

I Know You Hear Me, But Are You Listening?

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FAMILY PHYSICIANS

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Objectives

- Define the difference between the medical model and Independent Living Model of people with disabilities
- Become familiar with the different abilities and how to work with each
- How medical entities can improve access/medical service delivery to people with disabilities



Disability Defined Medically

- Bedridden
- Crippled
- Handicapped
- Impaired
- Incapacitated
- Lame
- Infirm
- Maimed
- Mutilated
- Physically challenged
- Weakened

<http://medical-dictionary.thefreedictionary.com>

Changed the Disability Definition-Ed Roberts



Independent Living Model definition of Disability

- “The Independent Living Model sees the problem differently and understands disability as a construct of society. In this model, the problem lies in the environment, not the individual. Though many people have physical, intellectual, or mental attributes that deviate from the ‘norm,’ disability is manifested in society through purposefully created and maintained physical, programmatic, and attitudinal barriers.”

<http://www.ncil.org/about/aboutil/>

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Population

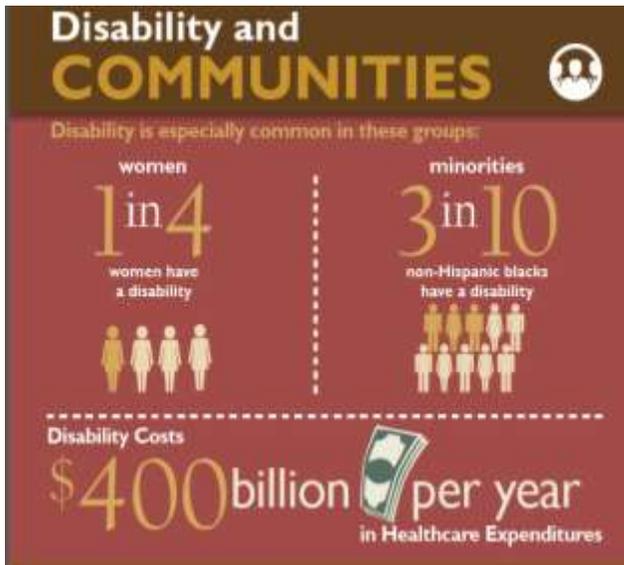
Approximately 54 million Americans live with a wide range of physical, cognitive, and emotional disabilities

Myths About the Disability Community. www.trynova.org/victiminfo/ovc-disability/myths.html

14% of US population had disabilities, living outside of institutions

Erika Harrell. *Crime Against Persons with Disabilities, 2009-2012 Statistical Tables.* U.S. Department of Justice: Bureau of Justice Statistics. February 2014

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Types of Disabilities

Developmental Disabilities

- **Begins in infancy of childhood, under 21 years old**

“language, mobility, learning, self-help, and independent living”

(Wikipedia)

Examples: Autism, Cerebral Palsy, Down Syndrome, Fetal

Alcohol Syndrome, Spinal Bifida

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Intellectual Disability

IQ below 70

Significantly impaired functions:

- 1) intellectual – ability to learn
- 2) adaptive – ability to adjust behavior

Down Syndrome, Autism

Cognitive Disability

“People with cognitive impairment have or previously had normal IQ but now show confusion, forgetfulness and difficulty concentrating;

Cognitive impairment is typical of brain injuries, side effects from medications, and dementia”

https://en.wikipedia.org/wiki/Disabilities_affecting_intellectual_abilities

Mental Health

- 1 in 5 have Mental Illness
- 18.5% (43.8 million) of US population have Mental Illness but 41% receive treatment

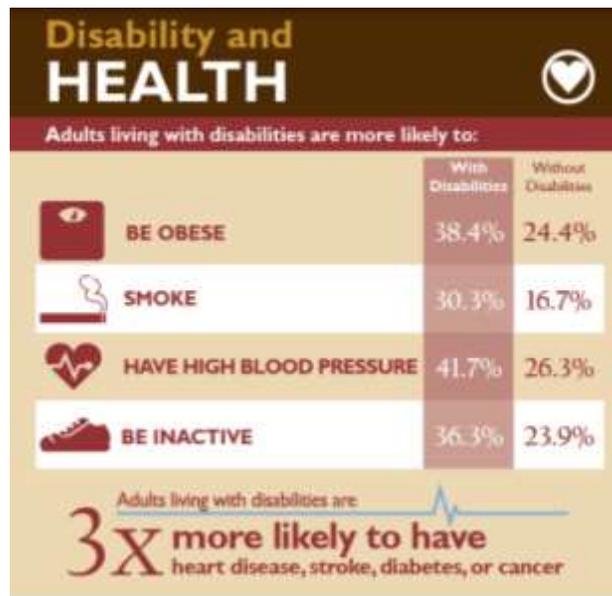
Most common diagnoses:

Depression- leading cause of mental illness

Anxiety

Bipolar

Schizophrenia



Can be acquired thru time

- Hearing/vision
- Mobility -
- Traumatic Brain Injury
- Stroke
- Dementia

Statistically Speaking.....

Women with disabilities are less likely to have pap smears.

- 71% who had pap smears had basic action difficulties
- 65% had complex limitations

COMPARED TO:

83% Had no disabilities

Mammagrams

- 51% had difficulties with instrumental and other activities of daily living
- 52% had cognitive disabilities
- 67% had basic disabilities
- 61% has complex limitations

COMPARED

74% HAD NO DISABILITIES

Barriers to Health Care

PROVIDER TRAINING/AWARENESS

- 91% reported having no training on developmental/ intellectual disabilities (ID)
- 71% (of the 91%) believed having training would benefit them

BUT....

Most respondents thought that providing care to ID individuals would be more difficult than caring for other patients

Stereotypes

- People with disabilities do not have a good quality of life
- People with developmental disabilities do not feel pain; no anesthesia required
- Women with disabilities do not have sex, therefore reproductive counseling and care not needed

Structural Barriers

- Inadequate transportation
- Access in facility and offices
- Accessible exam and diagnostic equipment

Discussion

- Mike is 60 yrs old, polio as child, paraplegic, uses wheelchair. Uses ventilator anytime he lays flat for post-polio syndrome. CT scan shows ill defined pelvic lesion. MRI ordered. **Nine months** later has MRI – not scheduled due to his needs when laying flat. By now the lesion has doubled in size.
- This is more than a civil rights issue. It is a quality of care issue, patient safety issue.

How To Work With People Who Have Different Abilities

Developmental and Intellectual/Cognitive

- Use short sentences
- Simple, concrete words
- Allow extra time to process information

Deaf or Hard of Hearing

- Find out the best communication method
 - Use of interpreter, address person
 - Lip Reading
 - Read and Write
- Get attention by tapping shoulder or wave hands
- If hard of hearing, avoid large noisy areas
- Repeat statement “What did you say?”

Low Vision or Blind

- Quite Mobile and Independent
- Identify Self
- Be descriptive when giving directions
- Lead someone only after they have accepted your help
- Offer large print or Braille (including prescriptions and education material)

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Written Materials

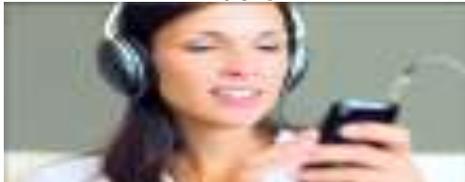
Braille



Large Print



Audio



Interpreters



Mobility

- Many reasons to use a wheelchair, walker, cane, and leg brace
- Use of wheelchair, get at their eye level
- Respect Personal Space
- Keep ramps and accessible doorways open

Difficulty with Speech

- Stressful situations can cause speech to become harder to understand
- Do not pretend to understand
- Consider writing
- Move to a quiet location
- Do not finish sentences
- Do not avoid or ignore

Be Considerate and Patient



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Speak directly to person with disability



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Terminology not to use:

- Autistic
- Brain Damaged
- Confined to a wheelchair
- Challenged
- Crippled
- Dumb
- Handicapped
- Mute
- Retard
- Suffer
- Victim
- Wheelchair Bound

RATHER.....

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Person First Language

- Eliminates generalizations & stereotypes
- Focus on person rather than disability
- Tells what a person has, not what a person is



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You are in a unique position to shape the public image of people with disabilities. By putting the person first and using these suggested words, you can convey a positive, objective view of an individual instead of a negative, insensitive image.

Do say	Don't say
Disability	Differently abled, challenged
People with disabilities	The disabled, handicapped
Person with spinal cord injury	Cripple
Person with autism, on the autism spectrum	Autistic
Person with Down syndrome	Downhand
Person of color's skin	Plugged, dark
User's physical, wheelchair user	Confined to a wheelchair, wheelbar-bound
Has a learning disability	Slow learner
Has chemical or environmental sensitivities	Chemophobic
Has a brain injury	Brain damaged
Blind, low vision	Visually handicapped, blind as a bat
Deaf, hard of hearing	Deaf-mute, deaf and dumb
Intellectual disability	Retarded, mental retardation
Amputee, has limb loss	Stump, lame
Cognitive disability	Brain defect
Seizure disorder	Seizure victim
Person with epilepsy	Suffers from epilepsy
Service animal or dog	Seeing-eye dog
Psychiatric disability, mental illness	Crazy, psychotic, schizophrenic
What should I describe you or your disability?	What happened to you?
Accessible parking or restroom	Handicapped parking, disabled restroom

Want more information?
Download our free book: *Guidelines: How to Write and Report About People with Disabilities* at www.ku.edu/ada

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Don't put unnecessary pressure on yourself to know and do everything right



What your clinic can do to improve access/service delivery to people with disabilities

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➤ **Increase disability competency to trainees**

- Disability knowledge, cultural competency, and ability to work effectively with people who have disabilities
- “Learning to Act in Partnership emphasizes many of the access issues embedded in the health care system relate to understanding disability from a social, medical and cultural context.”
- Know community and solutions to help bridge gap

Goals for your agency

1. Make all goods and services available to everyone
2. Train staff on disability etiquette
3. Streamline interview questions and intake procedures
4. Develop relationships - interagency



Resources

- Independent Living Centers
- Community Developmental Disability Organizations
- AMBUCS

During the break...

- Discuss / think about how you might implement the information you just heard.
- Fill out a session evaluation.



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