

TIP SHEET

Personal Responsibility Education Program

Personal Responsibility Education Program (PREP) Services For Youth With Disabilities



TIPS FOR EDUCATORS TO KEEP IN MIND

- Work closely with special education teachers to address each student's accommodations and needs for prevention education (as specified on the IEP).
- Acknowledge that youth with disabilities are sexual beings and have a right to a healthy and fulfilling sex life.
- Recognize and overcome your own biases.
- Become informed about the disability: challenges, impact on puberty, educational needs, etc.
- Explore and become creative about alternative formats for presenting and demonstrating attainment of information and skills. Presentations often need to be more literal and involve a lot of practice of physical skills.

INTRODUCTION AND OVERVIEW

One sub-population of individuals who are often overlooked when it comes to education on the prevention of pregnancy and sexually transmitted infections (STIs) among youth are youth with disabilities, particularly those served in our nation's special education programs. Disabilities can take on many forms—intellectual, emotional, behavioral, physical—and can have varying impacts on sexuality, including no impact at all. However, many educational systems serving youth with disabilities provide inadequate or no formal education on abstinence or contraceptive information to prevent pregnancy and STIs for these youth (Brown & McCann, 2018; Deschaine, 2011; Schaafsma et al., 2013, 2017; Shearer et al., 2002; Wilson et al., 2014). Instead, they defer to parents, who often feel uncomfortable approaching the subject, are uneducated about the subject, or do not recognize the need to teach their children about sex (Civjan, 1996; Schaafsma et al., 2013; Sinclair et al., 2015; Tice & Harnek Hall, 2008; Wilson et al., 2014). In both public and private educational systems, youth with disabilities can be excluded from all or a majority of PREP and related prevention education afforded to their peers.

This tip sheet elaborates on the challenges and

TIPS CONTINUED

- Work with parents to determine their value system and build education for parents and caregivers into your program.
- Include youth with various disabilities on advisory panels and curriculum development groups.
- Advocate for policy changes to increase awareness of and protect the sexual health education needs of these youth.
- When scheduling classrooms or community activities, consider if locations are accessible.
- Maintain a trauma-sensitive approach. Facilitators should be aware of triggers for individual participants.

OVERVIEW CONTINUED

barriers to providing abstinence and contraceptive education to youth with disabilities and debunks long-held myths about sexuality among people with disabilities. It covers the implications for providing education to youth with specific types of disabilities along with recommended educational strategies to meet youth's needs.



In 2017–2018, approximately 7 million students were served under the Individuals with Disabilities Act (IDEA), and 95% of these were enrolled in traditional schools. Of these, 63% spent at least 80% of their school time in a general education classroom (McFarland et al., 2019).

BARRIERS TO ABSTINENCE AND CONTRACEPTIVE EDUCATION AND DEVELOPING HEALTHY RELATIONSHIPS

Young people with disabilities may have a greater need for medically accurate and complete abstinence or contraceptive education to prevent pregnancy and STIs (hereafter, prevention education) than their peers without disabilities (Brown & McCann, 2018; Schaafsma et al., 2017). These youth, particularly those with intellectual, emotional, or learning disabilities, are often at increased risk of (1) high rates of sexual activity at younger ages; (2) teen pregnancy and subsequent early pregnancies; (3) contracting HIV and other STIs; (4) being subject to sexual abuse, victimization, or exploitation; and (5) acting on misinformation (Civjan, 1996; Deschaine, 2011; Halpern et al., 2000; Murphy & Elias, 2006; Schaafsma et al., 2017; Shearer et al., 2002).

Other youth with disabilities may not know how to meet their sexual and relationship needs in ways that are aligned with societal norms (Brown & McCann, 2018; Schaafsma et al., 2013, 2017; Whitehouse & McCabe, 1997; Wilson et al., 2014). It may also be the case that these youth are not empowered or able to make informed decisions about their own sexuality (Brown & McCann, 2018; Shearer et al., 2002).

The unique characteristics of the various disabilities present different challenges to educators. Youth with intellectual disabilities may have difficulty retaining or generalizing information. Youth with physical limitations may require adaptations to typical self-care or other more physical activities related to sex

(such as how to properly use a condom). Youth with hearing or visual impairments may have barriers to picking up on subtle social cues that may make them vulnerable to abuse or exploitation. Youth with autism or communication difficulties may have difficulty practicing or demonstrating communication skills such as refusal or negotiation. In short, youth with disabilities often experience barriers when engaging with prevention education that was developed for their general education peers. Furthermore, educators may be unprepared to teach prevention education to youth with disabilities (Bratlinger, 1992; Sinclair et al., 2015).

It is essential to include youth with disabilities in health education activities that not only keep them safe and healthy but also allow them to advocate for their sexual rights. The content of these programs should be broad and cover a range of topics, including anatomy, reproductive changes, adolescent development, contraception options, abstinence, consent, abuse and exploitation, healthy sexual expression, healthy relationships, and pregnancy (Schaafsma et al., 2017). PREP programs should also cover three of six Adulthood Preparation Subjects (adolescent development, education and career success, financial literacy, healthy life skills, healthy relationships, and parent–child communication).



THE REALITY FOR MANY YOUTH WITH DISABILITIES

There are many long-held myths about sexuality among people with disabilities. These myths are not reality, and these youth all need, want, and deserve comprehensive instruction related to prevention education.

MYTHS	REALITIES
People with disabilities are asexual and uninterested in or cannot have sex.	<ul style="list-style-type: none"> • Barring any physical issues that interfere with development, virtually all humans go through puberty and have sexual desires and feelings. There is no reason to assume that most individuals with disabilities will not be able to go on to have some type of sexual relationship (Brown & McCann, 2018; Murphy & Elias, 2006). • Seventy-three percent of 18 year olds with disabilities say they have had sex (Murphy & Ellis, 2006). • A review of studies on this topic found that adolescents with mild to moderate intellectual and developmental disabilities have similar rates of sexual activity as their peers (Roden, 2020).
People with disabilities do not want relationships, cannot get married, and cannot be good parents.	<ul style="list-style-type: none"> • Although lower than those without disabilities, the first-time marriage rate of people aged 18–49 with disabilities is 41.1 per 1,000 (Cohen, 2014). • Many individuals with disabilities have children and are good parents. • According to the National Transition Longitudinal Study, within 3 years of leaving high school almost 18% of men with disabilities had fathered a child and within 8 years this rose to over 36%. These numbers are similar to the general population. The majority of these fathers were living with their children (Newman et al., 2011).

MYTHS	REALITIES
No one would want to abuse an individual with a disability.	<ul style="list-style-type: none"> • “Adolescents and young adults with intellectual and developmental disabilities are at increased risk for sexual abuse and exploitation, and female adolescents and young adults with intellectual and developmental disabilities are at increased risk of pregnancy and sexually transmitted infection” (Roden, 2020). • Individuals with disabilities are more vulnerable and easily manipulated than those without disabilities (Deschaine, 2011). • Youth with disabilities are 3–4 times more likely than youth without disabilities to be sexually abused, with prevalence estimates of 13.7% (Jones et al., 2012; Murphy & Elias, 2006; Schaafsma et al., 2014; Turner et al., 2011). • Some studies show that nearly 80% of women with developmental disabilities have been sexually assaulted at some point in their lives, and they are often assaulted more than once (Deschaine, 2011). Offenders are often family members or caregivers who the young person is taught to trust.
Youth with disabilities get all the prevention education they need.	<ul style="list-style-type: none"> • Broad pregnancy and STI prevention education is not a standard part of the special education curriculum, especially for youth with more severe disabilities, and students with disabilities who are in mainstream classes are often pulled out of pregnancy prevention education either to receive other services or because it is thought that they will be upset, confused, and/or disruptive. Thus, many do not receive any pregnancy prevention education or, if they do, broad coverage of sexual health topics is scant (Brown & McCann, 2015; Schaafsma et al., 2013, 2017). • Much information is inaccurate or incomplete. Youth with disabilities want detailed information (Schaafsma et al., 2013, 2017). • Fewer than 50% of people with a mild intellectual disability receive formal sexual health education (Roden, 2020).

EDUCATIONAL IMPLICATIONS

Youth with disabilities face many challenges accessing education depending on the type and severity of their disability. The following are characteristics of specific disabilities followed by strategies for providing prevention education. Some youth have multiple disabilities, so the educator will need to consider a variety of strategies.

Intellectual Disabilities

Individuals with intellectual disabilities have limitations in cognitive functioning and adaptive behavior. They have difficulty processing and retaining information and difficulty generalizing and projecting consequences. Sometimes these individuals also have issues with executive functioning (e.g., planning, focusing, attending, remembering, multitasking).

Communication Disabilities

Communication disabilities affect those with a variety of conditions, including speech and language



Spotlight from the Field

[Wyoming Institute for Disabilities \(WIND\)](#) partners with the Wyoming Department of Health and the Wyoming Governors Council on Developmental Disabilities to offer an abstinence or contraceptive training course to individuals with disabilities. The project uses the [Friendships & Dating](#) curriculum, a program for individuals with intellectual disabilities focused on how to develop and maintain healthy relationships.

disorders, learning disabilities, intellectual disabilities, and autism spectrum disorder. Communication disabilities can affect both verbal and nonverbal

skills. Problems with communication affect individuals' abilities to converse with others and thereby to develop meaningful relationships. Communication disabilities affect how well individuals can negotiate what they want and explicitly communicate refusal for what they do not want. Disabilities in nonverbal communication such as difficulty processing facial expressions or social subtleties are associated with difficulty in understanding another's intentions and perspectives and can lead to an inability to stop unwanted behavior.

Social Disabilities

Social disabilities are a hallmark issue for individuals with autism spectrum disorder. They also can affect individuals with other disabilities, including learning disabilities. Individuals with social disabilities have difficulty understanding how others feel because they miss social cues. Social difficulties hinder the following:

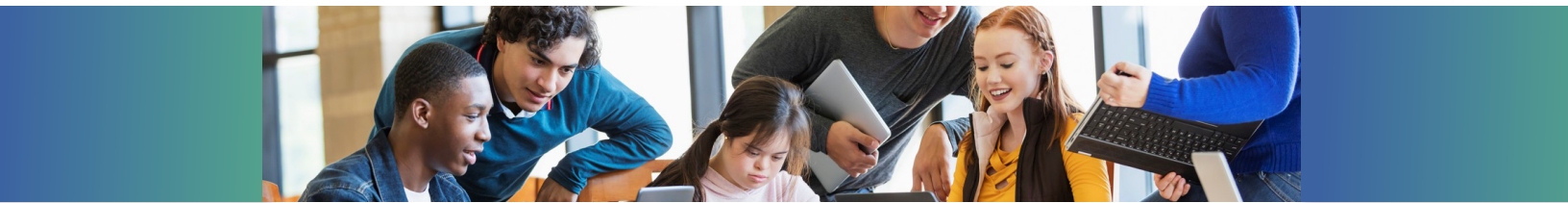
- knowledge of what is appropriate behavior for different settings;

- ability to connect with others in a meaningful way;
- safe pregnancy and STI prevention practices; and
- opportunities to engage in sexual behavior.

These individuals are more likely to be sexually exploited and to sexually exploit others.

Sensory Disabilities

Disabilities in hearing and/or vision impact the way individuals take in information and make sense of the world around them. Such sensory disabilities affect not only how individuals learn but also how they interact with others. Depending on the degree of impairment, sensory disabilities often cause individuals to feel isolated from others. It is often difficult for individuals with sensory disabilities to learn incidentally from their environment, which may result in additional academic, communication, and social disabilities or delays. These individuals need to learn how to navigate safely and effectively in a world that caters to sighted and hearing individuals.



EDUCATIONAL STRATEGIES FOR WORKING WITH YOUTH WITH DISABILITIES

The following strategies may be useful when working with youth with disabilities. Whenever possible, it is important to partner with special education teachers and learn about the specific strategies written in a youth's individualized education plan (IEP). Apply universal design for learning principles to increase the accessibility of materials to reach diverse learners (e.g., repetition, engagement, multiple types of media and tools for learning) (Roden, 2020).

- Present information in small chunks.
- Use simple, clear language. Avoid or define jargon.
- Provide media that do not require reading, hearing, vision, or mobility, depending on the student's level of ability.
- Use a variety of concrete teaching strategies to reinforce the information presented (e.g., written materials, audiovisual materials, role playing, interactive games).
- Include learning strategies that closely approximate real life.
- Offer opportunities for interaction with nondisabled peers and role models.
- Repeat and reinforce key concepts often.
- Vary your approaches (e.g., provide options for having someone read information to the youth).
- Encourage youth to ask questions.
- Use visual aids (e.g., drawn pictures of concepts), especially with youth with language-based learning disabilities.
- Create social scripts (verbal scripts that tell youth what to say in certain situations like on a date) to improve social and communication skills. Scripts are gradually removed or faded.
- Offer information in different formats like large print, braille, or digital text.
- Provide a vocabulary list that defines key terms used every week.
- Use modeling, guided practice, reinforcement, and corrective feedback.
- Modify handouts and materials to reduce the number of words, highlight key points, and incorporate visuals.
- Allow additional time for skill practice.



- “Educational tools using a framework with a universal design for learning are recommended to ensure that crucial sexual health information is accessible to those of all abilities” (Roden, 2020).
- “Tools based on a framework with a universal design for learning use clear and concise language, small amounts of written and pictorial information, and multiple different types of media (e.g., audio, text, and visual) to ensure that information is accessible to a broad spectrum of learners” (Roden, 2020).

CONCLUSION

All or most people, with or without disabilities, are sexual. Most youth with disabilities will go on to become independent or semi-independent adults, and many have children and are good parents. Youth with disabilities have the same feelings and intimacy needs as other youth. These youth need prevention education so they can protect themselves, recognize that they are sexual beings, learn appropriate and inappropriate ways to express their sexuality, and learn how to develop and maintain healthy relationships as they transition into adulthood.

View This Film Clip of Monica & David



Of all the barriers individuals with disabilities face regarding their sexuality, societal misperceptions and negative attitudes may be the greatest.

RESOURCES

Family & Youth Services Bureau: [*Sexual Health and Youth with Disabilities: Sexuality Education for All*](#)

Individuals with Disabilities Education Act: <https://sites.ed.gov/idea/>

CDC Developmental Disabilities: <https://www.cdc.gov/ncbddd/developmentaldisabilities/index.html>

American Association on Intellectual and Developmental Disabilities: [*Position Statement on Sexuality*](#)

American Academy of Pediatrics policy statement: [*Sexuality of Children and Adolescents with Developmental Disabilities*](#)

Massachusetts Department of Public Health and Massachusetts Department of Developmental Services: [*Healthy Relationships, Sexuality and Disability Resource Guide*](#)

Elevatus Training: [*ToolKit: Sexual Assault Awareness for People with Developmental Disabilities*](#)

Amaze: [*Disability and Sexuality*](#) (video)

REFERENCES

- Boehning, A. (2006). Sex education for students with disabilities. *Law & Disorder*, 1, 59–66.
- Brantlinger, E. (1992). Sexuality education in the secondary special education curriculum: Teachers' perceptions and concerns. *Teacher Education and Special Education*, 15(1), 32–40.
- Brown, M., & McCann, E. (2018). Sexuality issues and the voices of adults with intellectual disabilities: A systematic review of the literature. *Research in Developmental Disabilities*, 74, 124–138. doi:10.1016/j.ridd.2018.01.009
- Bryne, G. (2018). Prevalence and psychological sequelae of sexual abuse among individuals with an intellectual disability: A review of the recent literature. *Journal of Intellectual Disabilities*, 22(3), 294–310.
- Civjan, S. R. (1996). Being human: Issues in sexuality for people with developmental disabilities. *Bioethics Forum*, 31–36.
- Cohen, P. (2014). Marriage rates among people with disabilities (save the data edition). *Council on Contemporary Families. The Society Pages*. <https://thesocietypages.org/ccf/2014/11/24/marriage-rates-among-people-with-disabilities-save-the-data-edition/>
- Deschaine, M. (2011). How developmental disabilities impact the sexual health of young adults. Excerpted from *Sexual Health Disparities Among Disenfranchised Youth*. <https://www.pathwaysrtc.pdx.edu/pdf/pbSexualHealthDisparities.pdf>
- Fredriksen-Goldsen, K. I., Kim, H.-J., & Barkan, S. E. (2012). Disability among lesbians, gay, and bisexual adults: Disparities in prevalence and risk. *American Journal of Public Health*, 102(1), 16–21. doi:10.2105/AJPH.2011.300379
- Halpern, C. T., Joyner, K., Udry, J. R., & Suchindran, C. (2000). Smart teens don't have sex (or kiss much either). *Journal of Adolescent Health*, 26, 213–225.
- Jones, L., Bellis, M. A., Wood, S., et al. (2012). Prevalence and risk of violence against children with disabilities: A systematic review and meta-analysis of observational studies. *Lancet*, 380(9845), 899–907. doi:10.1016/S0140-6736(12)60692-8
- Jones, K., & Domenico, D. (2006). A technological approach for pregnancy prevention among youth with disabilities. *Journal of Family and Consumer Sciences Education*, 24(2), 61–67. <https://www.natefacts.org/Pages/v24no2/v24no2PraxisJones.pdf>
- Lofgren-Martenson, L. (2012). "I Want to Do it Right!" A pilot study of Swedish sex education and young people with intellectual disabilities. *Sexuality and Disability*, 30, 209–225.
- McFarland, J., Hussar, B., Zhang, J., Wang, X., Wang, K., Hein, S., Diliberti, M., Forrest Cataldi, E., Bullock Mann, F., and Barmer, A. (2019). *The Condition of Education 2019* (NCES 2019-144). U.S. Department of Education. Washington, DC: National Center for Education Statistics. Retrieved August 5, 2020 from <https://nces.ed.gov/programs/coe/>
- Murphy, N. A., & Elias, E. R. (2006). Sexuality of children and adolescents with developmental disabilities. *Pediatrics*, 118(1).
- Newman, L., Wagner, M., Knokey, A.-M., Marder, C., Nagle, K., Shaver, D., Wei, X., with Cameto, R., Contreras, E., Ferguson, K., Greene, S., & Schwarting, M. (2011). *The post-high school outcomes of young adults with disabilities up to 8 years after high school: A report from the National Longitudinal Transition Study-2 (NLTS2)* (NCSE 2011-3005). Menlo Park, CA: SRI International.
- Roden R.C., Schmidt E.K., & Holland-Hall C. (2020). Sexual health education for adolescents and young adults with intellectual and developmental disabilities: Recommendations for accessible sexual and reproductive health information. *The Lancet Child and Adolescent Health*. 4(9), 699-708. doi: 10.1016/S2352-4642(20)30098-5.
- Schaafsma, D., Stoffelen, J. M. T., Kok, G., & Curfs, L.M.G. (2013). Exploring the development of existing sex education programmes for people with intellectual disabilities: An intervention mapping approach. *Journal of Applied Research in Intellectual Disabilities*, 26, 157–166.
- Schaafsma, D., Kok, G., Stoffelen, J. M., & Curfs, L. M. (2014). Identifying effective methods for teaching sex education to individuals with intellectual disabilities: A systematic review, *The Journal of Sex Research*, 52(4), 412–432. doi: 10.1080/00224499.2014.919373
- Shearer, D. L., Mulvihill, B. A., Klerman, L. V., Wallander, J. L., Hovinga, M. E., & Redden, D. T. (2002). Association of early childbearing and low cognitive ability. *Perspectives on Sexual and Reproductive Health*, 34(5), 236–243
- 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.
- Swango-Wilson, A. (2008). Caregiver perceptions and implications for sex education for individuals with intellectual and developmental disabilities. *Sexuality and Disability*, 26, 167–174.

- Swango-Wilson, A. (2011). Meaningful sex education programs for individuals with intellectual/developmental disabilities. *Sexuality and Disability*, 29, 113–118.
- Tice, C. J., & Harnek Hall, D. M. (2008) Sexuality education and adolescents with developmental disabilities: Assessment, policy, and advocacy. *Journal of Social Work in Disability & Rehabilitation*, 7(1), 47–62.
- Turner, H. A., Vanderminden, J., Finkelhor, D., Hamby, S., & Shattuck, A. (2011). Disability and victimization in a national sample of children and youth. *Child Maltreatment*, 16, 275–286. doi: 10.1177/1077559511427178
- Watson, S. (2002). *Sex education for individuals who have a developmental disability: The need for assessment*. Submitted in partial fulfillment of the requirements for the degree of Master of Education, Department of Graduate and Undergraduate Studies in Education, Faculty of Education, Brock University, St. Catharine's, Ontario.
- Waxman, B. F., & Finger, A. (1991). The politics of sexuality, reproduction and disability. *Sexuality Update, National Task Force on Sexuality and Disability*, 4(1), 1–3.
- Whitehouse, M., & McCabe, M. P. (1997). Sex education programs for people with intellectual disability: How effective are they? *Education and Training in Mental Retardation and Developmental Disabilities*, 32(3), 229–240.
- Wilson, C., Marshall, Z., Flicker, S., McClelland, A., Vo, T., Nepveux, D., Proudfoot, D., Nixon, S., & Hart, T. (2014). Condoms and contradictions: Assessing sexual health knowledge in lesbian, gay, bisexual, trans, and queer youth labelled with intellectual disabilities. *Critical Disability Discourse/Discours Critiques dans le Champ du Handicap* 6, 107–139.
- World Health Organization (WHO). (2006). Sexual health document series. *Defining sexual health. Report of a technical consultation on sexual health*, 28–31 January 2002. Geneva, Switzerland: WHO Press.

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