Let's Talk About Sex:

Sex and Relationship Education for People with Intellectual Disabilities

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The critical importance of sex education for all

Sex education empowers people to make informed and healthy choices about their bodies and their relationships, but it is often not available or accessible for people with intellectual disabilities. All people, including people with intellectual disabilities, deserve full access to medically accurate and shame-free information about sex and relationships. All people deserve to have their questions about sexuality answered without judgment. All people deserve the opportunity to develop the skills they need to protect their health. Comprehensive sex education helps people avoid negative health outcomes; communicate better with parents, partners, and medical providers on sexuality topics; understand healthy and unhealthy relationships; have autonomy over their bodies; respect others' bodily autonomy; and show respect for people regardless of sexual orientation or gender identity.¹ Despite the evidence of the positive effects of sex education, only 30 states and the District of Columbia require sex education to be taught in schools, only 21 of those require information about contraception to be included, and only 10 require education on sexual consent.²

Myths surrounding sexuality and disability

The barriers to comprehensive sex education for people with intellectual disabilities are significant, and contribute to the lack of sex education for this population. They are sometimes denied access, have limited access, or receive inadequate sex education in school. Misperceptions held by caregivers, professionals, and our society perpetuate negativity around disability and sexuality and result in limited access to sex education. Reviews of the literature by Sinclair et al. and Campbell indicate that many parents and caregivers believe that people with intellectual disabilities are asexual, which feeds the myth that this population has no need for sex education.^{3,4} However, people with intellectual disabilities report dissatisfaction with their single relationship status and actively desire relationships.⁵ The myth of asexuality does not align with how people with intellectual disabilities are hypersexual or overtly sexual in public, when in fact, they often have not received any education on the difference between public and private behaviors.

Due to societal myths, teachers, parents, and/or caregivers often believe that sex education is inappropriate for people with intellectual disabilities, that they will not understand the content, or that they are not sexual and therefore have no need for the information. Whittle and Butler found that people with intellectual disabilities want to discuss sexuality with care staff, but care staff are unequipped or unwilling to discuss the topic.⁵ This leaves people with intellectual disabilities with few opportunities to discuss sexuality with those closest to them. In schools, health educators may lack the training needed to teach to students with intellectual disabilities, while special education instructors may lack the training needed to teach sex education.⁶ This limited access to sex education infringes on the right of people with intellectual disabilities to access

sexual health information and denies them the tools and skills they need to independently care for their sexual health. This creates barriers to developing positive and pleasurable sexual and/or romantic relationships. Comprehensive sex education empowers people to make informed and healthy choices about their bodies and their relationships.

Sex (positive) education and sexual self-advocacy

Many sex education programs and curricula for people with intellectual disabilities focus heavily on the prevention of sexually transmitted infections, pregnancy, and sexual assault,⁷ or focus solely on sexual assault prevention.⁸ While information about prevention and safety is important, comprehensive sex education includes much more. Comprehensive sex education covers the full range of human experience related to our sexual self and sexual relationships with others. It includes care for our bodies, accessing accurate sexuality information, decision-making about our bodies, and how we feel inside our own skin. Comprehensive sex education includes to whom we are attracted and with whom we want to experience intimacy. It includes talking about sexual feelings and how people respond to sexual feelings. It also includes understanding sexual violence and how past experiences of violence affect us.

People with intellectual disabilities experience sexual assault at rates seven times that of people without intellectual disabilities.⁹ They are victimized at higher rates in part because they are more likely to have others help them with day-to-day necessities such as bathing and dressing. This provides perpetrators of abuse and assault with the opportunity to groom for abuse and to be in a private space with the person while their body is exposed.⁹ Comprehensive sex education addresses these topics by discussing appropriate touch; private vs. public spaces and touches; information about sexual abuse and assault; and what to do if someone makes you uncomfortable or violates your boundaries. Research suggests that comprehensive sex education, which includes skill building around refusal of unwanted sex, may be an effective strategy for preventing sexual assault¹⁰ and increasing the likelihood of reporting any potential violation.

Sex education provides people with the skills to refuse unwanted touch, and more importantly, teaches people how to respect others' boundaries and practice affirmative consent. People must be taught to ask for consent to touch, to listen to the answer, and to respect the answer. People need to learn that if they do not have enthusiastic, freely given, informed and specific consent for each touch, they must not engage in that touch. All people need the information and skills to understand and practice consent, to recognize red flags in a relationship, and to advocate for their body and their rights. While sexual violence prevention is an important component of sex education, ultimately, comprehensive sex education must be sex positive. This means that the overarching goal of education is to learn how to have pleasurable, healthy, mutually supportive, consensual, and responsible sexual relationships with oneself and others. For many people with intellectual disabilities, their understanding of sex and sexuality is through a lens of sexual violence or past trauma. Sex positive education teaches that people can and do heal from past trauma and that sexuality can be pleasurable, safe, healthy, and consensual.

Individuals with intellectual disabilities in the U.S. are still living in a society that does not fully accept their rights, desires, and needs. The self-advocacy movement in the disability community redirects the focus to empowering the individual to reach their goals in a way that is accessible to them. Self-advocates speak for themselves and make their own decisions. Sexual self-advocacy enables people with intellectual disabilities to make informed decisions about sexuality and relationships in their own lives. Everyone has sexual rights and responsibilities both individually

and when interacting with others. These rights include the right to privacy; the right to be curious about sexuality; to ask questions and have them answered; and to make their own decisions about whether, when, and with whom they want to pursue a romantic relationship.¹¹ Sexual self-advocacy should be included in comprehensive sexuality education programs for people with intellectual disabilities.

Sex education for people with intellectual disabilities in Delaware

For over 10 years, Planned Parenthood of Delaware (PPDE) has been providing a variety of sex education and professional training for people with intellectual disabilities, their parents and caregivers, and the professionals who support them. We do this with support from the Delaware Division of Developmental Disabilities Services, the Delaware Developmental Disabilities Council, and the Planned Parenthood Federation of America. We provide tailored sex education lessons for individuals and groups, and workshops to build confidence and skills for parents and caregivers to have open discussions about sexuality with their loved ones. We also have a support group for LGBTQ+ adults with intellectual disabilities to learn sexual health information, advocacy skills, and build their social networks. In addition, we provide training for disability-serving professionals to build their understanding and confidence in supporting people with intellectual disabilities in their sexuality and relationship goals.

In 2019, we developed a sex education curriculum for people with intellectual disabilities entitled "You're in Charge: A Customizable Sex and Relationship Education Program for Self-Advocates with Intellectual and Developmental Disabilities."¹² The curriculum is divided into two parts: Unit 1, Your Sexuality, contains basic sex education on anatomy and reproduction, sexual health, puberty changes, public vs. private, sexual identity, sexual feelings, masturbation, and sexuality explicit media. Unit 2, Sexuality with a Partner, includes lessons that address healthy relationships, dating (including online dating), consent, safer sex practices, and sexual self-advocacy. The curriculum is designed to be taught by one educator to one student so that the learning experience is entirely customizable. The curriculum features positive and diverse representations of people with disabilities including illustrations of people with mobility devices and physical disabilities.

The curriculum uses multiple pedagogical methods to meet the diverse learning needs of people with intellectual disabilities. Plain language is used throughout the curriculum, handouts, and activities, so that the information is accessible. Mixed teaching methods are used to meet the diverse needs of learners. For example, the section on lesbian, gay, bisexual, transgender, and queer (LGBTQ+) inclusivity features illustrated handouts with definitions; opportunities for brainstorm; a video from Rooted in Rights (a disability justice organization based in Washington State); online resources; and a role-play to practice the experience of coming out. These mixed method lessons keep the learner engaged by ensuring the content is accessible, personal, and applicable to real life.

The goal of our programs and curriculum are to empower people with intellectual disabilities to advocate for their sexual lives, to pursue romantic relationships if they choose, and to learn the information needed to make the choices that are best for them. When people with intellectual disabilities are fully included in the sex education classroom and have access to sex-positive, comprehensive sex education, they can acquire the information and skills needed to be sexually healthy self-advocates.

Additional resources

- Elevatus Training curriculum and professional development
- <u>National Council on Independent Living sex education videos for and by people</u> <u>with IDD</u>

References

- 1. Bridges, E., & Hauser, D. (2014). Sexuality Education: Building an evidence- and rightsbased approach to healthy decision making. Advocates for Youth. Retrieved from: https://www.advocatesforyouth.org/resources/fact-sheets/sexuality-education-2/
- 2. Guttmacher Institute. (2021). Sex and HIV Education. Retrieved from: https://www.guttmacher.org/state-policy/explore/sex-and-hiv-education
- 3. Sinclair, J., Unruh, D., Lindstrom, L., & Scanlon, D. (2015). Barriers to sexuality for individuals with intellectual and developmental disabilities: A literature review. *Education and Training in Autism and Developmental Disabilities*, *50*(1), 3–16.
- 4. Campbell, M. (2017). Disabilities and sexual expression: A review of the literature. *Sociology Compass*.
- Whittle, C., & Butler, C. (2018, April). Sexuality in the lives of people with intellectual disabilities: A meta-ethnographic synthesis of qualitative studies. *Research in Developmental Disabilities*, 75, 68–81. <u>PubMed https://doi.org/10.1016/j.ridd.2018.02.008</u>
- 6. Shearer, N. (2019). Sexual health education for individuals with disabilities: A call to action. Nevada Today. Retrieved from: https://www.unr.edu/nevada-today/news/2019/sexual-health-for-individuals-with-disabilities
- Plunkett, S., & Laganà, L. (2012). The controversies surrounding the sexuality education of people living with developmental disabilities. in Handbook on Sexuality: Perspectives, Issues and Role in Society. Edited by N. Peterson and W. Campbell. Nova Science Publishers
- Wacker, J., Macy, R., Barger, E., & Parish, S. (2009, August). Sexual assault prevention for women with intellectual disabilities: A critical review of the evidence. *Intellectual and Developmental Disabilities*, 47(4), 249–262. <u>PubMed https://doi.org/10.1352/1934-9556-47.4.249</u>
- 9. Shapiro, J. (2018). The Sexual Assault Epidemic No One Talks About. Retrieved from: https://www.npr.org/2018/01/08/570224090/the-sexual-assault-epidemic-no-one-talks-about
- Santelli, J. S., Grilo, S. A., Choo, T. H., Diaz, G., Walsh, K., Wall, M., . . . Mellins, C. A. (2018, November 14). Does sex education before college protect students from sexual assault in college? *PLoS One*, *13*(11), e0205951. <u>PubMed</u> https://doi.org/10.1371/journal.pone.0205951
- 11. Sandman, L., Arnold, K., Bolyanatz, L., Friedman, C., Saunders, C., & Wickey, T. (2014). In My Voice: Sexual Self-Advocacy. Sexuality and Disability Consortium, University of Illinois at Chicago Department of Disability and Human Development. Retrieved from: https://www.elevatustraining.com/wp-content/uploads/2017/04/SexualSelf-Advocacybook.pdf

12. Planned Parenthood of Delaware. (2019). You're in charge. Retrieved from: https://www.plannedparenthood.org/planned-parenthood-delaware/local-trainingeducation/purchase-sex-education-program

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