

Enabling healthy sexuality and intimacy for individuals with intellectual and developmental disabilities

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Every individual deserves the right to explore and enjoy their sexuality in a safe and appropriate manner, yet sexuality education is often avoided in youth with intellectual and developmental disabilities. One of the central roles of a nurse practitioner (NP) is that of an educator, and human sexuality is a key component of comprehensive healthcare. The existence of a disability presents complexities to the implementation of sexuality education, especially in a clinical setting. Consideration of patients' unique abilities and learning styles allow NPs to bridge the gap in the delivery of sexuality education to individuals with intellectual and developmental disabilities.

As supported by the World Health Organization (WHO) declaration that sexuality is a fundamental human right and the American Association on Intellectual and Developmental Disabilities (AAIDD) and the Arc joint position statement, sexuality should be respected and protected for everyone regardless of cognitive, intellectual, and developmental abilities.^{1,2} Individuals of all abilities desire intimacy and, in many cases, puberty milestones occur at the same rate as typical peers, yet society often views individuals with disabilities as childlike and asexual.^{3,4} Because of this skewed societal perception, sexuality education is limited or even avoided in youth and young adults with intellectual and developmental disabilities (IDD).^{5,6}

As nurse practitioners (NPs), it is our job to provide consistent, high-quality healthcare to all patients inclusive of the diversities of race, ethnicity, sexual orientation, gender identity, socioeconomic status, religion, and intellectual and cognitive ability. As an integral component of overall health, sexuality is included in a comprehensive health assessment. Similarly, healthcare management includes sexuality education.

Sexual health assessment

Before initiating a conversation about sexuality, it is important to ask for permission to discuss sensitive topics and remind the patient that they always have the choice to abstain from answering questions or to terminate the conversation completely for any reason.⁹⁻¹¹ Also, the patient's communication style, baseline knowledge of sexuality, intimacy, human anatomy and sexual physiology, and level of understandability need to be assessed. As with any patient, a sexual health assessment for individuals with IDD includes questions about sexual experience and preferences, past and present partner(s), religious and cultural beliefs that may impact expression of sexuality, and potential need for contraception (*Table 1*). Validated questionnaires that facilitate sexual health conversations include the Female Sexual Function Index (FSFI), the Female Sexual Distress Scale-Revised (FSDS-R), Sexual Quality of Life-Female (SQOL-F), and the Sexual Function Questionnaire (SFQ28).¹²⁻¹⁵ Although not specifically validated in the IDD population, the aforementioned questionnaires may still facilitate conversations regarding sexual health between NPs and individuals with IDD if language is modified to the level of patient understanding.

Sexuality education

Sexuality education is important for the understanding of intimacy, the exploration of sexual pleasure, and the development of skills needed for personal protection. Of concern is that youth with disabilities are three times more likely to experience sexual abuse than their typical peers and four times more likely to be the victims of sexual assault.^{7,8} Individuals with IDD often struggle with the abstract concept of sexuality. In some cases, they experience difficulty deciphering between appropriate behaviors within different types of relationships such as that with parents, intimate partners, friends, teachers, delivery people, and strangers. To comprehend sexuality, one must first appreciate social boundaries, which is another challenging concept for many people with IDD. The relationship with oneself is the foundation of social boundaries and must be appreciated before expanding into relationships with others. For example, it is appropriate to examine ourselves and touch our own bodies in socially appropriate situations.

Unfortunately, there remains no clear consensus on the best method(s) for providing sexuality education within the clinical setting for individuals with IDD. However, several resources exist for caretakers of youth and young adults with IDDs that may also support NPs who

Table 1. Sexual health assessment questions

- What does sex mean to you?
- What do you know about sex?
- Are you sexually active/Do you have sex/Have you had sex?
- With whom?
 - What type?
 - How often?
- Do you use protection (specify condoms or other barrier methods)/Are you on contraception/birth control?
- What questions do you have about sex?
- Do you have any problems with sex?
- Additional questions regarding:
- Details of physical, cognitive, mental health condition related to sexual health
 - First exposure to concept of sex and masturbatory behavior(s)

Table 2. Sexual health resources for nurse practitioners caring for individuals with IDD

Resource	Link
National Down Syndrome Society: Sexuality	ndss.org/resources/sexuality/A
American Association on Intellectual and Developmental Disabilities	aaidd.org ^B
Impact feature issue: Sexuality and People with Intellectual, Developmental and Other Disabilities	publications.ici.umn.edu/impact/23-2/from-the-editorsC
Teaching Children with Down Syndrome about Their Bodies, Boundaries, and Sexuality	amazon.com/Teaching-Children-Syndrome-Boundaries-Sexuality/dp/189062733X ^D
Circles curriculum	stanfield.com/product/circles-curriculum-intimacy-relationships-level-1-w1004-18 ^E
Circles Social Skills Utility	circlesapp.com/F

IDD, intellectual and developmental disabilities.

care for individuals in this population (Table 2).

One resource, the Circles Social Skills Utility™, an app for purchase on iPads and Chromebooks, offers users a unique method for simplifying the abstract concept of sexuality by first teaching appropriate social boundaries. Although the Circles curriculum was originally designed

for use at home, school, and in the vocational setting, the Circles app may be of use in the clinic setting for NPs requiring an easy-to-use tool for teaching appropriate social boundaries to patients with IDD.

The app utilizes colorful concentric circles and animated videos to demonstrate appropriate physical contact with people in each circle. The user uploads photos or creates avatars to place within each colored circle as instructed by the animated videos within the app. Each circle represents conceptual social boundaries as well as socially acceptable physical boundaries.^{16,17} The purple center circle represents the user. Intimate physical contact such as hugging and kissing is more appropriate with individuals placed within the circles closest to the innermost purple circle. For example, the circle closest to the purple individual circle is the blue, big hug circle. It is appropriate to have consensual close contact with individuals in this ring, such as parents, siblings, best friends, and intimate partners.¹⁷

Technology, such as computers, tablets, and smart phones, can be an asset to enhance the unique learning needs of individuals with IDD, when used appropriately.^{18–20} Although research is needed on the use of the Circles Social Skills Utility in the clinical setting, published data support the potential efficacy of teaching social boundaries via the Circles app to individuals with Autism and Down syndrome.^{17,21} A recently published pilot study demonstrated significant improvement in comprehension of appropriate social boundaries by young-adult females with Down syndrome after completing the video series in the Circles app compared to baseline assessment. Improvement occurred within each circle, ranging from 3.4% to 2700%. The areas of greatest improvement occurred within the outermost circles where physical contact should be minimal or nonexistent.²¹ Assuming further research supports similar efficacy of the Circles app in populations with IDD, this app may serve as a critical resource for the provision of fundamental sexual healthcare by NPs in the clinic setting.

Conclusion

Humans are sexual creatures, and the presence of an IDD does not preclude the need for sexuality assessment and education as a part of comprehensive healthcare. NPs should assess sexual health in individuals with IDD in the same manner as any other patient, with consideration of their unique learning styles. To comprehend the abstract concept of sexuality and intimacy, one must first understand appropriate social boundaries. Although limited, there are resources available that may benefit NPs in managing the sexual health of individuals with IDD. ■

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Web resources

- A. ndss.org/resources/sexuality/
- B. aaid.org
- C. publications.ici.umn.edu/impact/23-2/from-the-editors
- D. amazon.com/Teaching-Children-Syndrome-Boundaries-Sexuality/dp/189062733X
- E. stanfield.com/product/circles-curriculum-intimacy-relationships-level-1-w1004-18/
- F. circlesapp.com/