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Ethics in sexual behavior assessment and support for people with intellectual disability

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Abstract

Sexuality is an issue of equality, rights, and ethics, especially when it comes to the sexuality of people with intellectual and developmental disabilities. This paper offers a discussion of ethics related to the assessment and intervention supports of sexual behavior in people with intellectual and developmental disabilities. A brief history of sexuality and disability is presented. Issues of sexual abuse of people with intellectual and developmental disabilities and the laws related to sterilization, pornography, sexual rights, and consent are explored. Finally, specific ethical concerns related to intervention by behavior analysts in the realm of sexual behavior are examined.

Ethics in sexual behavior assessment and support for people with intellectual disability

Sexuality, especially in the context of disability, is a subject that can make parents and providers uncomfortable (1). Many parents of children with intellectual and developmental disabilities (IDD) tend to see their children as asexual, less likely to engage in sexual behavior and less likely to require sexuality education (2). Because of clinician discomfort, or due to inadequate education and skill specific to human sexuality, behavior analysts might be too quick to initiate assessment, or worse, treatment assumptions based on topography, and overlooking the myriad possibilities contributing to a behavior with a sexual topography, thus butting up against any number of potential ethical concerns. While there are situations that should involve the input of a certified sexuality educator, counselor or therapist with expertise in IDD, such as dangerous masturbation or sexually assaultive behavior, many other behaviours, such as masturbating in a public space or topographically sexual grabbing of others, can usually be handled appropriately and ethically by the individual's primary care team (1). The purpose of this paper is to provide an overview of the history of sexuality and IDD in the United States and make recommendations for ethical practice related to inappropriate sexual behavior.

History of sexuality and disability

Historically, people believed that crime, poverty, and disease were innate and closely associated with sexual promiscuity, mental illness, and "idiocy" (3) and that one of the main problems was that people with IDD can and do have children (4). People,

such as Henry Goddard (5), a prominent psychologist in the early part of the 20th century, believed “feeble-mindedness has shown that it is very largely hereditary, at least two-thirds of the cases being the children of feeble-minded parents or grandparents or both” (p. 424). Thus, people with IDD were denied access to sexual expression and sexual freedoms. Such individuals were historically believed to be ‘oversexed’ and therefore a threat to the gene pool and to the public in general (6). Planned parenthood was born from the idea that the population could be improved through eugenics (7). To address this concern, people with IDD were, and many still are, prevented from marrying and having children.

As a nation-wide means of preventing procreation, twenty-eight states in the USA had sterilization laws by 1963; twenty-six of them included compulsory sterilization - with or without the consent of the patient. California and Virginia performed the most sterilizations in the USA (8). In addition to preventing reproduction, some of the concepts that underpinned involuntary sterilization included the notions that it would prevent the expression of sexuality, decrease chances of sexual exploitation, and decrease likelihood of acquiring a sexually transmitted infection (STI). However, in addition to being unethical, sterilization, voluntary or involuntary, did not accomplish any of these aims (9). Even with sterilization, individuals with IDD expressed their sexuality, experienced sexual exploitation (10, 11, 12), and acquired STI (13).

Abuse statistics

The American Association on Intellectual and Developmental Disability position statement on sexuality (AAIDD) (14) defines sexual abuse as forcing, threatening,

coercing, tricking, or manipulating another person into unwanted sexual contact or into sexual contact to which the other person does not have the capacity to consent.

Several recent studies indicate that people with IDD experience much higher rates of non-consensual sexual encounters than non-disabled individuals, with worldwide incidence ranging from 44% in children with IDD (10, 12) to 83% in adults with IDD (11).

Despite the fact that just over one quarter of parents (28.6%) of children with IDD believe that their child will experience non-consensual sex, over half of the parents of both girls and boys with IDD (57% and 52.4%, respectively) identified personal protection as important for their child. Yet, only 42.9% of parents of girls with DD and 33.3% of parents of boys with IDD thought that privacy skills were important target skills for their child (2).

Current laws regarding sex and people with intellectual disability

Although many accept that people with IDD have the right to sexual expression (15, 16), this can be a difficult issue for parents and providers (2, 9, 17, 18, 19). One problem is lack of clear understanding of just what it means for people with IDD to have and exercise sexual rights (20).

Expressions of sexuality are thought to enhance quality of life and individuals with IDD are sexual beings, just as much as everyone else (21). According to the United Nations Convention for the Rights of Persons with Disabilities and the World Association for Sexual Health Declaration of Sexual Rights, people with disabilities have the right to express themselves sexually and thus have the potential to enhance their quality of life

(6). Within the field of applied behavior analysis (ABA), the discourse about sexuality is increasing in focus, as evidenced in publications, conferences, seminars, Webinars, and in online discussions. However, this is not without risk and concern by those with expertise in the field of human sexuality.

Among the many barriers to healthy sexual expression for people with physical and developmental disabilities is lack of privacy (9). Individuals have the right to privacy and to consensual sexual relations. These rights are restricted, obviously, for children, and also for those individuals who are determined to be incapable of consenting to sexual activities. However, the right to privacy is often restricted in the case of an individual who engages in severe self-injurious behavior, property destruction, or wandering/eloping. In these cases, the individual's service plan frequently requires 'line-of-sight' supervision, which challenges their right to privacy. This is not a simple matter, as it exemplifies the conflict between concern for the wellbeing and upholding of the rights of the individual.

There is a delicate balance to be struck between the legal and ethical requirement to protect people with IDD from harm, while at the same time protect their rights to express sexuality. Traditionally, parents, professionals, and the law erred on the side of protection from harm, consequently limiting sexual expression, i.e., the same laws that are designed to protect people with IDD from harm prevented them from engaging in normal sexual activities (6). What appears to be concern for the welfare of people with IDD therefore could, in reality, be masking an anti-sexual bias (22).

Clearly, some individuals with severe IDD are incapable of giving informed consent to partnered sexual activities, while others may be particularly vulnerable to

psychological manipulation. They all need protection from the potential of non-consensual sexual abuse. However, there are no laws that necessitate consent for sexual activities on their own; that is, there is no need to consent to masturbation and having private space in which to do so is the right of people with IDD (23). Nevertheless, there are instances in which an individual is denied access to time in his or her bedroom alone, when staff members walk into bedrooms or bathrooms without knocking and despite closed doors, or when people are more overtly prevented from masturbation whether by chemical or physical restraint.

The policies surrounding sexuality within an agency, such as a residential home for persons with IDD must be in line with Government guidelines and the law. Since the law enshrines the rights for sexual activity for and between individuals with IDD, service provider cannot have a policy prohibiting it (20). Instead, agencies should have policies towards helping people learn about and express their sexuality (18, 22, 24, 25).

Advocates and educators should find creative ways to enable individuals to have safe and socially acceptable ways in which to engage in sexual activities and lead sexually fulfilling lives (26). Overprotection may not be necessary; in fact, people without IDD tend make far more mistakes in their sexual lives than people with IDD (6).

Consent

Capacity to consent can vary over time, i.e., it is a state rather than a trait. For example, inebriation or certain kinds of medication can inhibit even an otherwise competent adult from giving informed consent, while sexuality education can enhance the capacity of people previously deemed unable to make informed decisions. Thus,

repeating an assessment for capacity to consent may yield different findings across time and may indicate that even an individual with IDD who was previously deemed incapable, has developed the capacity to consent to sexual interactions.

Additionally, the requirements of consent can vary based on the nature of the sexual interaction. Thus, to best help the people make informed choices, good quality on-going sexuality education is necessary so as to increase individuals' ability to exercise their sexual rights while protecting them from abuse and increasing their quality of life (27). The crucial components of capacity to consent are knowledge, rationality, and voluntariness (28).

Sexual knowledge starts with the ability to label body parts, identify sexual behaviors, and understand where and when it is appropriate to engage in sexual behaviors and where and when it is not appropriate. It includes being able to state the consequences of sexual behavior, specifically pregnancy and sexually transmitted infections, and how to prevent them. Knowledge also means the person can demonstrate how to obtain and use contraception (28).

Voluntariness means the person can decide without coercion, that, 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. Voluntariness also means that the person has the ability to say, "No," either vocally or non-vocally, and to remove him/herself from a situation and indicate a desire to discontinue an interaction (26, 28, 29).

Rationality means the ability to evaluate and weigh the pros and cons of a sexual situation and make a rational decision. When considering someone's ability to be

rational, any neurological conditions the person has that can impair judgment need to be considered. Determining rationality includes the individual's awareness of person, place and time; his or her ability to accurately report events; and to discriminate between fantasies, lies, and truth. The individual should be able to describe the process for deciding to engage, or not, in a partnered sexual interaction, to demonstrate an understanding of mutual consent, and chose socially appropriate times and places to engage in sexual behaviors. Finally, he or she should be able to perceive and respond to the vocal and non-vocal signals of the feelings of his or her partner, specifically the desire to continue or discontinue the interaction (28).

Assessment of the ability to give informed consent can comprise asking the individual questions to determine what information they can report that addresses rationality, voluntariness, and knowledge. For example, a mini-mental status exam, which assesses cognitive ability, including orientation to person, place, and time, attention, and recall (30) can help address rationality; asking where babies come from or how a woman becomes pregnant can help address knowledge; and asking the individual what they can say to someone who asks for undesired sexual acts can help address voluntariness. Consent assessments need not be vocal; they can be administered via picture symbols, sign language, or gestures, and should always be completed using the method of communication with which the individual is most fluent.

Assessment of capacity for consent can be done systematically with an established tool, such as the Tool For The Assessment Of Levels Of Knowledge Sexuality And Consent (TALK-SC). The TALK-SC was designed as a pre-post test for people with IDD who receive sexuality education and as a tool to use as part of the

assessment of capacity to consent and has questions that require a verbal (spoken, written, signed, etc.) response, addressing the areas of knowledge, rationality, and voluntariness (31). While the tool is easily accessible and might be administered as a pre-test by any clinician who plans to provide sexuality education, those with some training in human sexuality would be best equipped to carry out an assessment. In fact, the authors of the tool state that '[p]ost assessment should only be done by a trained sex educator or clinician [and, when used to assess consent, the tool] [w]ill be used in conjunction with a second interview. This interview may only be done by those trained in the area of sexuality for education or consultation' (31, p.2).

Training in sexuality

Sexuality education is best left to sexuality educators or sex therapists with certification from The American Association of Sexuality Educators, Counselors and Therapists (AASECT), Our Whole Lives (OWL), Planned Parenthood, or equivalent. These certifications are often as comprehensive as those pursued in other clinical licenses and certifications, including content area and supervision requirements. While many clinicians know and can access to good information about human sexuality, certified sexuality educators are trained in and adhere to specific ethical guidelines, including restriction on genital touch and may therefore have more information and resources available. Certainly, only those with specific expertise in human sexuality should carry out interventions that address displays of inappropriate sexual behavior (32).

However there are extremely few clinicians who work with people with IDD and who have additional certification in sexuality education or sex therapy, which can limit

access to assistance. Before seeking out and involving one of the few clinicians with dual expertise, there are a few things that other clinicians, with appropriate training, can do.

1. Check medication side effects. Most antidepressants, atypical and traditional antipsychotics, blood pressure medications, and some anti-anxiety medications can cause a variety of sexual side effects, including erectile dysfunction, ejaculation disorder, and priapism (persistent erection) in males, and inadequate lubrication and anorgasmia in women (33).

2. Consider that interventions that are used are least restrictive, meaning that they are not restricting access to time in the privacy of the bedroom or otherwise preventing socially appropriate means of sexual behavior.

Appropriate sexual expression is generally considered to be a human right, although this varies by State and national jurisdiction and, at times, by culture. However, seeing sexual expression as a human right suggests that people have the right to express their sexuality and appropriate sexual behavior, within the context of the law, in other words, sexual behavior that does not happen in a public place and in which all parties are able to consent to the specific sexual act in which they engage (16). Therefore, restriction with regards to finding a suitable sexual partner or to time in a private, unsupervised location in which to engage in sexual activities might be a violation of these human rights (9, 22). Access to legal pornographic materials and sex toys is also a right for those over the age of 18, in geographic areas that permit them. However, providing pornography or sex toys to someone under the age of 18 is illegal in most countries, and of course this also applies to children with disabilities. Likewise, access to clothing items worn for

enhancement of sexual pleasure, or as personal choice (i.e., a male who likes to wear women's dresses) should be the individual's right and should not be restricted unreasonably. Restricting access to any of these rights is technically a human rights violation. However, instances or policies in which these rights are restricted are not uncommon, especially in residential care for persons with disabilities. The clinician's role in this can be to advocate for the individual's rights.

While at times a seemingly logical course of action, restriction of community access to prevent sexual behavior of someone who has no history of sexual offending is not warranted. For individuals who have history of sexual offending, restriction of community access might still be unwarranted depending on circumstances. Certainly any adjudicated restrictions to areas of the community have to be observed, but other community access should still occur, with added supervision (e.g., 1:1, line of sight) to ensure safety of the individual and those in the community.

Restriction of unsupervised time alone is also potentially problematic. Some individuals have '24-7 line of sight' supervision requirements in their individualized treatment plans for various safety reasons, including prevention of self-injury or elopement from supervised environments. However, many of these individuals are allowed to toilet, bathe, and dress without direct, immediate supervision; i.e., they are allowed to close the door for these activities. These individuals should be allowed time to masturbate with their bedroom doors closed. If needed, staff should remove potentially dangerous items with which the individual can self-injure to ensure safety, before allowing closed-door time. Safety cameras and alarms can also be installed in areas that

will alert staff to the individual leaving the premises, but not violate his or her privacy. Here, too, the role of the clinician may best be advocacy on behalf of the client.

Intrusiveness of assessment

There are times when a team asks a behavior clinician to address a sexually inappropriate behavior, such as public masturbation (34), masturbation with harmful or otherwise inappropriate items (34, 35), sexual touching of others without consent, etc. To do so, the clinician must first determine why the behavior is inappropriate. For example, many behaviours that are inappropriate in a public location are permissible in private spaces? What is the frequency of the behavior and is it such that it interferes with activities of daily living? Does it cause injury to the individual or someone else? Is it illegal? (1, 34). Sexual behaviors that are legal, consensual, and do not cause distress to the individual and/or partner are likely not inappropriate. This includes, but is not limited to many paraphilias, masturbation in a private place that does not interfere with activities of daily living, and intercourse with a consenting partner. Similarly, preoccupations and obsessions associated with autism spectrum disorder might, superficially appear to be paraphilias, but not lead to sexual arousal (36).

Next, the clinician must determine why the behavior occurs (34, 37). Some well-trained behavior clinicians could initiate a preliminary investigation, but while the topography suggests the reinforcer would be automatic reinforcement (32) the clinician must be cautious not to assume this and instead investigate other possible functions of the behaviour (34, 38, 39).

For example, Fyffe et al. (39) demonstrated that for their subject the function of ‘attempting to touch others in the area of the groin, buttocks, or breasts’ (p. 402) was gaining staff attention and not automatic reinforcement. Dozier et al. (38) conducted two functional analyses to assess an apparent foot fetish that interfered with daily living: one in which they manipulated the antecedent, i.e., the type of footwear to which the individual was exposed, holding the gender of the wearer of the footwear constant; the other in which they manipulated the context of the footwear (i.e., male and female in similar footwear, shoes alone, bare feet). These analyses confirmed that the behavior was occasioned by access to female feet (bare or in sandals) and not by any other foot-related stimuli. Stein and Frugoli (40) demonstrated that lewd comments and sexualized behavior directed at female staff, by an 8-year-old with Down Syndrome, resulted in escape from non-preferred female staff and access to preferred male staff.

A Board Certified Behavior Analyst (BCBA) with explicit and extensive training in conducting functional analyses might be needed to complete functional analyses for problem behavior. They must consider the appropriateness due to frequency and intensity of the behavior (32), and the legality and ethics of conducting a functional analysis when the behavior has a sexual topography and the subjects is an individual with IDD. When completing a functional analysis (37), environmental stimuli are arranged such that the target behavior is evoked. This can be a potential legal and ethical problem with respect to sexual behaviors in a number of ways:

- Evoking sexual behavior in a minor is unethical, even in the context of assessment for intervention;

- Similarly, evoking sexual behavior in a non-consenting adult is illegal even for the purpose of intervention;
- By definition of the functional analysis, sexual behavior would have to be observed and thus, would not occur in an appropriately private environment.

In the situation in which determination of function for a behavior with a sexual topography is necessary, BCBA's should consider alternate means of functional assessment, such as structural analysis (41), precursor analysis (42), brief functional analysis (43), and single-trial (44, 45.).

Clinicians must also consider that while sexual behavior has operant properties and is subject to behavioral interventions (32), it is inherently more complex than much of other operant behavior given interactions of hormones, possible medication side effects, social interaction, possible social positive reinforcement, and interaction with media depictions of sexuality combined with vicarious reinforcement, just to name a few. This complexity underscores the importance of consultation with those with education, training, and expertise in sexuality before implementing interventions.

Intrusiveness of interventions

There is general consensus that certain skills (e.g., masturbation, menstrual hygiene) may need to be taught to persons with IDD (34, 46, 47). The key question is of course, who should provide this instruction. However, this is often not clearly established in laws and regulations and therefore there is the danger of accusations of inappropriate behavior, both for staff and for families (32). Clarity in regulations is essential to avoid such concerns and possibly inefficient service delivery due to fear of overstepping

boundaries. However, it remains to be essential and ethical course to ensure that appropriate sexuality skills are taught to persons with IDD to reduce likelihood of injury to self (35) or others or legal implications of engaging in sexual behavior in a public place (25).

When specific instruction in masturbation is needed, teams should consider using synthetic models (48), picture schedules, and video models. Direct masturbation instruction with physical contact between the instructor and learner is not feasible as it increases the risks of abuse, possibly via the instructor or via generalization for the learner, i.e., they may learn that it is acceptable for someone with whom they do not have an intimate relationship is touching their genitals. Additionally, by providing direct instruction of masturbation, the student also learns that being observed during masturbation is acceptable. Thus, direct instruction violates rules of privacy and rules of touch (D. Hingsburger, personal communication, August 1, 2013).

Medical interventions should be assessed for potential sexual side-effects such as anorgasmia and erectile dysfunction. Often, if there is a medication that has these kinds of side-effects, the prescribing professional should seek a dosage reduction or cross-titration to another medication. Second, especially for males, giving a lubricant (and possibly instructions on use vocally or via picture schedule) can yield success and increased sexual pleasure and decreasing the likelihood of friction-induced injury (49).

In conclusion, sexual expression and experiences are a human right for everyone, and of course, this includes individuals with disabilities. However, it can be difficult to assess if a person with IDD has the capacity to give informed consent to partnered sexual activities

and therefore, staff may err on the side of caution to prevent abuse or exploitation. While protection is obviously imperative, it is also important to allow as much personal freedom as possible and safe. Seeking sexual gratification on their own is less likely to include vulnerability but some individuals may still need protection (i.e., in cases of self injury) and education (i.e., in cases of public masturbation). Professionals who work in the area of sexuality education require training and certification by approved professional bodies.

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