

Cultural Considerations and the Patient with Intellectual Disability

In recent years there has been an increase in emphasis on the concept of cultural competency, particularly in the training of medical professionals (Weissman et al., 2005). There are a variety of approaches to teaching cultural competency, as well as several perspectives on its definition and place in medicine (Barrera & Corso, 2002; Juarez, Marvel, Brezinski, Glazner, Towbin, & Lawton, 2006). The provision of cultural competency training in general is beyond the scope of this module; rather, we will focus on several specific cultural factors to consider when providing care to individuals with intellectual disabilities. While primary care providers are often encouraged to consider the impact of ethnicity, gender, socio-economic status, sexual orientation, religion, and age on health care decision-making and provision of care, there is typically a dearth of discussion about the interaction of disability with these other facets of identity.

A patient's cultural background may affect how he or she perceives his or her disability and how the patient's family and community respond to it. There may be varying degrees of acceptance and support of the person with a disability within the family and/or community setting. A patient's disability and cultural background may influence how and when the patient seeks treatment for a medical condition, mental health symptom(s), or traumatic experience. The primary care provider should recognize that the individual's and/or family's past experiences certainly contribute to their overall attitude toward healthcare providers. Additionally, historically poor treatment of a particular group often fosters distrust among members of that group.

A variety of factors influence how, when, and to whom a patient may report abuse or neglect. An individual's willingness to report abuse or neglect is often influenced both by the way the patient perceives the likelihood of fair treatment and how much guilt and/or responsibility the patient feels about the abuse. Furthermore, cultural and religious traditions influence how a patient's community responds to allegations of abuse, particularly sexual abuse.

Immigrant families often face additional barriers, including language barriers, when attempting to access community resources and medical care. Undocumented immigrants may fear negative consequences (such as reporting and deportation) will occur upon contacting perceived authority figures, such as medical care providers. Consequently, immigrant women with disabilities may not receive adequate preventative healthcare, including reproductive and prenatal care.

It is essential that primary care providers endeavor to balance cultural considerations with the rights of the individual patient. This may at times be demanding. For example, the patient may be engaging in sexual practices (such as same-sex sexual activity or sexual activity outside of marriage) that are disapproved of by the individual's family, culture, or religion. The patient may thus be hesitant to acknowledge these types of practices in the presence of family members or caregivers from his or her community. Alternatively, the patient may be seeking an abortion, birth control, or other medical intervention that is in contradiction to her family's cultural values or religious beliefs.

For people with intellectual and developmental disabilities, family members such as parents and siblings often play a more powerful role throughout the person's life, even through adulthood. These family members may exert a great deal of influence on the person, and may feel very strongly that they have a stake and a right to participate in the individual's decisions, particularly those decisions related to medical care and sexual activity. However, unless the family member has legal guardianship which specifically includes the right to make those decisions (see the resource document on Legal and Ethical Issues), the rights, choices, and privacy of the individual patient prevails. The American Association on Mental Retardation recommends that primary care providers take the following steps to maximize the patient's ability to exert control and make decisions about her own medical care:

- Make a separate appointment to address medical findings and to explain possible courses of treatment, risks, and benefits
- Conduct this discussion in an office instead of the examination room
- With the permission of the patient, conduct the discussion in the presence of an independent support person, such as a hospital or clinic social worker, ombudsman, or advocate, and allow this person to meet with the patient at a later time to review the discussion and provide an opportunity for the patient to ask questions (AAMR, 1999, p. 45).

If the primary care provider is uncertain about the patient's (even a patient who is his or her own guardian) capacity to consent to a particularly procedure, he or she may request a review. For persons with intellectual disabilities, this review typically involves a multidisciplinary clinical team and formal assessment procedures. Most state laws do not permit a surrogate decision-maker to consent to treatment when the patient is resisting non-emergency treatment, such as a gynecological examination. State law may also require additional review by a board or court before a surrogate may consent on behalf of the patient for certain types of medications, sterilization, or abortion procedures. Primary care providers should educate themselves about the laws specific to their state.

Note: The above document contains general legal information; it is not legal advice and it does not create an attorney/client relationship. As laws and circumstances differ, the prudent health care practitioner should discuss these issues with his or her attorney before proceeding.

This material was adapted from the following:

Barrera, I., Corso, R.M. (2002). Cultural competency as skilled dialogue. *Topics in Early Childhood Special education*, 22,103-133.

Dinerstein, R.D., Herr, S.S., & O'Sullivan, J.L. (Eds.) *A guide to consent*. Washington, DC: American Association on Mental Retardation.

Juarez, J.A., Marvel, K., Brezinski, K.L., Glazner, C., Towbin, M.M., & Lawton, S. (2006) Bridging the gap: A curriculum to teach residents cultural humility. *Family Medicine*, 38, 97-102.

Wiessman, J.S., Betancourt, J., Campbell, E.G., Park, E.R., Kim, M., Clarridge, B. et al. (2005). Resident physicians' preparedness to provide cross-cultural care. *Journal of the American Medical Association*, 294, 1058-1067.