Understanding the Lived Experience of Disability

Leading Healthcare Practices and Training:
Defining and Delivering Disability-Competent Care

The lived experience of disability, distinct from the clinical experience, manifests itself in three ways:

- Limited health care provider awareness of and education about disability,
- Limited capacity of providers to accommodate individuals with disabilities in health care settings, and
- Physical barriers to accessing care.

When providers lack information about disability, a culture of stereotyping, negative assumptions, and misinformation is perpetuated that results in miscommunication between providers and participants.[1] Providers and health plans can help remedy this situation by promoting disability-competent care (DCC). Providers can dispel stereotypes through accurate information. Health plans can support their providers by understanding the importance of disability-competent care. They should also assess the capacity of their network providers to appropriately care for people with disabilities and make this information available to members.

All people need **access** to quality, timely, and affordable health care. Under the DCC model, access encompasses *attitudinal access*, *communication access*, *access to medical equipment*, and *physical access*.

Attitudinal Access: Here are some examples of common stereotypes about participants:

- Sick
- Helpless
- Outcasts
- Homebound
- Fragile
- Depressed
- Need charity and welfare
- Biologically inferior
- Unable
- Asexual
- Lack skills and talents

Providers and staff should also be aware of how the language they use conveys these stereotypes to participants or their caregivers.

Disability-Competent Language: Examples	Language Based on Stereotypes: Examples
You will have to explore alternatives that will allow you to continue to work.	You will never be able to work again.
We will have you explore ways to use your strengths and skills to meet your goals.	You will always be an invalid.
Together, we can explore ways to maximize your independence.	You will have to care for him/her.

[1] The Disability-Competent Care Model refers to the consumer, individual, member or person being treated as the participant, to emphasize the importance of his or her engagement.

Communication Access: It is critical for participants to be fully engaged in their care. The provider and participant should explore how best to communicate with one another. This may involve using auditory and visual aids or extra time for discussion.

Access to Medical Equipment: Providers should fully understand any physical limitations of their participants and have appropriate accommodations in their office. Properly trained lift teams or lift equipment should be available, for example, and weighing equipment should be accessible.

Physical Access: This includes ensuring that participants with disabilities can get into the office building and can comfortably move through exam rooms and offices. Before seeing a provider, participants should know whether there will be any physical barriers that may impede their access. Providers should also coordinate their referrals to ensure that the other providers have an appropriate level of access for participants with disability.

Additional Resources

The Disability-Competent Care Model is based on the lived experiences of persons with disabilities and over 20 years of experience at three health plans. For more information, please visit the *Resources for Integrated Care* website (www.resourcesforintegratedcare.com). There you will find the "Defining and Delivering Disability-Competent Care" webinar series, which was the basis for this brief and other resources on the Disability-Competent Care Model.