Sexuality

110

Sorah Stein and Mitchell Tepper

Abstract

This chapter begins with setting the goal of helping people with intellectual and developmental disabilities (IDD) attain positive sexual self-esteem and fulfilling intimate relationships and, for those who are able and desire, parenthood. These goals stem from the recognition of people with IDD as sexual beings, with the same rights to sexuality education and access to sexual health care as their non-disabled peers. We discuss opportunities for sexual pleasure, expression, and experience, including masturbation and partnered sexual relationships. Sexuality is defined and a brief history of sexuality and developmental disabilities that is grounded in the eugenics movement is provided. We discuss ensuring safety from sexual exploitation and abuse, protection against unwarranted sterilization, and the right to make choices regarding alternative forms of contraception. The topic of consent to sexual activity is explored in depth.

Introduction

We recognize that sexuality, especially within the context of disability, is a sensitive subject and can make people uncomfortable. However, to ignore this topic or the more touchy issues would be a disservice to both the provider and person with the disability. Our goal is to provide practical resources towards promoting sexual health and responsible sexual behavior and addressing problems in a constructive way when they arise. While there are situations that require the input of a certified sexuality educator, counselor, or therapist with expertise in intellectual and developmental disabilities (IDD), such as dangerous masturbation or sexually assaultive behavior, many others, such as masturbating in a public space or sexual grabbing of others, can usually be handled by the individual's primary team.

Pleasure, in all its varieties, is an affirmation of life and a centrally motivating and defining feature of social action. Virgina Johnson referred to sexual pleasure as making

S. Stein, M.A., B.C.B.A., C.S.E. (✉)
Department of Psychology, Indiana University South Bend, 1700 Mishawaka Ave, South Bend, IN 46634-7111, USA
e-mail: steinsorah@yahoo.com

M. Tepper, Ph.D., M.P.H.
Private Practice, 600 Forest Hills Dr NE, Atlanta, GA 30342, USA
e-mail: drtepper@mitchelltepper.com

© Springer International Publishing Switzerland 2016

I.L. Rubin et al. (eds.), *Health Care for People with Intellectual and Developmental Disabilities across the Lifespan*, DOI 10.1007/978-3-319-18096-0_110

"us feel like complete human beings" [1]. Sexual pleasure can enhance an intimate relationship, add a sense of connectedness to the world and each other, and heal a sense of emotional isolation many feel even when they are socially integrated. "When we do not include a discussion of pleasure, we perpetuate an asexual and victimization status and contribute to the low sexual self-esteem among many people with disabilities" [2].

Anna Freud is famously quoted as stating, "Sex is something you do, sexuality is who you are." Historically, sex was viewed as serving only the purpose of reproduction. Today, we recognize that sexuality is also an important part of our health, quality of life, and human fulfillment. What then is sexuality? The WHO (World Health Organization) working definition says sexuality is: "…a central aspect of being human throughout life, encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviors, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, legal, historical, religious and spiritual factors" [3]. While not all people are sexually active or have sexual partners, all people are sexual beings. Sexuality comes through in our interactions, socializations, friendships, boundaries in relationships, self-image, and assertiveness; it is apparent in how we talk, walk, and dress. We are sexual from birth to death. With the proper information and opportunities, we all discover means to express that sexuality.

Although sexuality is an integral part of every human, defining who we are, and comprising an integral part of our self-esteem [4], myths abound concerning the sexuality of people with IDD [5]. Because all people are social and sexual beings from the day they are born, it is important to consider that people with IDD are, and experience themselves as, sexual, even if they never have partnered sexual relationships [6]. Medical research indicates that most people with IDD proceed through puberty and sexual development within similar patterns and times as their non-disabled peers [7, 8]. However, for years, the sexuality of people with disabilities was ignored, suppressed, or denied. We have not, generally, given proper consideration to the needs for sexuality education, access to sexual health care, and the right to sexual expression of people with IDD [7].

Current habilitation and rehabilitation programs are in place to assist with transition into adulthood for youth, born with or who acquire disabilities. The goal of such programs is typically to prepare participants for the adult world by focusing on educational and career success, including developing skills for employment preparation, job seeking, independent living, financial self-sufficiency, and workplace productivity. These are all survival goals. Helping people with IDD negotiate safe and fulfilling relationships with romantic partners is virtually ignored in the current system of care or, even worse, efforts are made to dissuade them from embarking on such relationships.

History

Historically, many people believed that crime, poverty, and disease were innate and closely associated with sexual promiscuity, mental illness, and "idiocy" [9]. Planned Parenthood was born from Margaret Sanger's idea (1879–1966) that the population and these problems could be improved through eugenics [10, 11]. People believed "feeblemindedness" was "largely hereditary" [12] and that instead of allowing these people to procreate; they should be sterilized [9]. Justice Oliver Wendell Holmes (1841–1935) is cited as stating, "Three generations of imbeciles are enough," in his support of compulsory sterilization. Additionally, such individuals were historically believed to be 'oversexed' and therefore a threat to the gene pool and to the public in general [13].

Thus, historically, people we now recognize as those with IDD were denied access to sexual expression and sexual freedom [13]. Beginning in 1895 in Connecticut, people with IDD were, and many still are, prevented from marrying and procreating [9]. One solution, made by Alexander Johnson, then superintendent of the Indiana School for Feebleminded Youth, not far from where Dr. Harry Sharp developed the vasectomy in 1899, was to segregate women of childbearing age with cognitive and/or emotional impairments [14]. Goddard, a noted eugenicist, recommended "colonizing" such individuals [12]. Yet another practice was to prevent marriage between those considered "feebleminded" or to have "social maladjustment" [15]. In 1907, Indiana was the first state to adopt a compulsory sterilization law. By the end of the 1920s, 24 states had mandatory sterilization laws [9]. By 1963, 28 states had sterilization laws with 26 of them including compulsory sterilization with or without the consent of the patient, but this was to soon turn around [16]. California and Virginia performed the most sterilizations in the country [17] with California performing its last one in 1963; in 1974, Indiana, the state in which it all began, repealed its mandatory sterilization law [18] and in 1981, Oregon performed the last legal, forced sterilization in the United States [19].

Some of the reasons for sterilization, beside the fear of pregnancy, included preventing expression of sexuality, decreased chance of sexual exploitation, and decreased likelihood of acquiring a STI. We now realize that in addition to being unethical, sterilization, voluntary or involuntary, does not accomplish anything beyond pregnancy prevention [20, 21]. Thus, fortunately, some of these beliefs have changed in more recent years. The Committee on Bioethics [22] suggested that since most courts did not have them at the time, laws should be passed in each state to prevent sterilization of the "mentally retarded;" unless the court finds it is in the best interests of the individual. While this should prevent sterilization for the benefit or convenience of others, more is needed to ensure this.

In 1971, the Declaration of the Rights of Mentally Retarded Persons by the United Nations Assembly proclaimed, "The mentally retarded person has, to the maximum degree of feasibility the same rights as other human beings" [23, 24]. Consequently, more recently, instead of mandating or illegalizing sterilization, the courts are finding a different path; the right to sterilization [25] and the protection against the abuse of it [21]. This is better than a blanket ban on sterilization and allows for people with disabilities to make their own decisions, just as the rest of society does [26]. A person who can demonstrate the capacity to understand the facts and concepts associated with contraception can provide informed consent for his or her preferred method of contraception, including sterilization [22].

Rights

Although we now generally accept that, in principle, people with IDD have the right to sexual expression, there remains anxiety and uncertainty concerning the sexuality of people with IDD [20]. The problem lies in the lack of clear understanding of what this means [27]. Individuals have the right to privacy, to sexuality education, to general sexual expression, and, for some, to have consensual sexual relations [7, 28].

Rights to partnered sexual behaviors are restricted, obviously, for children, and for those individuals who are determined to be incapable of consenting to sexual activities. In general, as the level of risk and potential for negative outcome increases, scrutiny and restrictiveness of the law increases, too [29]. We have the responsibility to achieve the delicate balance between needing to protect people with IDD from harm, with their right to express their sexuality.

Traditionally, this balance fell towards protection from harm and we limited sexual expression for people with IDD. Ironically, the same laws designed to protect people with IDD from harm prevent them from engaging in partnered sexual activities [13, 30]. Not all of the individuals we support have the ability to provide adequately informed consent to sexual behaviors [13]; thus, we prevent them from any sexual activity. We must be aware that what appears to be concern for the welfare of people with IDD may really mask anti-sexual bias. Providers may argue they provide protection from the increased risks of sexually transmitted infections, sexual abuse, and pregnancy, while really hiding beliefs that the people they serve are not and should not be sexual.

If state or other local law allows for sexual activity between individuals with IDD, a service provider cannot have an opposing policy prohibiting it [27]; to do so would be a violation of the individuals' human rights [28]. In residential settings with fewer people, this is easier to facilitate. Historically, institutions and larger facilities poorly manage the sexual needs and desires of those with disabilities, even to the extent of intentionally separating partners who were both consenting and behaving responsibly [31]. Edgerton [32] wisely pointed out the ineffectiveness of this attempt when describing the success of people, even whose with significant cognitive limitations, in accomplishing rendezvous with partners on hospital grounds.

Thus, the charge for parents, medical professionals, advocates, and educators is to find ways for individuals to have safe, socially acceptable means to engage in sexual activities and lead sexually fulfilling lives [31], whether in solo or partnered sexual experiences.

Access to Medical Care

It is essential that adolescents and adults with IDD receive sexual health care. This is more involved for females, requiring both pelvic and breast exams [7]. Because women in this population are less likely to have children, they are at increased risk for some cancers [33]. Increased risk of sexual abuse and decreased education about STI prevention increase risk of sexually transmitted infection [34]. Additionally, good gynecological care will assess for and address menstrual disorders [7]. It can be helpful to have the woman or her caregivers maintain a menstrual calendar, noting any behavioral or mood changes and bleeding irregularities as a means to monitor for problems [7]. Such data collection can also help inform if a woman experiences catamenial epilepsy and requires adjustment of anti-epileptic medication around her period [30].

Individuals with IDD, and even more so those with associated physical disabilities, often encounter challenges when accessing the health care system in general, and, in particular, providers to meet their sexual health needs. For example, physical disabilities can limit access to pelvic exams and mammograms for women due to architectural barriers, such as offices that are not wheelchair accessible, exam tables that are not adaptive, mammography machines that do not lower to wheelchair height [35, 36]. However, communication deficits, discomfort, and anxiety can interfere in the same medical screenings for women with IDD [33, 37]. In general, while women with disabilities receive annual physical exams and flu shots, they do not access sexual health screenings, such as mammograms and pap smears with the same frequency as their counterparts without disabilities [37].

Medical providers should not assume their patients to be asexual or sexually inactive and should ensure screening for women and men with IDD for sexually transmitted infections with the same regularity of non-disabled peers. We also need to offer choices for contraception while taking careful note of comorbid medical conditions and other medications already prescribed [7, 35, 36]. Many women with IDD are unable to consistently take medications on their own and would have difficulty with using barrier methods. Thus when considering the optimal form of contraceptive for a woman the prescribing clinician needs to determine what is going to be used with the greatest fidelity. Perhaps not surprisingly then, IUDs and Depo-Provera are the most commonly used contraceptives for women with IDD [7, 30]. However, providers must be careful not to prescribe contraception for staff or care taker convenience, to eliminate menstruation, or in lieu of a less restrictive option, such as sexuality education or counseling [35].

Parents, caregivers, and people with IDD need to be aware of the requisite sexual health screenings for STIs and general sexual healthcare. Medical providers should encourage these screenings and educate caregivers to their necessity instead of making the assumption that not engaging in partnered sexual activity eliminates the need [7, 33, 37]. Parents and caregivers can facilitate the exams by helping to prepare the individual ahead of time, and by being present and supportive during the exam. However, some women require sedative or anti-anxiety medication to tolerate pelvic exams [37].

Sexuality of People with Intellectual and Developmental Disability

In the realm of sexuality and disability there is public discourse on deviance and inappropriate behavior, abuse and victimization, asexuality, gender, and orientation. However, there is a missing discourse of pleasure. When there is deviation from "normal" sexual response, i.e., lack of desire, difficulty with erection, or delay or absence of orgasm, in people without disabilities, these issues are considered a problem, i.e., hypoactive sexual desire disorder, erectile dysfunction, or orgasmic disorder, and are provided treatment [2]. Sexual dysfunction in people with IDD may be attributed to general medical problems, such as diabetes; gynecological concerns, such as yeast infection or UTI; psychiatric conditions, such as depression, or effects of medications, such as SSRI or antipsychotic drugs, [38] however, if a person with an IDD experiences one of these difficulties, caregivers may be relieved rather than concerned to find a cause.

Education on Sexuality

Just like sexuality is more than 'having sex,' sexuality education is more than learning to have sex [39]. Lack of expertise and training may disturb professionals and caregivers and thus prevent them from providing direct service and education in areas of sexuality for people with IDD. In addition, clinicians, family members, and teachers often erroneously believe that if a person does not have a sexual partner, or the capacity to consent for one, he or she does not need sexuality education [7, 39] or that providing such education will initiate or increase sexual interest [40]. These sentiments are inaccurate, create an impending Pandora's box for the individual as he or she grows up, and increase vulnerability to abuse [7, 8].

Comprehensive sexuality education is not only about sexual intercourse; it acknowledges and celebrates individuality and individual differences [41]; it helps people learn who they are and who they will become. Sexuality education, tailored to the person's level of understanding, is essential for individuals with IDD to learn the risks associated with 'indiscriminate' sexual behavior (i.e., promiscuity, having multiple partners, not using condoms) and the means to protect themselves against pregnancy, sexually transmitted infections, and exploitation [4, 7]. Comprehensive sexuality education is essential to increasing assertive behavior and helping people evade situations of would-be abuse [7, 8, 42, 43].

When providing comprehensive sexuality education, information and materials need to be accurate and evidence-based [44]. This is not a simple task, however, given the paucity of curricula available for learners with special education requirements, despite overwhelming evidence of need [45]. Many US states exclude students with special education needs from mandated sexuality education in the schools. Materials and the manner in which they are presented should be age-appropriate [41], however, we must keep in mind that learners with IDD may learn at a slower pace than non-disabled peers [44, 46] and conduct education at a comprehensible level that is appropriate for the cognitive level and individual needs of each person [7]. We should be prepared to use simple language, videos, pictures, and other means of demonstration [46], while allowing ample time for discussion and questions and plan for many instructional sessions before the needed learning is complete. Alternatively, for students with a history of success with Social Stories®, Tarnai and Wolf [47] outlined the social skills related to sexuality that can be taught via this method and give guidelines to implementation. Finally, we need to ensure that someone who can competently answer questions is accessible as they are likely to arise outside of planned education sessions. Some resources for materials that are appropriate for learners with IDD are at the end of this chapter.

Giving inaccurate information, delivering information in a format that is not comprehensible to the person with IDD, using incomplete or inaccurate materials, or other inconsistencies can confuse and potentially upset the learner [44] and can easily put people in the dangerous situation of not having enough accurate information about risk to make good decisions about sexual behaviors [48]. Within the education process, we must take care to teach the proper names for body parts and talk about body rights and body ownership. This includes teaching individuals that they have the right to say no and to decide who can and cannot touch them and on what parts of their bodies [48]. This also includes the responsibility to take care of their bodies and not to put themselves at risk for diseases or injury. Some specific statements might include: “My body belongs to me,” “No one can make me share my body if I don’t want to,” and “If someone forces me to do sexual things, I should tell” [49].

Individuals need to know which behaviors and body parts are public and which are “private” [40]. This is not as simple as stating that body parts covered by underwear or bathing suits are private. Teaching that the only private body parts are those covered by underwear or bathing suits leads to the inference that all other body parts are public; this is not so. While we may walk around with other body parts showing, we do not necessarily want others touching us [47, 50, 51]. Hingsburger [48, 50] suggests starting by teaching privacy as a concept, and including it within conversations about sexuality and other personal issues. He suggests starting conversations with a statement such as, “Gee, we need to have a private chat. Where can we go where people will not hear us?” Such a comment will communicate from the start that privacy entails being in a place without others around.

When educating people with IDD and ensuring they can consent to partnered sexual activity, it is our responsibility to provide the needed information about the specific partnered sexual behaviors in which they plan to engage and teach that they have the choice to accept or reject solicitation of sexual activity with others [52]. Teaching the right to refuse is crucial. People with IDD are often over-compliant. From the time they are young, they are often taught not to refuse the instructions of caregivers, whether to complete a task, to eat a non-preferred food, or, dangerously, to engage in a sexual behavior [8, 48, 53]. This may be especially true for individuals who previously lived in institutional settings. Being passive, obedient, and docile are often reinforced in such settings.

People with IDD should know which behaviors are illegal and what the consequences of engaging in those behaviors could be. This includes appropriate touch [7], people with whom they cannot have sexual contact, and places in which sexual behaviors are not permitted [7, 50, 52]. When providing this aspect of education, we must be careful to be specific and accurate, avoiding euphemisms, which can be misunderstood. We need to be clear about who is a minor and where it is ok to masturbate. It is unjust for an adult with an IDD to spend time in jail because he or she didn’t know that the law stipulates a partner needs to be of an age to legally consent, as opposed to be “a woman” or “a man.” It is likewise unacceptable for an adult with an IDD to be arrested for masturbation in a public restroom because he or she was allowed to do so at school [50].

When using examples in sexuality education, keeping them concrete helps students with IDD to comprehend; many will not understand more abstract concepts. Consider using videos or pictures, such as those mentioned above, to help improve comprehension of the more abstract concepts, like the physical changes associated with puberty [53, 54]. Teaching in small segments with brief statements will also be helpful for learners who cannot process large amounts of information at once [44, 46].

Comprehensive sexuality education for people with IDD should include information about medical examinations and preparation for them. This allows individuals to be active participants in their healthcare and can help to reduce anxiety around examinations and treatment. We should be cautious when teaching about those body parts that are "private" that we impart the need to allow for cooperation with medical examination and treatment [33, 37]. The curriculum "Women be healthy" and videos, such as "The GYN exam" available from www.Stanfield.com and "Obtaining a pap smear" and "Pelvic exam" at www.sexsmartfilms.com, can help to prepare a woman for a gynecological exam.

Programs focusing on 'good touch-bad touch' can be dangerously narrow in what they consider good or bad. 'Bad touch' definitions tend to include any genital touching, possibly leading to generalizing that the genitals, themselves, are bad [50], that self-pleasuring is bad, and even that medical examinations are bad. Conversely, these programs may teach that all non-genital touch is 'good touch,' while this is also certainly not the case [48]. Comprehensive sexuality education programs should stress that sex is good and a source of pleasure, whether with a partner or alone [39, 48]. Ultimately, the goal is for people with ID to have a positive attitude towards their sexuality and to simultaneously learn proper social, health, and safety skills [27, 55].

Consent for Sexual Activity

The choice for partnered sexual activity can only be made by those with the capacity to consent to medical treatment or their conservators. The issues of both medical and sexual capacity to consent require recognition of the rights of individuals with IDD and the necessity of guardians and providers to ensure the safety of those to whom they provide services, while maximizing the expression of their rights and potential [52]. While the number of residential providers allowing individuals with IDD to participate in mutual sexual behavior has increased, there is still hesitation to allow such involvement for those individuals with a greater degree of IDD [13].

The capacity to consent is a state and not a trait, meaning it can vary over time, for people with and without IDD. Repeating an assessment for capacity to consent may yield different findings and may indicate that an individual achieved, or lost, capacity. By providing quality, on-going sexuality education, we can increase individuals' ability to exercise their sexual rights while protecting themselves from abuse [56]. Ultimately, this can only result in increased quality of life.

O'Callaghan and Murphy [55] conducted surveys of individuals with and without IDD to determine what people knew regarding sexuality, the law, and people with IDD. Their results indicated that over 50 % of individuals with IDD either did not know if they were allowed to have sex, or thought they were not allowed to by law. Thirty-two percent believed the law prohibited them from marrying, 40 % thought they could not make their own decision with regards to abortion, and only one person with an IDD knew that he or she could make decisions about sexual relationships if he or she demonstrated an understanding of the behavior and its implications. This suggests that those in the position to provide the needed sexuality education are not achieving enough success and much more work remains to be done.

However, consent for sterilization, contraception, or partnered sexual activity is a difficult topic, and one upon which the states do not all agree [52, 56]. There are not federally or internationally accepted criteria for determining the capacity of an individual to consent to partnered sexual activity; even a person with a guardian can have the capacity to consent to sex [52]. The National Guardianship Association Standards of Practice states:

> "The guardian shall acknowledge the ward's right to interpersonal relationships and sexual expression. The guardian must take steps to ensure that a ward's sexual expression is consensual, that the ward is not victimized, and that an environment conducive to this expression in privacy is provided [57]."

It is tempting for some professionals to determine that an individual with a severe or profound IDD lacks capacity to consent to sexual activity based on their cognitive impairment alone, and some US states support this notion [52]. However, even individuals with severe and profound IDD have been found to have the capacity to consent, within the context of a particular relationship

[13]. Thus there are six sets of criteria across the US for determining capacity to consent or not [8] with additional criteria internationally:

- Nature of the conduct addresses comprehension of the sexual act and its voluntariness, but not consequences, such as pregnancy and disease.
- Nature and consequences addresses the nature of the sexual act as well as potential consequences.
- Morality addresses moral understanding of the sexual act, plus nature and consequences.
- Totality of circumstances is unique to Illinois. Under this criterion, the person's ability to consent is determined by a judge, with whatever information he or she deems relevant.
- Evidence of mental disability allows for the courts to allow or disallow partnered sexual activities based on cognitive impairment.
- Judgment assesses ability to exercise judgment related to partnered sexual interactions.

Most of these criteria consider that sexual acts vary in their inherent risk. As examples, if two individuals only want to kiss and touch, but not have intercourse, they should not be held to the same knowledge standards as those who do want to have intercourse [52]; if a male requires instruction for effective masturbation, he should not be required to demonstrate knowledge about female genitalia; or, if an individual shows through actions, or vocalizes, an exclusively homosexual orientation, we might not require specific information about pregnancy and contraception; this is called limited capacity [13, 52]. In these situations, the consent capacity is not global, rather it is specific to the relationship; there is consent either with one particular partner, or for some sexual behaviors and not others. The crux of our education thus must be in addressing the areas needed by the individual to maintain his or her own safety and that of others around. There must be adequate supervision and guidance to the individuals in such a situation, to ensure that all is mutual and consensual [52].

There are three core components to the assessment of capacity to consent to partnered sexual activities: knowledge, rationality, and voluntariness [8, 52].

Knowledge starts with the basics of being able to label body parts, identify sexual behaviors, and understand when, where, and with whom it is appropriate to engage in sexual behaviors. It includes understanding the consequences of sexual behavior, specifically pregnancy and sexually transmitted infections, and how to prevent them. Knowledge also means knowing how to use contraception and how to obtain it; condom purchase and use should be the responsibility of both partners. Most importantly, knowledge reflects that the individual has the facts relevant to the specific sexual act(s) in which he or she is to engage [8, 52].

Rationality involves the ability to evaluate, weigh the pros and cons of a sexual situation, and make a sensible, risk-benefit-based decision. When considering someone's rationality, consider any neurological conditions the person has that can impair judgment. Determining rationality includes the individual's awareness of person, place and time, his or her ability to accurately report events, and ability to discriminate between fantasy, lies, and truth. The individual should be able to describe the process for deciding to engage in partnered sex, or not, to demonstrate an understanding of mutual consent, and chose socially appropriate times and places to have sex. Finally, he or she should be able to perceive and understand the vocal and non-vocal signals of the feelings of his or her partner, specific to desire to continue the interaction [52].

Voluntariness means the person can decide, without coercion, that, when, and with whom he or she wants to have sex. This also means he or she is able to take necessary, self-protective measures against abuse, exploitation, and other unwanted advances. Perhaps most importantly, voluntariness means that the person has the ability to communicate "No" vocally or non-vocally, to remove him or herself from a situation, and indicate a desire to discontinue an interaction, even if he or she previously consented [31, 52, 58].

In making a determination of an individual's capacity to consent, we must carefully review their records for relevant history, speak with staff and other people who know the person well, and meet with the individual directly. When completing an assessment for sexual consent capacity with an individual with IDD, it is imperative to communicate in the method he or she typically uses. This includes, but is not limited to the use of manikins, pictures, and models [52]. For example, Kaeser [13] taught two men with profound IDD to use a gesture to ask each other if they wanted to have sex. DynaVox Mayer-Johnson produced an add-on component "Communicating about Sexuality" to its popular Boardmaker® series. While originally developed in collaboration with "The Speak Up project" to enable people without vocal communication abilities to report sexual abuse [59], as a general tool "Communicating about Sexuality" allows production of symbolic picture symbols related to sexuality and sexual health. Finally, the Internet is a vast resource for other tools, such as manikins and models. Any of these, alone or in combination, may allow an individual with limitations in communication to provide consent to and solicit consent from a desired partner. Appropriately, these tools can also be used in sexuality education efforts and planning.

Sexual Diversity: Sexual Orientation, Gender Identity and Intersex

Sexual diversity amongst people with IDD reflects the diversity of people within the general population. An analysis of the National Survey of Family Growth suggests that, overall, people with disabilities are more likely than those without disabilities to identify or express themselves in ways other-than-heterosexual [60]. Although it can be a challenge to the beliefs of others because of personal or religious objections, the sexual diversity of people with IDD should be respected; their rights to engage with partners of their choosing and to express their gender should be protected.

Vulnerability to Sexual Exploitation and Abuse

People with IDD are at significantly increased risk for sexual abuse [7, 48]. Sexual abuse or assault is any unwanted sexual act, and includes, but is not limited to touching, kissing, oral sex, and anal or vaginal intercourse. Some people also consider sexual harassment a form of sexual abuse [5, 44]. Hingsbuger [48] added that being denied the right to, or punished for appropriate sexual behaviors, alone or with a partner, is a form of abuse as well.

Data from varied sources indicate that people with IDD are significantly more likely than others to experience some form of sexual abuse over the course of their lifetimes [8]. For the purposes of this discussion, sexual abuse comprises any unwanted touch or forced intercourse. The unacceptably high rates of sexual abuse among people with IDD are due, in part, to the generalized- and over-compliance encouraged [8, 48]. Unfortunately, the fact that people with IDD experience sexual abuse at all shouldn't come as a surprise. As Cole and Cole [61] pointed out, these are people who often depend on others to assist with physical and intimate, personal care needs. People with IQ <25 are typically more dependent upon others for their personal care and require additional supervision and protection from abuse [7].

A 2007 study [55] showed that less than 50 % of people with IDD knew that there were special laws pertaining to them and intended to protect them from sexual abuse. Sadly, they learned that most individuals with IDD did not know the laws about rape and sexual abuse that pertained to them specifically. O'Callaghan and Murphy [55] pointed out the importance of educating learners with disabilities about the laws pertaining to them and sexuality. Given the alarmingly high rates of abuse and exploitation committed against individuals with disabilities, it is essential that they know the law and know how to access needed protections.

Sexual abuse committed against people with IDD is most often perpetrated by men and against women [8, 43, 62, 63], however, Hingsburger [48] stresses being aware that anyone can be a victim and anyone can perpetrate. Most offenders are service providers; those entrusted with the care and safety of those they violate [8, 62]. There is a common and clear power differential, an 'us' vs. 'them' between services providers and people with IDD, making the people being served 'easy targets' [63].

Recognizing sexual abuse can be difficult, especially in people who have impaired communication. Certainly, physical signs, such as blood, torn clothing, symptoms of sexually transmitted infection, or bruising need to be addressed immediately. Sudden changes in behavior, such as aggression, can arouse concern; however, these need to be approached cautiously, as there can be multiple other causes for sudden changes in behavior, including medical concerns. Other signals include task refusals, especially with the offending staff person or related to hygiene, changes in personal boundaries and modesty, new aversion to being touched, and new difficulty in sleeping [48, 62–64]. Sometimes an individual discloses that abuse previously happened or is current. It is the responsibility of the care provider to help the individual access the appropriate care and therapy, and it goes without saying, to ensure immediate safety if the abuse is ongoing [64].

Treatment for those with IDD who endured sexual abuse, especially for those with communication deficits, can be challenging. Few sex therapists have the skill set to work with this population, and few clinicians with experience working with this population have expertise in sex therapy. This doesn't mean we ignore the needs of the individual; it means we consult with colleagues, seek assistance or supervision from those with expertise, and seek ways to provide ethical and effective care.

Approach to Sexual Activity

For the purposes of this discussion, masturbation is defined as self-stimulation for pleasure or soothing that may include rubbing the genitals directly, manually or with an object; through humping, indirectly through clothing; and/or inserting objects into the vagina or anus.

While a sensitive subject, masturbation is the most prevalent form of sexual expression for people with IDD) [13, 65]. Most sexual health professionals would agree with Hingsburger, who said, "Masturbation is a healthy form of sexual expression for both males and females. Masturbation is neither evil nor sick and, in fact, can be an alternative or addendum to other forms of sexual expression" [67]. Yet, caregivers frequently frown upon and, at times, even punish masturbation [66]. Even if we as caregivers and professionals are uncomfortable with masturbation, we need to ensure that the people we work with have the time and privacy they need to masturbate appropriately and safely. We cannot allow personal feelings or religious beliefs about sexuality and masturbation to negatively affect the individuals with whom we work [44]. Hingsburger [67] asserts that those working with individuals with developmental disabilities in an arena that includes sexuality must have a positive attitude towards both disabilities and sexuality. Anecdotal reports suggest that successful masturbation (masturbating to sexual satiation or to orgasm) can have extended benefits, including reduction in problem behavior, especially aggression [68]. Certainly masturbation in private, unless with objects that can cause injury, has no harmful effects [7].

Some individuals with severe or profound IDD have difficulty masturbating to orgasm. There is insufficient research to indicate how widespread this problem is [66]. However, Kaeser [66] suggested that we should expect this difficulty and investigate it as a possible cause of repetitive incidents of masturbation. He argued that masturbation is a learned behavior, not something that just happens. Each person learns through experience what works for him or her to facilitate successful masturbation. Intensity, duration of touch, friction, pressure, and grip, as well as speed and lubrication are all part of a personalized, learned technique, which can vary given new experiences. We also must consider the sexual side effects of medications commonly prescribed for people with IDD as a causative factor. For example, many antidepressant, antipsychotic, and antiepileptic medications have side effects including priapism, erectile dysfunction, ejaculation disorder, and delayed orgasm [69]. The first course should always be to rule out a medication side effect and make possible medication changes before embarking on other treatments [38].

For the general public who experience orgasmic dysfunction, the first line of treatment is usually masturbation training via bibliotherapy (recommending books like “Becoming orgasmic” by Julia Heiman and Joseph LoPiccolo or “For yourself” by Lonnie Barbach) or videos to watch at home. These basic interventions are often quite successful for difficulties rooted in lack of sexuality education and poor technique. The use of educational videos for teaching about masturbation, and masturbation training by qualified professionals can be useful interventions for those with IDD as well [65]. Unfortunately, while the acceptance of masturbation for people with IDD increased, there are few materials available for proactive education [13, 67]. There are two videos available for masturbation training for individuals with IDD – “Hand Made Love” (for males) and “Finger Tips” (for females), both by Dave Hingsburger. Additionally, there are brief video clips available at www.sexsmartfilms.com for a small fee. In all of these videos, a live person models masturbation, including privacy, use of lubrication, and hand washing when finished. Before any sexually explicit video is used it should be reviewed by a member of the treatment team who is familiar with the cognitive abilities of the person with IDD, general sexuality education should be provided first, and then the person should be informed ahead of time about what they will be watching, why, and the possible reactions they may have to viewing sexually explicit scenes [70]. Sexually explicit videos may trigger reactions from embarrassment, shame, and guilt, to laughter, sexual arousal or any combination of confusing emotions and reactions. The viewer should be given permission to experience their feelings without fear of judgment or reprisal. Hence, an experienced educator, counselor, or therapist who is trained in their proper use should be the one to show explicit videos to help process whatever feelings or emotions arise. The use of sexually explicit educational videos should not be left up to untrained staff in order to first, do no harm, and second, limit the risk of exploitation for the individual.

For more advanced treatments for ineffective masturbation, only trained specialists should be called upon. Kaeser and O’Neill [65] task analyzed the masturbation process and effectively taught, via hand-over-hand instruction, an adult male with profound IDD appropriate, nonharmful, and successful means of masturbation. For some, the thought of helping someone learn the mechanics of masturbation is uncomfortable and overwhelming. There are many ethical, moral, religious, and legal concerns involved in such a practice. This increases if the teaching involves hand-over-hand assistance. While Kaeser [66] asserts there are people for whom this is the only way they are likely to learn, in the clinical experience of this chapter’s authors and their colleagues, this is extremely rare and should always be the last resort of the clinical team, and then only with data that prove other, less intrusive and potentially safety-compromising methods have been unsuccessful. Hingsburger [67] recommends using synthetic penises and clitorises to teach appropriate hand placement and force. He insists that all training of this nature take place within clinical sessions, that there should not be hand-over-hand on the individual’s body, and no demonstration of sexual aids or toys should occur on the person’s body. The risks of illegal, abusive, or coercive actions on the part of a provider under the guise of education are great (D. Hingsburger, conversation, August 1, 2013).

When addressing sexual concerns, such as incomplete masturbation, it is helpful to consider a progressive approach, as we would with a person without an IDD. This includes starting with addressing any possible medical concerns and continuing with what is within the scope of sexual health training and the skillset of the clinical team, until the situation proves too difficult, at which point the appropriate course is to refer out to a trained expert. If you cannot find one locally, consult with one remotely, investigate further academic references, such as those included within this chapter, and above all, ensure there is sufficient oversight to make sure abuse does not occur.

The skills, however, that should always be taught towards appropriate and safe masturbation include basic hygiene, such as washing hands and any toys used while masturbating. The website www.comeasyouare.com has detailed, yet simple to understand instructions for care and maintenance of sex toys. Staff or others providing supervision for the person must also ensure items he or she uses for genital or anal insertion are safe for that purpose. If a person does not have access to safe items to use during masturbation, he or she might instead use items that can cause injury [71].

Inappropriate Masturbation

A common misconception is that inappropriate masturbation is due to an excessive or abnormal sexual drive. Treatment based on this assumption frequently involves medications that interfere with sexual function (e.g., Depo-Provera for men), but do not necessarily result in the desired behavioral change. These medications also raise an issue of informed consent and human rights restrictions. Instead, approach masturbation as a normal behavior in which people sometimes engage inappropriately [67]. In this light, we can look at teaching social skills, and not at punishing "deviance."

However, before treating inappropriate masturbation as a behavioral matter, it is important to rule out medical issues such as infection or irritation. Changing the fabric of underpants, for example, can also make a difference as some fabrics can cause irritation or discomfort, as well as stimulation (E. Mooney. Personal communication, 2010). Lubricants and other sexual aids can help with the effectiveness of masturbation, decreasing frustration and consequently frequency. If we can determine that frequent or excessively long masturbation is not a behavioral matter, we should assume that the individual is not masturbating to satiation. In this case, he or she may require additional instruction as mentioned above [65–67].

Robison et al. [71] discussed that some masturbatory methods, including some we may deem as unusual or abnormal, can result in injury or illness. They suggest that while everyone has the right to choose the method of masturbation that works best for him or her, it is important for us to provide proper education to individuals, and opportunity to obtain items and learn methods that are safer to use. They stress a focus on masturbation as a normal adaptive behavior, with an individual presenting with an inappropriate topography. Hingsburger [67] suggests relaxation training to help decrease the force with which a person masturbates. He states that many individuals masturbate too quickly and with too much force in an attempt to avoid discovery by staff. Other inappropriate masturbatory behaviors include public masturbation and excessive masturbation – defined as engaging with such frequency that it interferes with activities of daily living [67].

It may be helpful to look on the Internet at sex toy stores that will make adaptations for individuals with disabilities. Many can make suggestions for toys that an individual would be best able to use and what might help them achieve the sensation they are looking for. Again, www.comeasyouare.com is an excellent resource.

It is crucial not to disapprove of masturbation in and of itself, as it is, for many people with IDD, the only source of sexual pleasure or release of sexual tension available. Instead, looking at the specific concerns related to an individual's masturbation practices could lead us to valuable teaching opportunities. One example is when we need to teach people that masturbating in public is unacceptable, and instead when and where they can masturbate [72]. Hingsburger [67] cautions against teaching individuals it is acceptable to use the bathroom as a private location in which to masturbate. Many bathrooms that an individual encounters are not private and masturbation in these locations is not only inappropriate, but also illegal. Another example is people who have difficulty with arousal in their bedrooms, without the visual stimuli available in public areas [53]. For these individuals, it may be necessary to provide pictures, magazines, or videos that will help with arousal in an appropriate way or to otherwise provide replicas of the arousing stimuli in the person's bedroom.

Although there is a dearth of literature on the use of pornography by people with IDD, the topic deserves mention. The concerns around pornography and people with IDD are significant, including the right to access pornographic materials for one's use and pleasure, perseverative viewing of pornographic materials, exposure to media without consent, and exploitation in the form of illicit photographs taken. To some, the right to access pornography is a given, and included in one's right to express sexuality. To others, pornographic materials are offensive or religiously forbidden [68]. The balance to achieve is one that acknowledges and protects the rights of the individual to access, purchase, and view materials of his or her choosing with the obligation to protect people who may be vulnerable to exploitation and abuse, including housemates who do not want to be exposed to explicit materials.

We must agree that the goal is not to eliminate masturbation altogether. Such a goal is unethical, unfair, and would ultimately fail. The approach instead is to increase and promote appropriate masturbation [44]. Looking at masturbation, and sexuality in general, as part of an individual's social skills repertoire will help guide appropriate decisions, provide proper assistance, and treat individuals with IDD in a respectful and dignified manner.

Inappropriate Sexual Behavior

Once in residential or other facility-based service, sexual behavior may be punished by staff who fail to recognize sexual expression as a right [73]; the service providing agencies may prohibit sexual activity on their premises, or may neglect to provide or allow the privacy necessary for such activities [20, 74, 75]. However, there are situations that clearly constitute inappropriate behavior.

When clinicians encounter individuals who engage in any form of inappropriate sexual behavior, there are several questions that must be asked. We first need to determine for whom the behavior is a problem, i.e., parents, caregivers, members of the community, or the individual, and why. Thus, we next ask:

- What makes it inappropriate, specifically, is the behavior harmful to the individual or others?
- Is it illegal, such as masturbating in public or engaging in sexual acts with minors or other people who cannot consent?
- Is it immoral – and if so, by whose standards?
- Is the behavior in some other way socially inappropriate, but not illegal, for example, a sexual behavior that occurs in the wrong place, such as the living room at home, or with inappropriate partners based on the conservators' values, such as partners of the same sex or of a different race, ethnicity, social class, or undesirable disability status.

Next, we need to look at the behavior more closely, and, as with any other behavior of clinical concern, understand its function and not make assumptions or judgments. The goal is to determine if the behavior is goal directed, i.e., to reduce sexual arousal, self-soothing, or occurring for some other reason such as escape from task demands or access to attention.

Only after we establish why the behavior occurs, can we address it ethically and effectively with behavior change procedures, including, but not limited to replacement behavior that accesses the same function [76] or education towards the appropriate time and place for the behavior to occur. Any clinician who purports to remedy the situation without proper assessment neglects to give the individual proper and ethical clinical attention and service [77].

Unfortunately, little is found in the research to guide clinicians working with individuals who engage in inappropriate sexual behavior. Only two papers address functional analysis of inappropriate sexual behavior [78, 79]. In the Fyffe et al. study [78] the authors conducted a functional analysis with a 9-year-old boy with traumatic brain injury who touched or attempted to touch the groin, buttocks, or breast areas of staff they determined that attention maintained the behavior, and successfully replaced it with a socially appropriate means of requesting staff attention. In the Dozier study [79] they conducted functional analysis with an adult male with autism who engaged in masturbation in the presence of women wearing sandals they determined the behavior was maintained by automatic reinforcement, or the innate sensation resulting from masturbation, and implemented an intervention in which they interrupted the response and instituted a brief time-out.

Based on the clinical experience of one of this chapter's authors, functional analysis is an appropriate means to determine the variables maintaining various topographies of inappropriate sexual behavior (i.e., masturbation in a public place) and inform methods towards effecting behavior change [80]. Once function is determined, as in the Fyffe et al. paper [78], we teach and reinforce socially appropriate, alternate behaviors, such as asking for help, attention, a break [81], or access to a private area in which to masturbate; provide education towards teaching the skills needed to engage in sexual behaviors within appropriate contexts; or modify the environment to remove arousing stimuli [80]. Within the clinical setting, we often teach rules of touch and privacy (i.e., those activities that should only take place behind a closed door) and appropriate verbal interactions (e.g., not saying, "I love you" to a staff member) to bring the behavior into the realm of appropriate context [82].

Medical Sterilization for Management of Inappropriate Sexual Behavior

Medications, including psychotropic medications, e.g., SSRI and antipsychotics, are commonly prescribed to help decrease problem behavior in people with IDD [83, 84]. While there is some discussion related to medication use and sterilization related to women for contraception and management of menstruation, there is little discussion and legal guidance for medical sterilization treatment of men with IDD. While surgical sterilization only controls for fertility some men are given medications, i.e., androgen-depleting drugs and Depo-Provera, as chemical castration similar to those in the criminal justice system, to decrease libido and consequently decrease sexual behavior [84, 85]. Little discussion of the ethics and efficacy for this type of treatment for men with IDD exists.

Conclusions

Providers should address the intimacy gap in habilitation and rehabilitation programs by working to end emotional isolation and to help people thrive through meaningful and safe relationships. This, we suggest, can be achieved through educational and motivational activities that help adolescents and adults with IDD achieve the following objectives:

- Learn about expected physical, emotional, and biological changes associated with their condition as related to relationships and intimacy;
- Develop healthy attitudes and values about growth and development, body image, gender roles, racial and ethnic diversity, among other subjects;
- Promote self-esteem and positive interpersonal skills focusing on relationship dynamics, including, but not limited to, friendships, dating, romantic involvement, marriage and family interactions;
- Develop and practice healthy life skills including goal-setting, decision making, negotiation, communication, and stress management;
- Develop the knowledge and skills necessary to ensure and protect their sexual and reproductive health through out their lifespan;
- Develop skills to make responsible decisions about sexuality, including how to avoid unwanted verbal, physical, and sexual advances and how not to make unwanted verbal, physical, and sexual advances;
- Learn that becoming a parent is a right, if they chose and that there is not necessarily increased risk for them having a child with a disability compared with the general population;
- Develop parenting skills and establish a support system to assist with parenting;

- Increase awareness of how alcohol and drug use can affect responsible decision-making.

Service providers must also establish environments that support the healthy sexuality of the people they serve. Polices that establish private time and space, and require that staff respect these will allow individuals healthy sexual expression [75].

Resources

- FLASH lesson plans for special education. URL: http://www.kingcounty.gov/healthservices/health/personal/famplan/educators/SpecialEducation.aspx
- Couwenhoven T. Teaching children with Down syndrome about their bodies, boundaries, and sexuality. URL: lhttp://www.woodbinehouse.com/ main. asp_Q_ product_ id_E_978-1--890627-33-1_A_.asp
- Couwenhoven T. The girls' Guide to growing up. Bethesda, MD: Woodbine House. URL: http://www.woodbinehouse.com/main.asp_Q_ PRODUCT_ ID_E_978- 1-60613-026-1
- Couwenhoven T. The boys' guide to growing up. Bethesda, MD: Woodbine House. URL: http://www.woodbinehouse.com/main.asp_Q_ product_ id_E_978-1-60613-089-6_A_.asp
- Women be healthy curriculum, teaches about mammograms and pelvic exams. URL: http://lurie.brandeis.edu/women/curriculum.html

References

1. Masters WH, Johnson VH. The pleasure bond: a new look at sexuality and commitment. Boston: Little Brown; 1974.
2. Tepper MS. Sex and disability: the missing discourse of pleasure. Sex Disabil. 2000;18(4):283–90.
3. World Health Organization. Sexual and reproductive health. Defining sexual health. 2006. URL: http://www.who.int/reproductivehealth/topics/sexual_health/sh_definitio ns/en/
4. Matich-Maroney J, Boyle PS, Crocker MM. The psychosexual assessment and treatment continuum: a tool for conceptualizing the range of sexuality-related issues and support needs of individuals with developmental disabilities. Ment Health Aspects Dev Disabil. 2005;8(3):1–14.
5. Kaufman M, Silverberg C, Odette F. The ultimate guide to sex and disability. San Francisco: Cleis Press; 2003.
6. Timmers RL, Ducharme P, Jacobs G. Sexual knowledge and behavior of developmentally disabled adults living in a normalized apartment setting. Sex Disabil. 1981;4(1):27–39.
7. Greydanus DE, Omar HA. Sexuality issues and gynecologic care of adolescents with developmental disabilities. Pediatr Clin North Am. 2008;55(6):1315–35.
8. Morano JP. Sexual abuse of the mentally retarded patient: medical and legal analysis for the primary care physician. Prim Care Companion J Clin Psychiatry. 2001;3(3):126.
9. Bernson MJ, Cruz B. Eugenics past and present: remembering Buck v. Bell. Social Education. 2001 Sept 1. URL: http://members.ncss.org/se/6505/650507.html
10. Michigan Bar Journal. Haynes v Lapeer Circuit Judge January 2009: 9–13.
11. Moalem S. How sex works. New York: Harper Collins; 2009.
12. Goddard HH. Sterilization and segregation. Indiana Bull Charities Correction. 1912:424–8.
13. Kaeser F. Can people with severe mental retardation consent to mutual sex? Sex Disabil. 1992;10(1):33–42.
14. Osgood R. The menace of the feebleminded: George Bliss, Amos Butler, and the Indiana Committee on Mental Defectives. Indiana Magazine History. 2001 Dec.
15. Hurty JN. Practical eugenics in Indiana. Ohio State Med J. 1912;8:55–60.
16. Eugenic Sterilization in Indiana. Indiana Law J. 1963;38(2):275–89. URL: http://www.repository.law.indiana.edu/ilj/vol38/iss2/4
17. Claude Moore Health Sciences Library. Three generations, no imbeciles: Virginia, eugenics, and Buck v. Bell. URL: http://exhibits.hsl.virginia.edu/eugenics/
18. Indiana Historical Bureau. 1907 Indiana Eugenics Law. Indiana: Indiana Historical Bureau. URL: www.in.gov/history/markers/524.htm
19. Lawrence C. Oregon State Board of Eugenics. Embryo Project Encyclopedia. 2013. URL: embryo.asu.edu/pages/oregon-state-board-eugenics
20. DiGuilio G. Sexuality and people living with physical or developmental disabilities: a review of key issues. Can J Hum Sex. 2003;12(1):53–68.
21. Goldman EB, Quint EH. Arguments against sterilization of developmentally disabled minors. J Child Neurol. 2011;26(5):654–6.
22. Committee on Bioethics. Sterilization of minors with developmental disabilities. Pediatrics. 1999;10(4):337–40.
23. Office of the United Nations High Commissioner for Human Rights. Declaration of the Rights of Mentally

Retarded Persons, Geneva. 1971. URL: www.unhchr.ch/html/menu3/b/m_mental.htm

24. Denkens JPM, Nys H, Stuer H. Sterilization of incompetent mentally handicapped persons: a model for decision making. J Med Ethics. 1999;25:237–41.
25. Weisleder P. Sterilization for individuals with mental disabilities: the other half of the equation. J Child Neurol. 2011;26(5):649–50.
26. Annas GJ. Sterilization of the mentally retarded: a decision for the courts. Hastings Cent Rep. 1981;11(4):18–19.
27. Fegan L, Rauch A, McCarthy W. Sexuality and people with intellectual disability. 2nd ed. Baltimore: Paul H Brooks; 1993.
28. Merrick J, Kandel I, Morad M. Parenthood. In: Patel DR, Greydanus DE, Omar HA, Merrick J, editors. Neurodevelopmental disabilities. Dordrecht: Springer; 2011. p. 473–82.
29. American Association on Intellectual and Developmental Disability. Fact sheet: sexuality and intellectual disability. URL: http://www.aamr.org/policies/.sexuality.shtml
30. Greydanus DE, Pratt HD, Patel DR. Concepts of contraception for adolescent and young adult women with chronic illness and disability. Dis Mon. 2012;58(5):258–320.
31. Steinberg D. 'Touch' photos at good vibes. Respecting the sexual needs of the developmentally disabled. Spectator Magazine. 1996. URL: http://www.sexuality.org/authors/steinberg/cn45.html
32. Edgerton RB, Dingman HF. Good reasons for bad supervision: "dating" in a hospital for the mentally retarded. Psychiatr Q Suppl. 1964;38:221–33.
33. Parish SL, Rose RA, Luken K, Swaine JG, O'Hare L. Cancer screening knowledge changes results from a randomized control trial of women with developmental disabilities. Res Soc Work Pract. 2012;22(1):43–53.
34. Mandell DS, Eleey CC, Cederbaum JA, Noll E, Hutchinson MK, Jemmott LS, Blank MB. Sexually transmitted infection among adolescents receiving special education services. J Sch Health. 2008;78(7):382–8.
35. Kaplan C. Special issues in contraception: caring for women with disabilities. J Midwifery Womens Health. 2006;51(6):450–6.
36. Welner SL. Conducting a physical examination on a woman with a disability. Sex Disabil. 1999;17(3):199–202.
37. Swaine JG, Dababnah S, Parish SL, Luken K. Family caregivers' perspectives on barriers and facilitators of cervical and breast cancer screening for women with intellectual disability. Intellect Dev Disabil. 2013;51(1):62–73.
38. Greydanus DE, Matysina L. Female sexual dysfunction and adolescents. Curr Opin Obstet Gynecol. 2010;22:375–80.
39. Walker-Hirsch L. The facts of life and more: sexuality and intimacy for people with intellectual disabilities. Baltimore: Paul H Brookes; 2007.
40. Tissot C. Establishing a sexual identity: case studies of learners with autism and learning difficulties. Autism. 2009;13(6):551–66.
41. Silverberg C. What is good sex education? 2009. URL: http://sexuality.about.com/od/seekingsexualhelp/p/sex_education.htm
42. Furey EM, Niesen JJ. Sexual abuse of adults with mental retardation by other consumers. Sex Disabil. 1994;12(4):285–95.
43. McCabe MP, Cummins RA, Reid SB. An empirical study of the sexual abuse of people with intellectual disability. Sex Disabil. 1994;12(4):297–305.
44. Walsh A. Improve and care: responding to inappropriate masturbation in people with severe intellectual disabilities. Sex Disabil. 2000;18(1):27–39.
45. Gougeon NA. Sexuality education for students with intellectual disabilities, a critical approach: outing the ignored curriculum. Sex Educ. 2009;9(3):277–91.
46. Zylla T, Demetral GD. A behavioral approach to sex education. Sex Disabil. 1981;4(1):40–8.
47. Tarnai B, Wolfe PS. Social stories for sexuality education for persons with autism/pervasive developmental disorder. Sex Disabil. 2008;26:29–36.
48. Hingsburger D. Just say know! Eastman: Diverse City Press; 1995.
49. Couwenhoven T. Teaching children with down syndrome about their bodies, boundaries, and sexuality. Bethesda: Woodbine House; 2007.
50. Hingsburger D. I contact. Mountville: Vida; 1990.
51. Gerhardt P. Sexuality instruction and learners with ASD: what behavior analysts need to know. Presented at Association of Professional Behavior Analysts, Tampa, FL, 2012 Apr 14.
52. Lyden M. Assessment of sexual consent capacity. Sex Disabil. 2007;25(3):3–20.
53. Sexualityandu.ca. Teaching sex education: sex education for youth with intellectual disabilities. 2007. URL: http://sexualityandu.ca/en/teachers/teaching-sex-ed-for-youth-with-intellectual-disabilities
54. AVERT. Puberty and sexual organs: your body and puberty. URL: http://www.avert.org/puberty-and-sexual-organs.htm
55. O'Callaghan AC, Murphy GH. Sexual relationships in adults with intellectual disabilities: understanding the law. J Intellect Disabil Res. 2007;51(3):197–206.
56. Murphy GH, O'Callaghan A. Capacity of adults with intellectual disability to consent to sexual relationships. Psychol Med. 2004;34:1347–57.
57. National guardianship association. Standards of practice. 2000. URL: http://guardianship.org/guardianship_standards.htm
58. Kennedy CH, Niederbuhl J. Establishing criteria for sexual consent capacity. Am J Ment Retard. 2001;106(6):503–10.
59. Collier B, McGhie-Richmond D, Odette F. Reducing the risk of sexual abuse for people who use augmentative communication. Toronto: Speak Up Project; 2004.
60. Hendershot G, Kurki A, Tepper M. Sexual behavior among persons with disabilities: new data from the

National Survey of Family Growth Abstract #105309, American Public Health Association National Conference, Philadelphia. 2005. URL: https://apha.confex.com/apha/133am/techprogram/paper_105309.htm

61. Cole SS, Cole TM. Sexuality, disability, and reproductive issues through the lifespan. Sex Disabil. 1993;11(3):189–205.
62. McCarthy M, Thompson D. A prevalence study of sexual abuse of adults with intellectual disabilities referred for sex education. J Appl Res Intellect Disabil. 1997;10(2):105–24.
63. American College of Obstetricians and Gynecologists. Access to reproductive health care for women with disabilities. Washington, DC: ACOG; 2004.
64. Burke L, Bedard C, Ludwig S. Dealing with sexual abuse of adults with a developmental disability who also have impaired communication: supportive procedures for detection, disclosure, and follow-up. SIECCAN Newsl. 1998;33(1):79–91.
65. Kaeser F, O'Neill J. Task analyzed masturbation instruction for a profoundly mentally retarded adult male: a data based case study. Sex Disabil. 1987;8(1):17–24.
66. Kaeser F. Developing a philosophy of masturbation training for persons with severe or profound mental retardation. Sex Disabil. 1996;14(4):295–307.
67. Hingsburger D. Masturbation: a consultation for those who support individuals with developmental disabilities. Can J Hum Sex. 1994;3(3):278–82.
68. Wilson NJ, Parmenter TR, Stancliffe RJ, Shuttleworth RP. Conditionally sexual: men and teenage boys with moderate to profound intellectual disability. Sex Disabil. 2011;29(3):275–89.
69. Steve Lamm. Webmd. Sexual health. The side effects of medications. 2006. URL: http://www.webmd.com/sex/video/sex-side-effects-medications
70. Tepper MS. Use of sexually explicit films in spinal cord injury rehabilitation programs. Sex Disabil. 1997;15(3):167–81.
71. Robison CP, Conahan F, Brady W. Reducing self-injurious masturbation using a least intrusive model and adaptive equipment. Sex Disabil. 1992;10(1):43–55.
72. Koller R. Sexuality and adolescents with autism. Sex Disabil. 2000;18(2):125–35.
73. Lesseliers J, Van Hove G. Barriers to the development of intimate relationships and the expression of sexuality among people with developmental disabilities: their perceptions. Res Pract Pers Severe Disabil. 2002;27(1):69–81.
74. Hamilton CA. 'Now I'd like to sleep with Rachael' researching sexuality support in a service agency group home. Disabil Soc. 2009;24(3):303–15.
75. Hingsburger D, Tough S. Healthy sexuality: attitudes, systems, and policies. Res Pract Pers Severe Disabil. 2002;27(1):8–17.
76. Iwata BA, Dorsey MF, Slifer KJ, Bauman KE, Richman GS. Toward a functional analysis of self-injury. Anal Interv Dev Disabil. 1982;2(1):3–20.
77. Van Houten R, Axelrod S, Bailey JS, Favell JE, Foxx RM, Iwata BA, Lovaas OI. The right to effective behavioral treatment. J Appl Behav Anal. 1988;21(4):381–4.
78. Fyffe CE, Kahng SW, Fittro E, Russell D. Functional analysis and treatment of inappropriate sexual behavior. J Appl Behav Anal. 2004;37(3):401–4.
79. Dozier CL, Iwata BA, Worsdell AS. Assessment and treatment of foot—shoe fetish displayed by a man with autism. J Appl Behav Anal. 2011;44(1):133–7.
80. DePoy M, Stein S. Alternate means of functional assessment for sexually inappropriate behavior. Paper presented at Hoosier Association For Behavior Analysis annual conference, Indianapolis, IN. 2013 Oct 11. URL: https://scholarworks.iu.edu/dspace/handle/2022/16954
81. Carr EG, Durand VM. Reducing behavior problems through functional communication training. J Appl Behav Anal. 1985;18(2):111–26.
82. Gorski SL, Stein S. Closing the bathroom door: the effect of teaching a categorization task on a crucial safety behavior. Association for Behavior Analysis International, 40th annual convention, Chicago, IL. 2014 May 24.
83. Tate BG, Baroff GS. Aversive control of self-injurious behavior in a psychotic boy. Behav Res Ther. 1966;4(1):281–7.
84. Sajith SG, Morgan C, Clarke D. Pharmacological management of inappropriate behaviours: a review of its evidence, rationale and scope in relation to men with intellectual disabilities. J Int Disabil Res. 2008;52(12):1078–90.
85. Carlson G, Taylor M, Wilson J. Sterilisation, drugs which suppress sexual drive, and young men who have intellectual disability. J Int Dev Disabil. 2000;25(2):21–104.