Healthcare Access for Persons with Disabilities

Part 1: Persons with Physical and Sensory Disabilities

Support for this training comes from the Centers for Disease Control & Prevention through the Florida Office on Disability and Health, CFDA# 93.184 State Implementation Projects for Preventing Secondary Conditions and Promoting the Health of People with Disabilities

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Objectives

- Participants will gain a better understanding of health, wellness, and care issues concerning people with physical and sensory disabilities and will:
  - Identify the four goals of The Surgeon General's Call to Action to Improve the Health and Wellness of People with Disabilities,
  - Recognize the four barriers to quality healthcare, as addressed in the Americans with Disabilities Act,
  - Learn a minimum of five skills to increase good communication and rapport to enhance accurate assessment and delivery of quality care.

What is health?

World Health Organization (WHO) definition:

- Health is a state of complete physical, mental and social well-being…
- Health is a resource for everyday life, not the objective of living.
- Health is a positive concept emphasizing social and personal resources, as well as physical capacities.

What is Disability?

ADA definition

The term ‘disability’ means, with respect to an individual –

a. a physical or mental impairment that substantially limits one or more of the major life activities of such individual;

b. a record of such impairment; or

c. “being regarded as having such an impairment.” (P.L. 101-336, Sec. )
International Classification of Functioning, Disability, and Health (ICF)

• Developed by the World Health Organization.
• Provides a unified language and framework for the description of health and health related states.
• The ICF puts the notions of 'health' and 'disability' in a new light.
  – It acknowledges that every human being can experience a decrement in health and thereby experience some degree of disability.
• ‘Mainstreams’ the experience of disability and recognizes it as a universal human experience.

Definition of Disability from ICF

• For ICF, disability serves as an umbrella term for impairments, activity limitations or participation restrictions.
• In general, impairments are problems in body function or structure that, to a greater or lesser extent, affect a person's ability to engage independently in some or all aspects of day-to-day life.

International Classification of Functioning, Disability, and Health

• Shifts the focus from cause to impact, which places all health conditions on an equal footing allowing them to be compared using a common metric – the ruler of health and disability.
• ICF attempts to combine the medical and social models in order to provide a coherent view of health from a biological, social, and individual perspective.
• ICF measures the impact of the environment on the person's functioning by documenting Contextual Factors.
Today, 54 million Americans, or one in five people, are living with at least one disability, and most Americans will experience a disability some time during the course of their lives.

As we age, the likelihood of having a disability of some kind increases. However, disability can become a fact of life for anyone at any time.

Some people are born with a disability; others acquire a disability from an accident or illness; and still other people develop a disability as they age.

The reality is that just about everyone — women, men and children of all ages, races and ethnicities — will experience a disability some time during his or her life.
The Surgeon General's Call to Action to Improve the Health and Wellness of Persons with Disabilities, 2005

- People with disabilities have healthcare needs like everyone else.
- To get and stay healthy, people with disabilities need to be able to obtain the healthcare they need when they need it, just like everyone else.
- People with disabilities need healthcare professionals who really listen to, communicate with, and respect them.

People with disabilities need healthcare professionals who treat all of their health needs, not just their disability.

The four goals of this “Call to Action” are:

1. Increase understanding nationwide that people with disabilities can lead long, healthy, and productive lives
2. Increase knowledge among healthcare professionals and give them tools to screen, diagnose, and treat the whole person with a disability with dignity
3. Increase awareness among people with disabilities of the steps they can take to develop and maintain a healthy lifestyle
4. Increase accessible healthcare and support services to promote independence for people with disabilities
According to the most recent census data, around 52 million people with disabilities live in their community. About 2 million live in nursing homes and other long-term care facilities.

Health Challenges

- People with disabilities share many of the same challenges as those without disabilities when it comes to their own health and well-being.
- Foremost is having the tools and the knowledge — and knowledgeable healthcare professionals — to help them enjoy and maintain full, healthy lives.

Long, productive, healthy lives can be achieved with:

- Accommodations and supports,
- Ample access to healthcare,
- Engagement in wellness activities,
- and the impetus that comes from supportive friends and families.
Health Disparities for Persons with Disabilities

• Only 28.4% of people with disabilities report their health to be excellent or very good vs. 61.4% of people without a disability (CDC, 2004a).
• While a disability doesn’t necessarily imply illness, some disabilities may lower the threshold to an array of secondary conditions that can negatively impact their health status and the quality of their lives.
  – 87% of persons with a disability report at least one secondary condition vs. 49% of those people without a disability (Kinne et al., 2004).

What are secondary conditions?

• Physical, medical, cognitive, emotional, or psychosocial consequences to which persons with disabilities are more susceptible by virtue of an underlying condition
• Secondary conditions cause adverse outcomes in health, wellness, community participation, and quality of life

(Hough, 1999)

Common Secondary Conditions

• Depression
• Urinary tract infections
• Unwanted weight gain
• Chronic pain
• Excessive fatigue
• Respiratory infections

• Hypertension
• Fractures
• Skin lesions
• Contractures
• Social isolation

(Simeonsson & McDevitt, 1999)
Preventive care and early intervention can reduce some complications.

- Some secondary conditions can be prevented or decreased by:
  - a combination of health maintenance practices,
  - removal of environmental barriers, and
  - improved access to effective medical care
- Other conditions are inevitable components of certain types of disabilities and can be managed but not prevented.

Many people with disabilities consider themselves healthy and well, which likely enhances their quality of life.

A healthy lifestyle enables people with disabilities to learn, work, and live actively in their own communities,

but health risks and disparities associated with disability can make achieving good health more difficult.
Providers who understand that people with disabilities can be healthy, active, and assertive participants and co-managers of their health and healthcare, can be of tremendous assistance in helping people select and practice health promotion behaviors and activities that increase well-being.

Access to Healthcare Challenges include:

- Insufficient knowledge and awareness of disability by the public, healthcare and wellness service providers, educators, administrators, the media and others.
- In a recent survey, 25% of adults with disabilities reported that they had difficulty finding a doctor who “understands my disability” (Henry J. Kaiser Family Foundation, 2003).

Access to Healthcare Challenges include:

- Healthcare professional and community attitudes and behaviors that see and respond only to the disability not to the whole person.
- For example, women with disabilities are less likely to receive preventive care.
  - Only 74% of women with disabilities ages 18+ report receiving a pap smear vs. 78% of women without a disability (CDC, 2004)
  - 55% of women with disabilities ages 40+ report receiving a mammogram vs. 61% of women without a disability (CDC, 2004)
Other Challenges:

- Insufficient healthcare and wellness promotion services and information that is adapted for persons with disabilities.
- Service systems that do not make use of innovative and creative approaches to enhance the health and wellness of persons with disabilities.

Barriers to Care

- Physical/architectural barriers
- Communication barriers
- Attitudinal barriers
- Social/economic policy barriers

Understanding these barriers and obtaining accessibility training is helpful for both professionals and support staff.

ADA Requirements for Health Facilities and Practitioners

- Provide access for people with disabilities to healthcare services.
- The law requires reasonable accommodation - meaning those changes that are readily achievable and do not present an undue hardship on the facility.
- Practitioners and facilities need to learn about and provide specific accommodations for people with the full range of disabilities.
Key Points

- People with disabilities require the same quality of health service and preventive care as any patient, but may be under-served and receive less than quality care.

- Defining “health” as the absence of disability or chronic illness negatively affects people with disabilities.

Avoid stereotyped assumptions

People with disabilities can lead active, fulfilling lives, which include work and community involvement, sexual relationships and parenting, or could achieve these with appropriate community resources.
Key Points

• Advance access planning in the clinic can save time and improve quality of care.
• Listen attentively to your patients with disabilities to understand their background and functional needs.
• Many people with disabilities have an expertise in their conditions, which should be respected and reinforced. Others, particularly people who have recently acquired a disability, need training and support to become active partners in their care.

Key Points

• A team approach works best to accommodate complex health needs.
• Avoid unnecessary referrals to specialists.
• Check accessibility when referring patients to diagnostic testing and specialty clinics. Check that referred-to-providers accept the patient’s insurance.

When treating a person with a disability, remember:

• Talk to the patient, not someone who accompanies them.
• Ask, “How can I help you?” and respect the answer.
• Ensure that educational materials are easily accessible.
• Allow sufficient time for history taking and exam.
• Use people first language—refer to the individual first, then to his or her disability. (It is better to say “the person with a disability,” rather than “the disabled person.”)
When treating a person who is blind or visually impaired:

- Identify yourself and others who may be with you when walking into the exam room.
- Speak using a natural conversational tone and speed.
- Feel free to use words that refer to vision during the course of conversation.
- Guide people who request assistance by allowing them to take your arm just above the elbow when your arm is bent. Walk ahead of the person you are guiding. \textit{Never grab a person who is blind or visually impaired by the arm and push him/her forward.}

For people who are blind or visually impaired:

- Provide written material:
  - In an auditory format
  - On computer disc
  - In Braille or large print

When treating a person who is deaf or hard of hearing:

- Ask how to best communicate.
- Provide an interpreter, if necessary for effective communication.
  - Patients cannot be charged for interpretation.
  - Family members should not be pressured to interpret to save time or expense.
- Provide written educational material.
- Look at the person while speaking. Do not place your hands in front of your face or lips when talking.
- Speak using a natural conversational tone and speed. Avoid shouting.
Resources to locate Interpreters

- Florida Registry of Interpreters for the Deaf
  - [http://www.fridcentral.com](http://www.fridcentral.com)
- Florida Coordinating Council for the Deaf and Hard of Hearing (FCCDHH)
  - [http://www.fccdhh.org](http://www.fccdhh.org)
- Deaf Services Bureau of West Central Florida
  - [http://www.deafservicesbureau.org](http://www.deafservicesbureau.org)
  - 1-800-616-4293
- American Sign Language Services, Inc.
  - [http://www.aslservices.com](http://www.aslservices.com)

When treating someone who uses a wheelchair:

- Place yourself at eye level in front of the person to facilitate conversation.
- Never patronize people who use wheelchairs by patting them on the head or shoulder.
- Provide access to exam areas.
- Provide assistance if necessary for a full and complete exam (even if it requires more time or assistance).
- Avoid pushing a wheelchair unless asked.
- Obtain adjustable exam tables for your facility, if possible.

Interacting with people who have speech impairments:

- Be respectful; never assume that the person has a cognitive disability just because he or she has difficulty speaking.
- Listen attentively when they are speaking. Be patient and wait for the person to finish, rather than correcting or speaking for the person.
- If you do not understand what the person has said, do not pretend that you did. Ask the person to repeat it; or, repeat what you understood and allow the person to respond.
Considerations

• Is there an accessible entrance to the facility? Is it clearly marked?
• Are exam rooms accessible to wheelchair users?
• Was a sexual history taken? (often neglected due to a stereotype of asexuality.)
• Are medical and non-medical staff trained to be respectful and non-patronizing?
• Is there adequate time scheduled in the appointment for the patient to adequately communicate without pressure to hurry?
• Are staff familiar with TDDs and available communication relay systems?

Helpful Resources

• Access Equals Opportunity: ADA FAQ for Outpatient Healthcare Facilities
  • http://metroke.gov/dias/ocre/medical/htm
• A family physician’s practical guide to culturally competent care
  • http://thinkculturalhealth.org
• Removing Barriers to Healthcare (architectural access issues)
  • http://www.design.ncsu.edu.cud
• Tips and Strategies to Promote Accessible Communication
  • http://www.fpg.uc.edu/~ncodh

We wish to thank the World Institute on Disability for the use of their video: Access to Medical Care: Adults with Physical Disabilities.

www.wid.org
References

References