions" (CBC, 2003, p. 15), but the guide will not help the captioner understand where to draw the line between too much and not enough, with the exception of providing examples of how to edit content to achieve a set presentation rate. (It is worth noting that examples in the style guides of editing draw solely on speech captions; they never draw on NSI for examples of how to edit content [e.g., see DCMP, 2009, pp. 12-13]). For rhetoricians, then, NSI is of interest for at least three reasons: 1) NSI is often the most distinctive and subjective aspect of a caption track, highlighting the captioner's rhetorical agency; 2) NSI calls attention to the relationship between writing and sound because similar sounds may have different captions and different sounds may have the same caption; and 3) NSI raises awareness of the challenges of distinguishing significant from insignificant sounds.

The question of significance cuts to the heart of a rhetorical approach to captioning, as I will suggest in the next section. Definitions of captioning often make a distinction, sometimes implicit, between significant and insignificant sounds. But they seem to assume that the question of significance, importance, or essence is a straightforward one, easily answered. Captioning Key (DCMP, 2009) states that "background sound effects" should only be captioned "when they're essential to the plot" (p. 21). Background music "that is not important to the content of the program" (p. 24) only needs to be captioned with a music icon. And "background audio that is essential to the plot, such as a PA system or TV" (p. 17), needs to be captioned in italics. These directives assume either that the captioner already understands implicitly which sounds are important or essential, or that the style guide authors do not believe that the question of significance is a significant one. As a result, the style guides are weighed down by the micro details of presentation and design, some of which have resulted in guidelines that are misguided, arbitrary or inconsistent from one manual to the next:

- **Alignment.** Caption alignment continues to be an ongoing area of inconsistency. Should caption lines be center-aligned at bottom center of the screen, as CBC (2003, p. 3) and CaptionMax recommend, or "left-aligned at center screen on the bottom two lines within the safe zone," as Captioning Key (DCMP, 2009, p. 6) recommends? Why have captioners not drawn more heavily on the convention in written English of using a strong left alignment
with ample margins? What reasons continue to implicitly support centered alignment in an era of high resolution digital captioning?

**Type Case.** Why does uppercase text style persist as a viable and popular option for captions? The technical challenges of the early days of TV captioning (i.e., low resolution) have been resolved (Clark, 2008). Given the superior readability of sentence case for all other types of extended reading (both on the printed page and on the computer screen), why haven't more major captioning vendors changed their practices? The persistence of all-caps style for offline, prerecorded captioning has to be the most troubling and baffling aspect of the visual rhetoric of closed captioning.

**New Sentences.** Two major style guides advocate starting new sentences on their own line for offline, pop-on style captioning (DCMP, 2009, p. 10; WGBH, 2002). According to *Captioning Key* (DCMP, 2009, p. 10), captioners should "Never end a sentence and begin a new sentence on the same line unless they are short, related sentences containing one or two words." According to WGBH (2002), "A period usually indicates the end of a caption, and the next sentence starts with a new caption." Nowhere else in the world of English sentences do we find such an unusual guideline. New readers of English learn to move their eyes from the end of one line to the beginning of the next without needing each new sentence to begin on a new line. Captioners should always break lines for sense, but guidelines for breaking lines need not include breaking lines after periods.

**Caption Shape.** Readability should always take precedence over the desire to create an allegedly pleasing shape out of a multi-line caption. In other words, breaking caption lines for sense should always take precedence over the desire to "present a block of captions that are similar in size and duration" (CBC, 2003, p. 8) or to present "captions [that] appear in a two-line pyramid or inverted pyramid shape" (CBC, 2003, p. 17).

**Maximum Number Of Lines.** According to CBC's (2003, p. 8) style guide, "Captions should always be one or two lines in length. Three line captions are acceptable when time or space is limited. Four line captions are unacceptable." This prohibition against 4-line captions seems arbitrary. If a captioner is trying to honor the viewer's preference for verbatim captions and avoid editing captions to meet a specified presentation rate, then why deny the captioner an extra line, especially for no reason, if the presentation speed and nature of the text call for it?

The style guides avoid higher-level issues that seem crucial to a full account of how captions make meaning. These issues are grounded in a rhetorical concern for how readers and viewers make meaning; how genre, context, and purpose can and should shape caption production and reception; and the differences between
making meaning through reading and making meaning through listening. In the next section, I address these issues in the context of a central and underexplored question for closed captioning: *Which sounds are significant?*

**Towards a rhetoric of closed captioning**

A rhetoric of closed captioning goes beyond questions of accuracy, timing, and screen placement to consider the ways in which users, multimedia texts, and genres interface with captions to make meaning. While "The CBC Captioning Style Guide" (CBC, 2003) asserts that a "caption viewer should not receive more or less information than a hearing one" (p. 15), a rhetorical perspective starts from the assumption that sound and writing are fundamentally different. Providing precisely the same "information" verbally and visually (in writing and sound) is not possible. This does not mean that captions are not capable of providing sufficient accommodations for deaf and hard-of-hearing viewers. But it does entail a different way of thinking about what captions do and mean. The rhetorician starts from the perspective that the caption mode, simply by nature of its written form, provides a different interpretation and experience of the text. In this section, I explore a central and deceptively easy question: *Which sounds are significant?* I developed my response to this question in 2009-11 over the course of creating a number of video commentaries for my blog (AccessibleRhetoric.com). I have included links to relevant blog entries below. All examples refer to the official DVD captions. The analysis is admittedly limited by my own viewing preferences. I did not randomly select movies and TV shows to watch on DVD. The analysis is also limited by genre, broadly speaking. All of the texts are mainstream, Hollywood narrative fare. Despite these limitations, the perspective I offer is broad enough to encompass a much more diverse set of narrative texts.

Most definitions of closed captions either 1) assume naively that captions embody the full complement of audible sounds in a text, or 2) draw on an undefined notion of *significant* or *important* sounds. Consider these definitions of closed captioning:

- "Captions describe all the audio content, as well as information about the identity of speakers and their tone of voice." (WordIQ, my emphasis)
- Closed captions "display speech and non-speech information..." (eHow)
- "Closed captions are a text version of the spoken part of a television, movie, or computer presentation." (WhatIs)
- "Captions' aim to describe to the deaf and hard of hearing all significant audio content..." (Wikipedia, my emphasis)

The first two definitions assume simplistically that captions can, by default and without qualification, capture *every* sound in a movie, TV show, or other multimedia
text. The third definition reflects a misunderstanding of the distinction between subtitles and captions, because true closed captions not only capture "the spoken part" but the non-speech content as well (i.e., music, sound effects, speaker IDs, etc.). The fourth definition introduces a qualifier ("significant"), which implies that some sounds are insignificant and need not be captioned.

Definitions that simplistically assume that all sounds can be captioned are not based on a deep understanding of the sound content of most movies and TV shows. In mainstream movies, captions do not "describe all the audio content," because sound is pervasive and multi-layered. In addition, the space for captions is severely limited. Action movies, especially, tend to be built on multiple layers of overlapping and competing sound tracks: dialogue, background music, sound effects, etc. Captioning style guides, even when they make or imply a distinction between significant and insignificant sounds, do not provide criteria for distinguishing the former from the latter. Sometimes such a distinction is easy to make. At other times, the captioner must decide which sounds are significant and which are not.

Let me offer an example of what I call overcaptioning, and then try to rebut the charge that any attempt by the captioner to decide which sounds should be captioned amounts to censorship. In this example, an emotional family reunion at the end of Taken, a 2008 thriller starring Liam Neeson, is disrupted by a captioned, incomplete, and ironic announcement over the airport’s public address (PA) system (see http://accessiblerhetoric.com/?p=986). As the family embraces and speaks to each other in person for the first time since their daughter was kidnapped, sold into sex slavery, and then rescued by biological father Neeson, a partially muffled PA announcement interjects:

[Man on P.A.]
Attention travelers, you are not required—
Shall we go?
This airport does not sponsor their activities.

In these three consecutive captions, a question from the stepfather ("Shall we go?") interrupts the PA announcement just as the announcer is about to tell viewers and listeners what is "not required." The main point of the announcement is muffled as the stepfather speaks. It is not possible for hearing viewers to make out the uncaptioned spoken words of the PA. Ironically, the movie itself is about activities that are not officially "sponsored" (i.e., kidnapping, human trafficking). In this sense,
the PA announcement is relevant to the larger themes of the movie, even if the announcement is most likely not a public warning about kidnapping or slavery. But irony should never be enough to trump a scene's thematic intensity. Because the announcement disrupts the emotional intensity of the triumphant reunion and its main idea is inaudible (whose activities are not sponsored?), it should not have been captioned verbatim. A complete, verbatim rendering of the announcement is impossible anyway and only leads to confusion and distraction.

When we assume that only significant sounds should be captioned (rather than starting from the mistaken assumption that all sounds can be captioned), we begin to explore significance beyond volume level. The loudest sounds are not always the most significant, just as quiet and even partly inaudible sounds are sometimes in need of captioning. Captioners must **honor the narrative** above all. The stepfather whispers in his returned stepdaughter's ear in this scene but his words are hard to make out as clearly as other spoken words in this scene (including the PA announcement). A manner caption ("[Whispers]") modulates the spoken words, "It's so good to have you back." The daughter audibly cries out while the whisper is being uttered, making it difficult for hearing viewers to determine precisely what is said without the aid of captions. Yet despite the low volume of the whisper, it needs to be captioned because it is a crucial component of the emotional reunion at the end of the film. Captioning should thus be driven by the scene's purpose. Volume level alone may be helpful but not sufficient in determining which sounds should be captioned.

Based on my reading of this scene from *Taken*, I offer five guidelines for thinking through the question of significance:

1. Captions should support the emotional arc of a text.
2. A sound is significant if it contributes to the purpose of scene.
3. Caption space is precious. It should never be wasted on superfluous sounds that may confuse viewers or diminish their sense of identification with the protagonist(s).
4. Sounds in the background do not necessarily need to be captioned, even if they are loud.
5. Every caption should honor and respect the narrative. While the narrative does not have one correct reading, it does have a sequence and arc that must be nourished.

By suggesting that the captioned PA announcement at the end of *Taken* might be edited down to a sound description such as "PA announcement" or "crowd talks indistinctly," I realize that I open myself up to charges of censorship. Indeed, I am acutely aware that deaf, hearing, and hard-of-hearing viewers do not want
dumbed-down captions. Every viewer deserves equal access. The original practice at WGBH of editing speech for comprehension (Earley, 1978) is no longer advocated today—for good reason. But what discussions of verbatim captioning leave out are 1) the differences between writing and speech, and 2) the limited space available for captions. Everything cannot be captioned. There are some pretty loud footsteps in the *Taken* scene, some loud but indistinct chatter, and at least one loud car horn. Someone had the good sense not to caption them. Caption space is limited. Only significant sounds should be captioned. The footsteps seem to be almost as loud as the PA caption, but volume alone should never drive caption design. Captioning is an art. The captioner must contend with spatial and temporal constraints while being responsive to the rhetorical needs of the narrative. Countless sounds are left out of every caption file—they have to be left out. Time and space are working against the captioner, but more importantly viewers do not want to be burdened by a screen full of insignificant captions. Censorship is simply the wrong word to describe the selective and creative process of captioning. What I am describing is not censorship—far from it—but the art and rhetoric of captioning. Someone must make these decisions. Captioning is not an objective science; it is a highly interpretative practice. (By the way, it sounds as if there is a foreign language PA at the beginning of the *Taken* scene. It is not significant and thankfully there is no reference to it—even a vague one like "Foreign PA announcement"—in the caption file. It is not censorship to leave it out but reflects instead an attempt to be responsive to this scene’s purpose.)

The flip side of overcaptioning—what I appropriately call *undercaptioning*—reveals the extent to which captioning is a rhetorical, purpose-driven act that can not be objectively reduced either to a production script or to the volume level of individual sounds. In *Curb Your Enthusiasm*, only speech is captioned. 2 This so-called subtitle approach to captioning leaves out sound descriptions entirely, thus cutting deaf and hard-of-hearing viewers off from significant non-speech content. Descriptions of sounds, even seemingly minor or barely audible sounds, are necessary to convey the full significance of the sound track. Episode 9 of Season 1 (2000) centers around Larry’s repeated attempts to fill a prescription for Cheryl, thereby alleviating her desire to scratch (see http://accessiblerhetoric.com/?p=1048). When Cheryl is visibly scratching, captions are usually unnecessary or can be kept to a minimum. But when Cheryl's scratching can be heard but not seen, the need to caption it increases. A subtitle (dialogue-only) approach is insufficient. Some examples of scratching in this episode are both invisible (off-screen) and barely audible. Cheryl scratches off-screen in the darkened interior of a car and, later in the episode, scratches off-screen as loud background music plays. At one point, Larry stares at the ceiling as both background music and soft scratching sounds are heard. Because the humor of this scene depends upon the soft sound of scratching in the background, it needs to be captioned. Similarly, the
background music, borrowed from the soundtrack to Psycho, is rhetorically significant and needs to be captioned. In the final seconds of the episode, Larry ascends the stairs of his home to the slight sound of scratching, revealing his inability to fill Cheryl's prescription. The full significance of this final moment is not available to deaf and hard-of-hearing viewers who rely on captions to provide information about both speech and non-speech content. Even barely audible sounds such as light scratching need to be captioned if they are significant to the narrative. In this case, significance is not simply a matter of sound volume. In a second Curb video, I explore five significant non-speech sounds from season two that should have been captioned but were not (see http://accessiblerhetoric.com/?p=1343).

Captioners need to understand a movie or TV show in context. Individual scenes may need to be captioned with a view to how the narrative is unfolding at any given moment. In other words, significance is a contextual issue and can only be addressed from inside the arc of a particular narrative. The background music in the scratching scene from Curb establishes an emotional context that must be carefully captioned to convey that context to caption users. A musical note would be insufficient in this case, although it might be perfectly acceptable in others.

Captioners may also need to be responsive to context beyond the individual scene or episode, what I refer to as series awareness. When TV episodes are closed captioned in isolation, without an awareness of how individual sounds are connected intertextually to other episodes in the series, caption users may be cut off from important themes in the show. Because every TV series builds a set of relationships that connects all the episodes together, these relationships, when mediated through sound, need to be captioned. Consider recurring music that's identified with a specific character or show theme. The difference between "[Disco]" and "[The Final Countdown]" is no small difference if the show is Arrested Development and the character is Gob. Fans associate Europe's 1986 hit "The Final Countdown" with Gob. The song always accompanies Gob's magic act. It has been called "his trademark opening song" (Arrested Development Wikia). Consider a clip from episode 8 of season 3 (see http://accessiblerhetoric.com/?p=2933). As a recurring element intimately tied to a major character, the song must be captioned by title, such as ["The Final Countdown"] or [Europe's "The Final Countdown"], and accompanied by the requisite music note. A generic caption such as [Disco] will not suffice to convey the full meaning of the music in the series. While [Disco] may work in isolation, it does not work from a series perspective. In this clip, a snippet from another recurring song in the series—"It ain't easy"—is undercaptioned as [Country]. Only someone unfamiliar with the show would reduce this song to [Country]. When captions are considered from a series perspective, themes are more likely to be visible on the caption track.
When scenes or episodes are not captioned contextually, captioners may provide crucial, significant information but at the wrong narrative moment. For example, the caption track of *Pirates of the Caribbean 2: Dead Man’s Chest* (2006) gives away the natives' big secret a full fifteen minutes before the narrative is ready to do so (see http://accessiblerhetoric.com/?p=803). The natives' cannibalism—a significant plot device that is revealed all at once in the narrative—is revealed in the captions too soon through the use of sound descriptions such as [speaks cannibals' language] and [cannibals murmur]. As a result, the captions provide too much information and thus fail to nurture suspense and surprise. Movie captions must never reveal information prematurely. To caption contextually requires a rhetorical sensibility that takes the act of captioning beyond simple transcription of speech content. In order to understand what a narrative needs from captions, the captioner must draw from a global understanding of the text. Applied to movies, the notion of series awareness directs captioners to account for how individual scenes are intimately connected and should thus not be captioned in isolation. Individual captions must work together to support and reflect the movie's emotional intensity and developmental arc. Surprise and suspense must be nurtured and captions must be situated firmly in the moment, never ahead of it.

This example from *Pirates* also suggests that captions have the power to manipulate time. The viewer watching with captions knows ahead of the viewer watching without captions that the natives are cannibals. On a local (single caption) level, captions may allow experienced readers to read ahead of the speech being captioned. A short two-line call-and-response between two speakers can be read very quickly. In my house, we have laughed or otherwise responded to a captioned joke before the joke has been uttered. Captioners need to be sensitive to the ways in which captions necessarily modify time. Consider the guideline to identify the name of any speaker who is off-screen or cannot be identified visually. This guideline may come into conflict with the captioner's need to be responsive to a narrative that contains elements of mystery, suspense, or surprise. In a scene from the TV show *Dollhouse* (Season 1, episode 10), a man lurking in the shadows says something to Echo (played by Eliza Dushku). Unable to see who it is, Echo responds, "Who's there?" At which point, the man comes out of the shadows and Echo recognizes him as Nicolas (see http://accessiblerhetoric.com/?p=605).

NICOLAS:
Strange—he doesn't like most people.

Who's there?

I have a better question.
While speaking the third caption ("I have a better question"), Nicolas comes into the light and reveals himself. But closed-caption viewers knew it was Nicolas from the moment he started to speak from the shadows, because the caption had identified him with a Speaker ID. For better or worse, captions have the potential to make time travel possible.

From the viewer's perspective, knowing the future does have a price. No longer do we ride that same wave of suspense with Echo. We know right away that Nicolas is skulking around in the shadows. Closed captioners need to consider carefully how captions affect the emotional arc and intensity of a scene or show. Captions need to be situated. The captioning convention that calls for Speaker IDs (we cannot see Nicolas so we better identify him in the caption) should not have been invoked in this case. The need to build suspense in this particular scene trumps the need to identify speakers who are off-screen (or obscured by that terrifying darkness). The practice of captioning should be rhetorical. Captioning, done well, demands that conventions be applied flexibly. A rhetorical approach uses purpose, genre, structure, emotion, content, and audience to determine the best course of action.

For another example of the time-traveling potential of captions, see http://accessiblerhetoric.com/?p=483.

Caption viewers may be out of sync, just slightly, with the action, or worse, stripped of the full experience of surprise and suspense. Perhaps it is not an advantage to us, after all, when captions reveal secrets before the movie is ready to share them. But the larger point—encompassing any discussion of specific advantages or disadvantages—is that no one is really talking about the rhetoric of closed captioning, the ways in which captions (and the interplay of writing and sound more broadly) create experiences for users that are different from uncaptioned experiences. Captions are not simply the text equivalent of spoken dialogue but create different opportunities for users, mediate meaning making differently, and add subtle and complex layers of meaning to video texts. By analyzing the rhetorics of closed captioning, we can offer new critiques of the limits of current thinking about caption style and, hopefully, improve caption technology and stylistic conventions. By showing how closed captions can provide different (even advantageous) viewing experiences over traditional, non-captioned experiences, we can help to bring closed captions into the mainstream.

In closing this section, let me offer two final examples to suggest how captioned viewing experiences can be notably different than uncaptioned viewing experiences, despite the best efforts of captioners to ensure equal access to information. The first example involves what I call the backchannel. The term usually refers to audience discussions at conferences that take place live and behind the scenes—e.g., on Twitter using hashtags. I want to appropriate the term here to describe background sounds that come forward when they are captioned.
Every sound becomes equally "loud" when it is transferred to the caption track. The distinction between background and foreground blurs. *The Happening* (2008), for example, contains a number of scenes of crowds of various sizes chattering and murmuring in the background (see http://accessiblerhetoric.com/?p=1041). When the crowd's chatter is captioned as indistinct sound (e.g., "chattering"), it remains in the background. When the crowd's chattering is captioned verbatim, it comes forward and becomes clear. Examples of verbatim backchannel sounds include:

[Man] We need an extension over here.

I've never seen anything like it.

[Man] Go back to the laughing please.

Sir, we'll need to check your suitcase.

[Man] Please have your tickets out and ready.

I know, I know you don't want to.

- Do you have a phone?
- No, no. I'm sorry, I don't.

They're not telling us anything.

[Woman] Drive. Just roll up the window.

- We have no communication.
- We don't have a cell phone.

Has anyone seen any other people on the roads?

[Man] I just walked down a quarter mile. It was clean.


In these examples, the crowd's chatter is brought forward because it is captioned. Without captions, this background chatter remains indistinct to hearing viewers. Put another way, captions equalize sounds by removing or downplaying the distinctions between loud and quiet sounds. All sounds become equally "loud" on the caption track. For hearing viewers, captions make speech and other sounds accessible that are otherwise hard to understand, not loud enough, spoken too quickly, and so on. In this way, captions clarify. Because the distinction between foreground and background breaks down on the caption track, captioners need to ensure that only
significant sounds in the background are brought forward.

Captioned viewing experiences are also notably different because the affordances of writing and sound are different. A single non-speech sound can be captioned in multiple ways. Consider "breathy" sounds such as gasps, scoffs, pants, sighs, grunts, and heaving breathing. The difference between a gasp and a pant may come down to more than the objective qualities of the sound itself. Facial expression and context influence how a sound should be described. Similar "breathy" sounds may warrant different captions, just as different sounds may rely on the same caption. The English lexicon is quite limited when it comes to offering a descriptive language for paralinguistic sounds. With this in mind, I offer a compilation of breathy, non-speech sounds from the movie *Twilight* (2008), a movie I only half-jokingly call the "gaspiest movie in the world" (see http://www.accessiblerhetoric.com/?p=54). Dramatic breathing, especially from Bella (Kristen Stewart), plays a recurring, visible, and captioned role in the film. Bella gasps, sighs, grunts, and pants her way through the narrative. What we learn about paralanguage and captions from *Twilight* is that:

- Captions are situated in the context of the narrative. How a sound should be described depends on what that sound does—i.e., the purpose it plays in the context of the scene.
- Captions may be arbitrary (e.g., two "gasps" may sound very different).
- The English lexicon offers few options for captioning paralanguage. A single caption ("gasp") is called on to represent a range of sounds and emotions, including fear, surprise, desire, anger and pain.
- Captioning everything is not practical, feasible, or necessary. Not every "breathy" sound in the film is captioned. Space may not allow, and context may not require, the inclusion of some paralinguistic sounds as captions.

We do not yet have any rhetorical studies of closed captions. I hope that other scholars will begin to find here a fertile ground on which to explore the intersection of multimodal composition and accessibility, and sound and writing more broadly.

**Conclusion: Naturalizing Captions**

A rhetoric of closed captions, in keeping with the examples I have explored here, is rooted in the following claims:

- Captioning is a rhetorically complex and creative act. Captioners are rhetorical agents who must, at times, make decisions about which sounds to caption and how to caption them.
- Captions provide a different experience of the text.
Captions do not merely transcribe audio content but transform it.

Significant sounds do not exist in a vacuum. Significance is contextual, not simply a function of volume level.

At their best, captioners are rhetorical agents who choose what and how to caption based on a thorough understanding of the text, including its narrative and emotional arcs. While texts do not have single meanings, they do have relationships and contexts that must be reconstructed and nourished.

Closed captions have wide, universal appeal, and as they become more visible and common on the Web, my hope is that they will begin to seem more natural and even desirable among a wider range of viewers. When captions are seen as universally desirable, they will be considered by more scholars as central as opposed to incidental or not considered at all. For example, captioning technology is being leveraged to produce richer viewing experiences on the Web through interactive transcripts, which allow users to click anywhere in a video transcript and be transported to that moment in the video where the clicked words are spoken. Ted.com provides some of the best examples of interactive transcripts. Users can listen to a video presentation in English, load captions in a second language, and read the transcript in a third language. Loading all three in English provides excellent support for deaf, hearing, and hard-of-hearing viewers. Interactive transcripts signify a leap forward for captioning technology (see Zdenek, forthcoming). Interactive transcripts, like enhanced TV episodes that rely on captioned commentary, suggest an expanded role for captions that could, one hopes, make them part of the standard topography of the typical web video.

Captions also have a crucial role to play in certain genres of user-generated content, such as popular songs accompanied by on-screen (captioned) lyrics, and so-called "literal music videos," which are parodies that replace the original lyrics with new lyrics based on what is happening visually in the official music video. These parody videos depend for their humorous effect on open captions. Captions are an integral part of the genre. (For my own attempt at caption-based parody, see http://accessiblerhetoric.com/?p=1100). Moreover, parody provides a direct route from accessibility to multimodal composition. Consider the countless parody videos of Downfall (search YouTube for "downfall parody"), including one published anonymously in Kairos (theamishaugur, 2008). The Kairos submission is explained in a brief footnote by the journal editor in terms of the ethics of publishing anonymously (Ball, 2008). But we might just as well discuss the Downfall meme in terms of universal design. You do not need to be a hearing person to get the Downfall joke. With this seemingly simple and obvious point, we can counter the tendency in our fields to assume an able-bodied user/student. Parody is leveraged into a discussion of universal design.
Captioning research has the potential to make a number of contributions to the study of multimodal composition. Captioners and captioning researchers study the meaning and significance of sound, the relationship between writing and sound, the visual display of sound, remediations of sound, how to convert sound into writing, the sonic backchannel, how to make sound accessible, sonic intertextuality (e.g., series awareness), and the design of accessible pedagogical soundscapes. These topics complement and can potentially inform sound studies in composition and related fields (e.g., Alexander 2008; McKee 2006; Mueller 2009; Shipka 2006). But more importantly, captioning research—and disability studies more generally—calls attention to our underlying beliefs and assumptions about users and students. If we start from the assumption that our pedagogies and multimodal compositions need to be accessible, if we assume that not all of our students are able-bodied digital natives, we can develop richer, more informed, more robust, and more accessible pedagogies, tools, technologies, and texts. We limit our theories when we assume that all of our students are hearing (e.g., see Alexander 2008), or, as McKee (2006) does in her essay on sound in multimodal texts, when we recognize the "important issue" of accessibility but simply choose not to discuss it. McKee (2006) describes accessibility in terms of discrete guidelines (e.g., "providing subtitles for all sounds" [p. 335]), but my preceding analysis has tied accessibility to a set of broader questions about sound and writing that transcend such a narrow and simplistic definition of subtitles. (As I have shown, no subtitle or caption track can ever account for "all sounds." Anyone who has given the slightest thought to captioning quickly arrives at the same conclusion.) If we wish to provide robust accounts of multimodal composition, we need to inform our understanding of sound with an accessibility-infused sensitivity to the broader questions about sound, writing, and rhetoric at the heart of this essay’s analysis. We need to start with universal design, not dismiss it.

Captioning research can and should be done in concert with deaf and hard-of-hearing users and researchers. My own view of captioning is informed by the style guides’ insistence that deaf and hard-of-hearing caption viewers prefer verbatim captions, and by studies such as Jensema et al.’s (2000) on the amount of time deaf and hard-of-hearing viewers spend reading captions. Gallaudet University's extensive study of 37 hours of non-speech information, coded in "deaf and hearing teams," is another example of how captioning research can be informed by the experiences and preferences of deaf and hard-of-hearing users and researchers (Harkins et al., 1996). More broadly, research in deaf studies can provide a context for understanding the complex relationships of deaf people to sound (Brueggemann, 1999; Edwards, 2010; Lane, 2010; Padden & Humphries, 1990).

Given the explosion of online video and the growing awareness of the importance of web accessibility, we ignore or simplify captioning at our peril. Future research
can extend the framework offered here in a number of directions. The handful of examples analyzed in this essay are intended to be a starting point for larger studies over a wider range of multimodal texts. Recently, I have begun collecting DVD caption files, extracting non-speech captions from them, and coding these captions across a large, representative corpus of movies (see http://accessiblerhetoric.com/?p=2361). Future studies will explore large collections of captions from a rhetorical perspective. How different scenes, episodes, or movies are or should be intertextually linked on the caption layer is an ongoing question of interest for me, one that grows out of my recent work, as mentioned above, with "series awareness." Comedy and parody are also promising areas of research, if simply because mainstream audiences have recognized the importance of captions for delivering parody. To explore the question of rhetorical agency, studies of captioning practices are needed (e.g., interviews with and observations of captioners). Sonic allusions and cultural literacy are promising areas of research as well (e.g., see http://accessiblerhetoric.com/?p=3116). Finally, the influence of commercial interests on the display of captions is a potential problem worth exploring (e.g., see http://accessiblerhetoric.com/?p=2695).

The promise of an increasingly captioned digital world and the growing importance of web accessibility and universal design make captioning an exciting, important, and as of yet unexplored area for rhetoricians.

Works Cited


Endnotes

1. On June 29, 2010, I used "Power Search" in iTunes to search for closed-captioned content. I enabled the checkbox to search for CC content while leaving all the other fields blank, and this search returned a list of all the movies with closed captions. Unfortunately, I was unable to determine the total number of movies available on iTunes. According to Apple (2010), the total is somewhere in the "thousands."

Return to Text

2. Seasons 1 and 2 on DVD adopt a dialogue-only (subtitle) approach to captioning. I do not know whether the same is true for other seasons of Curb Your Enthusiasm.

Return to Text
If you encounter problems with the site or have comments to offer, including any access difficulty due to incompatibility with adaptive technology, please contact the web manager, Ingrid Schneider. Disability Studies Quarterly is published by The Ohio State University Libraries in partnership with the Society for Disability Studies.