

Sexuality and Self-Determination

How does self-determination apply to sexuality?

According to Wehmeyer (1996, p.18), self-determination is "acting as the primary causal agent in one's life and making choices and decisions regarding one's quality of life free from undue external influence or interference." The concept of self-determination has gained prominence in the area of advocacy for and by people with intellectual and developmental disabilities (ID/DD) over the last three decades, and international studies have confirmed the importance of self-determination in enhancing the quality of life for people with ID/DD (Lachapelle et al., 2005).

Self-determination in the area of sexuality has proven to be a controversial topic, however, for a variety of reasons. Agencies which provide support services tend to fear legal liability for the consequences of sexual activity by individuals served, and may restrict or prohibit sexual activity or specific types of sexual activity. Family members and service providers may not accept the sexual needs and rights of a person with ID/DD and may seek to restrict or deny the person's expression of sexuality. Erroneous stereotypes about the sexuality of people with ID/DD (e.g., that people with ID/DD are asexual, hypersexual, or sexual predators) contribute to this denial of the person's rights and needs. Lastly, there is an inherent tension between the responsibility of agencies and guardians to protect the safety of the person, and the person's right to the dignity of risk that is an inextricable component of self-determination. Sexual self-determination risks contracting sexually transmitted disease, pregnancy, abuse or exploitation, and emotional pain. This is a reality that should not be overlooked. There is no simple answer or approach that resolves the tension between safety and self-determination. Each family's and individual's unique issues in this area must be addressed on an individualized basis (Watson, Venema, Molloy, & Reich, 2002).

Support for self-determination in sexual expression

There are a variety of ways to support the self-determination of a person with ID/DD in his or her sexual expression. Both providing and encouraging sex education assists individuals in making informed sexual health and relationship decisions. Appropriate preventative sexual health care and screening are additional components of self-determination in this area. Finally, showing support for the person's right to privacy and respect for her choices is a key way to support her self-determination. This may include the person's choice to associate and have relationships, marry, or raise children. Researchers have found that care providers and family members are much more likely to disapprove of same-sex relationships and same-sex sexual activity (Watson, Venema, Molloy, & Reich, 2002). Although it is important to consider the cultural and religious values of the person's family and community, it is also necessary to recognize that it is a violation of the person's rights when family members or service providers actively prevent the person from engaging in consensual legal relationships with individuals of her choice.

Role of the Primary Care Provider

The primary care provider is in a position to provide education and support to families that help to combat negative stereotypes and promote healthy self-determination in sexual expression. The primary care provider should inform individuals, guardians, and caregivers that it is healthy and normal for individuals with ID/DD to have sexual rights and needs. The provider may also provide sex education and or sex education resources as needed. Finally, the provider may advocate for the patient's right to sex education, privacy, and self-determination.

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.

Lachapelle, Y., Wehmeyer, M.L., Haelewyck, M.C., Courbois, Y., Keith, K.D., Schalock, R., et al. (2005). The relationship between quality of life and self-determination: An international study. *Journal of Intellectual Disability Research*, 49, 740-744.

Watson S.L., Venema, T., Molloy, W., & Reich, M. (2002). Sexual rights and individuals who have a developmental disability. In D. M.Griffiths, D. Richards, P. Fedoroff, & S.L. Watson (Eds.), *Ethical dilemmas: Sexuality and developmental disability* (pp. 19-52). Kingston, NY: NADD Press.

Wehmeyer, M.L. (1996). Self-determination as an educational outcome: Why is it important to children, youth, and adults with developmental disability? In D.J.Sands & M.L.Wehmeyer (Eds.), *Self-determination across the life span: Independence and choice for people with disabilities* (17-37). Baltimore: Paul H. Brookes Publishing.