

# Recognizing and Confronting Ableism in Healthcare

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# Goals

- Define ableism and how it impacts health outcomes for the people we serve.
- Recognize ableism in many forms and how it is pervasive in medical settings.
- Discuss strategies to confront ableism including systemic change and personal growth.

# We have no disclosures

- Except I am physically disabled and have been my entire life.
- Our presentation pulls from personal experiences.
- The references are diverse, and we intentionally included recommendations outside of academia.

# A little about me!

## Lindsey Vaughn

- I have been with Children's Mercy now for 15 years!
- I am a registered dietitian.
- I received my master's degree at KUMC and my undergrad at KSU.
- I am married and have one son.
- I was born with Spina Bifida and am affected at the L4 level.
- I now am an orange belt in Kenpo 5.0



# Ableism: My personal Experiences

- When I was born, my family was told to put me into an institution because I would likely not make anything of myself and would be a burden.
- I had to do cognitive testing to prove I could do mainstream kindergarten. Also, the school was afraid of me hurting myself at recess, so I was not allowed to go outside with my friends.
- I couldn't go to the same junior high with my friends because if I went to that junior high the principal demanded I have a paraprofessional to open doors and carry things for me. To be independent I went to a different school in the same district.
- My initial major in college was nursing. I wanted to be an APRN. The head of nursing registered me and tried to talk me out of it. When that didn't work, I had to show her how I would do every piece of the curriculum, my first week as a freshman. When I couldn't move a 200# man by myself, I left the major.
- Last year, I flew out of state and everyone at every airport talked to my husband and didn't acknowledge me, even when I answered their questions. My husband had to repeat what I said.





# A little about me!

## Patti Pepple

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- I have been with Children's Mercy now for 8 years.
- I am a clinical social worker.
- In the Beacon Clinic, I serve children who are medically complex and their families.
- I received my master's degree at the University of Kansas.
- I am always learning (usually the hard way 😊).

# Definitions and History

# Before Ableism, Let's Talk Bias

- <https://www.youtube.com/watch?v=ze7Fff2YKfM>
- [https://www.youtube.com/watch?v=4zkNbk\\_RbQs](https://www.youtube.com/watch?v=4zkNbk_RbQs)
  - Approved to broadcast with thanks from the Institute for Healthcare Improvement



# What is Ableism?

“The term ‘ableism’ can be defined as practices or policies that treat people with disabilities as if they were invisible, disposable and less than human, while taking for granted able-bodiedness as humanity’s default state. (S. Neilson, 2020)”

# And why should I care?

- Disability Impacts ALL of US
- Health outcomes show we have a long way to go in better serving people with disabilities.

# A Few Stats about Disability

- 61 MILLION Americans have a disability, that makes 26% (1/4) of the US has a disability!
  - Numbers are higher in the south
- People with a disability have higher rates of obesity, smoking, heart disease, and diabetes than the rest of the US population.
- 1 in 3 adults with disabilities (18-44) do not have a health provider
- 1 in 3 adults with disabilities (18-44) do not seek healthcare due to cost (Center for Disease Control, 2020)

# Ableism and Discrimination: A basic history

- 1973 Rehabilitation Act
  - not entirely enacted until a “sit in” in 1977. Judy Huemann organized the sit-in. She recently wrote a book called "Being Huemann." There is a documentary called "Crip Camp" on Netflix that talks about that sit-in. She goes into detail about it in her book as well.
- 1975 Education of All Handicapped Children Act- 1990 renamed to the Individuals with Disabilities Education Act (IDEA)
- 1990 Americans with Disability Act
- 2008 ADA Amendments Act

# Recognizing and Confronting Types of Ableism



# Social Work Can Lead the Change

- Ableism goes beyond access.
- Confronting ableism requires a mind shift.
- Lenses that are helpful to this mind shift:
  - Strengths based perspective
  - Intersectionality (Crenshaw, 1989 and 2017)



# Recognizing Ableism in Words

- Person first language
  - Definition: Putting the person before their disability.
  - Has been discussed as early as 1959 in some semantic citations, but the phrase was coined in 1988 in education from advocacy groups
  - People First Respectful Language Modernization act of 2016 (Office of Disability Rights) was enacted by the Council of the District of Columbia on July 11, 2006, to “require the use of respectful language when referring to people with disabilities in all new and revised District laws, regulations, rules, and publications and all internet publications.”

# People First Language: pros and cons

- Pros: Meant to put the person first and separate the person from the perceived disability
- Cons: Many in the disabled communities believe this is another form of political correctness, and if the idea is to normalize disability, one must be comfortable in the disability as part of their individuality and uniqueness.
  - An example is some in the diabetic world feel the word diabetic is taboo and should be a person with diabetes.
- Studies have found only 2% feel person first language has increased sensitivities. (Mousavi, 2020)

# Ableism and words: More than what you say

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- <https://www.youtube.com/watch?v=suFqOXmhkcY>
- "Words Matter aims to raise awareness of ableism. As an organization we advocate to college students to use less offensive ableist terminology on college campuses. This public service campaign ultimate goal is to get students to be more cognizant of their words and to know that their words matter. The following video will depict short scenarios of commonly used phrases and how can impact people. Please share this video online with the people that matter most to you." Song: Sovereign Quarter by Kevin MacLeod



# Confronting Ableism in Words

- Use person first language in formal situations and written materials.
- In more personal situations, ask the person how they want others to address them (identify first, “autistic”).
- Call out ableist rhetoric (jokes, terminology, etc).



# Inspiration Porn

**Definition:** the portrayal of people with disabilities as inspirational solely or in part based on their disability. Inspiration porn is images, videos, and memes of disabled people used to motivate able-bodied people, suggesting that if a disabled person can accomplish something, then surely an able-bodied person can. Supporters of inspiration porn claim these images inspire disabled people themselves because it showcases members of their community making accomplishments.



# Inspiration Porn

- Phrase coined in 2012 by Australian Activist, Stella Young.
  - [https://www.youtube.com/watch?v=SxrS7-I\\_sMQ](https://www.youtube.com/watch?v=SxrS7-I_sMQ)
- Inspiration porn does not make people with disabilities feel better about being disabled. It is an objectification of a people for others use.



# Confronting Inspirational Porn

- Be aware of marketing materials and social media that contain this messaging. (Hospitals are big offenders.)
- Be mindful of how we praise people.
- Do not make assumptions about a person's story.
- Asking about patient centered goals beyond just existing.

# Ableism and Access: Physical

- Physical accessibility is a bottom of a barrel goal.
- Can someone with a physical disability get into the building, able to go to bathroom while there, or can get there safely?
  - Dayniah Manderson, an English teacher in the Bronx recent won a discrimination case against the city's DOE. For 8 years, she could not physically go to the bathroom in the middle school she had been placed in.
- Design is important, but also making sure accommodations are truly user friendly is a must.
- Safety plan for disaster.

# Ableism and Access: Transportation

- Mobility – safe, reliable, usable, and affordable transportation along with have a safe place to park and exit the vehicle
- Make sure there are accessible options for transportation support!
- Do a ride along with a person with a disability to learn about opportunities for improvement.
- Solicit input from people with disabilities when doing remodeling/construction.

# Ableism and Access: Education

- Education – accessible location and material (print size, audio, visual, etc)
- Leverage technology to include people with disabilities.
- In pediatrics, assess that educational needs are being met.

# Ableism and Access: Healthcare

- All aspects of ableism already discussed collide in healthcare settings (words, transportation, access, etc).
- Healthcare – Financial and accessible location and equipment.
- Advocate that teams provide the evidence-based standard of care for all people.
  - Learn to use a lift or specialized scale.
  - Provide appropriate sex education and care for people with disabilities. (Shapiro, 2018)

# Normal vs. Healthy

- Heidi L. Janz, writes that disabled people “remain subjected to ableist attitudes in many sectors, including – often especially – the healthcare system”. The reason, as Janz correctly identifies, is based in medicine’s presumption. that “not normal” is the same as “not healthy” (Janz, 2019).
  - <https://www.youtube.com/watch?v=CtVRbx1NVQ4>



# Time to Change how we think in Healthcare Pathological Terms

- “To the audience of fellow physicians, I said, ‘I have always been ‘ill.’ And this is, to me, ‘normal.’ There is no origin story to be found, or overcoming narrative I have to provide.’ I asked, “What can you do to address *this* problem?” (Neilson S, 2020)
- Medicine has traditionally been viewed as a benevolent discipline in which every human life is valued equally, without any form of prejudice or discrimination. Although this may remain the ideal to which medicine aspires, the reality is that, as individuals, medical professionals are not immune to the influence of dominant societal understandings of, and attitudes toward, individuals and groups of people deemed to be “others” (Neilson S, 2020)

# Bias In Healthcare

Galli and colleagues observe that “despite their intentions, personal goals and normative expectations, even health professionals are unconscious bearers of implicit social biases that affect the quality of professional interventions.” They further contend that “immediately, and from early life and thereafter, people perceive individuals with disability as ‘vulnerable’ and of low competence, and, accordingly, treat members of this group differently.” Consequently, people with disabilities often continue to experience social devaluation on account of their disabilities (i.e., ableism), despite the fact that the last few decades have seen an increased awareness and a decreased social acceptability of discrimination based on other characteristics such as race (i.e., racism) and gender (i.e., sexism). People with disabilities thus remain subjected to ableist attitudes in many sectors, including — often especially — the health care system. (Galli, 2015)

# Bias In Healthcare

“It is, therefore, both serious and troubling that studies have consistently shown that, as a group, health care professionals tend to underestimate substantially the quality of life of people with disabilities. Indeed, the very notion of “quality of life” as a reliable indicator of the appropriateness or inappropriateness of a medical course of treatment for a person with disabilities is thus deeply problematic.

Such erroneous judgments about the quality of life experienced by people with disabilities can result in treatment options for people with disabilities being either limited, or altogether eliminated. (Galli, 2015)”

# Strengths Based Perspective

- Strengths based work challenges:
  - pathological terms
  - ideas of what is “normal”
- Strengths based work acknowledges:
  - Personal goal and priorities
  - Identity

# Representation Matters

- We need to include people with disabilities in all levels of decision making (Khullar, 2017).
- Job descriptions often contain ableist requirements. Reflect on what is needed- does this job require someone to sit/stand/lift 30 lbs.?
- Leverage technology to make employment as inclusive as possible.
- Make sure wellness initiatives are inclusive.

# Leadership Considerations

- Include ableism in unconscious bias training.
- Take a proactive approach to human relations/personal needs.
- Safety planning for people with disabilities.



# Advocating for Health Equity

- The following video is not directed towards disability but other marginalized people. The idea remains the same. One cannot treat a person physically, mentally, or spiritually if there remains a health disparity. The first step in decreasing the disparity for the disabled is facing ableism in society and healthcare. (Institute for Healthcare Improvement, 2016)
- <https://www.youtube.com/watch?v=q3qEZ2d-Cnw>

# Questions? Discussion if time.



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**Mission Forward.**  
**People Focused.**

