

## **Disability Stigma and Your Patients**

or people with disabilities, stigma can be a major barrier to participation. Stigmatizing attitudes about disabilities can also affect relationships between patients and providers. However, health care providers can be allies with their patients and help reduce the impact of stigma.

### What Is Disability Stigma?

The word stigma comes from the Greek word for "mark." Generally, stigma is a negative set of beliefs about people with specific characteristics. For example, ethnic or sexual minorities, or people with unusual facial appearance may encounter stigma.

People with disabilities have been stigmatized throughout history. In many cultures, disability has been associated with curses, disease, dependence, and helplessness. Disability stigma can play out in a number of ways, including:

Social Avoidance – People with disabilities may be left out of social activities, or they may find that friends become more distant after they develop a disability. People may be hesitant to make eye contact or start a conversation with someone who has a visible disability.

- Stereotyping People with disabilities may be presumed to be helpless, unable to care for themselves, or unable to make their own decisions. People with one disability, such as a speech impairment, may be presumed to have other disabilities they don't have, such as an intellectual disability.
- **Discrimination** People with disabilities may be denied jobs, housing, or other opportunities due to false assumptions or stereotypes about disabilities. This still occurs today, despite disability rights laws such as the Americans with Disabilities Act (ADA).
- Condescension People with disabilities may be coddled or overprotected due to perceptions of their helplessness.
- Blaming People may be blamed for their disability, or accused of using their disability to gain unfair benefits.
- Internalization People with disabilities may themselves adopt negative beliefs about their disability and feel ashamed or embarrassed about it.
- Hate Crimes and Violence People with disabilities may be targeted in hate crimes. They are more likely to be victims of physical or sexual violence than people without disabilities.

# How Can Disability Stigma Affect Your Relationship with Your Patients?

People with disabilities may manage their condition in ways that guard against being stigmatized. In addition, people with disabilities may be especially sensitive to signs of possible stigmatizing from their providers.

Some issues related to stigma that may arise include:

- Concealment If possible, some people may choose to conceal their disability in public in order to minimize stigma. As a result, they may be reluctant to use assistive devices, such as mobility devices or hearing aids, or to tell others about their diagnosis. They may also forgo some medical services.
- Disability Pride On the other hand, some people express pride and a positive identity around their disability as a way to counteract stigma. These individuals may wish to join groups of people who share their disability, where it is no longer stigmatized. They may also opt against medical treatment intended to "cure" their disability because they have developed a positive identity around the condition.
- Social Integration Stigma is social in nature and may interfere with social integration. In contrast to "concealment," people may choose to make their disability more evident in order to improve their options for social

- participation. For example, a person with a mobility impairment may choose to use a wheelchair instead of a walker if the wheelchair would allow him or her to travel to work or family activities without fatigue.
- Need for Respect Your patients may be especially sensitive to your attitude about their disability. Building a collaborative partnership with your patient built on trust and respect communicates your support for the patient as a whole person.

### Tips for Respectful, Stigma-free Interactions

### Establish Respectful Communication

- Do speak directly to your patient, even if he or she has a companion or interpreter in the room. Make eye contact with the patient, not the companion.
- Do use ordinary language. It's OK to say "see you later" to a patient who is blind, or to talk about going for a walk with a patient who is non-ambulatory. Using ordinary expressions signals that you see your patients as full members of their community.
- Do ask patients with speech impairments how they prefer to communicate. Some patients may write or type to communicate if they have impaired speech, for example, or they may have established yes/no signals.
- **Do** use age appropriate language and tone with adult patients, and assume

- that a patient with a disability will understand basic instructions unless you have a clear indication otherwise.
- Don't interrupt or rush a patient who communicates slowly because of a speech impairment.
- Don't guess what a patient is saying. If you don't understand the communication, ask for clarification.

# Respect Patient Privacy and Autonomy

- Do provide written materials in an electronic format when possible, for patients with visual impairments and those who have difficulty with handwriting or manipulating print materials. A patient can independently fill out an electronic form in advance of an appointment. Provide medical record information, treatment plans, and instructions in a digital format when requested.
- Do ensure that your office building and toilets are accessible to people using mobility aids such as walkers and wheelchairs, so that they can navigate the space independently.
- Do ensure that your office practice is accessible. For example, your patients with disabilities should be able to get weighed, use the exam tables, and access radiological exams.
- Do ask a patient the best way to provide physical assistance if it is needed.
- **Don't** touch, pull or grab a patient's body

- without asking for consent. For patients with some physical conditions, inappropriate touch can cause pain or interfere with balance. For others, unwanted touch can cause anxiety. Asking for consent respects the patient's bodily autonomy.
- Don't handle a patient's mobility device without consent.

### Respect Disability Identity and Culture

- Do respect a patient's choice to downplay or highlight their disability in particular settings.
- Do introduce your patients to disability support groups. Organizations like the <u>National Multiple Sclerosis Society</u> or the <u>United Spinal Association</u> may have local chapters in your area. Your local independent living center may also have resources.
- Don't use negative words to describe disabilities. Words such as "tragedy" or "suffering" can convey a stigmatizing view of disability to your patients. Patients are not "confined to wheel chairs," but rather use wheelchairs.
- Don't fall into the trap of "golden rule thinking." This is imagining how you would personally feel with a disability as a way to infer how your patients feel. Disability is a complex experience that differs from person to person and changes over time. Listen to your patients to discover how you can be their best ally.

### AGING WELL WITH A PHYSICAL DISABILITY FACTSHEET SERIES

### **Additional Resources:**

Society for Disability Studies:

www.disstudies.org

Disability law and accommodations in health care: <a href="http://adata.org">http://adata.org</a>

List of national disability advocacy and support organizations:

www.ncdj.org/resources/organizations/

Alliance for Disability in Health Care Education: <a href="https://www.adhce.org">www.adhce.org</a>

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Olkin, R. (1999). What Psychotherapists Should Know About Disability. New York: Guilford Press. **Authorship:** "Disability Stigma and Your Patients" was developed by Arielle Silverman, PhD, and published by the University of Washington Aging RRTC. Content is based on research evidence and/or professional consensus.

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