

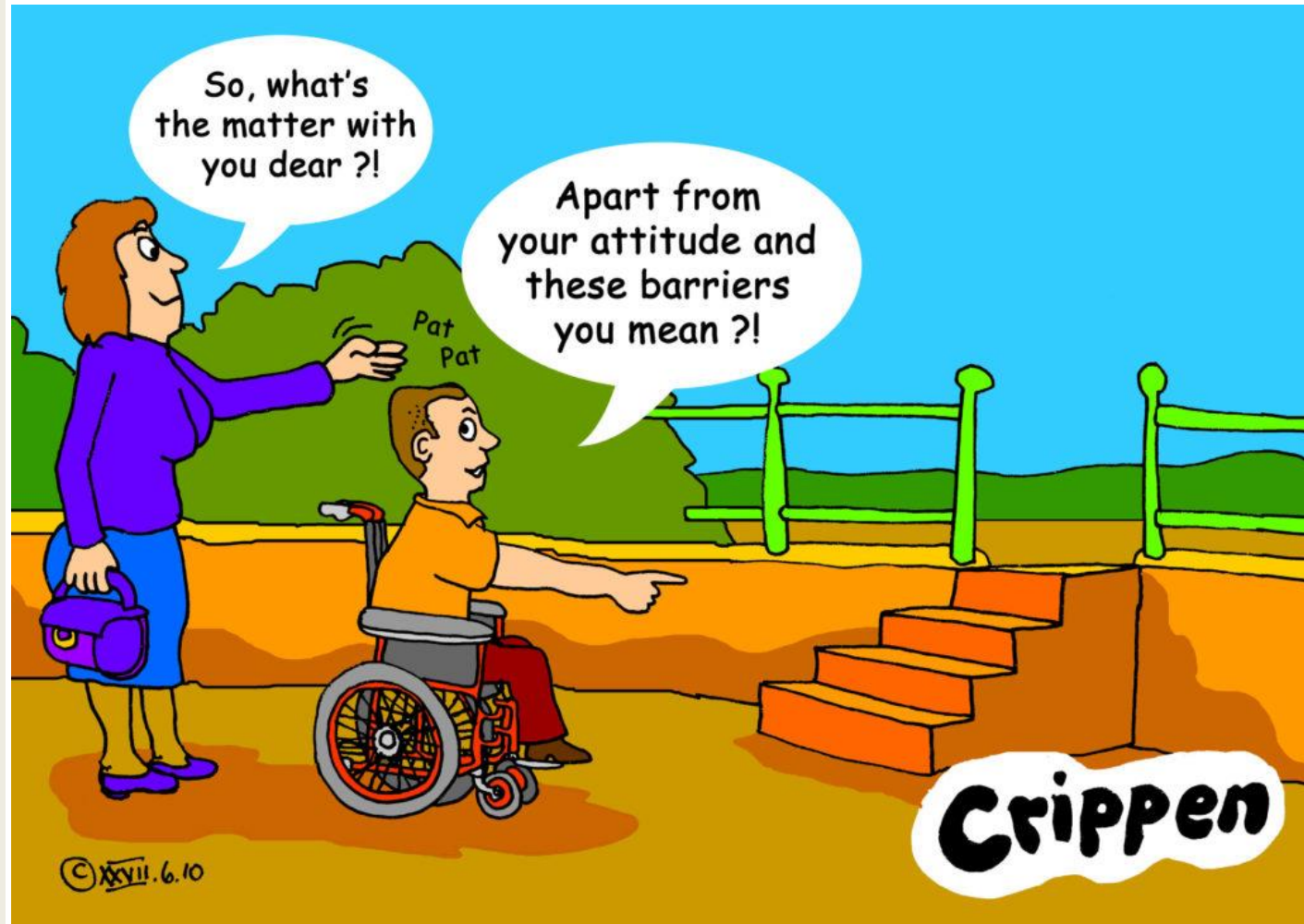
DISABILITY AWARENESS:
HOW CASE MANAGEMENT CAN SUCCESSFULLY
COLLABORATE WITH THOSE WITH LIVED
EXPERIENCE



Presented by: Breaking Silences



LET'S GET A BIT
UNCOMFORTABLE





What does disability mean to you?

- Needing help with something that an able-bodied person can do themselves;
- Demanding respect regardless of ability;
- Relying on SSI or SSDI and other social services for total support;
- Having special needs;
- Facing barriers within society that prevent equity;
- Suffering from a sickness or being chronically unhealthy.



Civil Rights Laws

- 1964—Civil Rights Act
- 1968—Architectural Barriers Act
- 1970—Urban Mass Transit Act
- 1973—Rehabilitation Act
- 1975—Developmental Disabilities Bill of Rights Act
- 1975—Education of All Handicapped Children Act
- 1978—Amendments to the Rehabilitation Act
- 1983—Amendments to the Rehabilitation Act
- 1985—Mental Illness Bill of Rights Act
- 1988—Civil Rights Restoration Act
- 1988—Fair Housing Amendments Act
- 1990—Americans with Disabilities Act
- 1996—Telecommunications Act
- 1996—Air Carrier Access Act
- 1999—Supreme Court upholds *Olmstead v. L.C.*

Disability History Key Facts

- Architectural Barriers Act 1968
- The beginning of the Independent Living (IL) Movement
- Willowbrook State School investigation and lawsuit
- Rehabilitation Act of 1973
- ADAPT Bus Boycott
- ADA Signed in 1990
- The 2020 Film, *Crip Camp: A Disability Revolution*, provides a personalized perspective on several of these events
 - Link: <https://bit.ly/3qoJnBa>
 - Also available on Netflix

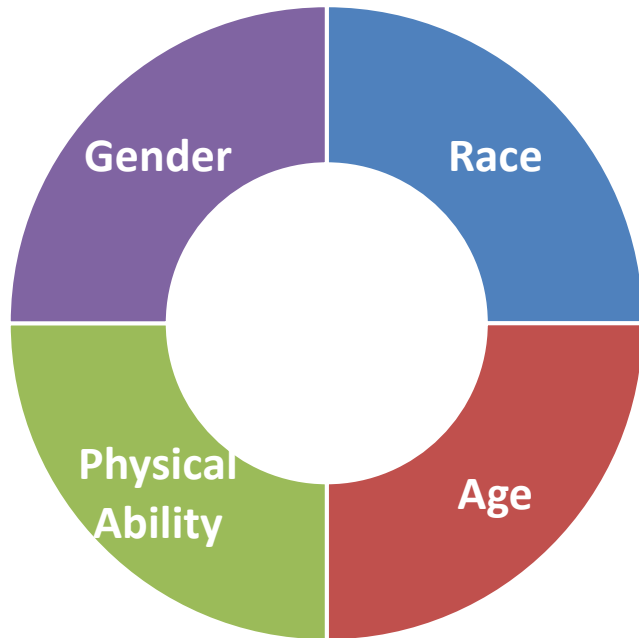


The Culture of Disability:

We filter the world through our own unique culture.

Culture is the root of bias.

PRIMARY SUBGROUPS



SECONDARY SUBGROUPS





The Reality of Disability

- The World Health Organization (WHO) defines disability as a functional concept; disability is any long-term limitation in activity resulting from a condition or health problem. This is the recommended international standard for data collection of disability.
- People with disabilities are a diverse group who share the experience of living with significant limitations in functioning and, as a result, often experience exclusion from full participation in their communities.



WHO 16 January 2018



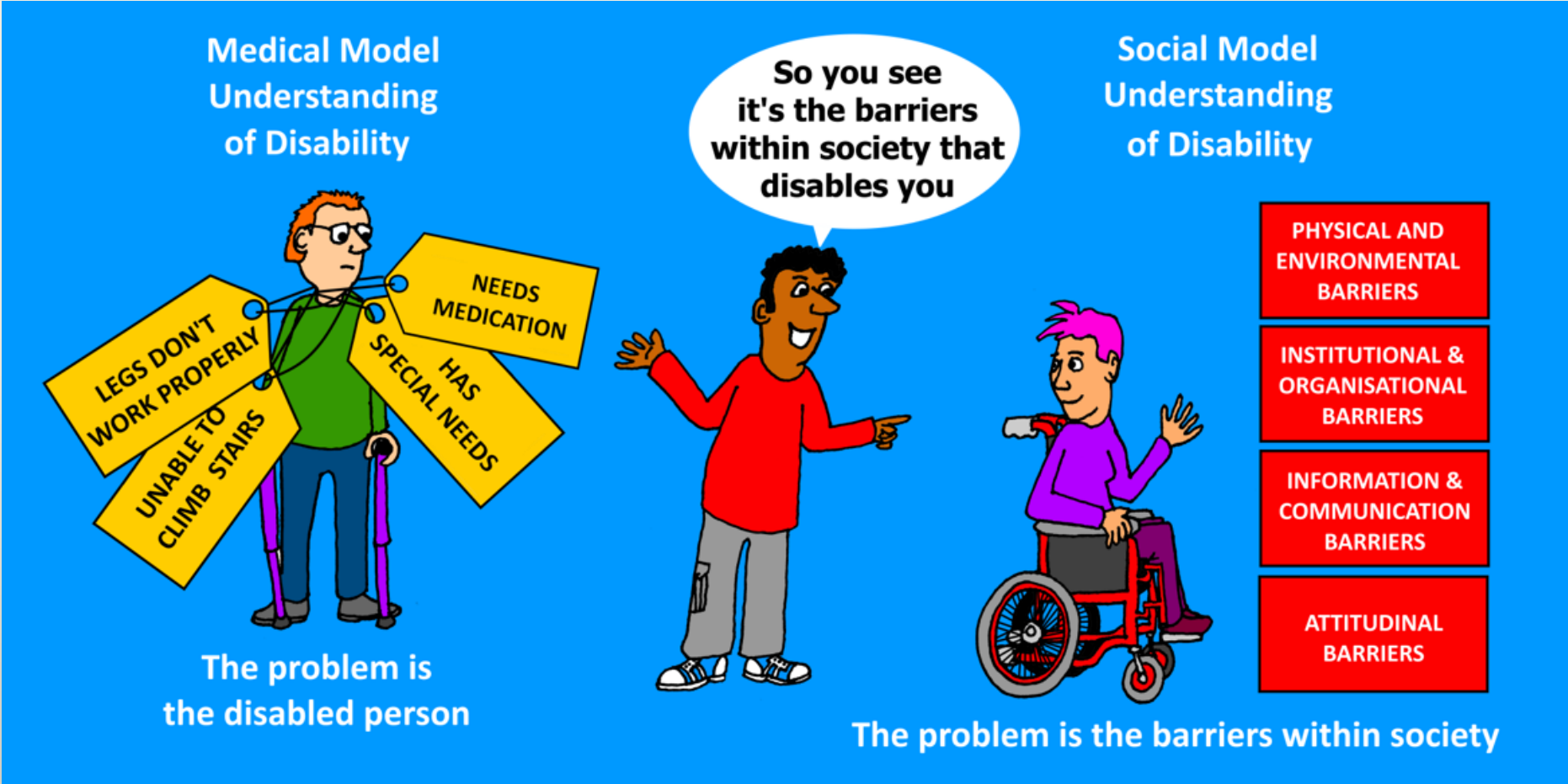
Disability is Part of Human Existence



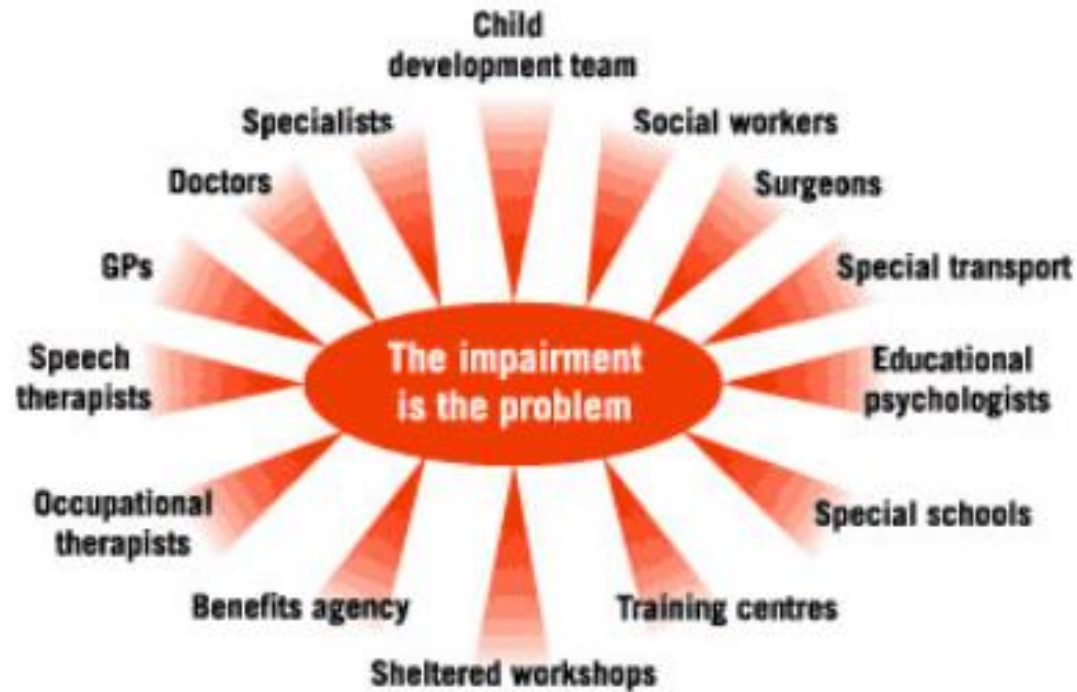
- A diagnosis of disability should not define us, our talents and abilities, or health behaviors and health status;
- To be healthy, all individuals with or without disabilities must have opportunities to take part in meaningful daily activities that add to their growth, development, fulfillment, and community contribution;
- Meeting the disability and health objectives over the decade will require that all public health programs develop and implement ways to include individuals with disabilities in program activities and planning.

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Models of Disability



Partner not Patient



Disabled people as passive receivers of services aimed at cure or management



Disabled people as active fighters for equality working in partnership with allies.

Equality vs. Equity

EQUALITY:

Everyone gets the same – regardless if it's needed or right for them.



EQUITY:

Everyone gets what they need – understanding the barriers, circumstances, and conditions.



Equity

Custom tools that identify and address inequality



With apologies to Shel Silverstein from @lunchbreak

2019 Design In Tech Report | Addressing Imbalance

Justice

Fixing the system to offer equal access to both tools and opportunities



With apologies to Shel Silverstein from @lunchbreak

2019 Design In Tech Report | Addressing Imbalance

EQUITY AND JUSTICE



What are the most important tasks of a case manager?



- Understanding the healthcare needs and wants of the member;
- Responding in a timely manner to urgent requests;
- Making sure a member's care plan is fulfilled without service gaps;
- Speaking to the member with dignity and respect regardless of disability or age;
- Being an advocate for your members and their needs;
- Ensuring the member is in control of their care, even if they fail.



Terminology: Handicapped vs. Disability

- The term “handicapped” connotes the negative image of a person on the street corner with a “handy cap” in hand, begging for money;
- The ADA was not called the “Americans with Handicaps Act”, “handicap” does not appear anywhere in the ADA;
- This is an outdated term.
- The word “disability” means the lack of ability or power;
- A disability can mean that a person may do something differently as compared to a person who does not have a disability, but with equal participation and equal results;
- This is the preferred term.



DISABLED BUT
ABLE TO VOTE
Why Be Normal

Person First vs. Identity First Philosophy



- Person-first philosophy is putting individuals before their disability;
- This is important because our philosophy directly connects to the language we use, our attitudes, and our actions;
- Some examples:
 - People with disabilities;
 - She has autism;
 - Communicates with her eyes/a device/etc.,
 - They are of short stature
- Some people prefer identity first language, as they view their disability as part of their identity;
- When using identity first language, you put the descriptor first, such as “deaf person”;
- Always consider a person’s preference when writing or talking about a person and their disability. However, if you aren’t sure, and you can’t ask the person, use person-first language.

Appropriate Language

- The language we use can intentionally or unintentionally express biases. It is important to portray individuals in a way that is respectful, objective, and neutral.
- Concepts to understand:
 - Ask someone how they want to be identified (person-first vs. identity first);
 - Avoid using the Medical Model and instead use the Social Model;
 - Avoid euphemisms;
 - Avoid pity; and
 - Avoid inspirational rhetoric.



Examples of Updated Language

Don't Use	Use
Wheelchair bound or wheelchair victim	Wheelchair user
Handicapped parking	Accessible parking
Hearing impaired, deaf and dumb, or deaf and mute	Deaf person, hard of hearing person, deafblind person, person who is deaf, person with a hearing disability, person with hearing loss
Special needs	Functional needs
Visual impairment	Blind or low vision

Understanding Ableism

Discrimination of and social prejudice of against people with disabilities based on the belief that typical abilities are superior



- Hosting an inaccessible website;
- Failing to provide alternate formats for documents;
- Choosing an inaccessible location or virtual platform for a meeting;
- Using language like crazy or stupid;
- Questioning if someone has a disability or how much they are disabled;
- Suggesting someone should live in a facility instead of their own home;
- Viewing a person with a disability as inspirational for accomplishing tasks or milestones expected of anyone else.





Right to Fail: Dignity of Risk (coined by Robert Perske)

- In American society, people with disabilities are usually not put in the position to fail by the people that care for them;
- In contrast, people without disabilities make choices all the time that could be positive and negative, and then must accept the consequences;
- Trial and error, succeeding and failing, are all typical parts of the human experience. If you ever fail, you won't grow or change. Everyone deserves to fail.





Right to Fail: Dignity of Risk (coined by Robert Perske)

Example:

The Special Olympics

- Participants choose whether to compete or not. Obviously, not everyone will win but even if the person loses, they've learned valuable lessons about themselves. They could choose not to participate in the future or work harder to improve for the next competition.
- Participants risk mild or serious injury, but even injuries help people learn things like being more careful, practicing more, etc.
- People without disabilities get to make their own decisions, with good and bad results, why not people with disabilities?
- <https://www.google.com/amp/s/www.psychologytoday.com/intl/blog/nobodys-normal/202011/the-dignity-fail%3famp>

Dignity

- Assessment tools do not consider individual capabilities;
- Demeaning members by asking them to justify for their health care and community-based services needs by explaining intimate details of their life, and subjecting them to explaining this over and over;
- Showing lack of empathy for the complexity of a world that does not naturally support people with disabilities;
- Adopting a dismissive attitude if requests require an accommodation or modification;
- Threatening a member with an impending Nursing Facility placement for any reason.



A black stethoscope is positioned diagonally across the frame, resting on a white computer keyboard. The stethoscope's chest piece is on the left, and its two earpieces extend towards the bottom right. The keyboard keys are visible, including letters like S, D, F, G, H, J, K, L, and numbers like 8, 9, 0, as well as function keys like shift, control, option, and command.

Which member services are you responsible for coordinating?

- Alternative format documents;
- Virtual or in-person accommodations for a meeting;
- Accessible medical service providers;
- Finding skilled and non-skilled homecare workers;
- Billing problems related to waiver services;
- Understanding what is needed, and when it is needed, for Prior Authorizations;
- Pharmacy and/or medication denials;
- A request for an appeal.

As members, we
would suggest the
answer is: ALL



Reason 1:

- Coordinate: bring the different elements of a complex activity or organization into a relationship that will ensure efficiency or harmony

Reason 2:

- Care coordinators and waiver service providers are the gatekeepers for members' services

Reason 3:

- Members with disabilities are entitled to reasonable modifications under the ADA

The Americans with Disabilities Act

The ADA is organized into 5 sections called titles:

- Title I Employment: prohibits disability discrimination in all employment processes
- Title II Accessibility in State and Local Government: physical and program accessibility in state/local government entities
- Title III Accessibility in Public Accommodations: physical and program accessibility in stores, restaurants, hotels, and other places open to the public
- Title IV Telecommunications: telephone and communication systems for the public
- Title V Miscellaneous: protection from retaliation, etc.



The ADA and Health Care:

The ADA requires that health care entities provide full and equal access for people with disabilities.

Reasonable Modifications of Policies, Practices, and Procedures: adjusting policies, practices, and procedures, if needed, to provide goods, services, facilities, privileges, advantages, or accommodations;

Effective Communication: making accommodations, in all forms, easily understood;

Accessible Facilities: ensuring physical accessibility;

Healthcare agencies run by state and local governments are covered under Title II of the ADA. Health care organizations run by private businesses or nonprofit organizations are covered under Title III of the ADA.



Reasonable Modifications of Policies, Practices, and Procedures

The term “reasonable modification” is a broad concept that covers every type of disability,

The ADA does not cover every modification for every situation. It requires entities to evaluate requests on a case-by-case basis,

Often, modifications are minor adjustments.



Reasonable Modifications of Policies, Practices, and Procedures Examples



- Modification to a prescription, such as a different dispensing method, like liquid instead of tablet, that is not found on approved formulary;
- Allowing additional time with home caregivers for individuals with complex medical needs;
- Waiving a consumer's signature on documentation;
- Allowing a service animal to accompany an individual into a procedure room.



Reasonable Modifications of Policies, Practices, and Procedures

The ADA has limits

Businesses are not required to change their policies and procedures in any way that would cause a “fundamental alteration” in their goods or services, would undermine safe operation, or would cause a “direct threat” to the health or safety of others

- A "fundamental alteration" is a change that is so significant that it alters the essential nature of the goods, services, facilities, privileges, advantages, or accommodations offered
- People with disabilities may not be excluded from any services or be isolated from other customers unless it is necessary for the safe operation of a business. If legitimate safety requirements make it necessary to exclude or isolate, they must be based on actual risks, not on stereotypes or generalizations
- A "direct threat" is a significant risk to the health or safety of others that cannot be eliminated.

Effective Communication

Effective communication is required by the ADA. This means that all communication, written and oral, must be as clear and understandable for people with disabilities as it is for those without disabilities.

- Auxiliary aids must be made available when requested;
- Provide materials in plain language;
 - Technical writing using clear and concise language that is understood by anyone regardless of disability;
- Speak directly to the person and not to an interpreter;
- Discuss communication needs with the individual to determine the most effective method moving forward.



Physical Accommodations



Health care facilities must ensure that their facilities are accessible to people with disabilities, including medical equipment whenever possible.

Health care providers must have an accessible facility that meets the 2010 ADA Standards for Accessible Design.



Physical Barriers To Health Care



- Insufficient accessible parking;
- Narrow entries, hallways and doorways;
- Poor signage;
- Waiting rooms with no wheelchair spaces;
- Inadequate bathroom facilities;
- Accessible exam, treatment, and procedure rooms;
- Accessible examination tables;
- Accessible imaging machines;
- Accessible scales; and
- Patient lifts.

THANK YOU!

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PANEL DISCUSSION

