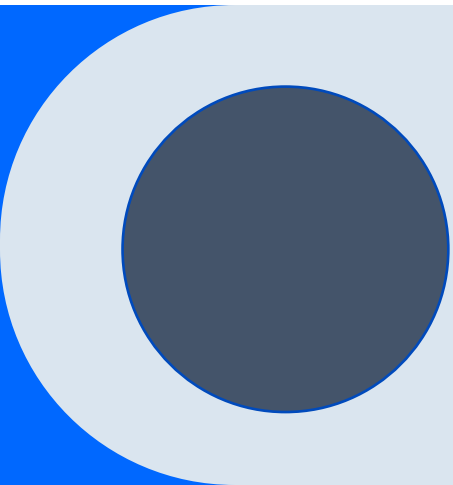




Health Equity and People with Disabilities

Melissa Winger CPHQ, CPXP
HCH Learning Days May 2024



Lived Experience

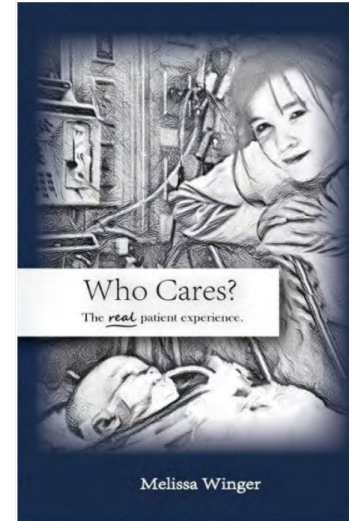
- Mom – Young adult (28) with significant developmental disabilities and medical complexity
- Previous member of MN Governor's Council on Developmental Disabilities (6 years)
- Past Chair of MN Olmstead Plan – Prevention of Abuse and Neglect workgroup.
- HCH consumer site evaluator since rule was created
- Current Chair Health Care Homes Advisory Committee



Who Cares? The Real Patient Experience

by Melissa Winger

★★★★★ 5.0 (2) [Write A Review](#)



<https://www.barnesandnoble.com/w/books/1144045649?ean=9798988067832>

www.whocaresbooks.com

History Disability Rights Movement

1935 Social Security Act Signed into Law

- President Franklin Delano Roosevelt signs the Social Security Act, establishing a program of permanent assistance for adults with disabilities.

1939 Nazi Program Kills Thousands of People with Disabilities

- 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.

1954 Brown v Board of Education

- School segregation is abolished, and public schools are given permission to educate children with significant intellectual disabilities.

1964 Civil Rights Bill Bypasses Persons with Disabilities

- While the 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.

History Disability Rights Movement Part 2

1974 Last of "Ugly Laws" Repealed

- These laws allowed police to arrest and jail people for no reason other than being "disfigured" or demonstrating some type of disability.

1990 Americans with Disabilities Act (ADA) is signed into law.

- President George H.W. Bush signs landmark legislation prohibiting the discrimination of people with disabilities in all areas of public life including jobs, schools, transportation, and all public and private places that are open to the general public.
- The ADA gives civil rights protections to individuals with disabilities similar to those provided to individuals on the basis of race, color, sex, national origin, age, and religion.

1990 Individuals with Disabilities Education Act (IDEA)

- Reauthorized Act requires students with disabilities to be involved in developing their transition plans, and their interests and preferences are to be considered.

1999 Olmstead v. L.C. and E.W.

- Most important civil rights decision for people with disabilities in US History. Olmstead requires states to provide services in the most integrated setting and reinforced the right of people with disabilities to live in the community.

1978 - The Gang of 19 and ADAPT



- July 5, 1978, a group of 19 people gathered at one of the busiest intersections in Denver. Got out of their wheelchairs and lay down to stop traffic.
- Their goal was to protest the inaccessibility of the city's public transit system.
- Protest ultimately led to the creation of the Americans Disabled for Accessible Public Transit (now the American Disabled for Attendant Programs Today), in 1983, which quickly expanded with chapters all around the country.



Section 504 of the Rehabilitation Act of 1973

“No otherwise qualified individual with a disability in the United States, as defined in section 705(20) of this title, shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance or under any program or activity conducted by any Executive agency or by the United States Postal Service.”

- Despite Section 504 of the Rehabilitation Act being signed into law by President Richard Nixon (albeit after being vetoed twice), **Section 504 had not been fully enforced**, leaving people with disabilities without the necessary accommodations and access to public services. **It remained unenforced and unaddressed for 4 years.** This was in large part due to businesses and organizations lobbying against implementing Section 504, arguing that it was burdensome and unfair to expect them to implement accessibility or else lose federal funding.

San Francisco's 504 Protest – April 1977 (26 days)

- 150 people with disabilities streamed into the Health, Education, and Welfare (HEW) Federal Building. They began climbing to the fourth floor where the HEW regional offices were located. **Over 120 activists occupied the building, and they refused to leave** the federal building until their demands were met, even when threatened with arrest and eviction.
- officials attempted to remove the activists from the building by cutting the phone lines and **denying them food, water, medicine, and more.** But the disabled protestors were more cunning than them, and they were prepared for this. **They used sign language to communicate through the windows of the building to the outside.** They worked with allied groups to get food, medicine, blankets, and more.
- Groups that supported the 504 protesters included the **Black Panther Party, Glide Memorial Church, Gay Men's Butterfly Brigade, Delancey Street, the United Farm Workers, the Gray Panthers, Salvation Army, and more.**



1990 Capitol Crawl Protest for ADA

- Disability rights activists arrive at the U.S. Capitol and demand the passage of the Americans with Disabilities Act (ADA). **Over 1,000 protesters from 30 states** to protest the delay in passing the Act.
- After a day of rallies and speeches, **over 60 activists** abandoned their wheelchairs and mobility devices and began **crawling the 83 stone steps** up to the U.S. Capitol Building.

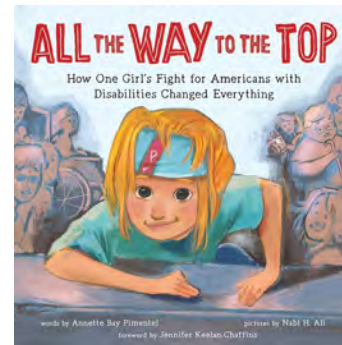


Capital Crawl Leader

8 year old led the crawl !

“ I realized these people with disabilities are fighting for their right to be acknowledged and accepted...and I can too, and I want to be a part of that.”

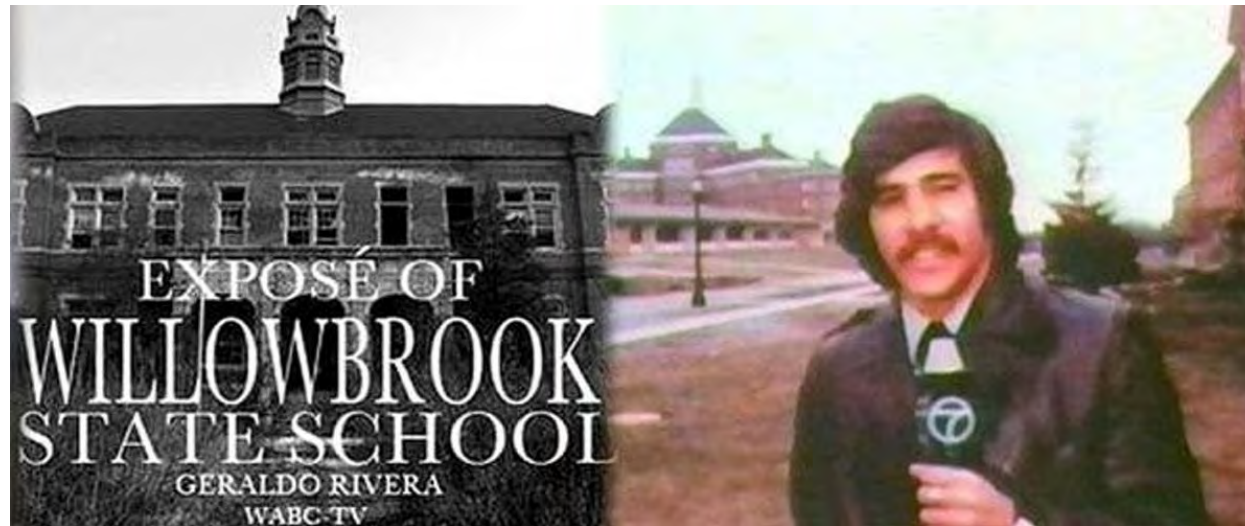
- The day after the crawl, police arrested 104 people at an ADAPT protest inside the Capitol rotunda. One of them was Keelan-Chaffins' mother, Cynthia Keelan.
- The year before in Montreal, police had arrested both Keelan and seven-year-old Keelan-Chaffins while protesting a conference for the American Public Transportation Association.
- Ironically, the police had to obtain **accessible school buses to transport the arrested demonstrators** because they didn't have accessible paddywagons.



8-YEAR-OLD JENNIFER KEELAN

Institutionalization

- Infants with developmental disabilities were removed from their families shortly after birth and placed in institutions. Some parents even turned their babies over in their strollers to prevent anyone from seeing their children's disabilities.
- In 1972, a young reporter exposed a sickening, state-run system of neglect and abuse carried out under the noses of millions of Americans and in one of the country's biggest cities.



Willowbrook

- Geraldo and a TV news camera crew were dispatched to Staten Island to see what they could find. They scrambled over a fence and snuck into Willowbrook's Building Six where they discovered, what Geraldo later described as, "**a crime against humanity.**"
- When the horrors of Willowbrook State School, in Staten Island, New York, were finally exposed, the ill-equipped, disease-ridden facility housed more than **6,000 developmentally and physically disabled people**, and it had been in operation for decades.
- Dr. Michael Wilkins shared with reporter Geraldo Rivera that a staggering **100% of residents at Willowbrook contracted hepatitis within six months**,³ and it was so rampant here that researchers took advantage of the situation using **residents in medical trials and intentionally exposing them to the deadly virus without their consent.**⁴
- Exposure of these conditions led to a landmark 1975 federal court settlement in which New York agreed to move Willowbrook's residents into small group homes. The state pledged that each individual had a "**constitutional right to protection from harm.**"
- But that vow has been broken: Many of the institution's **2,300 alumni who are alive today still suffer from mistreatment**, a New York Times investigation found.



Olmstead Act

- The case involved Lois Curtis and Elaine Wilson, two women with mental and intellectual disabilities who had been treated in Georgia hospitals but were held in institutions for years, caught in a bureaucratic limbo as they waited for placements in community-based facilities.
- The case against Tommy Olmstead, who was the commissioner of the Georgia Department of Human Resources, was filed in 1995 and made its way up to the Supreme Court. In 1999, the court ruled that unjustified segregation of people with disabilities
- The Supreme Court held that people with disabilities have a qualified right to receive state funded supports and services in the community rather than institutions when the following three-part test is met:
 - the person's treatment professionals determine that community supports are appropriate;
 - the person does not object to living in the community; and
 - the provision of services in the community would be a reasonable accommodation when balanced with other similarly situated individuals with disabilities. constituted discrimination that violated the A.D.A

Remembering with Dignity

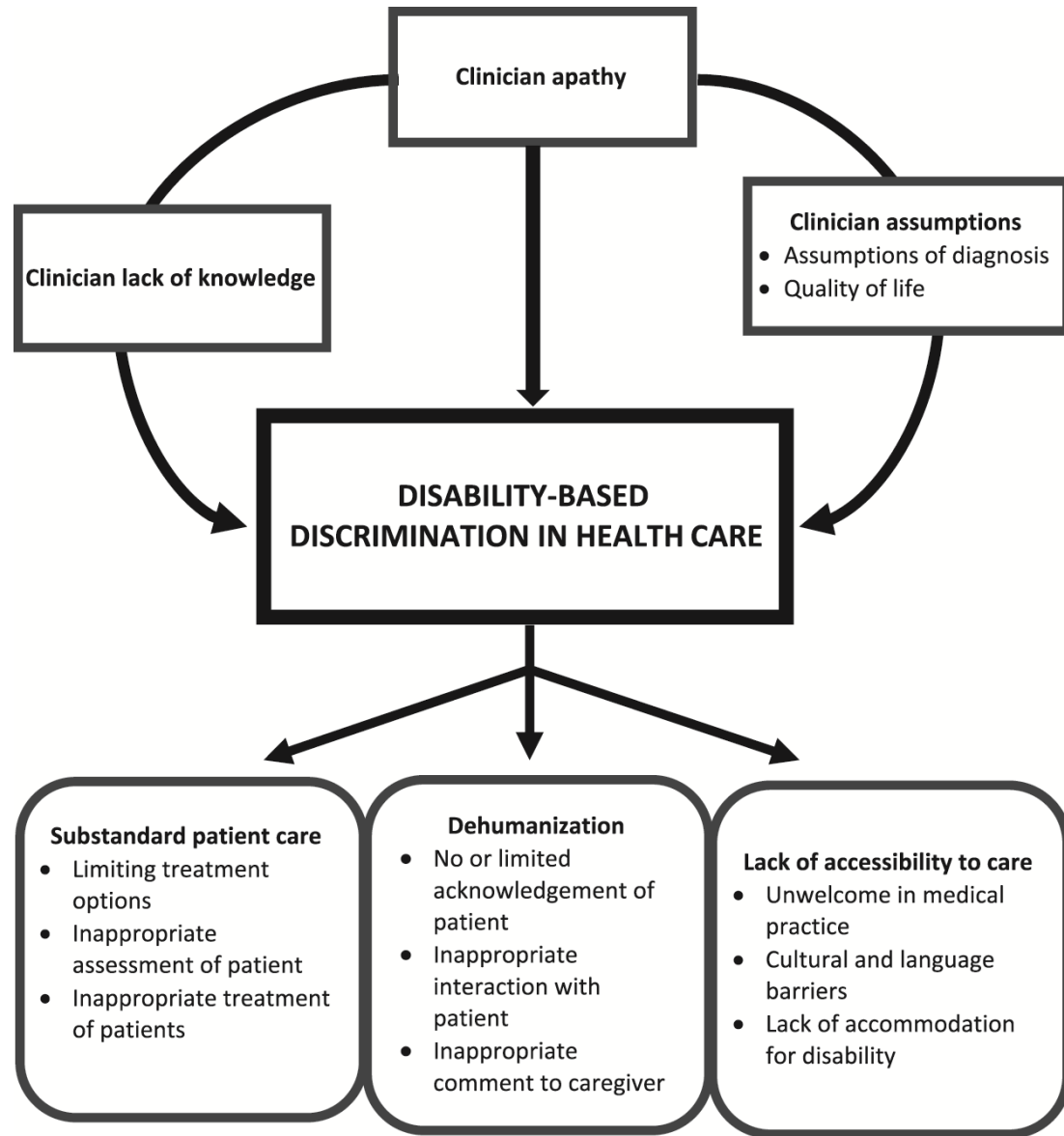
- Advocating Change Together (ACT), a non-profit organization whose members are individuals with developmental disabilities, called for a public apology to those who had lived – and died – in the state's regional treatment centers. ACT began an effort to mark the graves of former residents buried anonymously in regional treatment center cemeteries.
- The campaign, called "Remembering with Dignity," continues today.



Covid Crisis Standards of Care

- Alabama – triage guidance would exclude patients with “severe or profound mental retardation,” “moderate to severe dementia,” and “severe traumatic brain injury” from receiving mechanical ventilation if demand exceeded supply.
- New York - guidelines state that during a triage period, a person using their personal ventilator who enters into an acute care setting will be triaged like any other person and if they don’t meet the criteria for ventilation, they will have their personal ventilator removed.
- Oregon -Sarah McSweeney went to the hospital on April 21 with a high fever, doctors and social workers called family—and tried to get her to accept a do-not-resuscitate order for McSweeney.
 - McSweeney was not moved back to the ICU and was not put on a ventilator. She died on May 10
- Oregon- notices to LTC facilities. Fill out DNRs in advance for your other residents, in case one of them comes to the hospital.





Health Equity vs Equality

Considering the biopsychosocial perspective of disability—that occurs when a person with an impairment interacts with physical or social environments

Health inequity happens when a person's disability is not considered in their care, their needs are not accommodated, or their known needs are met with hostility or discrimination.

Equity vs. Equality



Same Treatment



Equitable Treatment



The systemic barrier has been removed.
This is Equality.



www.canadianequality.ca

Research, Articles, Studies (slide 1 of 3)

Northwestern University. (2022, October 3). Bias and Discrimination Toward Disabled Seeking Health Care. *Disabled World*. Retrieved October 14, 2022 from www.disabled-world.com/disability/discrimination/bias.php

<https://www.disabled-world.com/disability/discrimination/bias.php>

Iezzoni LI, Rao SR, Ressler J, Bolcic-Jankovic D, Agarannik ND, Donelan K, Lagu T, Campbell EG. Physicians' Perceptions Of People With Disability And Their Health Care. *Health Aff (Millwood)*. 2021 Feb;40(2):297-306. doi: 10.1377/hlthaff.2020.01452. PMID: 33523739; PMCID: PMC8722582.

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8722582/>

'I Am Not The Doctor For You': Physicians' Attitudes About Caring For People With Disabilities

Tara Lagu, Carol Haywood, Kimberly Reimold, Christene DeJong, Robin Walker Sterling, and Lisa I. Iezzoni
Health Affairs 2022 41:10, 1387-1395

<https://www.healthaffairs.org/doi/full/10.1377/hlthaff.2022.00475>

Research, Articles, Studies (2 of 2)

Physicians' Perceptions Of People With Disability And Their Health Care. (Health Affairs 2/2021)

- 56% reported that they welcome patients with disabilities to their practice.
- 36% said that they know "little or nothing" about the ADA.
- Only 41% were confident they could provide similar quality of care to patients with disabilities as they could to those without disabilities.

In response to the question, "If a wheelchair user comes and cannot stand on a weight scale, what is your approach to taking a weight?," physicians from two of the three groups reported sending patients to a supermarket, grain elevator, zoo, or cattle processing plant to obtain a weight.

In 2019–20 only 22.6 percent of US outpatient physicians reported always or usually using accessible weight scales for patients with significant mobility limitations,

" I think the problem is that you cannot refuse them straight. We have to give them an appointment. You have to come up with a solution that this is a small facility, we are not doing justice to you, it is better you would be taken care of in a special facility."

Nearly 70 percent reported that they were at risk for ADA-related lawsuits.

Research, Articles, Studies (slide 3 of 3)

Presence of Accessible Equipment and Interior Elements in Primary Care (Health Equity Volume 3.1, 2019 DOI: 10.1089/heq.2019.0006)

- In 2006 in California, a group of Medicaid Managed Care (MMC) plans began conducting physical site accessibility audits of their providers. Five plans sent us data from audits conducted in 2013–2016. **2389 physician practices.**
- 19.1% have a height adjustable examination table
- 10.9% have an accessible weight scale
- 5.9% a lift that can assist staff and patient with transfer to an examination table.

Some MMC plans have purchased accessible equipment for offices; our data do not indicate purchaser, but one plan's providers had a noticeably higher presence of accessible equipment.

NIH designates people with disabilities as a population with health disparities (Sept 2023)

The designation of people with disabilities as a population with health disparities aligns with a 2021 executive order [requiring the federal government to address barriers to equity for underserved and marginalized groups](#). This includes people with disabilities—the largest minority group in the country, comprising [more than 27% of the United States adult population](#).

Goals of the new designation include:

- Improved research funding and efforts aimed at addressing health and health care disparities affecting people with disabilities.
- Greater inclusion of researchers with disabilities and improved inclusion of people with disabilities in health disparities research studies as collaborators and/or participants.
- More evidence for identifying and eliminating barriers to equitable health and health care for people with disabilities.
- More comprehensive data collection focused on people with disabilities for policy- and decision-making.
- Advanced evidence-based practices and health and human services programs for people with a variety of disabilities, helping to close the knowledge gap on effective interventions.
- More explicit recognition and inclusion of people with disabilities as a health disparity population in national, state, and local programs that work to reduce inequities.
- Improved preparation and coordination for emergencies

Common Barriers to Disability Inclusion and Participation



The World Health Organization (WHO) describes barriers as factors in a person's environment that, through their absence or presence, limit functioning and create disability

Common barriers to the inclusion and integration of people with disabilities:

Attitudinal

Ableism, stereotyping, stigma, prejudice, and discrimination



Communication

Experienced by people who have disabilities that affect hearing, speaking, reading, writing, and or understanding



Physical

Obstacles that prevent access or block mobility, such as curbs and steps



Policy

Lack of enforcement or awareness of existing laws and regulations, e.g. the Americans with Disabilities Act (ADA)



Programmatic

Factors that limit the effective delivery of a public health or healthcare programs, such as inconvenient scheduling and poor communication with patients



Transportation

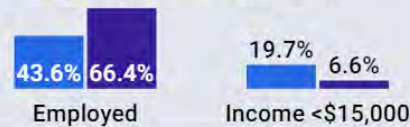
Lack of adequate and accessible transportation, which can interfere with a person's independence and participation



Social Drivers of Health

Social determinants of health, including lack of affordable and accessible housing and lower rates of employment, education & income

■ People with a disability
■ People without a disability



People with disabilities have less access to adequate health care due to factors such as:

Costs

26.7% of people with a disability could not see a doctor due to cost in the past 12 months compared to **10.1%** of people without a disability

Health care provider stereotypes about disabilities

82.4% of U.S. physicians reported that people with significant disability have worse quality of life than nondisabled people

Only **56.5%** strongly agreed that they welcomed patients with disability into their practices

Lack of appropriate provider training



Only **40.7%** of physicians were very confident about their ability to provide the same quality of care to patients with a disability

Lack of accessible medical facilities and equipment



Exam tables and chairs may not be adjustable



Scales may fail to accommodate wheelchairs or require a step up



People with visual disabilities or intellectual/developmental disabilities may not be able to access patient portals

Communication barriers



Care after a medical visit may be hindered by materials that are not available in plain language or braille

Lack of accommodations, such as sign language interpreters



Patient Reported Barriers

- [Perspectives of Patients with Diverse Disabilities Regarding Healthcare Accommodations to Promote Healthcare Equity: a Qualitative Study - PMC \(nih.gov\)](#)

Healthy People 2020 reported that

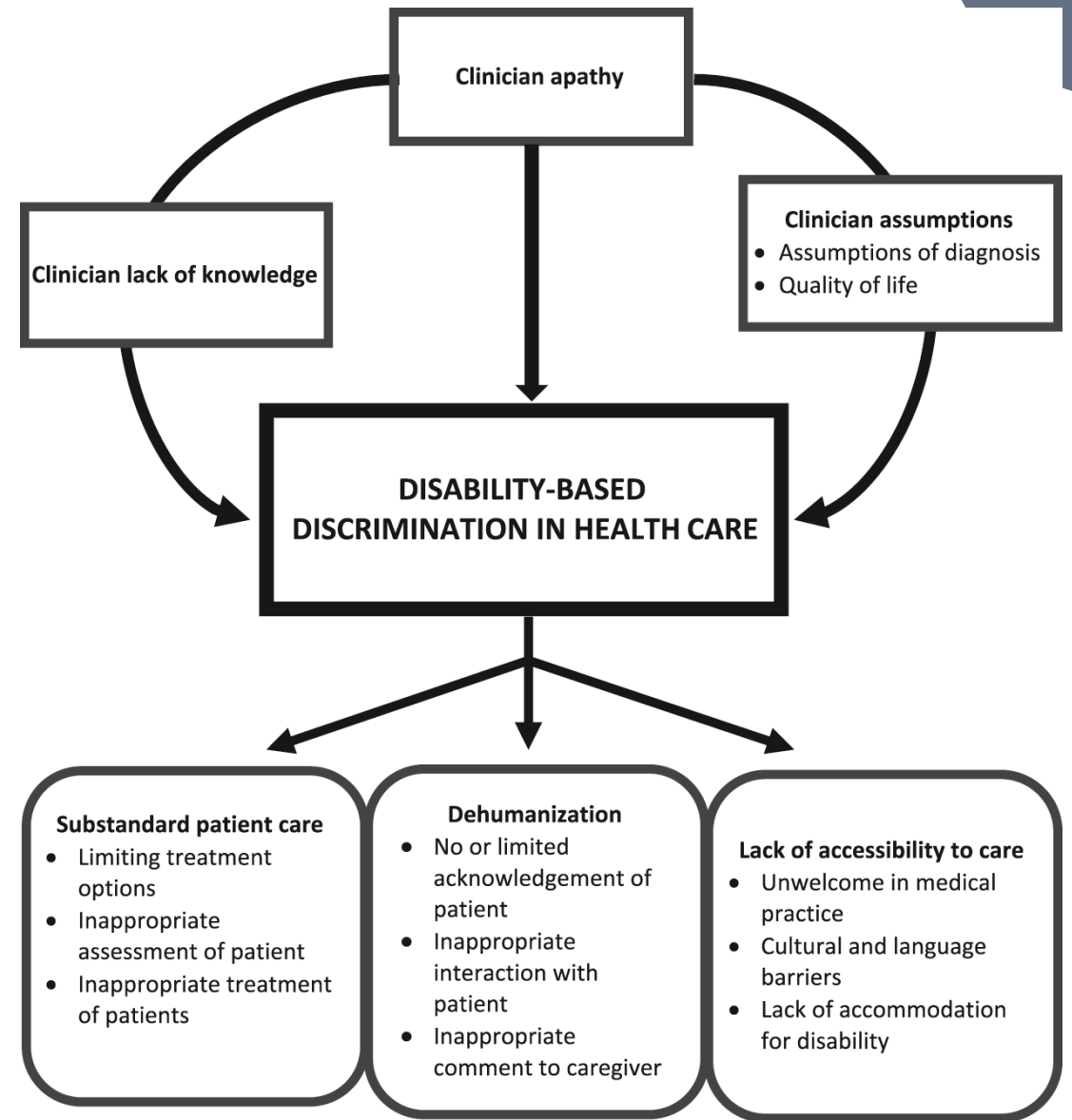
- 47.2% of adults with disabilities reported barriers to care that led to delays in receiving appropriate primary and preventive care. The experiences of patients with disabilities reflect the persistent barriers they face when receiving medical care.
- A survey of wheelchair users, for example, showed that 76.1% of them were examined in their wheelchair, 69.7% were seated during their physical exams, and 54.1% felt that their care was inadequate.
- The consequences of inadequate access include higher morbidity of preventable diseases such as obesity and diabetes; higher rates of smoking; and lower rates of cervical and breast cancer screening among patients with disabilities.

Bias in healthcare is shifting, but little for disabilities

While research out of Harvard has shown that attitudes can change and improve care, factors like disability, age, and body weight hasn't demonstrated change.

One study found that "Sexuality biases dropped 64% over 14 years, but it hasn't changed at all for disability, age, or body weight bias. Disability bias over 14 years has only shifted by 3%."

[Achieving Healthcare Equity For Disabled Individuals | RTI Health Advance](#)





Disparities Impact Statement

This tool can be used by all health care stakeholders to achieve health equity for racial and ethnic minorities, people with disabilities, sexual and gender minorities, individuals with limited English proficiency, and rural populations.

This worksheet has 5 steps:

- 1 Identify health disparities and priority populations
- 2 Define your goals
- 3 Establish your organization's health equity strategy
- 4 Determine what your organization needs to implement its strategy
- 5 Monitor and evaluate your progress

Health disparities—differences in health outcomes closely linked with social, economic, and environmental disadvantage—are often driven by the social conditions in which individuals live, learn, work, and play.



Documenting Disability

What and Where to Document:

- Disability is a **patient-reported demographic** characteristic like race, ethnicity, preferred language, gender identity, sexual orientation, etc
- Any processes for documenting other patient demographics could incorporate documentation of disability status. disability status should be displayed in the electronic health record (EHR) in the **same location as other demographic characteristics.**
- **Accessibility needs** to prepare for the appointment (Large print education etc)

What if ??

Patient is offended by the question

- High level of comfort with healthcare systems collecting the information. In another study in which we implemented collection of disability status for >3,000 patients, we had **no patient complaints about collection of patients' disability status.**
- Patients reported that they **expected their health care organization to collect disability status**, as disability information was less sensitive than other information that is routinely collected by their health care team.
- Patients can refuse to answer

Increased Bias if documented

- We cannot begin to address this discrimination until we collect patients' disability status. Collection of disability status allows organizations to **measure the extent of the problems and to develop and implement interventions to ameliorate the disparities.**
- The health care system has **collected demographic characteristics** such as race and ethnicity from patients for decades, without an increase in discrimination.

Language

- Rosa's Law President Obama signs October 5, 2010, U.S. law that replaces several instances of "mental retardation" with "intellectual disability" in federal health, labor and education statutes.
- "Spread the Word to End the Word" 2009 Disability Advocacy Campaign encouraging people to stop using the R-word –retard(ed)
- Make it relevant People living with disabilities often complain that their disability is mentioned even when the story has nothing to do with their disability.

Q1. Should a story about residents complaining about noisy airplanes flying over their houses note that one of the residents who is complaining uses a wheelchair?

People First vs Identity First

- **People-first language** Puts the emphasis on the person first; followed by a description of the disability. EXAMPLES: A person who lives with a disability vs. a disabled person A person with an intellectual disability vs. mentally disabled A person diagnosed with epilepsy vs. epileptic
- **Identity-first language** Puts the emphasis on the disability. EXAMPLES: Autistic, deaf, blind, disabled An autistic woman vs. woman with autism Several U.S. disability groups have always used identity-first terms, specifically the culturally Deaf community and the autistic rights community
- **Special/special need** The term “special needs” was popularized in the U.S. in the early 20th century during a push for special needs education to serve people with all kinds of disabilities. The word “special” in relationship to those with disabilities is now widely considered offensive because it euphemistically stigmatizes that which is different
 - *NCDJ Recommendation:* Avoid using the terms “special,” “special needs” or “functional needs” when describing a person with a disability or the programs designed to serve them, except for government references or formal names of organizations and programs.

What to Say

Remember, it's always best to ask a person what terms work for them based on their own lived experiences and identity. We'll unpack some of the words and concepts from this table throughout the book.

Say This

- ✓ disability/disabled
- ✓ person with a disability/
disabled person

- ✓ has a disability
- ✓ is disabled

- ✓ person who is able to

- ✓ person who is
unable to
- ✓ person with high
support needs

Not This

- ✗ differently abled
(unless preferred)
- ✗ handi-capable
- ✗ handicap/handicapped
- ✗ special needs
(unless preferred)

- ✗ afflicted by
- ✗ suffers from
- ✗ victim of

- ✗ high functioning

- ✗ low functioning



HEALTHCARE RESOURCES

TOOLS YOU CAN USE

We have compiled a wide variety of resources that support healthcare equity initiatives, including links to training materials for staff and guides for implementing accessibility initiatives. If you have resources you'd like to share, please contact us!

Information and links on this site are not a replacement for legal advice. Please consult your local state and federal guidelines for legal requirements.

[COVID-19 Related](#)

[Documenting Disability Status](#)

[Effective Communication](#)

[Electronic Tools & Information](#)

[Facilities & Equipment](#)

[Other Key Organizations & Websites](#)

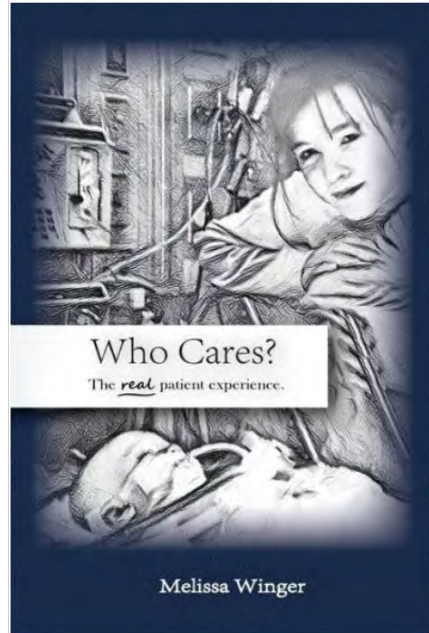
[Provider & Staff Education](#)

[Regulations](#)

FACILITIES

- **Access to Medical Care for Individuals with Mobility Disabilities (U.S. DOJ): Guide for accessible medical equipment.** This technical assistance publication provides guidance for medical care providers on the requirements of the ADA in medical settings with respect to people with mobility disabilities.
- **Accessible Healthcare (ADA National Network):** Suggested accommodations for patients with disabilities
- **Guide to ADA Standards (U.S. Access Board):** Chapters 3 and 4 highlight accessible spaces
- **Wheelchairs, Mobility Aids, and other Power-Driven Mobility Spaces (U.S. DOJ):** Overview of mobility accessibility
- **ADA Checklist for Existing Facilities (ADA National Network):** Detailed document which highlights standards for accessible facilities
- **ADA Standards for Accessible Design (DOJ):** The Department has assembled an official online version of the 2010 Standards for Accessible Design.
- **Accessible Temporary Events (ADATA):** A planning guide to making temporary events accessible for people with disabilities

Questions?



www.whocaresbooks.com

Thank you !
Melissa Winger