

# Sexuality Education for Adults with Intellectual & Developmental Disabilities

## Prevalence of Sex Education

People with intellectual and developmental disabilities (ID/DD) have consistently been found to have diminished levels of sexual awareness, activity, and education, as well as more negative attitudes toward sexual activity, when compared to the general population (Watson, Griffiths, Richards, & Dykstra, 2002). The sex education and information that people with ID/DD do receive tends to come from formal sex education or the media. Fifty percent of people with disabilities report receiving no sex education whatsoever. This is in contrast to findings that most people receive sex education and information from parents and friends (McCabe, 1999a). McCabe (1999a) has suggested that this lack of discussion with parents and friends "may convey negative messages to people with disability [sic] about their own sexuality" (p. 167). Although sex education curricula for children, adolescents, and adults with ID/DD have been developed, they do not appear to be widely utilized.

## Benefits of Sex Education

Accurate, appropriate, and positive sex education is a necessary component of overall health education, and offers several benefits to women with ID/DD. Sex education is required for a person to develop the capacity to consent to sexual activity (Niederbahl & Morris, 1993). Discussion of anatomy and basic reproductive physiology can assist the patient in developing the vocabulary and comfort level needed to report any health-related symptoms, as well as ask important sexual health-related questions. Sexual education should also serve to teach the patient to identify and report sexual victimization. Finally, sex education can promote healthy and safe sexual practices, potentially limiting the risk of unplanned pregnancy or sexually transmitted diseases.

## The Primary Care Provider Role

Primary care providers are in a key position to promote accurate and appropriate sex education for patients with ID/DD. Providers can consistently introduce conversations about sexuality and sex education to develop an improved comfort level with the topic, and should emphasize the importance of these discussions with the patient to her parent/guardian or service provider, if needed. Instruments are available for assessing patients' interest and knowledge about sexuality (Galea, Butler, Iacono, & Leighton, 2004; McCabe, Cummins, & Deeks, 1999). The primary care provider should also develop and maintain awareness of educational and community resources for sex education of people with ID/DD. For adolescent patients, the primary care provider should support the parent(s) in the role of primary sex educators. When parents are the primary sex educators, they may modify the content and format of information to suit the cognitive and functional abilities of their child, as well as their cultural or religious values.

**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.

## Sex Education Resources

Sipski, M.L., & Alexander, C.J. (Eds.)(1997). Sexual function in people with disability and chronic illness: A health professional's guide. Aspen Publishers, Inc.

The **American Sexual Health Organization** promotes the sexual health of individuals, families and communities by advocating sound policies and practices to foster healthy sexual behaviors and relationships and prevent adverse health outcomes. The website is at <http://www.ashasexualhealth.org>

### **Sexuality and Disability Training Center**

This center is located in Boston, MA, and provides training and workshops related sexuality and disability.

## For Parents

Schwier, K.M., & Hingsburger, D. (2000). Sexuality and your sons and daughters with intellectual disabilities. Paul H. Brookes Publishing. Available at [https://www.amazon.com/Sexuality-Daughters-Intellectual-Disabilities-Hingsburger/dp/B00ZLW6YJI/ref=sr\\_1\\_1?ie=UTF8&qid=1547594535&sr=8-1&keywords=schwier+disability](https://www.amazon.com/Sexuality-Daughters-Intellectual-Disabilities-Hingsburger/dp/B00ZLW6YJI/ref=sr_1_1?ie=UTF8&qid=1547594535&sr=8-1&keywords=schwier+disability)

## Videos

Lucaswrites Educational Video (1999). *All of us: Sex education for people with developmental disabilities*. Available from <http://www.lucaswrites.com/>

## REFERENCES

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