Disability

MODULE 3

On Disability and Identity

When discussing disability as it relates to a group of people, this course uses identity-first (e.g., "disabled people") and person-first ("people with disabilities") language interchangeably. It uses the term "abled" to describe people who have no disability that affects a given task. In more specific situations, we follow the National Center on Disability and Journalism style guide.

Disability

In 1978, Nora Ellen Groce was interviewing a man from Martha's Vineyard, a small island off the coast of Massachusetts, U.S.A., about his community. As they talked, the man, named Gale Huntington, pointed out an old neighbor's house, noting rather offhandedly that he was deaf. He went on to mention that the man's brother happened to be deaf, too. In all, Gale remembered that ten of his neighbors in Chilmark, a small village on the Vineyard, were deaf.

Groce, a medical anthropologist who is now a professor at University College London, inquired further. How, she wondered, was this high incidence of deafness so unremarkable to this man? She asked what the hearing people thought of their deaf neighbors, and Gale said they were "just like everyone else." Then she asked how they communicated. Did they just write everything down?

His response became the title of Groce's 1985 book: "Everyone here spoke sign language."

Hereditary deafness was an especially common trait on Martha's Vineyard, dating from its settlement by British colonists in the 17th century until the death of its last hereditary deaf person in 1952. At its height, the ratio of deaf to hearing residents in Chilmark was as high as one in three. Based on 19th century statistics, a person born on Martha's Vineyard was almost 40 times more likely to be born deaf than the national average.

As a result, deaf and hearing people who lived on the Vineyard found it normal to be in the company of one another. And so hearing people learned the island's sign language. They grew up together. They worked together. As one resident in her eighties said, "[T]here was nothing at all unusual about them."

Groce herself was taken aback by this point of view. She had learned that deafness was a medical condition, one that led to people that had it being treated differently from hearing people. But on this one island, they were equals. A decade after her book was published, this perspective on disability would be given a name.

Two Models of Disability

The way most people interact with the concept of disability is known as the "medical model." In this model, there are several thresholds indicating "normal" sensory, physical, cognitive and emotional function.[1] Should someone fall below one of these thresholds, the medical community considers them disabled.

For example, someone with "20/20 vision"[2] can see details 1.75-millimeter apart from 20 feet away. If, however, someone's vision cannot be corrected to 20/20 with glasses or surgery, they are considered to have *low vision*. If one's vision in either eye cannot be corrected to 20/200 (in other words, they can't see details from 20 feet away that someone with 20/20 vision can see from 200 feet away), they are considered in North America to be *legally blind*.

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[1] Refer back to the "Introduction to Inclusive Design" module for a brief history of how "normal" was measured and idealized in medicine and society.

[2] This is known as 6/6 vision where the metric system is in use, as 6 meters is roughly equal to 20 feet.

For a doctor or other clinician, these criteria are necessary to diagnose patients. Manuals full of statistics, thresholds and tests exist for different areas in the field of medicine. Likewise, common definitions for a given disability make it easier for a government, for example, to offer services to or make policies ostensibly to benefit people based on their perceived need.

But most of us are not doctors or policymakers. To laypeople, the medical model is perceived a measure of an individual against an abled person, and to be disabled is often interpreted as being less valuable than abled people. People with disabilities are commonly stigmatized, and frequently face barriers to equal participation in physical and virtual spaces. Disabled people are asked to prove themselves and their abilities to doctors, government and school officials, but also to shopkeepers, restaurant workers, and bus drivers.

The result of a medical approach to disability is to attempt to adapt the minds and bodies of each disabled person to the world as it is. In the world of design, this has resulted in abled designers building what Liz Jackson refers to as "disability dongles": gadgets intended for a specific disabled audience, frequently without seeking their participation in the process. Designers create bulky gloves that deaf people can wear to interpret their signing to speech or text. Designers build stair-climbing wheelchairs which are too unwieldy, unstable, uncomfortable and/or expensive to be usable. The message underlying these interventions is clear: you have a problem; let us help you.

The deaf people of Martha's Vineyard had a difference in their hearing function, that is true. But in the society in which they lived, their physiological condition presented no barrier to their ability to integrate. In a manner of speaking, their deafness was not an impediment to their equal participation.

This is the spirit behind a new way to understand disability.

The Social Model Of Disability

In 1997, the government of South Africa released a white paper to detail its intention to change the country's approach to disability. This paper distilled the difference between the medical and social models this way:

> The social model of disability implies a paradigm shift in how we construct disability.

> Thus:

- It is the stairs leading into a building that disable the wheelchair user rather than the wheelchair.
- It is defects in the design of everyday equipment that cause difficulties, not the abilities of people using it.
- It is society's lack of skill in using and accepting alternative ways to communicate that excludes people with communication disabilities.

- It is the inability of the ordinary schools to deal with diversity in the classroom that forces children with disabilities into special schools.

The social model therefore emphasizes two things: the shortcomings of society in respect of disability, and the abilities and capabilities of people with disabilities themselves.

Examine the word "disabled." The word itself is passive, implying something else has done the disabling. But what? The medical model states that a disability is connected to a clinical diagnosis, made up of symptoms that can be observed. A disability begins and ends with the patient.

The social model, however, has a different answer: a person is disabled by their environment. That places responsibility on society to build environments—from buildings to transportation to education to work to technology—that anticipate the needs of their users, so that everyone is able to participate equitably.

This work recognizes people with disabilities not only as underappreciated customers, but as stakeholders. User interviews and focus groups are good. Jobs and business partnerships are better. A process of inclusive design means that not only do we appreciate user diversity—not only around disability, but gender, race, economic status, age, and all the other ways we differ—but that we build this future together and share in the fruits of our labor.

Other Models Of Disability

As statistician George E. P. Box once said, "All models are wrong, but some are useful."[3] The social model is not the only alternative. Other frames for disability exist. For instance, the "identity model" shares many perspectives of the social model, but it emphasizes the common experiences of disabled people as a source of pride (and frustration), rather than focusing mainly on how they are excluded.[4]

These models of disability have been constructed as ways to discuss and counter the unspoken assumptions and stereotypes around disability and disabled people. Discussions about the meaning of disability may continue forever, but they are now, rightly, driven by people with disabilities and their own lived experiences.

A NOTE ABOUT POLICY

You may notice that laws and policies relating to disability such as the Americans with Disabilities Act, the UK Equality Act, Section 508 of the Rehabilitation Act, the W3C/WAI Web Content Accessibility Guidelines (WCAG), etc. are not covered in this course. This is by design. The

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[3] https://books.google.co.uk/books?id=dabiBQAAQBAJ&pg=PA201&lpg=PA201

[4] Brewer, E., Brueggemann, B., Hetrick, N. & Yergeau, M., 2012, 'Introduction, background, and history', in B. Brueggemann (ed.), Arts and humanities, pp. 1–62, Sage, Thousand Oaks, CA.

goal of design is not to meet specifications or policies, but to meet the needs of the user.

WCAG contains requirements and techniques to address many problems that disabled users experience. Policies based on these guidelines set a minimum acceptable level of service to people with disabilities. Standards, policies and laws are necessary to verify that everyone is working toward a common goal. But without some understanding about the users and situations they are intended for, it's entirely possible to meet the technical standard without making a usable, accessible or inclusive product.

Inclusive design does not seek to do the technical minimum, but to improve products and services for everyone by listening to and partnering with marginalized users. While our final products obviously must meet applicable laws and standards, our primary focus is to aim higher, and to make the best product we can for the greatest number of people. Inclusive design is work that doesn't end when you pass a certain threshold. It is a mindset that applies to every design decision.

Types of Disability

Disabilities can fall into a number of categories. It is important to know that disabilities can last an entire lifetime, and their effects can change over the years, over a month, and even minute to minute. Some disabilities, such as dyslexia and ADHD, tend to occur together.

Many disabilities are *invisible* to observers. They may be cognitive, intellectual, or psychological in nature. They may result in severe pain some or all of the time. They may only affect someone's abilities periodically or change in severity over time. People also experience symptoms that may point to a medical diagnosis, but not identify them as a disability. As you work with people with disabilities, it's critical to know that all of these variables are in effect, and not to associate disability only with what is visible—whether that's a wheelchair, a white cane, or a hearing aid.

The U.S. Centers for Disease Control and Prevention (CDC) report that 25.7% of Americans over 18 report having a disability.[5] This figure increases with age, from 16.6% among 18- to 44-year-olds, to 28.6% among 45- to 64-year-olds, to 41.7% among those age 65 and up.

On average, people whose income falls below the federal poverty line are between 2 and 3 times as likely to identify as disabled. This, combined with a significantly higher unemployment rate among disabled people, reflects a difficult truth: when products are designed without a range of abilities in mind, large numbers of people will struggle to use them. When people can't use those tools, or are *perceived* not to be able to use them, they're considered unqualified for jobs that require them. Breaking this cycle requires not only that companies design in collaboration with users with disabilities, but that they show how their products enable equitable participation in the workplace.

Sensory

A sensory disability relates to the ability to see, hear or feel.[6]

Sensory disabilities occur in degrees. For example, referring back to

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[5] Okoro CA, Hollis ND, Cyrus AC, Griffin-Blake S. Prevalence of Disabilities and Health Care Access by Disability Status and Type Among Adults — United States, 2016. MMWR Morb Mortal Wkly Rep 2018;67:882–887. DOI: http://dx.doi.org/10.15585/mmwr.mm6732a3

[6] The ability to smell or taste content is obviously sensory, but is not further explored here.

the medical model of vision, someone is said to have low vision if they cannot see 20/20 corrected, while one is legally blind if they cannot see 20/200 corrected.

It's very common for people to jump immediately to binary cases when thinking about sensory disabilities: totally blind, for example, or totally deaf. The reality is far more complex. Most people who are legally blind have some residual vision, ranging from the ability to see light to having relatively good vision in a narrowed visual field.

People are likewise inclined to believe that someone has been blind or deaf from birth. This is actually very rare: only 1% of Americans who are totally blind were born without vision. In fact, when (and sometimes how) someone becomes disabled can often determine what features they want or need. For example, someone who is born totally blind, and taught in schools for blind students, is more likely to learn braille and be more comfortable using it than someone who loses their vision later in life and might need voice interaction. Likewise, *late-deafened* people who are accustomed to spoken language are more likely to prefer captions for video content, while someone who became deaf before acquiring a spoken language would probably be more comfortable with sign language.

Senses can also have anomalies. For example, *colorblindness* refers to an absolute or relative impairment to one's ability to see the colors of the

spectrum. Here, too, there are degrees: someone with *deuteranopia* cannot see a difference between red and green, where someone with *deuteranomaly* may only have a reduced ability to discern the two. Someone may lose all sensation in one extremity, they may feel "pins and needles," or they may not be able to feel cold or heat.

Physical

A physical disability is one that affects a person's mobility, dexterity, or stamina.

Motor disabilities affect one's ability to move. A *gross* motor disability affects someone's ability to control large muscle groups, like those that control the arms or legs, while a *fine* motor disability affects the ability to control smaller muscle groups, like the ones found in the hand. Physical disabilities also include paralysis, amputation and deformity.

When we talk about physical disabilities, we need to think about everything from a tremor that can affect the ability to use a mouse or stylus to someone who may have no muscular control at all (e.g., locked-in syndrome). Designing for physical disability includes, among other things, reducing the amount of motion and effort necessary to complete a task; enabling multiple ways to complete a task (e.g., via keyboard or voice interaction rather than by mouse or stylus alone); and interfacing with assistive technology such as onscreen keyboards and single switch devices.

Intellectual, Developmental, Neurological and Psychological

Disabilities that affect the brain and nervous system are too many to name. We classify these in the following ways:

- Intellectual: relating to cognitive capacity and plasticity (i.e., the ability to adapt)
- Developmental: relating to the ability to acquire and contextualize knowledge over a lifetime
- Neurological: relating to the nervous system
- Psychological: relating to emotional wellbeing

These disabilities can include sensory and/or physical symptoms. For example, a person with multiple sclerosis may at different times experience optic neuritis, which can temporarily cause loss of vision; altered sensations such as numbness or "pins and needles," either locally or all over the body; and neurological and cognitive symptoms including dizziness, confusion and fatigue.

Basic usability advice—simplicity, consistency, error prevention and correction, and robust user help—is a great start when it comes to addressing intellectual and developmental disabilities.

Disability and Technology

The World Health Organization describes disability as "a complex phenomenon, reflecting the interaction between features of a person's body and features of the society in which (they live)." Much of the technical ecosystem around disability, what we would call accessibility support, is often hidden to users, but knowing the true variety of ways people use software beyond perfect control of a mouse, keyboard and stylus is critical to creating more equitable user experiences.

Self-adaptation

Often, people with disabilities struggle with inaccessible products. Without adequate support within a product, users are forced to find a way to complete a task using their own resources.

A user with low vision may invest in a larger monitor, which may help alleviate some problems reading small text or seeing the cursor, but may force them to move their head frequently and hold their eyes uncomfortably close to the display, causing both eye strain and body fatigue. Another user with ADHD may have to cover a flashing ad

with their hand in order to read the rest of a web page. Someone with muscular dystrophy may use props like books or pillows under their arm to control a mouse, or under their head to look at the screen more comfortably.

But the ability of someone to contort or strain themselves in order to use your product does not make it accessible or inclusive. People adapt themselves to a product because it didn't adapt to them, and because the added inconvenience they endure to complete a task is better than not being able to do it at all.[7]

Much of the inaccessibility in the products we use stems from a lack of understanding of how people with disabilities use technology. Some are unaware of the technologies that enable more users to interact with hardware and software. An inclusive view of product design requires us to understand an entire category of products made to level the playing field for disabled users, and to provide an equitable user experience for someone who uses one or more of these products to that of the idealized, abled user.

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[7] People adapt to products for reasons other than disability: for example, people who are unable to fix a broken home button on their iPhone often use the Assistive Touch feature in iOS to be able to keep using it.

Assistive Technology

"Assistive technology" refers to software and/or hardware designed specifically for the benefit of disabled users.

A number of the features you use every day were either invented for or found an early application in AT. For example, Ray Kurzweil's pioneering work in optical character recognition (OCR) and speech synthesis led to the release of the Kurzweil Reading Machine, which scanned printed text, like letters received in the mail, and read it aloud to print-disabled users.[8] This was in 1976. Kurzweil's work with OCR moved into the domain of neural networks in the 1980s, and the field of computer vision was born, leading to breakthroughs from data processing to medical research to library science.[9] Every book that's ever been digitized is thanks to the field of assistive technology.

ATs were often expensive tools with relatively small markets, but their early users would embrace new and untested technologies because they allowed them to do things they couldn't do otherwise. Research in OCR and other emerging fields such as speech recognition, was also geared toward users with disabilities.

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[8] A term defined by George Kerscher as "A person who cannot effectively read print because of a visual, physical, perceptual, developmental, cognitive, or learning disability." https://web.archive.org/web/20130320053044/http://www.readingrights.org/definition-print-disabled

[9] It's worth remembering that not all applications of computer vision are equally praiseworthy. Refer back to the Greater Inclusion module's section on race.

This work also benefited software vendors and researchers. A customer base that needed a given product in order to work led engineers to build up from the most essential features to something more capable of finding a mass-market use. The fruits of over 40 years of research into speech recognition and voice synthesis is probably in your pocket, if not on your counter, in smart assistants like Siri, Google Assistant, Alexa and Cortana.

Here's another example: the noisy, robotic synthesized voices of the early 1980s were not palatable to the mass market. But they were good enough for IBM researcher Dr. Jesse Wright, who was blind, and Dr. Jim Thatcher, who was sighted, to share their work with one another. Out of this collaboration came a product called IBM Screen Reader, which created an entire category of tools enabling blind users to access computers.

Screen Readers And The Importance Of Structure

Today, every modern operating system has a built-in screen reader, and many, such as NVAccess's open-source NVDA and Vispero's JAWS for Windows, are also available. Screen readers perform a complicated task: representing all of the visual information in a user experience non-visually, either through speech or a refreshable braille display.

The way they manage this task is through application programming interfaces (APIs) in each operating system. Accessibility APIs expose the most important information about every object on the screen in a

structured way, allowing users to find objects and understand:

- Its **role**, or what kind of object it is: a text field, a menu, a video player, etc. Common roles are well-known to users because we encounter them over and over, and usually have learned most of what we can do with them.
- Its **state**, or what it indicates. For example, a checkbox can be checked or unchecked (unless it's a tri-state checkbox, which has a third option). One or more options in a combo box can be selected. Some components can have several states at once, and interactive components can be disabled.
- Its **label**. Often labels are visually close to their fields, but they may not have a visible label, which means they need to be set programmatically. Sometimes, like with tables, an object may be defined by more than one label (like a row labeled "Paraguay" and a column labeled "population").[10]

This is a lot to process. And remember, users aren't relying on a persistent display that they can refer back to, but a stream of words in their ears or on their fingertips. The non-visual user experience is very different, and requires a lot of shortcuts, wayfinding and repetition. The structure of your apps and content is critical to enabling non-visual access.

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[10] Objects can also have descriptions associated, which can provide users more help.

Low-vision users often rely on AT as well. **Screen magnifiers** enable users to zoom in on a small portion of the screen at a high degree of magnification. This is often done in concert with a screen reader, or with high-contrast modes, so that users with low vision can discern different components and have content read out instead of scrolling both horizontally and vertically.

Switch Devices

Screen readers and magnifiers are only two of several different types of AT, both on desktop and mobile devices.

Now ubiquitous on mobile devices, **on-screen keyboards** were originally designed to allow keyboard input via mouse or other forms of input. On-screen keyboards are often used in conjunction with **switch devices**, a diverse category of input devices that send a single signal when activated. Switches can be simple buttons. Switches can be attached to any part of the body that someone can reliably control, from the headrest on a person's wheelchair, to a cheekbone. Some switches are connected to cameras that detect a blink of an eye, or a head movement, and relay that to the operating system. Some users prefer to use more than one switch; for example, one to select and one to cancel.

Switches allow typing on on-screen keyboards via "scanning." The keyboard will highlight one row at a time, for a preset interval. When the key the user wants to type is highlighted, they will press the switch, and the keyboard will scan left to right until the key is selected. The

user presses the switch again, and the letter is typed in. Obviously, this can be extremely tedious, so on-screen keyboards have features, such as hooks, into the operating system that enable navigation. You may use one feature invented for the benefit of switch users every day: text prediction.

Media Equivalents

How would you describe the *Mona Lisa* to someone over the phone? If it was a tourist, you might say it's a painting of a dark-haired woman that hangs in the Louvre. If you were talking to an art professor, on the other hand, you'd need a lot more detail: the painting style, the colors, the background, the mysterious smile.

This is the idea behind a *text equivalent*. You should never assume that someone can see, or understand, what you are trying to show them. It's important to be able to explain every image and icon you use in your interfaces concisely, but with enough detail to be useful in its context. These equivalents are often invisible in a product, but they are nonetheless an integral part of a given design.

Another form of media equivalents is *captioning* or *subtitling*.[11] The French Chef, Julia Child's cooking show, was the first to contain

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[11] In North America, captions refer to media equivalents for auditory content, and subtitles as translated material.

captions, in 1972. These first captions were "burned in" to the broadcast, something we now know as *open captions*. Captions were later encoded in the television signal for TVs and set-top boxes to display as an option, also known as *closed captioning*. Subtitles, used commonly for language translation, contain only spoken text[12], while captions also relay important auditory information, such as "whispers," "thunder," or "mouthing words."

Ofcom, the UK broadcasting authority, noted in 2006 that 4 out of 5 users of captions do not have hearing loss.[13] Captioning is not just an accessibility feature for deaf and hard of hearing viewers, it's an additional way to consume spoken and auditory content. It's also possible for users to choose captions and subtitles from the same interface, enabling even larger audiences to enjoy the same content. Transcripts and alternate text also help search engines index content that may otherwise be passed over.

Blind or low-vision users may miss lots of visual information onscreen: how one character looks at another, for example, or the details of where a scene is set. **Audio descriptions** use an additional track to describe those details, often using only the gaps between lines of dialogue. Described video isn't always necessary: if you're teaching a class, you may be able to describe the details of your experiment well enough

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[12] Subtitles can also translate any printed words that appear onscreen.

[13] https://www.ofcom.org.uk/consultations-and-statements/category-1/accessservs

that people who can't see it can follow along. However, when that's not possible, videos should have critical details described.

Operating System Features

Operating systems provide a critical interface between apps and technologies designed for disability access, commonly known as accessibility application programming interfaces (APIs). These interfaces communicate important semantic information about each component, including its role, state, label, description, the object's location on the screen, whether it controls another object (or is controlled by one), any keyboard shortcuts, and various other properties.

The API also defines relationships between all of these objects and creates a hierarchy for every application currently running. This hierarchy, or tree, determines the order that all assistive technology uses to navigate from object to object. You may know this as tab order because keyboard users can move back and forth between objects by pressing Tab (or Shift+Tab), but this order also applies to navigating with gestures on mobile devices, or with switch devices.

While tab order applies to interactive objects—effectively, anything a user can change—a *reading order* also includes static content like text, headings and tables. Many assistive technologies allow users to read the contents of an app from top to bottom, with an interactive mode that

skips static parts, making it faster to move around and make changes. ATs also offer shortcuts to simplify moving through lists, headings, links, form fields, and more—*if* you build them with the right semantics.

Why To Design With Semantics and Structure

This is a picture of a building.

At this point, it's not an actual building. It's a model that shows a potential future building. Right now, this is artwork. A lot of work needs to be done to turn this potential future into a reality of concrete, metal and glass.

This is the difference between art and architecture. Artists can produce all kinds of futures and render them sited in unrealistic locations. Science fiction is full of cities in the clouds, standing on impossibly narrow stilts, or comfortably, if impractically, underwater.

It's the role of an architect to determine what's possible to build where. Architects think about the details: can a given parcel of land hold up a given kind of building? How much of a foundation is needed? How many people will use the building, and how much space do they need? How many parking spaces are needed? How many restrooms, elevators, and meeting rooms and kitchens? How can the building remain at a comfortable temperature from season to season, whether it's sunny or cloudy? And how can people of all sizes, shapes, ages and abilities enter, exit and move around without barriers, both under typical conditions and in an emergency?

Before breaking ground on new construction, most if not all of these questions need to be answered. This is why we have blueprints: they show builders the technical steps necessary to turn the desired future into reality.

Software requires architecture. Just as we would never only hand a picture of the home we want to a contractor for them to build, we must do more than hand over artboards to software engineers to turn into applications. If designers cannot communicate the structures they're building, engineering teams are forced to guess what those structures

are, and once those are written in code, changing them is slow, difficult and costly.

Design systems are ideal for creating accessibility standards. Good accessibility documentation in a design system leads to more accessible outcomes in every product and framework built on that system. Each component in a design system should have information about:

- Keyboard events and shortcuts
- Role and state information for every supported accessibility API
- Information about how colors (e.g., text, background and border colors) change in high-contrast modes
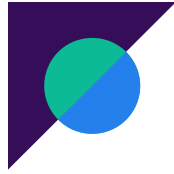
Exercise 3-5

Gather in groups of 4-8.

Teams will each receive an artboard from an existing product (use your own if possible; if not, we have provided some in the workshop materials). Using the Label, Role and Group tiles, they will discuss how these applications are (or ought to be) structured.

In the final exercise, teams will use the design tool of their choice to express accessibility-related information in a design deliverable.