Accessibility to Care for People with Disabilities and Children and Youth with Special Healthcare Needs

Cara N Whalen Smith, PT, DPT, MPH, CHES
The Ohio Colleges of Medicine Government Resource Center

David Ellsworth, MPH, CHES
The Ohio Disability and Health Program, OSU Nisonger Center
Session Purpose

• Identify physical barriers to care for people with disabilities and children and youth with special healthcare needs

• Recognize attitudinal barriers to care that prevents adequate access to care for people with disabilities

• List examples of low-cost accommodations that can be made in primary care practice to increase access to care for people with disabilities

• Learn about additional resources on this topic
What is Disability?

According to the World Health Organization’s International Classification of Functioning, Disability and Health (ICF) framework, a disability is any cognitive or physical impairment, activity limitation, and/or participation restriction.
Ohio Disability & Health Program

54 Million people in the United States have a disability. That is 1 out of 5 people.

Ohioans with disabilities have more barriers to quality health care, are more likely to suffer from a chronic disease, and have higher rates of poor health behaviors and risks.

97% of PWD live in the community which means they seek healthcare from the same providers as people without disabilities.

Disability is defined as a functional limitation in activities of daily living or related to a health condition and associated with significant impairment, activity limitation, and participation restrictions. Impairments may involve hearing, vision, movement, thinking, remembering, learning, communicating, mental health, or social relationships. These impairments may occur across the lifespan at any point in time.
The Importance of Access and Inclusion

• People with Disabilities are much more likely to experience barriers to accessing quality healthcare
  – Nearly 20% of Ohioans have some form of disability, and in some rural areas, the proportion may be even higher
  – People with disabilities have greater healthcare needs compared to the general population, however, they also have worse health outcomes

• This session will discuss physical, attitudinal, and other barriers to access that people with disabilities face that rural clinicians can address in their primary care sites
Children and Youth with Special Health Care Needs (CYSHCN)

- CYSHCN are “those who have or at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.” (McPherson et al., 1998, p. 138)

- There are approximately 10.2 million CYSHCN in the United States (Agrawal et al., 2012)
  - About 1 in 10 children in Ohio have some form of disability, accounting for nearly 130,000 kids under the age of 17 (ACS 2015 5-year Projections)
  - These 14% of children in the US consume 40-80% of healthcare expenditures (Agrawal et al., 2012)

- Like people with disabilities in general, CYSHCN and their families experience barriers to care and as a result experience high levels of unmet healthcare needs (Agrawal et al., 2012)
Remember, children with disabilities grow into adults
Prevalence of People With Disabilities in Ohio

Source: Counties designated as rural, partially rural, or urban under the definition used by the federal Office of Rural Health Policy, 9/2009

% Adults with a Disability
- 10.4% - 15.0%
- 15.1% - 20.0%
- 20.1% - 25.0%
- 25.1% - 30.7%
Physical Barriers to Access

• The experiences of People with Disabilities are often shaped by people who are not disabled

• ADA and Universal Design
  – Many of these barriers persist
  – Some leading to lawsuits
  – Costly to retrofit
Role of the Built Environment

A primary *Healthy People 2020* objective is to “reduce the proportion of people with disabilities who report delays in receiving care due to specific barriers”
It Takes More Than ramps to Solve the Crisis of Healthcare for People with Disabilities

– What might have helped to avoid this?
– Think broadly about interaction with clinical environment – not just disability
– Physicians and staff tend to greatly overestimate the degree to which their facility is accessible (Grabois, Nosek, Rossi, 1999)
Barriers to Care within the Clinic

Even when in the clinic, people with disabilities and CYSHCN may face barriers

– May be unable to undress self for an examination
– Staff may be uncomfortable or do not know how to assist a person with a disability
– Difficulty transferring from chair to examination table
– Inability to assume traditional positioning for examinations or testing
– Children with sensory processing disorders (such as autism) may have difficulty tolerating stimuli in the office
Video Clip – Barriers

Disability-Related Competencies

- Communication issues
- Patient and family beliefs about health care
- Folk or non traditional treatments
- Provider practices
- Normative cultural values

https://youtu.be/_XOppG13ctM?t=2403
Attitudinal Barriers to Access

“It amazes me that doctors still hold the medical model where people with disabilities are believed to be sick in need of a cure and that they don’t have that cure.”

-Darlene Bubis, MFT (Marriage and Family Therapist and woman with cerebral palsy)
Attitudinal Barriers to Access

• The Medical Model of Disability
  – Disability is a result of a person’s physical impairments and seeks to find a cure for those impairments even when they do not cause pain or illness

• The Social Model of Disability
  – Disability is a result of the way society is organized rather than by a person’s impairment and seeks to remove barriers that restrict quality of life
Attitudinal Barriers to Access

Providers or staff may hold the following attitudes:

- It is too difficult or impossible to perform a specific examination for people with disabilities or CYSHCN
- It is too time consuming to perform examination for people with disabilities or CYSHCN
- Make assumptions about a person’s abilities based on how they look or sound
- Belief that person with a disability is asexual and therefore does not need screening for STIs or cervical cancer screenings
- Belief that people with disabilities have a short life expectancy and therefore screenings associated with advanced age are not necessary (Armour et al., 2009; Smeltzer, 2006).
- Belief that people with disabilities do not have social lives, interests, or other activities that they participate
- Belief that people with disabilities and CYSHCN priority health need is related to their disability
Disability-Related Competencies

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https://youtu.be/_XOppG13ctM?t=2981
Additional Attitudinal Barriers for CYSHCN

• Assumptions about cognitive level based on how child looks or speaks
  – Results in not talking directly to child, but instead directs questions to parent/caregiver

• Assumptions about compliance based on child behavior

• Assumptions about abilities which limits child’s potential to achieve their highest level of quality of life
  – Disability does not mean inability
“It’s not that deaf and disabled people don’t have to battle with all kinds of barriers in life – of course we do. It’s the fact that society seems to forget that it’s often the world around us – physical barriers, communication issues, or attitudes – that are far more “disabling” than the disability itself. Non-disabled people may feel inspired by the idea of us “overcoming” or “beating” our disability, but we wouldn’t have much to overcome if society treated us more equally.”

-Charlie Swinbourne
Accommodations

- Height adjustable exam tables
- Scales that accommodate wheelchair users
- Adequate number of accessible parking spaces
- Arrange for lifts to assist patients on to exam tables
- Working knowledge of transferring and positioning patients with disabilities on exam tables—purchase a gait belt and sliding board to have on hand in the clinic
- Train health professionals in alternative ways to position patients for examinations
- Culturally competent staff and staff training for interactions with PWDs
- Train health professionals on how to communicate with PWDs
- Education to correct misconceptions about disability
- Think about how to set up the environment for a successful appointment
Elements of Quality Care

• Prepare patient for exam
  – Explain procedures well
  – Introduce instruments, encourage exploration

• Speak directly to the patient
  – Use plain language
  – If expressive language is difficult, use family/carer as interpreter

• Be patient
  – It may take longer to process information
  – Speech may be slow or halting
  – Avoid finishing patient’s statements to save time!

• Always treat patient with respect
  – Recognize that patients have expertise about their condition and want to be partners in their care

• Be sensitive to the needs of the caregiver
Benefits of Medical Home for CYSHCN

• In 2002, the American Academy of Pediatrics issued a policy statement to encourage primary care medical homes to be “accessible, continuous, family centered, coordinated, compassionate, and culturally effective for all children, especially CYSHCN.” (Agrawal et al., 2012; Sia et al., 2004; Pediatrics, 2002)

• The benefits of the medical home for CYSHCN have been well-documented (Agrawal et al., 2012) and include reduced:
  – Emergency department utilization
  – Delay in care
  – Unmet health needs
  – Overall costs for CYSHCN
How to Improve Visit

• Ask patient and caregivers what could be done to help patient cope with exam
  – Scheduling
  – Waiting area
  – Receptionist, nurses
  – Offer choices

• Listen to responses and note them in chart

• Remember to accommodate next time

• Remember they are a person first and their disability is second; the reason for their health visit may be unrelated to their disability
Accessibility Improvement Checklist

One in five people in Ohio report having some form of disability. Since people with disability represent such a large portion of the population that we serve, it is important that primary care services are accessible to everyone. Below are recommendations based on the Americans with Disabilities Act (ADA) to increase the accessibility of clinical spaces for Primary Care Facilities for people with disabilities.

**Approach and Entrance to Facility:**

1. At least one van accessible parking space should be available in the parking lot. The parking spot should have a van accessible sign placed at least 60 inches above the ground.
   - Cost: $20.00 for Accessibility Sign and Placard ($10.00 each)
   - Difficulty: Easy
   - Equipment: Adjustable wrench to install sign at correct height.

2. There should be at least 60 inches of space between the ground and the bottom of each accessible parking sign (most are too low and do not meet ADA standards)
   - Cost: $0.00
   - Difficulty: Very Easy
   - Equipment: Adjustable wrench to install sign at correct height.

3. Ensure that all doors take at least 5 seconds to close from an open position of 90 degrees to a position of 12 degrees from the door latch*.
   - Cost: $0.00
   - Difficulty: Easy
   - Equipment: Flat head or Phillips screwdriver

*To adjust the swing or latch speed, turn screwdriver clockwise to reduce the speed, counterclockwise to increase the speed. The set-screws are usually located on the end of the closer.
Other Resources

• Healthcare Access for Persons with Disabilities Part 1 and 2 CE courses
• Access to Medical Care for Individuals with Mobility Disabilities
• Standards for Accessible Medical Diagnostic Equipment
Other Resources

- Other Transfer Techniques: http://www.cdss.ca.gov/agedblinddisabled/res/VPTC2/4%20Care%20for%20the%20Caregiver/Transfer_Techniques.pdf
- Work with PT/OT to learn more techniques in patient transfers, as well as positioning and dressing
Conclusion

• You are equipped to provide care to people with disabilities
• Not all barriers are structural
• Improving access within the clinic doesn’t have to be costly
Questions?
References

• Smeltzer, S.C. Preventive health screening for breast and cervical cancer and osteoporosis in women with physical disabilities. Fam Community Health. 2006;29(1 Suppl):35S-43S.