Thank you for attending today’s training. By doing so you are strengthening the ability of your community-based and patient-directed health center to deliver comprehensive, culturally competent, high-quality primary health care services.

**Presented by:**
Julie Reiskin, LCSW and Andrew C. Montoya, JD, Colorado Cross-Disability Coalition (CCDC)

**Live Broadcast Date/Time:**
Tuesday, October 13, 2020
12:00–1:15PM Mountain Time / 1:00–2:15PM Central Time

**Target Audience:**
The presentations in the series are intended for health center and PCA staff from various positions including clinical and non-clinical. Please see the registration information sent out prior to each training for more information about learning objectives and other details.

**Event Overview:**
Working with specific populations requires specific strategies. This webinar will offer an introduction to serving people with disabilities with a health equity approach and how that can impact health center patients as a whole.

**Learning Objectives:**
Though this session, participants will:
- Understand the definition of disability and disability culture and how individuals can begin to become competent in the language around disability.
- Understand some of the multiple and shifting ways in which disability intersects with other sources of social disadvantage.
- Understand the reason for disability-related health disparities and steps they can take to mitigate these.

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CCHN/CHAMPS ARCHIVES
This event will be archived online. This online version will be posted within two weeks of the live event and will be available for at least one year from the live presentation date.

For information about all CCHN archives, please visit: www.CCHN.org/webinar-archive.

For information about all CHAMPS archives, please visit: www.CHAMPSonline.org/events-trainings/distance-learning.

DESCRIPTION OF CCHN
The Colorado Community Health Network (CCHN) represents the 20 Colorado Community Health Centers that together are the backbone of the primary health care safety-net in Colorado. For more information about CCHN, please visit www.CCHN.org.

DESCRIPTION OF CHAMPS
Community Health Association of Mountain/Plains States (CHAMPS) is a non-profit organization dedicated to supporting all Region VIII (CO, MT, ND, SD, UT, and WY) federally funded Community, Migrant, and Homeless Health Centers they can better serve our patients and communities. Currently, CHAMPS programs and services focus on education and training, collaboration and networking, workforce development, and the collection and dissemination of regional data. For more information about CHAMPS, and the benefits of CHAMPS Organizational Membership, please visit www.CHAMPSonline.org.
SPEAKER BIOGRAPHIES

Julie Reiskin, LCSW, is the Executive Director of the Colorado Cross-Disability Coalition (CCDC). CCDC advocates for social justice for people with all types of disabilities.

CCDC is a leading disability rights organization whose unique model of blending legal and non-attorney advocacy has achieved results for thousands of Coloradans with disabilities. With a motto of “Nothing About Us Without Us–Ever”, CCDC has led the way in citizen or “client” engagement and CCDC trained advocates permeate the Colorado public policy arena. CCDC and Reiskin assist other organizations with assuring real and meaningful participation by “clients” at all levels. Ms. Reiskin offers expertise on nonprofit accountability and best practices, publicly funded long-term community-based services, disability rights law, public benefits and the intersectionality of systemic and individual advocacy. Ms. Reiskin has proposed and helped to implement many solutions to create a sustainable and client friendly Medicaid program – such as the consumer direction as a delivery model, acted as a respected advocate for individuals, and has trained many others in health advocacy and health policy. Prior to becoming the Executive Director for CCDC in 1996, Ms. Reiskin served as the organization’s policy analyst.

In 2010, Ms. Reiskin was appointed by President Obama to serve on the Board of Directors of the Legal Services Corporation as the client representative. In 2018, she was elected to serve on the Board of the ACLU of Colorado and was also appointed as a member of the Board of Trustees for the Denver Foundation.

Ms. Reiskin is an adjunct faculty member at the University of Denver at the Graduate School of Social Work teaching both policy advocacy and program development. Ms. Reiskin provides consulting with organizations seeking to improve, expand, or enhance their ability to effectively practice real and meaningful client/constituent engagement at all levels of the organization. She also helps organizations develop disability cultural competence. She has her MSW and BS from the University of Connecticut.

Andrew C. Montoya, Esq. began his work with CCDC in 2005 as a Legal Program Assistant. After a hiatus he took to attend law school at the Florida Coastal School of Law, he returned in 2012 to serve as CCDC’s Legal Program Attorney. Andrew works on CCDC’s civil rights cases and has developed many presentations regarding the laws CCDC enforces.
CCHN/CHAMPS
2020 Health Equity Learning Series

Applying the Health Equity Lens: Serving People with Disabilities

Tuesday, October 13, 2020
12:00-1:15PM MT/1:00-2:15PM CT

COMMUNITY HEALTH ASSOCIATION OF MOUNTAIN/PLAINS STATES (CHAMPS)

www.CHAMPSonline.org
HOW MANY PEOPLE ARE WATCHING THE EVENT AT YOUR COMPUTER, INCLUDING YOURSELF?

Submit your answers using the Q&A Box.

PLEASE INTRODUCE YOURSELF:
NAME, ORGANIZATION, STATE

Submit your answers using the Chat.
Accessing annotation tools if you are viewing a shared screen

- While viewing a shared screen, click View Options then Annotate at the top.

Annotation tools

- You will see these annotation tools:

- For our purposes, the important ones are **Mouse**, **Text**, and **Stamp**.
  - **Mouse**: Deactivate annotation tools and switch to your mouse pointer. This button is blue if annotation tools are deactivated.
  - **Text**: Insert text.
  - **Stamp**: Insert predefined icons like a check mark or star.

**ANNOTATE PRACTICE**

Using the **Text** function, share a one-word description of your day so far:

Using the **Stamp** function, indicate which of the previous sessions in this series you have attended:

- Event 1 – Health Equity is Social Justice: Health Centers in the Context of Racial and Social Justice
- Event 2 – Health Equity in the Context of COVID-19
- Organizational Commitment and Strategies for Health Equity Communication
POLL QUESTION

On a scale of 1 to 5, (1 being not at all and 5 being very), how comfortable are you with discussions of disability?

LEARNING OBJECTIVES

• Participants will understand the definition of disability and disability culture and how individuals can begin to become competent in the language around disability.

• Participants will understand some of the multiple and shifting ways in which disability intersects with other sources of social disadvantage.

• Participants will understand the reason for disability-related health disparities and steps they can take to mitigate these.
FQHCs and Disability

Health Equity and Disability:
Integrating Disability from the Top Down

Colorado Cross-Disability Coalition

Julie Reiskin
Executive Director

Andrew C. Montoya
Attorney
Language of Disability

- Legal Definition of Disability
  - Substantial Limitation on Major Life Activity
- Social Model of Disability
  - Focus on societal barriers, not the person

The Language of Disability

- Person-first language
  - “Person with a disability”
- Identity-first language
  - “Deaf person”
Language Matters!

- Word Choice and First Impressions
  - Be sensitive to systemic devaluation
  - Do not take it personally if you are not immediately trusted
  - Avoid negative language
    - “Victim of” or “suffering from”
    - “Frequent flyer,” the R word
    - “Psycho”

“Fred always makes a poor first impression — he says it saves a lot of time.”

Interact!
What Have You Heard?

What are some of the most creative words you’ve heard to describe someone with a disability?
In 2017 45.7% of Coloradans with ANY disability were employed.

- People with disabilities earn $6,500 less than people without disabilities.
- In nonprofit organizations people with disabilities earn about 33% less than non-disabled peers doing the same work.
- Household income goes down by about $25,000 when there is a disability in the household.
- Before COVID the poverty rate of ALL disabled people was 22.1% in Colorado and 8.3% for people without disabilities.
Poverty

- 24% of white people with disabilities and 9% of people without disabilities lived in poverty in 2015
- 37% of Black people with disabilities and 20% without disabilities lived in poverty in 2015
- 29% of Latino people with disabilities and 18% of people without disabilities lived in poverty in 2015
- 19% of Asians with disabilities and 12% without disabilities lived in poverty in 2015
- Even if adjusting for educational level, African Americans with disabilities are more likely to be in poverty than other disability groups

Education

- In 2015 15% of whites have a Bachelor’s or beyond while only 9% Black or Latinos with disabilities have this level of education. 35% of whites without disabilities have this level of education, 20% of Blacks and 15% of Latinos without disabilities have a Bachelors or beyond.
- Black students with disabilities loose 77 days of instruction more a year compared to white students due to racist discipline policies. This leads to the school to prison pipeline and inability to advance in education which affects employment and skill development.
Attitudinal Barriers

- Paternalism
  - Jerry’s Kids
  - “Inspirational”
- Fear
  - Rather die
  - Angry PWD
- Outright Discrimination
  - Ignoring law
  - Angry at PWDs
- Housing
  - Limited accessible housing
  - Affordability, gentrification and NIMBYism

Transportation

Neighborhood Access

“Us” versus “Them”

We...
- Have intense passion and expertise on a specific topic
- Are strong willed and independent
- Are eccentric or unique
- Are a good lobbyist or negotiator

They...
- Are perseverate and obsess
- Are non-complaint and uncooperative
- Have poor social skills
- Are triangulating or manipulating
Comforting Narrative

- People with Disabilities were institutionalized and treated awfully
- “We” gave “them” some basic rights in the 1970s
- Rainbows erupted in 1990 with the ADA and Olmstead, and now everything’s great!

Kernels of Truth: Historical Treatment of People with Disabilities

- Institutionalization
- Forced sterilization
- Euthanasia
- Denial of transplants
- Sheltered workshops
- Holocaust
- Denial of citizenship
- Discrimination
- “Duty” to die

“Nothing About Us Without Us.”
Interact!
What do you think?

What are some things we know about disability that may have some truth?

Ableism

WHAT ABLEISM IS
A set of taught practices and subconscious or conscious behaviors against people with disabilities and illnesses which assumes that able is the norm, and people who have disabilities must either strive to fit that norm or keep their distance from people who are able. Ableism often sees disability as an error of life, a wrong way to live, and therefore often negates any life experiences of the disabled.

WHAT PEOPLE THINK ABLEISM IS
My feelings are hurt because you used the r-word.
Ableism in Practice

• **Ableism** is oppression or discrimination based on physical, intellectual, cognitive, psychiatric, sensory or other ability.

• All people with disabilities have experienced ableism whether they are aware of it or not.

• It has commonalities with racism, sexism and homophobia.

• Everyone has ableist ideas, thoughts or feelings.

---

**Interact!**

**Examples of Ableism**

• What examples of ableism can you come up with?

  • What do we say when someone gives birth?

  • What do we call people who may be in positions of leadership, who are mean, and abuse their power?

  • What are the ableist assumptions you have?

  • What is one thing you can do to combat ableism?
Equity, not Equality

Equality

Equity

Interact!
Clinical Equity

What is an example of an equitable policy in a clinic?
As an Ally:

**Ally**
- Nothing about us without us
- Support us in leading
- Understand and accept our cultural experience—even those that may not identify still feel it on a get level

**Not an Ally**
- Invite us after the fact to “tell our story”
- Invite us without thinking about accommodations or accessibility (programmatic, physical and financial)
- Tell us not to worry –that no one “intends” for X to happen.

Disclaimer and Copyright Information

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QUESTIONs?

Type any questions into the chat or Q&A box at the bottom of the screen.

POLL QUESTION

On a scale of 1 to 5, (1 being not at all and 5 being very), how comfortable are you with discussions of disability?
THANK YOU!

Please fill out the event evaluation here:
www.surveymonkey.com/r/HE2020-Event4

THANK YOU FOR ATTENDING THE SERIES!

Recordings of Past Events:
On the Online Archived CHAMPS Distance Learning Events:
champsonline.org/events-trainings/distance-learning/online-archived-champs-distance-learning-events#HE2020

CCHN Webinar Archive:
cchn.org/webinar-archive
Checking the Accessibility of a PDF

Checklist of accessibility

For text:

The 2 easiest ways to test if a PDF document is accessible, if you can highlight, copy and paste somewhere else its text, you have accessible text. And, if when highlighting the text, you can highlight every section in the order it is supposed to be read, then the reading order is set correctly.
Checking the Accessibility of a PDF

For images/graphics/pictures:
Checking the Accessibility of a PDF

When a PDF has images/graphics or pictures, the easiest of knowing if those images are accessible is to place the mouse on top of them, a yellow tag should pop-up, it should have text that describes the image/graphic or picture very clearly. If you see this, it is accessible.

Denver Health Care Activists Media Training

This will be a 2-day training held July 20-21st, 10am-6pm both days in Denver at the Washington Street Community Center.
Words simultaneously reflect and reinforce our attitudes and perceptions; words shape our world. Many disability descriptors evoke feelings and imagery that perpetuate archaic and negative stereotypical perceptions. And these perceptions create a powerful attitudinal barrier—the greatest obstacle to the success and inclusion of individuals with disabilities.

Using People First Language (PFL) is a step in the right direction. (See the PFL article.) And to speak more respectfully, many of us are consigning stigma-laden descriptors, like “high/low functioning,” “developmental age,” “wheelchair bound,” and others, to the junk heap. But one term—SPECIAL NEEDS—continues to be embraced by many. Because this term is so commonly used, we seldom consider what message it sends or what image it evokes.

SPECIAL NEEDS is a loaded descriptor that has done nothing to improve perceptions and everything to reinforce negative images. As a parent, I once used this term to describe my young son. Why not? That’s what I heard from the mouths of other parents, therapists, educators, and doctors. But I stopped using it years ago when I realized it generates pity. Tell a new acquaintance, “My child has SPECIAL NEEDS.” The response is predictable: a sad, “Ohhh...” accompanied by a sympathetic pat on the arm. Worse, some add, “I’m so sorry...” And this may occur in front of the child! What must it feel like to be the object of pity, especially when it comes from your own parent or someone who professes to care about you?

Many parents love this term and add, “But don’t all children have SPECIAL NEEDS?” or “Aren’t all children SPECIAL?” I might agree if the term had positive connotations and if we really meant SPECIAL. But it doesn’t and we don’t. Moreover, adults with developmental disabilities (our greatest teachers) vehemently disliked this term as children, and they detest it as adults. Shouldn’t we learn from them and care how they feel?

Once we use the SPECIAL NEEDS descriptor, we stop thinking about an individual child, and ingrained assumptions take over. “Oh, yes, we know about SPECIAL NEEDS kids...” And then, we effectively rob a child of opportunities and put limits on her potential.

First, we’ve stripped her of the opportunity to define herself; what child can defend herself against the words and actions of her parents, teachers, and others? Second, we continue our robber baron ways by stealing opportunities for the child to lead an ordinary life. When applied to children and adults with disabilities, SPECIAL NEEDS can automatically lead to segregation! If we say a child has SPECIAL NEEDS then by extension, she must need “special (segregated) ed,” “special” activities, and “special” environments. If she has SPECIAL NEEDS, she’s not “regular,” and is not entitled to participate in “regular” (ordinary) activities. SPECIAL has become a metaphor for “segregated.”

A mother may believe her child can and should be included in school and the community. But if she uses SPECIAL NEEDS when describing her child, others may believe inclusion isn’t an option—only a SPECIAL environment will do. The SPECIAL NEEDS descriptor puts a child in a box—a box of our making, a box she never asked to be put into, and a box that limits hopes, dreams, opportunities, and more. Many educators admit they have low expectations for children saddled with this descriptor.

If our society believed children with SPECIAL NEEDS were really SPECIAL, wouldn’t every parent dream of having a child with SPECIAL NEEDS? But the opposite is true: our society so devalues children with disabilities that identifying and aborting them is becoming common practice. And within the adoption world, children with SPECIAL NEEDS are the last to be adopted! So, again, just how SPECIAL are children with SPECIAL NEEDS? Isn’t the term actually a harmful euphemism that means just the opposite?

What do we really mean by SPECIAL NEEDS anyway? Like other disability descriptors, it may initially apply to one aspect of a person’s life (a medical condition), but it quickly defines every aspect of a person like a dark shroud. Some people use the longer descriptor:
**2 - The Case Against “Special Needs”**

**Children with Special Health Care Needs.** What makes one type of health care needs more *special* than another? Where is the dividing line between “regular” and *special health care needs*? Do children with disabilities go to *special needs* doctors or hospitals? No! At the office of my son’s pediatric orthopedic physician, we saw children with permanent physical disabilities and others with broken legs or arms. Does the child with a developmental disability have *special needs*, but the child with a broken leg has “regular needs”?

A child may need a wheelchair or other supports or assistive technology. And these may be different from the needs of the majority of children. But what makes them *special*? They’re not *special* to the child—they’re perfectly ordinary for him.

In one school district’s report on its “inclusive practices,” the terms *special education students* or *special needs students* littered every page. The very use of these terms contradicts the thesis of the report: that students with disabilities were “included.” Exclusion and marginalization always begin with the language we use and the mental images evoked by our words. In schools that are truly inclusive, there are no *special needs students*, but “students who receive special ed services”—they’re students, first!

Who benefits from the *special needs* descriptor? Not the children or adults we assign to that category! They’ve been set apart and marginalized. Supporters of this descriptor can argue that using the term is necessary when advocating for laws, programs, or services, or during fundraising. It’s used by many organizations, it’s on hundreds of websites, and it’s one of the best terms for pulling at heartstrings! Want to raise money for your organization? Promote it as a fundraiser for *special needs kids*, consider the imagery (“those poor, pitiful children”), and watch the dollars roll in—but at what price to the children who have been saddled with this pity-laden term?

Have we ever wondered how this descriptor might impact other children in the family? A brother might think, “If Mom says Katie is *special*, what does that make me? Does Mom love her more?” The descriptor can breed resentment and anger. But as the brother grows, he’ll probably realize he doesn’t *really* want to be *special*, as he learns that his *special* sister is marginalized, excluded, and pitied.

Far from being a compliment or an accurate term, *special needs* is a pejorative descriptor that creates a powerful attitudinal barrier to the inclusion of individuals who are so described. When using People First Language, we put the person first and also replace antiquated descriptors with words that are more respectful and accurate. But there is no singular replacement term for *special needs*.

Instead, we can use a variety of different descriptors, depending on the situation. In schools—and when it’s appropriate—we can say “students who receive special ed services.” And we can use the generic, “children with disabilities” or the specific, “A child with (the name of the medical diagnosis),” when appropriate. But the use of any descriptor should be restricted to specific times and places (at an IEP meeting, the doctor’s office, etc.). Disability descriptors are medical diagnoses, and just as most of us don’t share our diagnoses with every Tom, Dick, and Harry, we shouldn’t be sharing this personal information about children and adults with disabilities unless it’s absolutely necessary, under certain circumstances, and with the permission of the person!

If we’re serious about removing attitudinal barriers and creating an inclusive society, do we dare set one group apart with the *special needs* descriptor? Shall we continue to perpetuate pity and marginalize people by using this term? Isn’t it time to stop calling people names that they never chose to use about themselves?

When we change our language, we change perceptions and attitudes. And when the Great Wall of attitudinal barriers falls, other barriers will also come tumbling down. Are the words you’re using promoting a positive or negative image? Are they propping up the Great Wall of harmful perceptions or helping to tear it down?
Accessibility, Usability, and Inclusion

Accessibility, usability, and inclusion are closely related aspects in creating a web that works for everyone. Their goals, approaches, and guidelines overlap significantly. It is most effective to address them together when designing and developing websites and applications.

There are a few situations when it’s important to focus specifically on one aspect. For example, when developing standards and policies. Researching the accessibility needs of people with disabilities helps with developing those.

This article briefly:

- explains the distinctions and overlaps between accessibility, usability, and inclusive design,
- encourages increased coordination across research and practice in these disciplines, and,
- points out the importance of maintaining the focus of accessibility on people with disabilities.

Distinctions and Overlaps

**Accessibility**: addresses discriminatory aspects related to equivalent user experience for people with disabilities. Web accessibility means that people with disabilities can equally perceive, understand, navigate, and interact with websites and tools. It also means that they can contribute equally without barriers. For more information, see the [Accessibility introduction](https://www.w3.org/WAI/fundamentals/accessibility-intro/).

**Usability**: is about designing products to be effective, efficient, and satisfying. Usability includes *user experience design*. This may include general aspects that impact everyone and do not disproportionately impact people with disabilities. Usability practice and research often does not sufficiently address the needs of people with disabilities.
**Inclusion**: is about diversity, and ensuring involvement of everyone to the greatest extent possible. In some regions this is also referred to as *universal design* and *design for all*. It addresses a broad range of issues including:

- accessibility for people with disabilities;
- access to and quality of hardware, software, and Internet connectivity;
- computer literacy and skills;
- economic situation;
- education;
- geographic location;
- culture;
- age, including older and younger people;
- and language.

**Accessibility and Usability**

Accessibility primarily focuses on people with disabilities. Many accessibility requirements improve usability for everyone, especially in limiting situations. For example, providing sufficient contrast benefits people using the web on a mobile device in bright sunlight or in a dark room. Captions benefit people in noisy and in quiet environments. Some people have age-related functional limitations, and may not identify these as “disability”. Accessibility addresses these situations too.

Accessibility includes:

- **Requirements that are technical and relate to the underlying code rather than to the visual appearance**. For example, they ensure that websites work well with assistive technologies. This includes screen readers that read aloud content, and screen magnifiers that enlarge content. Voice recognition software used to input text is another form of assistive technology. These aspects are typically not a focus of usability research and practice.

- **Requirements that relate to user interaction and visual design**. Inadequate design can cause significant barriers for people with disabilities. That is why they are included. For example, understandable instructions and feedback for website forms and applications is good usability. They also help people with cognitive and learning disabilities. Without such requirements, some people with disabilities may be excluded from using the Web.
There is a significant overlap between accessibility and usability. ISO 9241-11 (http://www.iso.org/iso/catalogue_detail.htm?csnumber=16883), defines usability as:

“The extent to which a product can be used by specified users to achieve specified goals effectively, efficiently and with satisfaction in a specified context of use.”

This could address accessibility when:

- “specified users” includes people with a range of disabilities, and
- “specified context of use” includes accessibility considerations such as assistive technologies.

But usability practice and research often does not consider the needs of people with disabilities.

**Accessibility and Inclusion**

Several accessibility requirements also benefit people and situations that are a focus of inclusive design. For example, Web Accessibility Benefits People With and Without Disabilities (https://www.w3.org/WAI/bcase/soc#groups) describes accessibility benefits for:

- people with low literacy or not fluent in the language,
- people with low bandwidth connections or using older technologies,
- new and infrequent users, and,
- mobile device users (https://www.w3.org/WAI/standards-guidelines/wcag-mobile-overlap/).

However, accessibility focuses on disability and does not try to address broader issues. Other efforts, such as internationalization (https://www.w3.org/International/), address other inclusion issues. Keeping accessibility focused on disabilities encourages research and development on the specific needs of people with disabilities, and solutions that are optimized for these specific needs.

**Accessible Design**

There are guidelines, standards, and techniques for web accessibility (https://www.w3.org/WAI/standards-guidelines/), such as the Web Content Accessibility Guidelines (WCAG (https://www.w3.org/WAI/standards-guidelines/wcag/)), which is the international standard ISO/IEC 40500 (https://www.w3.org/blog/2012/10/wcag-20-is-now-also-
Yet when designers, developers, and project managers approach accessibility as a checklist to meet these standards, the focus is only on the technical aspects of accessibility. As a result, the human interaction aspect is often lost, and accessibility is not achieved.

Combining accessibility standards and usability processes with real people ensures that web design is technically and functionally usable by people with disabilities. This is referred to as usable accessibility or accessible user experience (UX).

**Usable Accessibility**

Web designers and developers can use usability processes, methods, and techniques, to address the user interface component of accessibility. While the considerations of people with disabilities are not always included in common practices, they can be easily integrated into user experience design.

A key aspect is incorporating real people in design:

- Ensuring that everyone involved in web projects understands the basics of [how people with disabilities use the Web](https://www.w3.org/WAI/people-use-web/),
- Involving users with disabilities ([https://www.w3.org/WAI/planning/involving-users/](https://www.w3.org/WAI/planning/involving-users/)) early and throughout the design process, and
- Involving users in evaluating web accessibility ([https://www.w3.org/WAI/test-evaluate/involving-users/](https://www.w3.org/WAI/test-evaluate/involving-users/)).

**Accessibility standards** also have an important role in accessible design. For example, understanding the basic [Accessibility Principles](https://www.w3.org/WAI/fundamentals/accessibility-principles/) and using them for developing and evaluating early prototypes helps the development team provide basic accessibility in the earliest stages. Addressing accessibility at later stages becomes increasingly difficult.

Also, usability processes and user involvement alone cannot address all accessibility issues. Even large projects cannot cover the diversity of disabilities, adaptive strategies, and assistive technologies. Accessibility guidelines, standards, and techniques ensure that the wide range of issues are adequately covered.

**Conclusion**
Accessibility practitioners and researchers can incorporate usability techniques to improve ‘usable accessibility’. User experience designers and researchers can incorporate accessibility to make their designs work better for more people in more situations. Addressing accessibility, usability, and inclusion together can more effectively lead to a more accessible, usable, and inclusive web for everyone. Resources to help are linked throughout this page.

For more on this topic, see The role of accessibility in a universal web (http://dspace.mit.edu/handle/1721.1/88013), which:

- provides a more in-depth exploration of the importance and benefits of accessibility as a distinct discipline, and
- encourages increased communication and coordination between accessibility, usability, and inclusion research and practice.

Date: Updated 6 May 2016. First published March 2010.


Developed by the Education and Outreach Working Group (EOWG (http://www.w3.org/WAI/EO/)). Previously developed with support of the WAI-AGE Project (https://www.w3.org/WAI/WAI-AGE/).
Words are powerful.

The words you use and the way you portray individuals with disabilities matters. This factsheet provides guidelines for portraying individuals with disabilities in a respectful and balanced way by using language that is accurate, neutral and objective.

1. **Ask to find out if an individual is willing to disclose their disability.**

Do not assume that people with disabilities are willing to disclose their disability. While some people prefer to be public about their disability, such as including information about their disability in a media article, others choose to not be publically identified as a person with a disability.

2. **Emphasize abilities, not limitations.**

Choosing language that emphasizes what people can do instead of what they can’t do is empowering.

<table>
<thead>
<tr>
<th>Use</th>
<th>Don't Use</th>
</tr>
</thead>
<tbody>
<tr>
<td>Person who uses a wheelchair</td>
<td>Wheelchair-bound; confined to a wheelchair</td>
</tr>
</tbody>
</table>
Person who uses a communication device; uses an alternative method of communication  | Is non-verbal; can’t talk

3. In general, refer to the person first and the disability second.

People with disabilities are, first and foremost, people. Labeling a person equates the person with a condition and can be disrespectful and dehumanizing. A person isn’t a disability, condition or diagnosis; a person has a disability, condition or diagnosis. This is called Person-First Language.

<table>
<thead>
<tr>
<th>Use</th>
<th>Don’t Use</th>
</tr>
</thead>
<tbody>
<tr>
<td>Person with a disability, people with disabilities</td>
<td>Disabled person; the disabled</td>
</tr>
<tr>
<td>Man with paraplegia</td>
<td>Paraplegic; paraplegic man</td>
</tr>
<tr>
<td>Person with a learning disability</td>
<td>Slow learner</td>
</tr>
<tr>
<td>Student receiving special education services</td>
<td>Special education student</td>
</tr>
<tr>
<td>A person of short stature or little person</td>
<td>Dwarf, midget</td>
</tr>
</tbody>
</table>

4. However, always ask to find out an individual’s language preferences.

People with disabilities have different preferences when referring to their disability. Some people see their disability as an essential part of who they are and prefer to be identified with their disability first – this is called Identity-First Language. Others prefer Person-First Language. Examples of Identity-First Language include identifying someone as a deaf person instead of a person who is deaf, or an autistic person instead of a person with autism.

5. Use neutral language.

Do not use language that portrays the person as passive or suggests a lack of something: victim, invalid, defective.

<table>
<thead>
<tr>
<th>Use</th>
<th>Don’t Use</th>
</tr>
</thead>
<tbody>
<tr>
<td>Person who has had a stroke</td>
<td>Stroke victim</td>
</tr>
<tr>
<td>Congenital disability</td>
<td>Birth defect</td>
</tr>
<tr>
<td>Person with epilepsy</td>
<td>Person afflicted with epilepsy, epileptic</td>
</tr>
<tr>
<td>Person with a brain injury</td>
<td>Brain damaged, brain injury sufferer</td>
</tr>
<tr>
<td>Burn survivor</td>
<td>Burn victim</td>
</tr>
</tbody>
</table>

6. Use language that emphasizes the need for accessibility rather than the presence of a disability.

<table>
<thead>
<tr>
<th>Use</th>
<th>Don’t Use</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accessible parking</td>
<td>Handicapped parking</td>
</tr>
<tr>
<td>Accessible restroom</td>
<td>Disabled restroom</td>
</tr>
</tbody>
</table>
Note that ‘handicapped’ is an outdated and unacceptable term to use when referring to individuals or accessible environments.

7. **Do not use condescending euphemisms.**

Terms like *differently-abled, challenged, handi-capable* or *special* are often considered condescending.

8. **Do not use offensive language.**

Examples of offensive language include *freak, retard, lame, imbecile, vegetable, cripple, crazy, or psycho.*

9. **Describing people without disabilities.**

In discussions that include people both with and without disabilities, do not use words that imply negative stereotypes of those with disabilities.

<table>
<thead>
<tr>
<th>Use</th>
<th>Don’t Use</th>
</tr>
</thead>
<tbody>
<tr>
<td>People without disabilities</td>
<td>Normal, healthy, able-bodied, whole</td>
</tr>
<tr>
<td>She is a child without disabilities</td>
<td>She is a normal child</td>
</tr>
</tbody>
</table>

10. **Remember that disability is not an illness and people with disabilities are not patients.**

People with disabilities can be healthy, although they may have a chronic condition such as arthritis or diabetes. Only refer to someone as a patient when his or her relationship with a health care provider is under discussion.

11. **Do not use language that perpetuates negative stereotypes about psychiatric disabilities.**

Much work needs to be done to break down stigma around psychiatric disabilities. The American Psychiatric Association has new guidelines for communicating responsibly about mental health.

<table>
<thead>
<tr>
<th>Use</th>
<th>Don’t Use</th>
</tr>
</thead>
<tbody>
<tr>
<td>He has a diagnosis of bipolar disorder; he is living with bipolar disorder</td>
<td>He is (a) bipolar; he is (a) manic-depressive</td>
</tr>
<tr>
<td>Attempted suicide</td>
<td>Unsuccessful suicide</td>
</tr>
<tr>
<td>Died by suicide</td>
<td>Committed suicide</td>
</tr>
<tr>
<td>Is receiving mental health services</td>
<td>Mental Health patient/case</td>
</tr>
<tr>
<td>Person with schizophrenia</td>
<td>Schizophrenic, schizo</td>
</tr>
<tr>
<td>Person with substance use disorder; person experiencing alcohol/drug problem</td>
<td>Addict, abuser; junkie</td>
</tr>
<tr>
<td>She has a mental health condition or psychiatric disability</td>
<td>She is mentally ill/emotionally disturbed/ insane</td>
</tr>
</tbody>
</table>
12. **Portray successful people with disabilities in a balanced way, not as heroic or superhuman.**

Do not make assumptions by saying a person with a disability is heroic or inspiring because they are simply living their lives. Stereotypes may raise false expectations that everyone with a disability is or should be an inspiration. People may be inspired by them just as they may be inspired by anyone else. Everyone faces challenges in life.

13. **Do not mention someone’s disability unless it is essential to the story.**

The fact that someone is blind or uses a wheelchair may or may not be relevant to the article you are writing. Only identify a person as having a disability if this information is essential to the story. For example, say “Board president Chris Jones called the meeting to order.” Do not say, “Board president Chris Jones, who is blind, called the meeting to order.” It’s ok to identify someone’s disability if it is essential to the story. For example, “Amy Jones, who uses a wheelchair, spoke about her experience with using accessible transportation.”

14. **Create balanced human-interest stories instead of tear-jerking stories.**

Tearjerkers about incurable diseases, congenital disabilities or severe injury that are intended to elicit pity perpetuate negative stereotypes.

**Resources**

- **People First Language and More, Disability is Natural** *(http://www.disabilityisnatural.com/people-first-language.html)*

Content was developed by the ADA Knowledge Translation Center, and is based on professional consensus of ADA experts and the ADA National Network.
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**Note: If you need answers to your ADA questions, email us.**
Producing accessible materials for print and online Text
Standard of Accessibility

AbilityNet is a registered national pan disability charity helping people adapt and adjust their information and communication technology.

Written material both on screen and on the printed page needs to be accessible in order for individuals to be able to easily extract information from the text.

Word processing and desktop publishing packages allow us to create eye catching content which can be often inaccessible to many readers due to over design, over use of colours and typefaces. But content can both look great and be accessible, by creating documents with a clear structure and layout and using a clear typeface, we can produce document that will not just be eye catching but much more readable.

Websites are also an important consideration in terms of providing accessible content, many of the points in this guide are also relevant to producing content for the web.

This guide aims to highlight some of the issues that can prevent text from being accessible and ways to improve the accessibility of your documents.
Fonts

The type face you use can have an impact on the readability of your document; some fonts can be used purely for design purposes and to create impact. Carefully considering the use of type face for your document or online content will greatly impact on how readable your document will be.

The two main types of typeface are Serif and Sans Serif, the difference between the two is that the Serif font ends in a curl or stroke at the end of each character, an example of a Serif font would be Times New Roman.

An example of a Sans Serif font would be Arial. Sans Serif fonts are considered to be easier to read particularly on screen, although certain characters such as ‘a’ may not be as easy to recognise as ‘a’.

Sans Serif fonts like Arial, Verdana and Helvetica are often used in web site design, this is because they are some of the most common fonts in use on your computer and they work well on screen.

Serif fonts are said to work better in print, but for accessibility it is often recommended that Sans Serif fonts are used as the characters are easier to distinguish for those with reading difficulties or a visual impairment.

Restrict your use of fonts in a document, too many different type faces on a page can make the text hard to distinguish and can make the page look messy, instead keep the minimum font use to two or less, perhaps using a different font for the headings to create an impact and another style for the body text.
Legibility

Legibility or how well you can distinguish type on the page can be influenced by many factors, though having some similarities with readability; legibility is mainly concerned with the use of the typeface or font used on the page. The legibility of a document can impact on how long the document takes to read.

Colour contrast between the font colour and the background both on the web and in print can impact those with a visual impairment, if there is not sufficient contrast the text is harder to distinguish.

Some colour contrasts can be beneficial particularly to those who are dyslexic or have learning difficulties, although colour combinations are as much down to personal preference, often black text on a yellow background can be often beneficial, so consider printing onto different colour paper.

Setting the text at good default font size of around 12pts will help whether it is on screen or in print.

On the web it is important that the font size can be increased in size on the page by making changes to the text size in the browser. This will affect content within text boxes, so in order to avoid text overflow, it is important that the text boxes increase in size along with the text.
Accessibility

Accessibility should be considered for documents that are going to be made available electronically such as websites and Adobe Portable Document Format (PDF) files. The accessibility of electronic content has become increasingly important with so much information being made available online.

How accessible the PDF file will be, is dependent on how accessible the document it was created from was. The easiest way to produce an accessible PDF file from Word is to create a structured document by applying styles to the text such as heading 1, titles etc. Headings should follow a logical order such as Heading 1 then Heading 2.

Hyperlinks can also be assigned a meaningful description, instead of including the website address as the hyperlink. Avoid using ‘Click Here’ instead use for example the name of the document or subject of the page the hyperlink is linked too.

You can assign alternative text to images in Word, which will allow them to be accessible to screen reader users by giving a description of what the image is displaying.
Images

Using images in a document can often help support what is being said in the text and therefore the use of images can often help readers with dyslexia and learning difficulties to follow what is happening in the text.

The placement of images on the page should be carefully considered. Images placed in a random way can interrupt the flow of the text and make it hard to follow. Consider placing images at the end of paragraphs and allow for space between the text and the image.

Avoid having text run over images for example where an image has been set as background as this can make the text hard to read.

If your document is going to be made available electronically for example as a PDF file or if you are adding images to a website, you should consider adding alternative text to your images. This will help provided a description of the image for screen reader users.

Images conveying information or in colour should also be described. If using an image of a map or a graph provide a summary of the information of what the image is showing you.
For images that are going to be used for print or in documents that are to be photocopied, use images where possible that have a good colour contrast and are clearly defined.

**Readability**

While legibility is influenced by typeface and how easy it is to recognise individual characters, readability focuses on words and blocks of text in print and online and how easy they are to read. Text using a decorative typeface that is noticeable may not necessarily be readable.

Blocks of text in CAPITALS or italics should be restricted to headings or very short sentences, large blocks of text in CAPS can impact on the legibility of a document as it can make the letters hard to distinguish as all of the letters are of the same height. Underlined text and text in *italics* and can also impact on readability as it can often make it hard to recognise the text.

**Avoid using LARGE BLOCKS OF CAPITAL LETTERS.**
Hyphenation refers to word breaks that occur at the end on lines and the word is carried onto the next line. This can have an effect on the readability of text as it interrupts the flow of the text especially for readers with dyslexia or learning difficulties. Hyphenation can be turned off in most word processors or Desktop publishing software and should be avoided where possible.

Avoid words being split between two lines, know as hyphenation.

 Altering the spacing between letters or words can improve the readability of the text. The space between letters or kerning and the spacing between words or tracking can also be altered to improve the readability of the body text.
In documents the text should be justified to the left rather than using full justification to make text easier to read. When using text wrap around images the text should be to the left of the image were possible.

Although not a direct consideration in terms of readability, what can have a big influence on the accessibility of a document is the quality of photocopied resources. The paper type too can have an influence glossy or thin paper that allows type from the reverse side of following pages can impact on the readability of the text.
Website Accessibility

Although not a comprehensive list, building in some of the following points into your website will help towards making your site more accessible.

- Include a proper heading structure, a heading structure such as ‘h1, h2’ etc will allow screen reader users to easily navigate around the web page.

- Text should be of a good default size and resizable, when text is resizable ensure it does not overlap onto surrounding content.

- Important images should have alternative text `<img src="logo.gif" alt="AbilityNet Logo" />` while cosmetic images should be assigned an empty alt attribute `alt=""`. Avoid using images of text as these cannot be resized.
BT Community Connections

If you are a community or charitable organisation that is looking to extend your work through use of the internet and ICT but don’t have the means, apply for an award today!

Find out more about BT Community Connections

Free Support Packages for AAC/AT Services

Free AbilityNet support packages for AAC / AT services supporting children with Speech, Language and Communication Needs

We are offering Local Authorities and PCT’s in England a number of free funded one year “Local Capacity” Service Level Agreements (SLA) to support their students and staff in their use of assistive technology to overcome communication difficulties.

Find out more about our Free Support Packages for AAC/AT Services

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Fig 1 Images

"School Children holding the BT Community Connections banner"

BT Community Connections

If you are a community or charitable organisation that is looking to extend your work through use of the internet and ICT but don’t have the means, apply for an award today!

Find out more about BT Community Connections

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Free Support Packages for AAC/AT Services

"Boy using assistive technology (headset)"

Free AbilityNet support packages for AAC / AT services supporting children with Speech, Language and Communication Needs

We are offering Local Authorities and PCT’s in England a number of free funded one year “Local Capacity” Service Level Agreements (SLA) to support their students and staff in their use of assistive technology to overcome communication difficulties. Find out more about our Free Support Packages for AAC/AT Services.

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Fig 2 Image Alt text

- Clear and easy to follow keyboard focus, allowing keyboard only users to follow their progress around the webpage.
• Is there good colour contrast between text and background colour combinations?

• Is there a site map and accessibility page?
Useful links for further information on document accessibility:

Access Materials Website
Document Accessibility
Widgit Symbols
RNIB Accessible Information
Typefaces for Dyslexia
Mencap Make it clear
Accessibility Standards

Adobe PDF Accessibility
Acrobat 9 Accessibility
Acrobat accessibility training resources

Preparing accessible lecture materials
The Naked Lecturer

Web browser Accessibility
Internet Explorer 8
Internet Explorer 7
Firefox Accessibility

Website Accessibility
Overview of Web Content Accessibility Guidelines (WCAG) 2.0
Colour contrast analyser by Juicy Studio
Download the Vischeck colour blindness plug-in

The RNIB’s clear print guidelines form part of this document RNIB See it Right.
The guidance on using Symbols in learning and education is provided by Widgit.
This disability history timeline is designed to help you learn about the rich history of people with disabilities. If you have a disability, this is about your history, but it may not be the history you know. Increasing your knowledge of disability history will help you inspire and lead others by telling the diverse stories of the many who have gone before. Starting shortly after the United States was founded, the disabilities timeline features examples of the remarkable diversity, creativity, and leadership that has shaped the disability community up through today.

Note: Although designed for youth and emerging leaders with disabilities, the Disability History Timeline and related activities can be used to educate a broader audience. For example, the materials may be useful for training service providers on the importance of educating youth with disabilities about their history or as an orientation for program staff before working with youth with disabilities.
**Founding Father Serves Despite Disability**
Stephen Hopkins, a man with cerebral palsy, is one of the signers of the Declaration of Independence. Hopkins is known for saying “my hands may tremble, my heart does not.”

**Improved Amputation Techniques**
Edward Alanson, an English surgeon, suggests a change in the way limbs are amputated, resulting in faster healing and less infection. This change has a positive impact on the quality of life for people who are amputees.

**Institution for Blind Children**
After seeing a group of blind men being cruelly exhibited in a Paris sideshow, Valentin Huay, known as the “father and apostle of the blind,” establishes the Institution for Blind Children to help make life for the blind more “tolerable.” Huay also discovered that sightless persons could read texts printed with raised letters.

**Mentally Ill Unchained**
Phillipe Pinel, a physician at La Bicetre, an asylum in Paris, removes the chains attached to people with mental illnesses. Some have been chained to walls for more than 30 years.
First Military Disability Law
Detail from painting shows U.S. President John Adams signing the act for the relief of sick and disabled seamen, July 16, 1798.

First Medical Classification of Mental Disorders
Phillipe Pinel writes Treatise on Insanity in which he develops a four-part medical classification for the major mental illnesses: melancholy, dementia, mania without delirium, and mania with delirium.

Education for Mentally Disabled
Jean-Marc Gaspard Itard establishes the principles and methods used today in the education of the mentally disabled through his controversial work with Victor, the “wild boy of Aveyron.”

Mental Disorders Documented
Dr. Benjamin Rush, considered the father of American psychiatry, publishes Medical Inquiries and Observations, the first modern attempt to explain mental disorders.

Birth of Louis Braille
Louis Braille is born on January 4, at Coupvray, near Paris. At three years of age, an accident caused him to become blind, and in 1819 he was sent to the Paris Blind School, which was originated by Valentin Huay.
Formal Deaf Education Begins in the U.S.
Thomas H. Gallaudet leaves the United States for Europe in 1815 to learn how to teach the deaf. Upon his return, he founds the Connecticut Asylum for the Education and Instruction of Deaf and Dumb Persons in Hartford, Connecticut, with Laurent Clerc. It is the first permanent school for the deaf in America. The opening of its doors, on April 15, 1817, marks the beginning of efforts in America to educate people with disabilities.

McLean Asylum for the Insane
The first patient is admitted to the Charlestown branch of the Massachusetts General Hospital, which is later named the McLean Asylum for the Insane. The hospital will become one of the best-known mental health facilities in the country, with services attracting such artists as Sylvia Plath, Anne Sexton, James Taylor, and Susanna Kaysen (author of Girl, Interrupted).

Braille Invents the Raised Point Alphabet
Louis Braille invents the raised point alphabet that makes him a household name today. His method doesn’t become well-known in the United States until more than 30 years after it is first taught at the St. Louis School for the Blind in 1860.

First “Sheltered Workshop” for the Blind
The first “sheltered workshop” is developed for the blind at the Perkins Institution in Massachusetts.
**Founding of Precursor to the American Psychiatric Association**

The Association of Medical Superintendents of American Institutions for the Insane, the precursor to the American Psychiatric Association, is founded.

**First Facility for the Criminally Insane**

The New York State Lunatic Asylum for Insane Convicts in Auburn is the first such facility designed specifically to house convicted criminals deemed to be insane. Previously, they were kept in prisons or hospitals.

**First Steps in Identifying Cerebral Palsy**

In the 1860s, William Little makes the first step toward identifying cerebral palsy (CP) by describing children with stiff and/or spastic muscles in their arms and legs. That particular condition, known at the time as Little's disease (now called spastic diplegia), is one of the major disorders included in CP. Little also correctly guesses that the condition is caused by lack of oxygen during birth.

**1861–1865 American Civil War**

The American Civil War results in 30,000 amputations in the Union Army alone. This event brings disability issues to the American consciousness.
Birth of “The Elephant Man”
Joseph Carey Merrick, better known in later years as “The Elephant Man,” is born in Leicester, England. Merrick’s head and body become covered in large tumors as a result of a rare nervous-system disorder, which is now known as neurofibromatosis and was diagnosed years after his death. He earns money by appearing in sideshows throughout England and is experimented on and tested on by a lot of doctors and scientists.

Bell Invents Telephone Trying To Help the Deaf
Alexander Graham Bell opens a speech school for deaf teachers in Boston. He invents the telephone while trying to develop a mechanical way to make speech visible. Bell reportedly believed that “deaf children should be educated orally and in day-school situations.”

Medical Degree For Freud
After researching the central nervous system, at Vienna University, Sigmund Freud, age 24, qualifies as a doctor of medicine. The following year, he begins work at Meynert’s Psychiatric Clinic and begins to formulate the ideas that will comprise his theories of psychoanalysis.

Helen Keller Meets New Tutor
Helen Keller, a deaf-blind seven-year-old living in Tuscombia, Alabama, meets her new tutor, Annie Sullivan.
**Eugenic Sterilization Law Spreads Like Wildfire**

Indiana becomes the first state to enact a eugenic sterilization law—for “confirmed idiots, imbeciles and rapists”—in state institutions. The law spreads like wildfire and is enacted in 24 other states.

**The Great War’s Disabled Veterans**

After being caught in an explosion and diagnosed with shell-shock as a result of combat in the British Army in World War I, Wilfred Owen, 24, arrives at Craiglockhart Hospital near Edinburgh, Scotland. There he meets the poet and soldier Siegfried Sassoon, who later introduces him to Robert Graves. Literary works from these three men, often touching on the subject of men disabled in battle, form the literary historical record for all the countries involved in “The Great War.”

**Funding for Rehabilitation**

As a result of the large number of WWI veterans returning with disabilities, Congress passes the first major rehabilitation program for soldiers. In 1920, a bill funding vocational rehabilitation guarantees federal money for job counseling and vocational training for disabled in the general public.

**Easter Seals, Model Charitable Organization**

Edgar Allen, a businessman in Elyria, Ohio, founds the Ohio Society for Crippled Children, which becomes the national Easter Seals organization. It serves as a model for many of today’s charitable organizations—in its methods and, some activists say, in its exclusion of people from the community being helped.
Frida Kahlo (1907–1954)
Frida Kahlo, 18, is injured in a bus accident in her hometown of Mexico City. Her spinal column, along with her collarbone, ribs, and pelvis, is broken. For a month, she remains in bed. Bored, she begins to paint, the first step toward becoming one of the most influential artists of the 20th century.

Study of Dyslexia
Samuel Orton begins his extensive study of dyslexia, hypothesizing that it could be neurological versus visual, and that it was likely connected to left-handedness. His first assumption is right. His second one, not so.

Compulsory Sterilization Ruled Constitutional
The Supreme Court rules in Buck v. Bell that the compulsory sterilization of mental defectives such as Carrie S. Buck, a young Virginia woman, is constitutional under “careful” state safeguards. Perhaps unbelievably, this ruling has never been overturned. In his opinion, Justice Oliver Wendell Holmes writes:

“(It) is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind…Three generations of imbeciles are enough.”
Iron Lung To Combat Polio

In 1927 Philip Drinker and Louis Shaw develop the iron lung, a chamber that provides artificial respiration for polio patients being treated for respiratory muscle paralysis.

Franklin D. Roosevelt Elected President

Franklin D. Roosevelt becomes the 32nd president of the United States and is re-elected for an unprecedented four terms before dying in office in April 1945. In August 1921, while vacationing at Campobello Island, New Brunswick, Roosevelt contracted an illness, believed to be polio, which resulted in total and permanent paralysis from the waist down. After becoming President, he helps found the National Foundation for Infantile Paralysis (now known as the March of Dimes). His leadership in this organization is one reason he is commemorated on the dime.

California Council of the Blind

At the age of 23, Jacobus tenBroek, blind since age 14, joins with Dr. Newel Perry and others to form the California Council of the Blind, which later becomes the National Federation of the Blind of California, a model for the nationwide organization he forms six years later.

Signing of the Social Security Act

President Franklin Delano Roosevelt signs the Social Security Act, establishing a program of permanent assistance to adults with disabilities.
1935 Disability Protest Results in WPA Jobs
To protest the fact that their requests for employment with the Works Progress Administration (WPA) have been stamped ‘PH’ (physically handicapped), 300 members of the League for the Physically Handicapped stage a nine-day sit in at the Home Relief Bureau of New York City. Eventually, they help secure several thousand jobs nationwide. The League of the Physically Handicapped is accepted as the first organization of people with disabilities by people with disabilities.

1937
Ray Charles Blind by Age Seven
At the age of seven Ray Charles Robinson (1930–2004) loses his sight completely due to glaucoma, which he’s had since the time of his birth in Albany, Georgia. He learns to read music in Braille and eventually drops his last name while performing on the Florida blues circuit.

1939
Nazi Program Kills Thousands
At the onset of World War II Adolph Hitler orders widespread “mercy killing” of the sick and disabled. Code-named *Aktion T4*, the Nazi euthanasia program is instituted to eliminate “life unworthy of life.” Between 75,000 to 250,000 people with intellectual or physical disabilities are systematically killed from 1939 to 1941.

Lou Gehrig Day
On July 4, 1939, Lou Gehrig Day is held at Yankee Stadium in New York City. The first baseman, nicknamed the Iron Horse, had been diagnosed with amyotrophic lateral sclerosis (ALS), but that day tells the world, “Today, I consider myself the luckiest man on the face of the earth.” His statement resounds long after his death in 1941.
Rosemary Kennedy Institutionalized after Failed Lobotomy

John F. Kennedy’s twenty-three year old sister Rosemary undergoes a prefrontal lobotomy as a “cure” for lifelong mild retardation and aggressive behavior that surfaces in late adolescence. The operation fails, resulting in total incapacity. To avoid scandal, Rosemary is moved permanently to the St. Coletta School for Exceptional Children in Wisconsin. Her sister, Eunice Kennedy Shriver, later founds the Special Olympics in Rosemary’s honor.

Rusk’s Theories Become Basis for Rehabilitation Medicine

Dr. Howard A. Rusk founds the Rusk Institute of Rehabilitation Medicine in New York City, where he develops techniques to improve the health of injured veterans from World War II. His theory focused on treating the emotional, psychological and social aspects of individuals with disabilities and later became the basis for modern rehabilitation medicine.

Beginning of National Barrier-Free Standards

In the 1950s, disabled veterans and people with disabilities begin the barrier-free movement. The combined efforts of the Veterans Administration, The President’s Committee on Employment of the Handicapped, and the National Easter Seals Society, among others, results in the development of national standards for “barrier-free” buildings.

The ARC Champions Abilities of Mentally Retarded

Parents of youth diagnosed with mental retardation found the Association for Retarded Citizens (ARC). The association works to change the public’s ideas about mental retardation. Its members educate parents and others, demonstrating that individuals with mental retardation have the ability to succeed in life. The ARC works to ensure that the estimated 7.2 million Americans with mental retardation and related developmental disabilities have the services and supports they need to grow, develop, and live in communities across the nation.
Radiation Experiment Conducted Without Consent

Clemens Benda, clinical director at the Fernald School in Waltham, Massachusetts, an institution for boys with mental retardation, invites 100 teenage students to participate in a “science club” in which they will be privy to special outings and extra snacks. In a letter requesting parental consent, Benda mentions an experiment in which “blood samples are taken after a special breakfast meal containing a certain amount of calcium,” but makes no mention of the inclusion of radioactive substances that are fed to the boys in their oatmeal.

Billy Barty Organizes Little People

Actor Billy Barty makes a national appeal to the little people of America to converge on Reno, Nevada. Twenty answer the call, creating the Midgets of America organization. Later renamed the Little People of America, his organization becomes the largest in the world devoted to people of short stature.

First Accessibility Standard Published


Stevie Wonder Discovered

Ronnie White (of The Miracles) discovers 11-year-old Steveland Judkins and arranges an audition with Motown CEO, Berry Gordy, who immediately signs the boy as “Little Stevie Wonder.”

Ed Roberts Fights for Admission to University

Ed Roberts, a young man with polio, enrolls at the University of California, Berkeley. After his admission is rejected, he fights to get the decision overturned. He becomes the father of the Independent Living Movement and helps establish the first Center for Independent Living (CIL).
Federal Funding Set Aside for Disability Infrastructure Support


Civil Rights Bill Bypasses Persons with Disabilities

The Civil Rights Act is passed. While this act helps end discrimination against African Americans and women in the workplace, it does not make any provision for people with disabilities. Individuals with disabilities still lack opportunities to participate in and be contributing members of society, are denied access to employment, and are discriminated against based on disability.

Baudot Merged with TTY Communication

In California, deaf orthodontist Dr. James C. Marsters of Pasadena sends a teletype machine (TTY) to deaf scientist Robert Weitbrecht, asking him to find a way to attach the TTY to the telephone system. Weitbrecht modifies an acoustic coupler, giving birth to “Baudot,” a code that is still used in TTY communication.

Medicaid Help for Low-Income and Disabled

Title XIX (19) of the Social Security Act creates a cooperative federal/state entitlement program, known as Medicaid, that pays medical costs for certain individuals with disabilities and families with low incomes.

First International Special Olympics Games

Eunice Kennedy Shriver founds the Special Olympics in 1962 to provide athletic training and competition for persons with intellectual disabilities. The organization grows into an international program enabling more than one million young people and adults to participate in 23 Olympic-type sports events each year. The first International Special Olympics Games are held in Chicago, Illinois in 1968.
Act Requires Accessible Buildings

The Architectural Barriers Act of 1968 mandates the removal of what is perceived to be the most significant obstacle to employment for people with disabilities—the physical design of the buildings and facilities on the job. The act requires that all buildings designed, constructed, altered, or leased with federal funds to be made accessible.

Educator and Disability Activist

Judy Heumann sues the New York City Board of Education when her application for a teaching license is denied. The stated reason is the same originally used to bar her from kindergarten—that her wheelchair is a fire hazard. The suit, settled out of court, launches Heumann’s activism. She later founds the Independent Living movement with Ed Roberts and oversees education and VR programs in the United States during the 1990s.

Governor Wallace of Alabama Paralyzed

Governor George C. Wallace of Alabama is paralyzed after being shot during a presidential campaign rally in Laurel, Maryland.

Public Entities Can’t Discriminate

Section 504 of the Rehabilitation Act of 1973 makes it illegal for federal agencies, public universities, and other public institutions receiving any federal funds to discriminate on the basis of disability.

Inaugural Convention of People First

The first convention for People First is held in Portland, Oregon. People First is a national organization of people with developmental disabilities learning to speak for themselves and supporting each other in doing so.
Last of “Ugly Laws” Repealed
The last “Ugly Law” is repealed in Chicago, Illinois, in 1974. These laws allowed police to arrest and jail people with “apparent” disabilities for no reason other than being disfigured or demonstrating some type of disability.

Law Guarantees Free, Appropriate, Public Education for All Disabled Children
The Education for Handicapped Children Act of 1975—now called the Individuals with Disabilities Education Act (IDEA)—is signed into law. It guarantees a free, appropriate, public education for all children with disabilities in the least restrictive environment.

Staten Island’s Willowbrook State School Finally Shuttered
After a five year battle with parents and advocates, New York Governor Hugh Carey signs the Willowbrook consent order, closing down a state institution notorious for its horrible conditions—broken plumbing, not enough doctors or medical supplies, patients living in filthy residences with no clean clothing, to name a few. Governor Carey pledges to relocate patients in community-based settings. Willowbrook remains open until 1978, but forever changes ideas about community-based care for people with developmental disabilities.

Deaf Actress Signs On with Sesame Street
Deaf actress Linda Bove, graduate of Gallaudet College and veteran of the National Theater for the Deaf, signs a long-term contract to play Linda the librarian on public television’s Sesame Street. James Earl Jones, a well known actor who has a speech-related disability, also gets his start on Sesame Street.

Disability Demonstrators Occupy Federal Office
Demonstrators led by Judy Heumann take over the Health Education and Welfare (HEW) office in UN Plaza, San Francisco, California, in protest of HEW Secretary Califano’s refusal to complete regulations for Section 504 of the Rehabilitation Act of 1973, which made it illegal for federal agencies, public universities, and other public institutions receiving any federal funds to discriminate on the basis of disability. After 25 days, Califano relents and signs the regulations into effect, making this take-over event the longest occupation of a federal office by protestors in U.S. history.
1978

**Disability Activists Protest Inaccessibility of Denver Buses**

In Denver, Colorado, nineteen members of the Atlantis Community block buses with their wheelchairs—chanting “We will ride!”—to demonstrate against the inaccessibility of public transportation.

**Organization for Hispanic Children with Disabilities**

Fiesta Educativa (Education Fest) is formed to address the lack of Spanish-speaking support services to families with disabled children in southern California.

**National Council on Disability Established**

The National Council on Disability is established as an advisory board within the Department of Education. Its purpose is to promote policies, programs, practices, and procedures that guarantee equal opportunity for all people with disabilities, regardless of the nature or severity of the disability, and to empower them to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society.

1980

**Institutions Can’t Hold People Against Their Will**

The Civil Rights of Institutionalized Persons Act (CRIPA) gives the Department of Justice power to sue state or local institutions that violate the rights of people held against their will, including those residing for care or treatment of mental illness.

**Diagnostic Criteria for Attention Deficit Disorder**

The term *Attention Deficit Disorder* is included for the first time in the Diagnostic and Statistical Manual of Mental Disorders (DSM), published by the American Psychiatric Association (APA).
1982

**Down’s Infant Allowed To Die**

On April 9, “Baby Doe” is born with Down’s syndrome and an under-developed esophagus. Doctors advise the parents not to opt for surgery and to allow him to die. On April 15, the child dies in an incubator.

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**UN Encourages Global Equality and Participation for the Disabled**

The United Nations General Assembly adopts “The World Program of Action Concerning the Disabled” in 1982 to encourage full participation and equality for people with disabilities around the world.

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**Reich Founds National Organization on Disability**

Alan A. Reich founds the National Organization on Disability (NOD) in 1982. NOD’s mission is to expand the participation and contribution of Americans with disabilities in all aspects of life and to close the participation gap by raising disability awareness through programs and information. As president of NOD, Reich builds the coalition of disability groups that successfully fight for the inclusion of a statue of President Franklin D. Roosevelt in his wheelchair at the FDR Memorial. Reich is an international leader in the disability community until his death in 2005.

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1983

**ADAPT Campaigns for Transportation Access**

Americans with Disabilities for Accessible Public Transportation, now known as ADAPT, began its national campaign for lifts on buses and access to public transit for people with disabilities. For seven years ADAPT—under the leadership of Bob Kafka, Stephanie Thomas, and Mike Auberger—blocked buses in cities across the U.S. to demonstrate the need for access to public transit. After the passage of the ADA (and transit measures gained by ADAPT’s hard work), ADAPT began to focus on attendant and community based services, becoming American Disabled for Attendant Programs Today.

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1986

**Air Carriers Can’t Discriminate Against Disabled**

*The Air Carrier Access Act* is implemented, which prohibits discrimination by domestic and foreign air carriers against qualified individuals with physical or mental disabilities. It applies only to air carriers that provide regularly scheduled services for hire to the public. Requirements include boarding assistance and certain accessibility features in newly built aircraft and new or altered airport facilities.
1988

**Gallaudet’s “Deaf President Now” Protest**

Students, faculty, and the community at Gallaudet University in Washington, D.C. organize a week-long protest on campus demanding the selection of a deaf president for the university. The protest is called “Deaf President Now” and the Dr. I. King Jordan is named.

**Mandated Accessible Housing in New Projects**

The *Fair Housing Amendments Act of 1988* expands on the *Civil Rights Act of 1968* to require that a certain number of accessible housing units be created in all new multi-family housing. The act covers both public and private homes and not only those in receipt of federal funding.

**Disabled Writer Burns Book In Protest**

Paul Longmore, noted disability historian, burns a copy of his book in front of the federal building in Los Angeles in protest of work disincentives, which stopped him from receiving payment as an author to keep his medical benefits.

**Assistive Technology Initiative**

*Technology-Related Assistance for Individuals with Disabilities Act of 1988* is passed. This piece of legislation increases access to, availability of, and funding for assistive technology through state and national initiatives.

**McAfee Chooses Life, Becomes Advocate**

Larry McAfee is granted the right, by a Georgia court, to be given a sedative and be taken off a ventilator in order to end his life. He changes his mind and becomes a disability-rights advocate.

1989
1990

Americans with Disabilities Act Becomes Law

The Americans with Disabilities Act (ADA) is signed into law by President George H. W. Bush (R) alongside its “founding father,” Justin Dart. The ADA is considered the most important civil rights law since Title 504 and has cross-disability support, bringing disability-specific organizations, advocates, and supporters all together for the same cause. Sitting alongside Dart and the President were Senators Harkin and Weiker and Congressmen Owens, Coehlo, and Hoyer.

Terry Schiavo Suffers Severe Brain Damage

Terry Schiavo is severely brain damaged after her heart stops because of a chemical imbalance that is believed to have been brought on by an eating disorder. Court-appointed doctors rule she is in a “persistent vegetative state” with no real consciousness or chance of recovery. Over a decade later, her case will spark much controversy and receive national media attention.

1992

California Hosts First Youth Leadership Forum

The first Youth Leadership Forum for youth with disabilities is developed in California by the Governor’s Committee for Employment of Disabled Persons. The U.S. Department of Labor funds other states to develop similar forums. By 2007, youth leadership forums are taking place in 23 states.

1995

American Association of People with Disabilities

Paul Hearne, a longtime leader in the disability community, achieves his dream of creating a national association to give people with disabilities more consumer power and a stronger public voice, with the creation of the American Association of People with Disabilities.
Christopher Reeve Paralyzed in 1995
Christopher Reeve's horse fails to complete a rail jump at an annual riding competition in Virginia. Reeve is thrown and sustains a severe C1–C2 vertebrae fracture that paralyzes him from the neck down. Best known for his Superman role, after the injury Reeve begins his own battle, searching for a cure to spinal cord injury. Though he dies in 2004 without seeing a cure, he receives both admiration and criticism for his attempts at finding one, leaving a legacy of ongoing research around spinal cord injuries.

Accessible Computer and Telecomm Equipment
The Telecommunications Act passes and requires that computers, telephones, closed captioning, and many other telecommunication devices and equipment be made accessible.

Dentist Must Treat HIV-Positive Patient
The Supreme Court, in Bragdon v. Abbott, extends ADA benefits to a woman with HIV who sued a dentist who refused to fill a cavity for fear of getting the disease himself. Persons with HIV/AIDS are considered disabled under the ADA.

Disabled Golfer Has Right To Use Cart in PGA
A federal judge rules that golfer Casey Martin—the first pro athlete to utilize the ADA to play a competitive sport—does have the right to use a golf cart in the PGA Tour tournaments due to a rare circulatory disorder that severely limits his ability to walk an entire course.

Soccer League Ordered To Allow Disabled Player
In November, a U.S. District Court judge issues an emergency court order telling the Lawton, Oklahoma, Evening Optimist Soccer League to allow Ryan Taylor, a nine-year-old with cerebral palsy, to play in the league. His walker, referred to as a safety hazard by the defendants, is padded during games.
Benefits Protected for Some Who Return To Work

The Ticket to Work and Work Incentives Improvements Act of 1999 (TWWIIA) expands the availability of Medicare and Medicaid so that certain disabled beneficiaries who return to work will not lose their medical benefits—the same issue Paul Longmore protests against back in 1988.

Unnecessary Institutionalization Discriminatory

In *Olmstead v. L.C.* the U.S. Supreme Court rules that unnecessary institutionalization of people with disabilities constitutes discrimination and violates the ADA, that individuals have a right to receive benefits in the “most integrated setting appropriate to their needs,” and that failure to find community-based placements for qualifying people with disabilities is illegal discrimination.

Genome Project Maps Human DNA Sequence

The Human Genome Project nears completion. President Clinton and leading scientists announce the completion of a “rough draft” of the DNA sequence (linked strands of protein, the “building blocks” of life) for human life. While some advocates are encouraged with the hope of finding cures and medical breakthroughs, others fear an end of “disability” altogether.

First Disability Pride Parade in Chicago

A coalition of disability rights advocates and organizations holds the first Disability Pride Parade. Organizers expect 500–600 people to attend the event, which is designed to “change the way people think about and define disability, to break down and end the internalized shame among people with disabilities, and to promote the belief in society that disability is a natural and beautiful part of life.” Almost 2,000 attend.
Tennessee Sued for Inaccessible Courts

In 2004, the United States Supreme Court hears *Tennessee v. Lane*, a case in which individuals sue the state of Tennessee for failing to ensure that courthouses are accessible to people with disabilities. One plaintiff is arrested when he refuses to crawl or be carried up stairs. The state argues that they can not be sued under Title II of the ADA. The Supreme Court decides in favor of people with disabilities, however, ruling that Tennessee can be sued for damages under Title II for failing to provide access to the courts.

Funding for Youth Information Centers

The Administration for Developmental Disabilities begins to fund Youth Information Centers (YICs). Modeled after Parent Training and Information Centers, YICs are designed to be run by and for youth and emerging leaders with disabilities, promoting a youth-led agenda and providing services within the disability community.

Cuts in Tennessee Medicaid Leads to Sit-In

Upset by Governor Bredesen's massive cuts to the state Medicaid System, TennCare, disability advocates in Tennessee begin a sit-in at the Governor's office that lasts 75 days, replacing the record set in 1977 by the HEW office takeover.

Schiavo’s Husband Has Right To Let Her Die

Terry Schiavo’s husband Michael is given the right to remove her feeding tube. Terry dies at the age of 41 after living 15 years in a “persistent vegetative” state. Despite numerous protests by her parents, she dies from dehydration after the feeding tube is removed by court order. The case gains national attention and continues to direct public focus on living wills and other forms of life/estate planning. Schiavo left no written instructions concerning her wishes if she were to ever become so severely disabled.
Gallaudet Students Protest New President

I. King Jordan resigns from Gallaudet University. Students protest the hiring of his replacement, citing issues such as not being raised using American Sign Language (ASL) and her lack of familiarity with deaf culture.

History of Disability Rights Enters Curricula

The first bill requiring that students in a K–12 public school system be taught the history of the disability rights movement is passed, largely due to the efforts of 20 young people with disabilities from the state of West Virginia.

50-State Road-To-Freedom Tour

The Road-to-Freedom tour kicked off on November 15th. This 50-state bus tour and photographic exhibit chronicles the history of the grassroots “people’s movement” that led to passage of the Americans with Disabilities Act (ADA).

Sources for some events on this timeline include information excerpted from Project YIELDD (Youth Information, Education and Leadership for Developmental Disabilities); Access Living, Chicago; and Parallels in Time from the Minnesota Developmental Disabilities Council.

Images published herein were obtained from the public domain as made available from public sources; are based on free licence use or fair-use rights for educational purposes; or are used by permission under rights-free, royalty-free agreements.
This resource and discussion guide is designed to help youth with disabilities and emerging leaders within the disability community learn about the rich history of people with disabilities. Increasing their knowledge of disability history will help them inspire and lead others by telling the diverse stories of the many who have gone before. Starting shortly after the United States was founded, the disabilities timeline features examples of the remarkable diversity, creativity, and leadership that has shaped the disability community up through today.

Note: Although designed for youth and emerging leaders with disabilities, the Disability History Timeline and related activities can be used to educate a broader audience. For example, the materials may be useful for training service providers on the importance of educating youth with disabilities about their history or as an orientation for program staff before working with youth with disabilities.
Why Study Disability History?
Research, conducted by the National Collaborative on Workforce and Disability for Youth in the field of transition, shows that youth with disabilities need exposure to disability history, understanding of disability public policy, and connections to role models and mentors in the disability community.

Much of the Disability History Timeline was compiled, reviewed, refined, and chosen by youth and emerging leaders with disabilities. To reflect the diversity of the disability community, they also researched the many different disability populations to include as many as possible.

These materials are part of a growing body of work that intends to help individuals working with youth with disabilities become empowered as leaders, and to learn about the rich history of people with disabilities in the United States.

These following activity and worksheets were also developed by youth and emerging leaders with disabilities.

ACTIVITY: Disability History Timeline
Conduct this activity prior to distributing the Disability History Timeline to participants. Use the exercise as a means for introducing the timeline and subsequent worksheets.

PURPOSE
To give participants a base of knowledge about the history of people with disabilities in the United States, which starts shortly after the nation’s founding up until the present day. Rather than just handing out the timeline, this activity is designed to help apply information in a personal way to promote empowerment of participants. It works best when it’s interactive.

TIME
45 minutes for preparation
20 minutes for the introductory activity
30-45 minutes for corrections
30-45 minutes for worksheet discussions

Preparation
1. Become familiar with the dates and events depicted in the Disability History Timeline.
2. Decide whether or not you want youth to work individually or within groups. If working individually, use one date per student. If working in groups, staff can assign 3 or 4 events per group.
3. Select a number of specific dates to use in the activity, making sure to include a diverse group of disabilities across a wide spectrum of the timeline.
4. Print out the selected dates, with each date displayed horizontally across a piece of white 8.5” X 11” paper. Under page setup select the landscape option. (See below).

5. Make sure that the dates are printed large enough to be read from the back of the room. (Use a 200-point font size).
6. Print out the events that correspond with the selected dates. Make sure to print each event in a large font size on white paper. Print using the landscape option as well.

Note: After conducting multiple trainings and testing out various date/event combinations, you may want to laminate a master set of the selected dates and events to cut printing costs and make the activity easier to repeat.
Implementation

1. Post the dates on the wall from left to right, starting with the first date and ending with the last date.

2. Mix up the event cards and distribute them among the participants. Give participants 20 minutes to post event cards on the wall under the dates that best match the events.

Facilitation

Note: This part usually takes the longest.

1. Give a 5 minute warning, then after the 20 minutes are up, walk through the timeline discussing which events go where.

   For example, a group guesses that Deaf President Now took place in 1782. Ask, “What about this event made you think it took place then?” Or say, “Well, it actually took place in 1988 and let’s talk about why.”

2. When facilitating this portion be sure to:
   a. Define concepts and ideas in accessible language (e.g., sheltered workshops, eugenics, sterilization).
   b. Make the connections between the events described and the models of disability in use at the time, as well as policies that have an impact on people with disabilities.

   For example, discuss how imbecile changed to mental retardation, then mental retardation changed to developmental disability, and now developmental disability has changed to intellectual disability.

3. After reviewing the timeline and making the necessary corrections (i.e., moving an event from the incorrect date to the correct one), distribute the Disability History Timeline to participants.

   Suggested introduction: “This is a timeline of your history. It may not be a history you’re familiar with, but it is the history of people with disabilities in the United States starting in 1782 and continuing on until 2006.”

4. Distribute discussion questions—using either Worksheets 1, 2, or 3 or all three—for completion by the participants on their own or to facilitate discussion among all of the participants.

   DISCUSSION WORKSHEET 1: Processing the Timeline

   DISCUSSION WORKSHEET 2: Discussion Geometry

   This activity has been adapted by the National Consortium on Leadership and Disability/Youth from an activity facilitated by the Institute for Educational Leadership.

   DISCUSSION WORKSHEET 3: Look Into Your Crystal Ball

Implementation

This exercise can be completed independently using the worksheets or worksheet questions can be used to facilitate discussion in large or small groups with youth and emerging leaders.
PROCESSING THE TIMELINE
After you’ve had a chance to read some of the different events important in the history of people with disabilities in the Disabilities History Timeline, take some time to do some processing. How does this information impact us, our community, and society?

Some people—both those with and without disabilities—think that the events depicted on the Disability History Timeline are only important for people with the types of disabilities listed. As a community, however, it’s important to share each other’s victories and to see them as steps in the progress for people with all different types of disabilities. As people with disabilities, our history is important on many levels.

Instructions:
Select three events you found interesting. After listing the first one, explain/discuss why the event is important to you as a person with a disability. For the second event, explain/discuss why the event is important to the disability community as a whole. For the third event, explain/discuss why it’s important that people without disabilities learn about this event.

EVENT 1:
Why is this event important to me as a leader?

EVENT 2:
Why is this event important to the disability community?
EVENT 3:

How could the non-disabled community benefit by knowing more about this event?

NOTES:
DISCUSSION GEOMETRY

Now that you’ve had a chance to glance through the Disability History Timeline and read about some of the different events important in the history of people with disabilities, it’s time to do some processing. How does the information impact us and how do we react to it? Discussion Geometry provides a simple way to do this and helps us organize our ideas and responses to the Disability History Timeline. Just answer the questions below.

**CIRCLE**
What is one idea or event that’s going around and around in your head after reading or discussing the timeline?

**SQUARE**
What is one idea or event that squares (or is similar) to what you already knew?
**TRIANGLE**

What are three things that you’re going to take away from this activity?

**HEXAGON**

What idea or event on the timeline made you feel uncomfortable or awkward, and why?
LOOK INTO YOUR CRYSTAL BALL

You’ve just had a chance to read and learn about a lot of different people and events in the Disability History Timeline that have had an impact on the lives of people with disabilities. Knowing about your past is important when thinking about what you want for your future! Take a moment to think about the future.

In the space below, write or draw what you want to happen in the future that will improve the lives of people with disabilities. Remember, these are your predictions and goals! Make them about issues important to you.

Example: *In five years anyone with a disability will live at home with their families instead of in nursing homes!*

**In five years:**

**In ten years:**

**In twenty years:**
In fifty years:

In one hundred years:

What are three things you’re going to do to help achieve one of your goals by the time you predicted?
National Consortium on Leadership and Disability/Youth

The National Consortium on Leadership and Disability for Youth (NCLD/Y) is a youth-led resource, information, and training center for youth and emerging leaders with developmental disabilities, housed at the Institute for Educational Leadership and funded by a grant/contract/cooperative agreement from the U.S. Department of Health and Human Services, Administration on Developmental Disabilities (Number #90DN0206). The project is led by the next generation of young leaders with disabilities and takes a positive development approach toward preparing youth for the transition to adulthood and leadership roles within the disability community. To assist in this preparation, all program materials are based on the five areas of youth development/leadership—learning, connecting, thriving, working, and leading.

NCLD/Youth supports and promotes youth with disabilities and emerging leaders in the disability community, by following these objectives:

- To identify and develop high quality, disability-specific curricula designed around the five areas of youth development and leadership;
- To test, refine, and disseminate instructional materials across multiple states, building networks of national, state, and local partnerships of peer mentors, adult advisors, and Councils of youth and emerging leaders;
- To develop, train, and mentor youth and emerging young leaders with developmental disabilities in each partner state to influence state and local-level public policy involving youth development and leadership; and,
- To educate school leaders, policymakers, families, and other youth about the importance of including disability history and awareness in all K–12 curricula.

The opinions expressed herein do not necessarily reflect the position or policy of the U.S. Department of Health and Human Services. Nor does mention of tradenames, commercial products, or organizations imply endorsement by the U.S. Department of Health and Human Services.

Visit the NCLD/Y Web site at: www.ncld-youth.info.
From Poster Child to Protester

Hershey, Laura. 1993.

Former "Poster Child", Laura Hershey, criticizes and protests fundraising telethons such as Jerry Lewis' Muscular Dystrophy event, claiming they use pity and bigotry and insult people with disabilities.

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Orange, pink, and lavender flyers fluttered in the breeze as we handed them to any passer-by willing to take one. "Tune Out Jerry!" the flyers urged. "Boycott the Telethon!" Some two dozen of us lined up in front of the hotel shouting chants, distributing leaflets, and answering questions from the media, while the local segment of the Jerry Lewis Labor Day Telethon broadcast from a ballroom two floors above. Though I would stay outside all afternoon, I remembered all too well the scene that was taking place inside.

The singers croon. The eyelids droop. The money pours in. The firefighters, the Boy Scouts, the business executives, the neighborhood kids, all tiredly smiling proud smiles, carry in their collected funds, in jars, in boots, in
oversized checks. The camera rolls. The host smiles. The money pours in. The Poster Child gives awkward answers to inane questions. The host smiles. The Poster Child smiles. The host cries. The money pours in.

You have to keep thinking about the money, because as everyone freely admits, that's what this is all about. The money raised represents hope -- year after year, promises of a miracle, the great cure that waits just around the corner. The money manifests faith -- faith in the noble research scientists working desperately to identify, and eliminate, flawed genes. The money testifies to human love and compassion, ruthlessly sentimentalized in songs like "They'll Never Walk Alone" which punctuate the twenty or so hours of the telethon.

The money is what justifies, even sanctifies, this annual ritual of tears and guilt. In 1999 the telethon raised over $53 million. That massive amount of money that people -- young and old, rich and poor -- feel compelled to donate, giving "till it hurts," as Jerry Lewis insists -- that money makes it very hard to challenge what is actually going on.

But there we were, back in September 1991, on Denver's busy 16th Street Mall, challenging the Jerry Lewis Labor Day Muscular Dystrophy Telethon. Along with activists in cities around the country, including Chicago, Los Angeles, and Las Vegas, we were protesting the telethon's portrayal of people with disabilities as helpless and pathetic. We were asserting publicly that this colossal begging festival, supposedly carried out on our behalf, is offensive to us and damaging to our efforts to become first-class citizens. Our protests were small, but they would become an annual tradition -- much to the annoyance of Jerry Lewis and MDA.

For years we had been protesting against the barriers which keep people with disabilities from using buses, public buildings, and other facilities. Now we were taking on one of the biggest barriers of all: the paternalistic attitudes which prevail in our society, and which are reflected so dramatically in the annual telethon.

It is difficult to raise objections to something like the telethon; people are reluctant to disparage, or even entertain questions about, an effort which
they perceive as fundamentally good, or at least well-meaning. That is understandable. It is an uncomfortable truth, in social work, in government activity, and in charitable endeavors, that actions which are intended to help a certain group of people may actually harm them. By harm, I mean -- among other things -- that these actions may reinforce the already devalued status of people with disabilities in this society. Looking closely and critically at the telethon, as some of us have started to do, brings up a number of issues which I feel are essential to understanding the status of people with disabilities as an oppressed minority group in America. These issues include: charity versus civil rights; cure versus accommodation; self-expression and self-determination; and the relationship between pity and bigotry.

The telethon has one goal -- to raise as much money as possible for the Muscular Dystrophy Association, or MDA. Conventional wisdom says that the most effective way to do this is to appeal directly to the emotions of viewers -- to move people so strongly, with stories of tragic suffering, that they will want to help "save Jerry's kids." Money is tight these days; charitable solicitation is a competitive business. Invoking sympathy sufficient to pry open wallets is not an easy task. But those orchestrating the telethon have a foolproof, not-so-secret weapon: children. Never mind that two-thirds of MDA's 1 million clients are adults -- the telethon is not in the business of trying to represent the real lives of people with muscular dystrophy. That's not the point. The point is to paint a picture of a victim so tragic, and at the same time so cute and appealing, that viewers will be compelled to call in a pledge. This victim must also appear helpless, utterly unable to help him/herself, so that the giver can gain a personal sense of virtue and superiority from the act of giving. Finally, the victim must display something called "courage," which does not resemble the bold, active kind of courage most people aspire to or at least fantasize about, in which one takes one's destiny into one's own hands and, by exercising will and choice, affirms oneself and/or one's place in the universe. No, the "courage" demanded in this instance is the willingness to deprecate oneself; to accept other people's versions of one's own reality; to reject one's own identity in favor of an eagerly anticipated cure (this is also called "hope"); to tolerate and even encourage the assumption that life with a disability is a life
scarcely worth carrying on with, except for the generosity of Jerry Lewis and everyone involved in the telethon.

At the age of eleven, I was enlisted into this role of cheerful victim. I was a Poster Child. In 1973-74, I became a mini-celebrity, appearing at fundraisers throughout Colorado. I learned to smile whenever a camera appeared, and to say "thank you" -- in other words, I learned to look, sound, and act cute and grateful. And on Labor Day, I became a prop in the TV studio where the local portion of the telethon was broadcast. To whole families, driving by to drop their contributions in a giant fishbowl outside the studio; to the camera's blinking red light; to the anchorman who squatted next to me, holding a huge microphone in my face; to everyone, I gave the same cute-and-grateful act, because that's what they wanted.

So I am no stranger to the telethon. And in the two decades since then, the telethon doesn't seem to have changed much. I watch it every year, just to make sure. It's still chillingly familiar. The sappy music, the camera close-ups of wistful faces, the voice-overs telling us about that person's dream to walk someday, the tearful stories told by parents "devastated" by their children's disability, and the contributors coming forward in droves -- it was all just the same as I remember it.

But some things have changed; I have changed. I don't know what my politics were as an eleven-year-old, if I had any. But my politics now -- which are not merely political but also personal, spiritual, and practical -- have led me to question and ultimately reject most of the values which the telethon represents.

Let's start with the money. Does it help? Doesn't it make the stereotypes, the appeals to pity, the obnoxious on-air begging worth putting up with?

Yes, the money does help -- some people, with some things. We are talking about a lot of money here. MDA Executive Director Robert Ross asserts that during its 26-year history, the telethon has raised over $600 million. In 1999, the telethon raised over $53 million.
With all this money coming in, I would expect the direct services provided to people with neuromuscular diseases to be much more extensive, and more relevant, than they actually are. I would expect, for example, that when a person develops a condition which begins to limit his or her mobility, that MDA might come through with some money for access modifications to the home, so that the family wouldn't have to choose between moving to an accessible house (which are hard to find), or hauling the person up and down stairs all day. I would expect some support services for independent living -- someone to assist with personal and household needs, training in things like cooking and cleaning from a wheelchair, and help with transportation. I would expect MDA to provide a motorized wheelchair for anyone who wants one. Such a chair can boost a disabled person’s quality of life enormously. Instead, MDA has very restrictive criteria for determining who receives a motorized wheelchair.

Far be it from me to advise a multimillion-dollar agency on how to spend its money. But when the telethon tells viewers that by donating money to MDA, they are answering the prayers of people with MD -- offering them a friend to turn to in times of need -- it exaggerates.

Okay, say the defenders of the telethon, so maybe the money doesn't help people now as much as it should. Isn't it still laudable that the telethon raises so much money to help find a cure?

Ah, the cure. That's the promise that keeps people sending in those checks. That's what keeps this humiliation going year after year. We're getting closer all the time! Jerry Lewis assures us frenetically. He's been saying it for four decades.

Shortly after my stint as Poster Child was over, I remember meeting a stranger in a store who recognized me from the telethon. He said to me, "I bet you really hope they find a cure soon!" When he said this, I realized that by this time, I almost never even contemplated that possibility anymore, let alone hoped for it. I told him that. I don’t think he believed me. I find the same reaction now, when I criticize the telethon for implying that people with disabilities sit around hoping and praying for a cure. I've encountered people who, never having tried it, think that living life with a disability is an
endless hardship. For many of us, it's actually quite interesting, though not without its problems. And the majority of those problems result from the barriers, both physical and attitudinal, which surround us, or from the lack of decent support services. These are things that can be changed, but only if we as a society recognize them for what they are. We'll never recognize them if we stay so focused on curing individuals of disability, rather than making changes to accommodate disability into our culture.

Now, I'm not arguing that medical research should halt entirely -- I'm just weighing the cost-benefit value, in my life and in the lives of my friends with disabilities, of the millions of dollars spent on the search for a cure, a search that will take decades, versus the things we really need now, on which society spends far less. We will probably never benefit from the cure. We will benefit from accessible buildings and transportation systems, job opportunities, and attendant services to provide us personal assistance. So will future generations.

We have begun making progress in those areas. In 1990, for example, the Americans with Disabilities Act became law, putting some legal teeth into our fight for civil rights and access.

But for all our progress in the areas of legal protection and accessibility, there's still this lingering attitude that what people with disabilities really need is to be cured. Society wants the problem to go away, so it won't have to accommodate people with long-term disabling conditions. It wants us to go away, or at least to "get better." One of my major objections to the telethon is the way it reinforces that attitude.

Sure, some people with muscular dystrophy do hope and dream of that day when the cure is finally found. As people with disabilities, we're conditioned just like everyone else to believe that disability is our problem. We've been told over and over that our need for accessibility to buses and buildings, and our need for health services, are too expensive, too unreasonable. Our culture considers it shameful to be physically unable to dress oneself, or to need assistance in going to the bathroom. Rather than demanding that the government provide such helping services, many people with disabilities end up hidden in nursing homes or in our own homes, where personal assistance
remains the private "burden" of individuals and families. Rather than insisting on having our personal needs and our access needs met, many prefer to keep quiet about these needs, fearful to show ourselves lacking. The telethon itself encourages such self-defeating thinking. We are primed to regard ourselves as substandard. We therefore hesitate to assert our right to have that which, because of our disabilities, we need. The telethon teaches us to think that others will provide for us because they are kind and generous, not because we are a strong and vocal community. When so many of us feel so negative about our disabilities and our needs, it's difficult to develop a political agenda to get our basic needs met. The cure is a simple, magical, non-political solution to all the problems in a disabled person's life. That's why it's so appealing, and so disempowering. The other solutions we have to work for, even fight for; we only have to dream about the cure.

The idea of a cure is at least in part an effort to homogenize, to make everyone the same. To draw a parallel, when I was a child and first learned about racial discrimination, I thought it would be great if people could all be one color so we wouldn't have problems like prejudice. What color did I envision for this one-color world? White, of course, because I'm white. I didn't bear black people any malice. I just thought they'd be happier, would suffer less, if they were more like me.

We all have our own ideas about which human condition is best, based on our own assumptions about other people's lives. These assumptions don't always jibe with reality. People who assume that I live for the day when a cure is found, when I (or future generations) can live disability-free, simply don't understand my reality. It's a question of priorities. On the list of things I want, a cure for my disability is pretty low. Higher up on the list would be achievement of my personal, professional, and social goals, and these are not in any way dependent on a cure.

Besides, there's an issue of pride involved. Disability is a part of my whole identity, one I'm not eager to change. Especially not at the cost of my dignity and personhood, as the telethon implicitly demands.

This gets to another important issue the telethon raises in relation to the oppression of people with disabilities: Whose job is it to tell the story, or
stories, of a group of people? The telethon is full of "profiles" of people with various forms of muscular dystrophy and their families. Yet these stories are packaged as products, not told as truth. Favorite subjects are children, for reasons discussed earlier -- children can be made to appear more helpless, more pathetic, more dependent on the public's generosity. Children are also cute; therefore they seem more deserving of help.

In comparison with my telethon years, recent telethons do profile more adults with muscular dystrophy. Some are successful, competent adults. Yet somehow, even these individuals were made to look desperate and pitiable.

On any given telethon -- both on the national broadcast from Las Vegas, and during the cut-aways to local segments -- you will see profiles of children and adults with muscular dystrophy. These spots are all fairly similar in tone and emphasis. As if by a prescribed formula, each one contains several key ingredients. In each, the parents speak about their reactions upon hearing their child's diagnosis -- even if, as in most cases, this has occurred years, or even decades, before. Naturally, these reactions include disbelief and grief. Yet there is rarely any discussion of how (or whether) the family has since come to accept the knowledge of their child's condition, to find resources (other than those offered by MDA), to plan for the child's future, or to promote the child's self-esteem. The situation is presented as an unmitigated tragedy.

I'm suspicious of this presentation. I'm not trying to minimize the pain a parent might feel upon learning that a child has a disabling, potentially even fatal, diagnosis. There is a very natural grieving process that goes along with disability at any stage. But when I see those emotions exploited so crassly, I can't help wincing. For most of us, our losses, gains, sorrows and joys are simply part of a rich human life. The telethon works very hard to convince people that our suffering is extraordinary. This produces pity, confusion and misunderstanding.

Another common element in these pieces is the emphasis on "what Johnny can't do." A child, usually a boy, is shown sitting at the edge of a playground. The narrator talks about the games the child can't play, and how he has to
watch other children running and jumping. He can only dream, the narrator tells us sadly.

Never mind that the kid might be adept at playing Nintendo, or making rude noises with his mouth. In the real world of children, these skills are valued at least as much as running and jumping. The truth is, all children play at different levels of skill; most can't run as fast as they would like, or jump as high, or play as well. Children in wheelchairs do play with other kids on the playground -- I did. A child in a motorized wheelchair can be mobile, active - and popular, if willing to give rides now and then. But instead of acknowledging any of this, the telethon encourages viewers to project their own worst fears onto people with muscular dystrophy: "Just imagine what it would be like if your child couldn't play baseball."

Finally, each piece puts forward an archaic and gloomy picture of the disabled family member's role, and of the role of the family in a disabled person's life. All the families are described as "courageous"; and they all seem to bear total responsibility for the care and support of the person with MD. Spouses and parents alike are shown carrying the person with MD up and down stairs, pushing their wheelchair, and so on. Rarely if ever is the disabled family member shown making any positive contribution. In these stories, the disabled person's status is clearly (even if the word was never used) that of "burden."

I am all for supportive families. My own parents and brother have stood by me throughout my life, backing me with assistance and encouragement. But I have also built a life apart from them. Many people with disabilities do so, getting educated, working, and having families of our own. I am able to live independently, working toward the goals I choose, as long as I have access to the support services I need -- primarily attendant services. I am lucky that the state of Colorado pays someone to come to my home and help me get up in the morning and get to bed at night. Most states do not offer this service, forcing people with disabilities to remain in the care of their families, or to enter nursing homes. Indeed, attendant services is the number one disability rights issue of the 1990's. Activists are demanding that the federal government divert a part of the huge budget which currently subsidizes the
nursing home industry, and create a national system of attendant services, available to anyone who needs them.

On the telethon, of course, this is a non-issue. Disability is a private problem, demanding faith and fortitude from families, demanding generosity from viewers, demanding nothing from the government, or from society as a whole. If the need for personal assistance is mentioned at all, it is only to highlight, once again, the purported helplessness of people with MD, as in phrases such as "totally dependent on others for the most basic activities the rest of us take for granted." In fact, the opposite is true: With decent attendant services at my disposal, I become more independent, not more dependent. But to present that truth might undermine that vision of the long-suffering, burden-bearing family.

The unvarying tone and content of the pieces made it difficult to distinguish one "patient" from another. The profiles put forward a stereotyped view of what it means to have a disability, rather than any genuine stories of real people. We are all individuals, and families are all different. Not on the telethon, though. There we are made to fit the mold. Even the language used on the telethon distorts our reality and thereby dehumanizes us: We are "victims," we "suffer" from our conditions, we are "desperate."

I have firsthand experience of this distortion effect. Six or seven years after my Poster Childhood was over, just before my second year of college, I was asked to be interviewed for a local pre-telethon TV special. At first I said no. I was by now quite leery of the telethon mentality. I had also started becoming politicized, and was now more interested in civil rights than in charity. And I couldn't see any reason to participate once again in the simple-minded propaganda I remembered from my on-camera appearances as Poster Child. Back then, I had been asked questions like, "What would you like to say to all those nice people who are calling in their pledges, Laura?" to which the obvious reply was, "Thank you." Such questions left little room for honest expression.

But the local MDA office promised that the interview would be handled differently in this program: The plan was to take a positive, realistic approach and portray the real lives of three real people. So I agreed.
A TV news reporter conducted the interview in my parents' home. She asked good questions and allowed me to give complete, intelligent answers. It was certainly a different process from my earlier experiences. Afterward, I felt good about the upcoming show. I had been able to discuss issues, describe my life as a college student, and project a strong, positive personality.

Or so I thought. When the program aired, I was horrified. Through careful editing, it had turned into a sob story entitled "Waiting For A Miracle." From that point on, I vowed to have nothing to do with the telethon.

Until 1991, that is. I learned that two Chicago activists, Chris Matthews and Mike Ervin, were interested in coordinating actions against the Jerry Lewis telethon. Like me, they were both former poster children. I urged people from Denver's community to join the campaign. My decision to organize a protest did not come without some thought. In fact, I had for years contemplated doing something like this, but had not. I knew that our message would not be an easy one to convey to the public. Many people are involved with the telethon, either as volunteers or as contributors. I knew that openly criticizing it would cause confusion and anger. The telethon enjoys widespread acceptance, even acclaim.

But that is exactly why it's so important, I feel, to raise our voices against it. Because it is accepted as our reality. This is my biggest gripe against Jerry Lewis, and against the telethon: the extent to which they claim to tell my story, our stories, without any legitimate authority to do so.

The telethon's hegemony over the image of disability is quite staggering. A 1996 press release issued by MDA states, "According to A.C. Nielsen, last year's Telethon was watched by some 70 million Americans or 27 million households. The MDA Telethon -- considered the granddaddy of all Telethons -- ranks in viewership with the World Series and the Academy Awards." Those 70 million people are absorbing a message shaped by greed, deception, and bigotry.

The bigotry of Jerry Lewis is worth discussing. I don't necessarily enjoy attacking another person's motives, but I hear defenders saying, "Jerry Lewis is trying to help so many people. How dare you criticize his methods?"
This means-justifies-the-ends argument has a long and despicable history, which I don't need to go into here. Even more dangerous is the attitude that people who are "being helped" have no right to say how they want to be helped, or treated, or thought of. This is paternalism at its worst. By being the object of charitable efforts, do we thereby waive our right to respect, and to free speech? If people are really interested in helping me, wouldn't they want to hear me tell my own story, rather than hearing a distorted version of it from someone who not only doesn't share my experience, but who doesn't even seem to want to listen to me? With the stated goal of "helping" his "kids," Jerry Lewis is helping to keep alive the most pernicious myths about people who have disabilities. He ignores our truth, substituting his own distorted assumptions.

If our protest did nothing else, it allowed some of us the opportunity to say, "No, this is not our reality. If you want to know what our lives are like, listen to us. If you want to know what we need, ask us. If you truly want to help us, let us tell you how. And if you pity and fear us, please own that; then let us work together at changing the world so that disability will not be something to fear, but something to try to understand."

The response to our protest has been interesting. Many people seem to resent our daring to object to these distortions, half-truths, and stereotypes. I have been called "ungrateful," "cruel," and "insensitive" -- simply for trying to counter all this with the truth, with my truth. At the very least, I feel that the protest has enabled me and others to begin getting on record our own stories, in contrast to the misleading accounts that come from the telethon.

Media is a powerful thing. It can deceive, or it can enlighten. About a week after that 1991 telethon, a publication arrived in my mailbox called MDA News Magazine, put out by the national Muscular Dystrophy Association office. I started to leaf through it, expecting to find the same kinds of negative stereotypes that permeate the hours of the telethon. Instead, I found articles about job-seeking strategies; profiles of successful individuals who have neuromuscular diseases; honest and thoughtful pieces about families of children with neuromuscular diseases; lists of useful resources; and clinical updates. All of it was written in a positive, realistic tone, using...
respectful and appropriate language. The phrase "people with disabilities" was used at all times -- never "victims," or "sufferers," and certainly not "cripples."

One article, written by Marie Hite, whose son has muscular dystrophy, stood out. Its basic theme was very similar to some of the telethon spots I had viewed: the difficulties a child has in coping with a progressively disabling condition. But Hite's treatment of the subject couldn't have been more different from that presented on the telethon. In her article, her son confided that he could no longer climb a neighbor's tree; he asked his mother for an explanation. She replied that his muscles didn't work the same as other children's.

Whereas the telethon would have used this situation to create pity, this article used it to tell a touching, upbeat story. In it, the focus was not so much on how the boy differs from other children, but on how the author helped her son understand his disability, and on his own resourcefulness in adapting to it. The grief was not denied, but neither was it overdone.

Tears instantly flowed down Petey's cheeks. 'But, Mom, I want to climb trees, too,' his voice pleaded.

Silence....

What to say?...

I let him know that it was OK to feel sad, and I stayed with him.

Five minutes later, he was OK again.

'Petey, I'm going to help you climb Mrs. Kurly's tree when I get home from work,' I said. His face lit up....

Her conclusion emphasized the boy's fundamental similarity to other children in struggling to understand and come to terms with himself and his world:
He had accepted his limitation as only a 6-year-old can, with childish grace and fantasy.

There are limits -- and tree trunks -- that love, with a little ingenuity, can rise above. Like other 6-year-olds, Petey just wanted to play in the tree.

In Hite's piece, Petey got what he wanted, with some assistance and adaptation; in fact, this describes fairly well how most people with severe disabilities live -- with assistance and adaptation. Petey was portrayed as a real child, full of humanity. What a different view from that to which telethon viewers are exposed annually!

I was impressed by the sophistication and sensitivity of the writing in this magazine -- but also a little baffled. How could the same organization that edits this publication, with its realism and insight, also produce the Jerry Lewis telethon? They know better! I thought.

Then I realized the reason for the apparent split personality within MDA. I was seeing two very different presentations, intended for two very different audiences. The magazine is aimed at people with neuromuscular diseases and their families. I commend MDA for offering their clients such a high-quality forum for education, information, and the sharing of experiences.

However, I am dismayed that when it comes to informing the general public, MDA chooses to take the opposite approach. Does the organization fear exposing potential donors to the truths revealed so eloquently in its magazine? Does it foresee a decline in contributions if nondisabled people start to see people with disabilities as we really are? Is respect and awareness bad for the bottom line? Is raising consciousness incompatible with raising money?

Images of people with disabilities sink into the public mind every Labor Day, images of helplessness and eternal childhood. We see children frolicking at summer camp, while an announcer tells us how miserable those children are the rest of the year. We hear tear-jerking stories from parents lamenting their child's condition. Pity is the name of the game in telethonland. Pity brings in big bucks.
So what's wrong with that?

Pity is a complex and deceptive emotion. It pretends to care, to have an interest in another human being. It seems to want to take away pain and suffering. But if you look at pity up close, you notice that it also wants to distance itself from its object. A woman calls in a pledge and boasts, "My two children are perfectly healthy, thank God!" Pity does not share another's reality, only remark upon it.

Pity can be very hostile to the achievement of equality and respect. If you feel sorry for someone, you might pledge a donation, but you are not likely to offer them a good job, or approve of them dating your sister or brother. If emotions were to be grouped into families, pity has some rather unsavory kin. On this emotional family tree, pity is very close to -- sometimes indistinguishable from -- contempt and fear, which are uncomfortably near to hatred.

That might sound like a strong statement. But I would argue that any reaction which creates separation and inequality between people -- which pity certainly does, however benevolent it might appear -- is destructive. People cannot live together in community, recognizing and respecting each other as human beings, if one group feels superior to the other for any reason.

Pity paves the way for paternalism, for the attempt to control people on the basis of disability. I have lived with the implications of this reaction, this assumption that I am less able to, have less of a right to, run my own life. I saw it in the eyes of the high school journalism teacher who didn't want me in her class. I see it on the faces of people who pass me on the street, and wonder (perhaps) what I am doing out in public.

Of course, many experiences and many emotions go into the formation of bigotry. I cannot blame all discrimination on pity. Nor can I blame all tendencies toward pity on the Jerry Lewis Telethon. But we need to analyze the way this annual event capitalizes on, and feeds, those tendencies. We need to ask ourselves whether all that money, tracked exuberantly on those giant tally boards, is worth it.
I say it's not.

The effects of our protests on the Jerry Lewis Labor Day Telethon have been mixed. It has become a TV show with a split personality.

Beginning with the 1992 telethon, we began to see some changes from previous years. We saw lawyers, accountants, teachers and journalists with muscular dystrophy, receiving recognition as winners of Personal Achievement Awards. We heard the words "dignity" and "self-respect" used over and over, sometimes in strange contexts -- as in "Please call in your pledge to help us save these kids' dignity and self-respect." We heard talk about the Americans with Disabilities Act and the need for a personal assistance program.

But we also saw the old familiar scenes: tuxedo-clad local hosts sweating and beaming, well-groomed two-parent families poised to look brave and desperate, Jerry Lewis mugging and weeping.

The Muscular Dystrophy Association has consistently, obstinately refused to acknowledge the validity of our concerns. Marshalling all its defenses, MDA feverishly protects the decades-old tradition. Those of us identified as the telethon's chief critics continue to be told how ungrateful, unreasonable, vicious, and emotionally disturbed we are.

Yet we'll continue to critique this twenty-plus-hour-long epic. It's a microcosm of so many of our society's attitudes towards disability. It's the details which, for me, sum up the telethon perfectly -- both its attempts to change and its intrinsic flaws.

A few examples:

The telethon has often featured a Florida woman named Shelley, an obviously intelligent person with a graduate degree and a professional career. In one typical segment, Shelley and her mother were both interviewed about their hope for a cure for muscular dystrophy. Her mother raised one hand a few inches and, near tears, said something like, "If only she could do this, that would be all I would ask for her." While other
mothers wish for their grown children to have personal happiness, professional success, and a family, the telethon encourages the belief that the mother of a disabled adult can only hope for one thing -- either total or partial cure.

The mother also stated that she is afraid to leave Shelley at home alone, because she can't use the telephone, or answer the doorbell, by herself. I had to wonder why Shelley did not have access to the relatively simple and inexpensive devices now available, such as hands-free telephones, and doorbell intercoms.

This scene was typical of several telethon segments: In presenting an individual with a neuromuscular disorder, the focus would be on functions the person couldn't do. When I see a story like that, I start this mental process of problem-solving -- thinking about adaptive equipment, attendant services, access modifications, etc. -- things which could help the person function more independently.

But apparently, the general public takes these things at face value: If Shelley can't answer her own telephone, the only possible solution is to cure her disability.

The telethon certainly doesn't encourage viewers to think of other options. If the person can use equipment and personal assistance to live more independently, then viewers may not feel as sorry for her.

There was another vignette about a family with two sons, one of whom has MD. In focusing on the younger, non-disabled son, the narrator made a statement to the effect that he doesn't have a big brother who can take him places and teach him things -- he has a brother he has to take care of.

This statement implies that people with disabilities are incapable of giving to any kind of relationship, that we are undesirable even as siblings. (The telethon also promotes the idea that people with disabilities are miserable parents: Fathers and mothers are shown passively watching as their kids run and play, as if someone in a wheelchair could never provide children with affection, discipline, or moral or financial support. And forget any notion
that people with MD can be sexual. The telethon presents even spouses as caretakers, not lovers. The denigration of our potential for relationships is perhaps one of the most dehumanizing and negative aspects of the telethon.

The next day, a different family appeared on the local segment of the telethon. Like the first family, there were two teenage boys, one, named Paul, with MD. The brothers were obviously very close. Again, the host made a major point of talking about how the non-disabled boy "takes care of" and assists his brother Paul. At this statement, the father leaned over to the microphone and said pointedly, "Paul helps him a lot too."

The host ignored this attempt to set the record straight, but I was very moved by it. I feel real compassion for people like that family, who participate in the telethon, yet try (usually in vain) to preserve their own dignity and truth.

MDA representatives have stated again and again that pity works, it makes people give money. They might be willing to change a few things, add some references to the ADA here and there, recognize some "achievers" with MD. But they are not about to tone down, in any significant way, their appeals to pity.

We can take credit, though MDA would never acknowledge it, for the changes that have occurred -- they are certainly a direct result of our criticism and protests. But we have to increase the pressure, keep raising awareness, and stop this annual insult once and for all.

Read more of Laura's writing at: Laura Hershey's Weekly Web Column

Language
English
Microsoft Office PowerPoint

Microsoft Office PowerPoint, available for both PC and Mac, is a presentation development application used ubiquitously in business and educational settings to create slide-based complements to presentations. The versatility of this slideshow tool allows for the creation of highly customizable live and web presentations, handouts, and outlines.

Accessibility Barriers

- Screen reader users will not be able to access content within a text box.
- Information presented as an image, animation, or video will be inaccessible to screen reader users when alternative text is not included.
- Slides that use low contrast or patterned backgrounds will be inaccessible to low vision users.
- Slide transitions and animations that require a mouse click may also result in inaccessible presentations, particularly for users who are blind or have mobility impairments.
- Screen readers read containers within a slide in the order that they were created and not in the order they appear.
- Animations and slide transitions may cause screen readers to re-read slides.
- Automatic slide transitions may not give users enough time to read slide content.
- Speech recognition software is not fully compatible with PowerPoint, as PowerPoint does not support the Text Services Framework (TSF).
- Speech recognition software will cause a video playing in a slideshow to freeze.

Best Practices

Structure

- Use unique heading titles for each slide.
• Text included on slides should be included in the outline.
• Use pre-defined PowerPoint slide templates rather than creating custom templates.

Images

• Charts, tables, and graphs should be inserted by selecting the appropriate slide layout or using the Insert menu.
• Include alt text for images.
• Include extended descriptions for charts and other graphics intended to convey information.

Content

• Use sans-serif fonts.
• Use appropriate punctuation at the end of each bullet point.
• Avoid using text boxes not in a pre-defined template.
  o Adaptive technology may interpret text boxes as inaccessible graphical elements.
  o Screen readers will read text in the order created, not in the order in which it appears.
• Use a color scheme that presents a sharp contrast between text and background.
• Caption embedded video.

Additional Information

Microsoft PowerPoint 2010 includes new accessibility features such as a Document Accessibility Checker and video trigger. Akin to a spell check, the Document Accessibility Checker scans PowerPoint presentations for accessibility issues. Grouped into three categories, these issues include, but are not limited to:

• Errors: Alt Text, Table Headers, Slide Titles, IRM Access;
• Warnings: Blank Table Cells, 2D Table Structure, Meaningful Link Text;
• Tips: Captions, Slide Reading Order, Unique Titles.

Video Trigger allows users to create captioning for embedded video by marking locations in a video (bookmarking) and employing animated text sequences. This feature will allow users to easily caption media thus expanding the amount of video options available to the user.

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How person-first language isolates disabled people

Ryan Theodosia  Follow
Apr 13, 2019 · 6 min read ★

Note: This article uses a couple of uncensored, ableist slurs as examples of language carrying stigma in the first paragraph of the section “Who does person-first language really benefit?”. In context, they do not refer to anyone in particular.

As I progress through college writing, arts, and social science courses, I often run into this hard-and-fast rule that, when describing disabled people, person-first language is “correct”. Person-first language includes terms like “people with disabilities”, as opposed to the identity-first “disabled people”. Though there were good-faith arguments for using person-first language over identity-first language when it first emerged, in the decades since it has often been questioned. As a disabled person, I strongly prefer identity-first language for two main reasons: person-first language limits our identity creation and social ties, and it benefits able-bodied people over disabled people.
Effects on disabled identity, communities, and pride

One of the primary arguments against person-first language is that it separates people from their disability, which often is central to their life experience. “Disabilities” like autism, deafness, blindness, and paralysis alter a person’s perception and sensory experiences. After being disabled for some time, it becomes difficult to imagine life without the disability. Using person-first language implies that any disabled individual would be the same without their disability. Our life histories shape who we are, so this is not and cannot be true.

Using person-first language for disability alone, while still using identity-first language for most other traits, separates disability from other social identities. It dissuades disabled people from identifying as disabled, even as many of us feel this is central to who we are. Disability changes a person’s life, and many of us find comfort in finding others with similarly-altered experiences. When identity-first language is the default, treating disability differently implies that disabled people should not identify as such. We are discouraged from feeling kinship with each other, which isolates us and prevents us from linking our experiences as disabled people with other parts of who we are.

Person-first language relies on Western cultures’ stubborn individualism. It rests on the concept that each person should identify first and foremost as an individual, but this is not how humans work. We are social animals, and we identify ourselves as compared or contrasted to others in our group. These identities lead to social groups with either exclusive, discriminatory beliefs or inclusive, accepting beliefs. We cannot deny how central social experiences are to human life, and disability is, in most parts of daily life, a social experience. Denying this social reality ends up increasing isolation and self-blame among disabled people.

Who does person-first language really benefit?

Person-first language developed in 1988 as a way to, in theory, increase awareness of disabled people’s humanity. The basic idea was that, in putting the label before the word “person”, the phrase “disabled person” was somehow stripping us of personhood. This rational is, in itself, suspect. While linguistic relativity is real, we cannot simply change how a culture views a group by changing the labels we use. Rather, when language
changes, the new words often adopt the same stigma held by the old. Think of all the
terms used to describe intellectually disabled people over the years, and how many of
them (including “imbecile”, “stupid”, “idiot”, etc.) are no longer medical terms. They are
now merely insults, and the same thing happened not long ago with the word
“retarded”.

So, the premise that changing sentence structure alone will change the way we perceive
a group is flawed. Further, the idea of person-first language quickly became a way for
people to prove they are “allies”. It allows organizations to say they are making efforts to
be inclusive without spending much money. Compared to the effort needed to fully
accommodate disabled people, this shift is cheap and easy. Inclusion efforts often stop
there. No real efforts to center disabled people as real humans occur.

Disabled people can and often are rejected for jobs we apply to or fired from jobs we
have just for being disabled. For those of us who can even attempt to hide our
disabilities, we have a choice: hide the disability for as long as possible, or give up on
searching for work and spend our time and energy apply for social security. The fact that
businesses act like they are including us just by adjusting their language when they still
largely refuse to hire disabled people or pay us even minimum wage is a massive insult.

Three decades after the term “person-first language” became popular, many disabled
people reject the general idea (see the end of this article for links to examples of this).
We believe it is awkward and does not work with the way English speakers naturally use
our language. For my part, I want to be seen as a disabled person and an Autistic person,
just as I want to be seen as a nonbinary person and a queer person. I don’t want to be a
“person with autism” or a “person with a disability” just as I don’t want to be a “person
with a nonbinary gender” or a “person with queerness”. The Deaf and Blind
communities have made this point repeatedly to no avail.

Using person-first language even with real, live disabled people who say we don’t prefer
this language is, strangely, the real ableism here. It is ableist to assume we all prefer the
same terms, and it is ableist to insist that non-disabled people know us better than we
know ourselves. It is ableist to assume that identity-first language is somehow bad, or
that it is wrong to identify as a “disabled person”. When deciding how to treat disabled
people, the disabled people’s opinions should always outweigh those of able-bodied
people.
There is nothing wrong with being disabled, and it should not be treated as worse or separate from other social identities. The sooner we learn this, the sooner we can start to address ageism, transphobia, and all sorts of other forms of discrimination that rely on turning certain traits and identities into diseases. Ableism is present in all sorts of discriminatory beliefs. If we can accept that being “weak” or “faint” is not solely negative, that being “crazy” is okay, and that every single person has value no matter how different they are, bigots not be able to fall back on treating stigmatized people as diseased to justify their hatred. We will be able to replace this deeply-embedded trope with communal healing and pride in both variety and sameness.

**Further reading**

The Problem with Person-First Language (Rachel Cohen-Rottenberg, 2015; the body is not an apology)

Why I Don’t Use People First Language: A Brief History of My Relationship with the Language and Disability (crippledscholar, 2015; crippledscholar on Wordpress)

WHY PERSON-FIRST LANGUAGE DOESN’T ALWAYS PUT THE PERSON FIRST (Emily Ladau, 2015; Think Inclusive)

ON “PERSON-FIRST LANGUAGE”: IT’S TIME TO ACTUALLY PUT THE PERSON FIRST (Alex Kapitan, 2017; Radical Copyeditor)

Person-first language: Noble intent but to what effect? (Roger Collier, 2012; CMAJ on PMC)

The Significance of Semantics: Person-First Language: Why It Matters (Lydia X. Z. Brown, 2011; Autistic Hoya)

Identity and Hypocrisy: A Second Argument Against Person-First Language (Lydia X. Z. Brown, 2011; Autistic Hoya)

**More from Journal**
There are many Black creators doing incredible work in Tech. This collection of resources shines a light on some of us:
Introduction to Web Accessibility

Summary

When websites and web tools are properly designed and coded, people with disabilities can use them. However, currently many sites and tools are developed with accessibility barriers that make them difficult or impossible for some people to use.

Making the web accessible benefits individuals, businesses, and society. International web standards define what is needed for accessibility.

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- Accessibility in Context
- What is Web Accessibility
- Accessibility is Important for Individuals, Businesses, Society
- Making the Web Accessible
- Evaluating Accessibility
- Examples
- For More Information
Accessibility in Context

"The power of the Web is in its universality. Access by everyone regardless of disability is an essential aspect.”

— Tim Berners-Lee, W3C Director and inventor of the World Wide Web

The Web is fundamentally designed to work for all people, whatever their hardware, software, language, location, or ability. When the Web meets this goal, it is accessible to people with a diverse range of hearing, movement, sight, and cognitive ability.

Thus the impact of disability is radically changed on the Web because the Web removes barriers to communication and interaction that many people face in the physical world. However, when websites, applications, technologies, or tools are badly designed, they can create barriers that exclude people from using the Web.

Accessibility is essential for developers and organizations that want to create high-quality websites and web tools, and not exclude people from using their products and services.
What is Web Accessibility

Web accessibility means that websites, tools, and technologies are designed and developed so that people with disabilities can use them. More specifically, people can:

- perceive, understand, navigate, and interact with the Web
- contribute to the Web

Web accessibility encompasses all disabilities that affect access to the Web, including:

- auditory
- cognitive
- neurological
- physical
- speech
- visual

Web accessibility also benefits people without disabilities, for example:

- people using mobile phones, smart watches, smart TVs, and other devices with small screens, different input modes, etc.
- older people with changing abilities due to ageing
- people with “temporary disabilities” such as a broken arm or lost glasses
- people with “situational limitations” such as in bright sunlight or in an environment where they cannot listen to audio
- people using a slow Internet connection, or who have limited or expensive bandwidth

For a 7-minute video with examples of how accessibility is essential for people with disabilities and useful for everyone in a variety of situations, see:

Web Accessibility Perspectives Video (YouTube) (https://www.youtube.com/watch?v=3f31oufqFSM)
More Info on What is Accessibility

- When you want to learn more about how different disabilities affect Web use, and read about scenarios of people with disabilities using the Web, see How People with Disabilities Use the Web (https://www.w3.org/WAI/people-use-web/).

- If you want more examples of benefits for others, with WCAG to back it up, see Shared Web Experiences: Barriers Common to Mobile Device Users and People with Disabilities (https://www.w3.org/WAI/standards-guidelines/shared-experiences/) and the archived Web Accessibility Benefits People With and Without Disabilities (https://www.w3.org/WAI/business-case/archive/soc#groups).

Accessibility is Important for Individuals, Businesses, Society

The Web is an increasingly important resource in many aspects of life: education, employment, government, commerce, health care, recreation, and more. It is essential that the Web be accessible in order to provide equal access and equal opportunity to people with diverse abilities. Access to information and communications technologies, including the Web, is defined as a basic human right in the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD (https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html)).

The Web offers the possibility of unprecedented access to information and interaction for many people with disabilities. That is, the accessibility barriers to print, audio, and visual media can be much more easily overcome through web technologies.

Accessibility supports social inclusion for people with disabilities as well as others, such as:

- older people
- people in rural areas
- people in developing countries

There is also a strong business case for accessibility. As shown in the previous section, accessible design improves overall user experience and satisfaction, especially in a variety of situations, across different devices, and for older users. Accessibility can enhance your brand, drive innovation, and extend your market reach.

Web accessibility is required by law in many situations.
Making the Web Accessible

Web accessibility depends on several components working together, including web technologies, web browsers and other "user agents", authoring tools, and websites.

The W3C Web Accessibility Initiative (WAI (https://www.w3.org/WAI/get-involved/)) develops technical specifications, guidelines, techniques, and supporting resources that describe accessibility solutions. These are considered international standards for web accessibility; for example, WCAG 2.0 is also an ISO standard: ISO/IEC 40500.

More Info on Making the Web Accessible

- More about these aspects of accessibility working together is in Essential Components of Web Accessibility (https://www.w3.org/WAI/fundamentals/components/).
- Web Content Accessibility Guidelines (WCAG), Authoring Tool Accessibility Guidelines (ATAG), ARIA for Accessible Rich Internet Applications, and other important resources are introduced in W3C Accessibility Standards Overview (https://www.w3.org/WAI/standards-guidelines/).
- To learn more about how W3C WAI develops material through multi-stakeholder, international participation and how you can contribute, see About W3C WAI (https://www.w3.org/WAI/about/) and Participating in WAI (https://www.w3.org/WAI/get-involved/).

Making Your Website Accessible

Many aspects of accessibility are fairly easy to understand and implement. Some accessibility solutions are more complex and take more knowledge to implement.

It is most efficient and effective to incorporate accessibility from the very beginning of projects, so you don't need go back and to re-do work.

More Info on Making Your Website Accessible

- For an introduction to accessibility requirements and international standards, see Accessibility Principles (https://www.w3.org/WAI/fundamentals/accessibility-principles/).
- To understand some common accessibility barriers from the perspective of testing, see Easy Checks – A First Review of Web Accessibility (https://www.w3.org/WAI/test-evaluate/preliminary/).
• For some basic considerations on designing, writing, and developing for accessibility, see Tips for Getting Started (https://www.w3.org/WAI/tips/).

• When you're ready to know more about developing and designing, you'll probably use resources such as:
  • How to Meet WCAG (Quick Reference) (http://www.w3.org/WAI/WCAG21/quickref/)
  • Web Accessibility Tutorials (https://www.w3.org/WAI/tutorials/)

• For project management and organizational considerations, see Planning and Managing Web Accessibility (https://www.w3.org/WAI/planning-and-managing/).

If you need to make quick fixes now, see Approaches for Interim Repairs (https://www.w3.org/WAI/planning/interim-repairs/).

Evaluating Accessibility

When developing or redesigning a website, evaluate accessibility early and throughout the development process to identify accessibility problems early, when it is easier to address them. Simple steps, such as changing settings in a browser, can help you evaluate some aspects of accessibility. Comprehensive evaluation to determine if a website meets all accessibility guidelines takes more effort.

There are evaluation tools that help with evaluation. However, no tool alone can determine if a site meets accessibility guidelines. Knowledgeable human evaluation is required to determine if a site is accessible.

More Info on Evaluating Accessibility

• Resources to help with accessibility evaluation are described in Evaluating Web Accessibility Overview (https://www.w3.org/WAI/test-evaluate/).

Examples

For More Information

W3C WAI provides a wide range of resources on different aspects of web accessibility standards (https://www.w3.org/WAI/standards-guidelines/), education (https://www.w3.org/WAI/teach-advocate/), testing/evaluation (https://www.w3.org/WAI/test-
evaluate/). project management, and policy (https://www.w3.org/WAI/planning/). We encourage you to explore this website, or look through the WAI Resources (https://www.w3.org/WAI/Resources/) list.

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Reasonable Modification of Policy, Practice and Procedure or Reasonable Accommodation

Decision Tree -- This is a generic decision tree--facts and specifics always impact the overall process.

The ADA requires that you make reasonable modifications to policies, practices and procedures unless doing so would cause a fundamental alteration to the program, service or benefit. If someone makes a request to make a policy change based on a disability related concern and it would be impossible or unreasonable to meet that request, the shelter or entity must engage in an interactive process with the individual to figure out how to meet the need.

Question One: Is the requester a qualified person with a disability? If you want to ask questions you may ask in what major life activity the person is substantially impaired. For employment and some other situations reasonable proof may be requested but this cannot be used to go on a fishing expedition into private medical records.

Question Two: What is the policy, practice or procedure in question?

Question Three: What is the specific modification requested? There must be a specific request, however some people will not know enough about the existing policies or about their rights to know to make a specific request. It might be presented in terms of a problem or request for help. It is appropriate to discuss with the person possible solutions and useful to suggest that someone make a request for a reasonable modification/accommodation.

Question Four: Is there a nexus between the disability related need and request. Again, there may be a reason to help someone explain this if the person cannot articulate. If there is truly no nexus gently explain this to the individual.

Question Five: Is there a reason why this modification cannot be made? If no, provide the modification.

If yes, what is the reason?
Does the reason rise to a fundamental alteration of the program, service or benefit? This means that providing this modification will so alter the service as to make it a completely different program, service or benefit.

If yes, engage with individual in interactive process to figure out alternative.

This is generic guidance not legal advice-© CCDC 2013
If you are not proud
for who you are, for what you say, for how you look;
if every time you stop
to think of yourself, you do not see yourself glowing
with golden light; do not, therefore, give up on yourself.
You can
get proud.

You do not need
a better body, a purer spirit, or a Ph.D.
to be proud.
You do not need
a lot of money, a handsome boyfriend, or a nice car.
You do not need
to be able to walk, or see, or hear,
or use big, complicated words,
or do any of the things that you just can't do
to be proud. A caseworker
cannot make you proud,
or a doctor.
You only need
more practice.
You get proud
by practicing.
There are many many ways to get proud.
You can try riding a horse, or skiing on one leg,
or playing guitar,
and do well or not so well,
and be glad you tried
either way.
You can show
something you've made
to someone you respect
and be happy with it no matter
what they say.
You can say
what you think, though you know
other people do not think the same way, and you can
keep saying it, even if they tell you
you are crazy.
You can add your voice
all night to the voices
of a hundred and fifty others
in a circle
around a jailhouse
where your brothers and sisters are being held
for blocking buses with no lift,
or you can be one of the ones
inside the jailhouse,
knowing of the circle outside.
You can speak your love
to a friend
without fear.
You can find someone
who will listen to you
without judging you or doubting you or being
afraid of you
and let you hear yourself perhaps
for the first time.
These are all ways
of getting proud.
None of them are easy, but all of them are possible. You can do all of these things, or just one of them again and again. You get proud by practicing.

Power makes you proud, and power comes in many fine forms supple and rich as butterfly wings. It is music when you practice opening your mouth and liking what you hear because it is the sound of your own true voice. It is sunlight when you practice seeing strength and beauty in everyone including yourself. It is dance when you practice knowing that what you do and the way you do it is the right way for you and can't be called wrong. All these hold more power than weapons or money or lies. All these practices bring power, and power makes you proud. You get proud by practicing.
Remember, you weren't the one who made you ashamed, but you are the one who can make you proud. Just practice, practice until you get proud, and once you are proud, keep practicing so you won't forget. You get proud by practicing.

Click here for information about the new poster featuring the poem "You Get Proud by Practicing."