

Smashing Stigma: Navigating the Path to Disability Inclusion

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Conflict of Interest

No conflict of interest to disclose.

Objectives:

Define disability, identify types of disabilities and describe various models of disabilities.

Discuss the impact of ableism in healthcare, education and employment.

List strategies to promote disability inclusion and dismantle ableism.

Statistics

- ☐ 61 million adults in the U.S. live with a disability (CDC)
- \square 27% one in four adults in the U.S. (CDC)
- ☐ Largest minoritized group in the US (US Bureau of labor and statistics)



Definition according to ADA (Americans with Disabilities Act)

Disability is defined as a current or history of physical or mental impairment that substantially limits one or more major life activities.

- ☐ Chronic, acute or episodic
- ☐ Present at birth or acquired at any point in life
- ☐ Apparent or non-apparent

Common examples: diabetes, heart disease, chronic migraines, auto-immune disease, cancer, epilepsy, autism, ADHD, depression, anxiety, PTSD







96% of severe disabilities are not visible at first glance (Forbes)

Reflection

Charitable Model:

- Deserving pity, victim of tragedy
- Institutionalization

Identity/Diversity Model:

- A diverse social, political and cultural model
- Not negative, not weak



Medical Model

- •"Deficit" needs to be fixed or "cured"
- Stigma, separation
 - •For example: An individual with visual impairment cannot enjoy exhibits at a museum.

Social Model:

- Society needs to change so disabilities can fit in
 - For example: Museums are inaccessible because they are not providing audio guides.

https://blogs.perficient.com/2023/06/30/exploring-theoretical-models-of-disability-understanding-the-different-perspectives/ https://doi.org/10.1016/j.dhjo.2022.101328 The Evolution of Disability Language: Choosing Terms to Describe Disability" Erin E Andrews et.al

Ableism

- Assumption that the "normal" non-disabled body is the superior and preferred.
- Prejudicial attitudes and discriminatory behavior and policies that exclude, denigrate and harm people with disabilities

Prejudice is a burden
that confuses the past,
threatens the future,
and renders the
present inaccessible.

Maya Angelou

Campbell F. A. K (2001) Griffith Law Review

Multi-level ableism

Macro-level

 Physical barriers, policies, laws, regulations and practices that exclude people with disabilities from full participation and equal opportunities.

Internalized

 Unconscious and harmful beliefs about disability to oneself.



Micro-level

- Occurs in social interactions
- Bullying, microaggression, social awkwardness

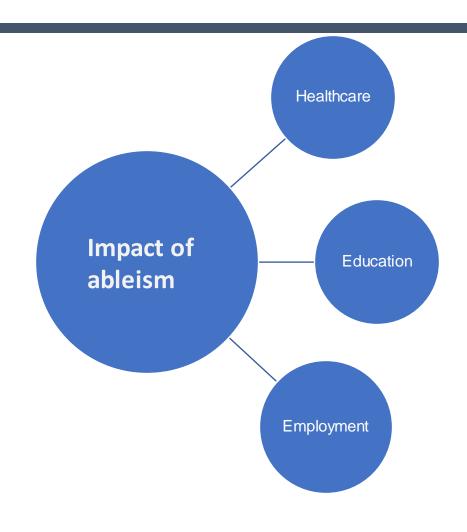
Mackelprang & Salsgiver, 2016

Knowledge Check

Which of the following statements are true about ableism?

- A. It is based on an assumption that "normal" body is considered superior and preferred.
- B. It is often seen at multiple levels, such as institutional, interpersonal or internalized level.
- C. It can cause health, educational and employment inequities and discrimination.
- D. All of the above statements are true.

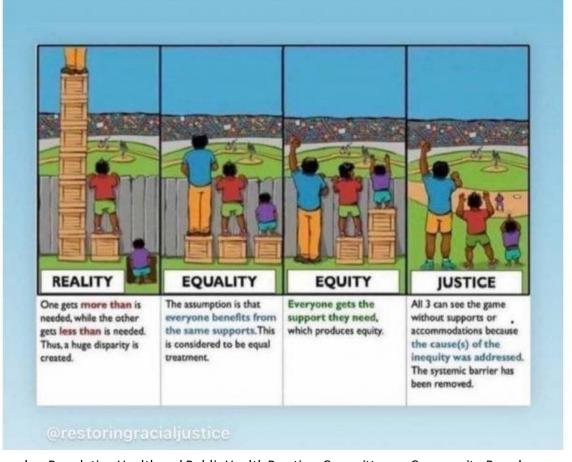
Impact of Ableism



Health Inequity

 Systemic differences in the opportunities that groups have in order to achieve optimal health.

 Leads to unfair and avoidable differences in health outcomes



National Academies of Sciences, Engineering, and Medicine; Health and Medicine Division; Board on Population Health and Public Health Practice; Committee on Community-Based Solutions to Promote Health Equity in the United States; Baciu A, Negussie Y, Geller A, et al., editors. Communities in Action: Pathways to Health Equity. Washington (DC): National Academies Press (US); 2017 Jan 11. 3, The Root Causes of Health Inequity. Available from: https://www.ncbi.nlm.nih.gov/books/NBK425845/

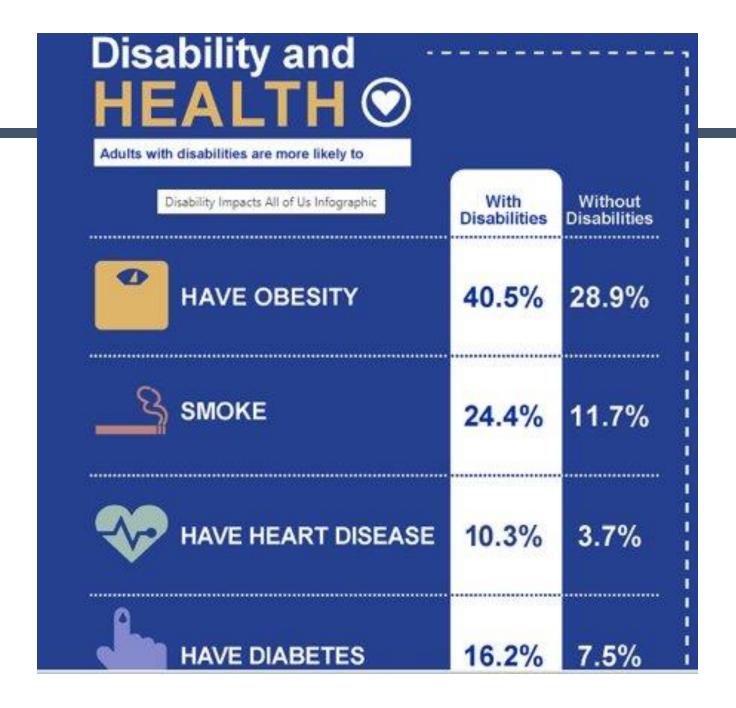
Disability and Health Inequity

☐ 4 times as likely to report fair or poor health
lacktriangle Twice as likely to find health care providers' skills and facilities inadequate
☐ Nearly 3 times more likely to be denied health care services
☐ Less likely to be asked about smoking history or contraceptive use
☐ Among adults with disabilities, 1 in 4 do not have a usual healthcare provider*

Issues People With Disabilities Face in the Healthcare System | Duquesne University School of Nursing; Health disparities among adults with physical disabilities or cognitive limitations compared to individuals with no disabilities in the United States — ScienceDirect; Healthy People 2030 | health.gov

Beyond Equality: Providing equitable care for persons with disabilities

CDC Data



Barriers

□ Physical access

- Ex: Obstacles such as curbs, inaccessible weighing scale

□Communication

- Lack of inaccessible screen reading format, ASL interpreter, video captions, clear masks

□Programmatic

- Lack of sensitivity training, insufficient time for appointment

Barriers (cont.)

□ Attitudinal (perception of providers)

- Stereotypes, stigma, prejudice
- Believing that disability = poor health

Findings from study:

Physicians' perceptions of people with disabilities and their health care.

• 82% of 714 physicians believe people with disabilities have a lower quality of life than those without disabilities.

The New York Times

These Doctors Admit They Don't Want Patients With Disabilities

When granted anonymity in focus groups, physicians let their guards down and shared opinions consistent with experiences of many people with disabilities.





Lisa Iezzoni, a professor of medicine at Harvard, wanted to understand why people with disabilities kept reporting receiving substandard care. "I thought I needed to start talking to doctors," she said. M. Scott Brauer for The New York Times

Why would you need a pap smear? Seriously?... You aren't sexually active are you? #RBPHealth @rawbeautyproject

WAITING ROOM





Education and Employment

Inequity:

- 3.1% among physicians with disabilities (Zakia Nouri et. al. 2021)
- 10% in science and engineering (National Science Foundation, 2019)
- Limited data in pharmacy

"The exclusion of people with disabilities from the biomedical workforce undermines the goal of achieving true diversity and is a missed opportunity for science and medicine" -Dr. Bonnie Swenor & Dr. Lisa Meeks

Prevailing Ableist Beliefs in Education and Employment

Hearing is normal –
Everyone wants to hear,
should hear, and needs to
hear to communicate
effectively with patients
and become a healthcare
professional.

People using wheelchairs require significant assistance, are 'bound' to their wheelchair and could never become health care providers.

Someone who is blind cannot read package insert's fine print, pill shapes and colors, hence cannot function as pharmacist.

Someone with bipolar disorder is incapable of fulfilling a demanding job, such as being a pharmacist.

^{*}Meeks et al., 2022 Medical Education; Meeks and Moreland, 2021 AMA Journal of Ethics

Why is it important to dismantle ableism?

Oath of a

→ Pharmacist — &

I promise to devote myself to a lifetime of service to others through the profession of pharmacy. In fulfilling this vow:

I will consider the welfare of humanity and relief of suffering my primary concerns.

I will promote inclusion, embrace diversity, and advocate for justice to advance health equity.

I will apply my knowledge, experience, and skills to the best of my ability to assure optimal outcomes for all patients.

I will respect and protect all personal and health information entrusted to me.

I will accept the responsibility to improve my professional knowledge, expertise, and self-awareness.

I will hold myself and my colleagues to the highest principles of our profession's moral, ethical and legal conduct.

I will embrace and advocate changes that improve patient care.

I will utilize my knowledge, skills, experiences, and values to prepare the next generation of pharmacists.

I take these vows voluntarily with the full realization of the responsibility with which I am entrusted by the public.



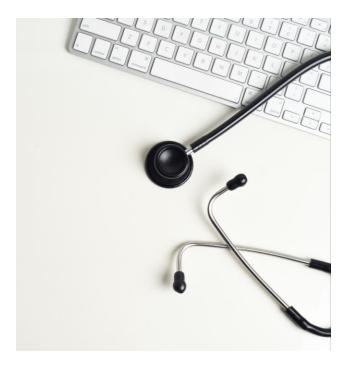




Our role as pharmacists

- <u>Accessible</u>: Pharmacy professionals are at the forefront, providing accessible healthcare.
- <u>Collaborators</u>: We work closely with patients as well as healthcare providers as educators.
- <u>Powerful:</u> We have the power and responsibility to advocate for our patients.
- <u>Leaders</u> in being agents of change, lead with love and empathy





How to dismantle ableism?

Check and challenge implicit bias

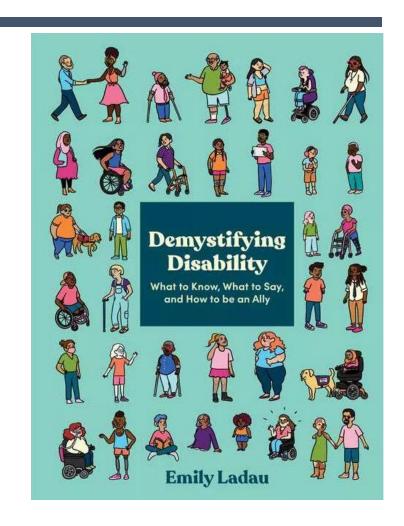
Disability inclusive language and sensitivity training

Be an ally

Disability Language and Etiquette

Disability Language: Why Does it Matter?

- Use of proper language shows respect, compassion and inclusion
- Our language is always evolving
- Person first vs identity first language:
 - Ex: person who is blind vs autistic person
 - People with disabilities may have individual preferences
 - Best course of action? Ask people what they prefer



Disability Language – what to keep in mind

Avoid using	Alternatives	Reason
Handicapped; Insane, retarded	Disability; person with a disability; disabled person	Some words are outdated – come from time of eugenics and Institutionalization
AIDS victim; Man suffering from Epilepsy	Person living with AIDS; A man who has epilepsy	Some common phrases paint disability as negative or victimize the person
Differently-abled, challenged, handi-capable	Disability/Disabled	Avoid euphemism. By shying away from mentioning disability, we may reinforce the notion that disability is something of which to be ashamed.
Offensive language/joke: crazy, insane, mad, psycho, freak, tone deaf, "are you blind?"	Avoid using these phrases	Offensive and ableist language disabilit is not a bad wor

Disability Etiquette

- Meeting with someone who is blind?
 - Identify yourself and others
- With someone who uses a service animal, wheelchair, or other assistive technology?
 - Do not touch or lean against the animal or technology
- With someone who uses a wheelchair?
 - Consider sitting so you are at eyelevel
- With someone who is deaf or hard of hearing?
 - Face them when you speak; no need to shout
- With someone who is neurodiverse?
 - Autism spectrum disorder: Be mindful of different communication style do not be sarcastic.
 - ADHD: Limit distractions, provide appointment/meeting agenda, offer extra time for appointment.
 - Dyslexia Provide alternative forms of reading material
- Other
 - If caregiver or interpreter present, primary communication should be with patient



Be an ALLY



WHAT CAN YOU DO?

Be anti-ableist

Prioritize accessibility

Include people with disabilities

Don't wait to take action!

Knowledge check

Why is it important to be familiar with inclusive language and disability etiquettes?

- A. Conveys respect and understanding for ALL.
- B. Help remove barriers and avoid gatekeeping.
- C. Words have the power to create a diverse and an inclusive culture.
- D. Both A and B
- E. All of the above.

Providers with disabilities – real life







Disability Employment Awareness Month

A critical part of accepting vision impairment is understanding that you are valuable — you may contribute to society in an even more meaningful way.

Bonnie Swenor, MPH, PhD Associate professor of ophthalmology

#NDEAM #VisionForWork







Additional resources:

<u>DOCS with Disabilities initiatives</u>: Podcasts on stories and Research and Resources.

Stanford Medicine Alliance for Disability Inclusion and Equity

• Annual conference in Spring – recorded events from past years

Mentorship opportunities with <u>Disability in Medicine Mutual</u> <u>Mentorship Program</u>

Disability Lead Fellowship

YouTube channel by Dr. Stephany Van – This Ability Clinic

Where are disabled health professionals? Rachael's story



Questions?

Connect, reach out and learn more!

- Email: kruti p shah@rush.edu
- Beyond Awareness power of disability inclusion <u>Newsweek Article</u>
- <u>Docs With Disabilities Podcast Interview with Dr. Lisa Meeks</u>
- Connect on <u>LinkedIn</u>

