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Promoting sexuality across the life span for individuals with intellectual and developmental disabilities

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No group in this country faces the sort of sexual and reproductive restrictions disabled people do: we are frequently prevented from marrying, bearing and/or rearing children, learning about sexuality, having sexual relationships and having access to sexual literature ... [sexual] confusion arises as a consequence of society forcing us to internalize the notion that we are sexually inferior. This conspiracy, which society manufactures by way of discriminatory social policies which lead to our sexual subjugation, is keeping us in a state of sexual self-hate. I believe that this is done tacitly to keep us from doing the thing that poses an overwhelming threat to our disability-phobic society: taking their sons and daughters as sexual and

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life partners, bearing their grandchildren. If I sound full of rage to you, you're reading me correctly, I am outraged.

—Barbara Faye Waxman, 1991, p. 85–6 [1]

Sexuality is an integral part of the emotional, ethical, physical, psychological, social, and spiritual selves that makes us human [2,3]. As a central component to the sense of liking or disliking oneself and society, sexuality plays a major role in an individual's overall self-identity. Developing a healthy sexual identity requires the opportunities to make decisions to control one's life and build relationships with others. To engage in fulfilling sexual relationships, people must experience a range of feelings and emotions, develop a sense of self, and feel safe within their environment [4]. Although sexuality is an intricate part of socialization for all persons, promoting sexuality among individuals with intellectual and developmental disabilities (I/DD) across the life span is especially critical, because they have been systematically and routinely denied opportunities to develop and express their sexuality.

Sexuality involves how people see themselves as well as how others see them. Children, adolescents, and adults with I/DD are frequently seen as asexual beings at one end of the spectrum and as sexual deviants at the opposite end. Although many laud the advances of "mainstreaming," "normalization," and societal integration of individuals with I/DD, sexuality and sexual expression continue to be controversial and highly charged [5]. For individuals with I/DD, having the freedom and opportunity to develop a strong sexual identity and engage in sexual behavior may be a litmus test as to whether they have truly gained their civil rights as human beings.

This article reviews the structural and attitudinal barriers that prevent individuals with I/DD from developing and perceiving themselves as sexual beings. The philosophical underpinnings that have previously guided sex education programs will be examined, along with the paradigm shifts that are advancing ways to promote sexuality and sexual identity among individuals with I/DD. The article also reviews literature regarding the lives of individuals with I/DD and current sexuality education in relation to particular content areas for sexuality education. Finally, the discussion will illuminate strategies to teach advocacy skills and increase knowledge regarding sexuality for individuals with I/DD.

Barriers to sexuality development

Structural barriers

Many structural barriers, such as organizational and institutional policies, exist in schools and community-based and institutional residential and work-site settings that prevent sexual expression for individuals with

I/DD. For children with disabilities, social isolation and parental overprotection may inhibit their development as sexual and social beings [6]. Although individuals with I/DD have opportunities to network with others in their schools and their places of employment, these settings are frequently viewed at a functional level rather than places that afford individuals the occasion to form meaningful personal relationships with others [7]. In our experience, children and adolescents in mainstreamed school settings may have little contact with other individuals whom they could expect to form more intimate relationships, including friendships and partnered-type relationships. For children and adolescents in segregated settings, they may be denied the opportunity to form intimate relationships and enjoy little or no time to see or visit with friends outside of school settings. Adults with I/DD living apart from their family in the community frequently have their living arrangement chosen and controlled by an agency or guardian. This process often results in people sharing a room with someone they do not like or being denied the opportunity to see friends or ''boyfriendsgirlfriends'' in other locations outside of their workplace. Additionally, families or agencies may intentionally try to keep them from participating in intimate relationships. These barriers to sexuality are often successful in denying individuals with I/DD their right to sexual expression.

Case example

Anne and David are clients of a workshop. They attend a money management class at the workshop. At one of the classes Anne says she wants to learn how to manage money so that she and David can pay for a wedding. She says she wants a band and champagne at the wedding because champagne is her favorite drink. Anne says she and David want to honeymoon in Hawaii and that she wants a see-through nightgown because David thinks she is pretty. David agrees that Anne is pretty. Both Anne and David live in group homes. They are able to call each other, and occasionally see each other on the weekend when the workshop has weekend events such as trips to the zoo. Mostly they see each other at work. A staff person who drives Anne home at the end of the day comes into the class at the end of this discussion. She mentions to the director of the class that she does not know how this wedding will take place. Both Anne and David have siblings who are their guardians and it is unlikely that the siblings would agree to this. In addition, the agencies that provide housing for Anne and David have no policy for dual-sex housing.

Attitudinal barriers

Parents, staff, and professionals often have attitudes and practices that deny individuals with I/DD the right to healthy sexual expression. Parents of adolescents with I/DD are less likely to allow their children to associate with peers outside of school hours than are parents of their nondisabled peers [8].

Individuals with I/DD are likely to have limited circles of friends and social contacts [9]. In a study of social support networks among adults with I/DD who were living at home, informants reported that over 40% of the adults had no friends and over half of the reported members of the social support networks of the adults with I/DD were members of the mothers' social support networks [9].

Health professionals also have many attitudes that impede the development of healthy sexuality for their clients. In the nursing profession, Wall-Haas [10] determined that most nurses handle sexuality by avoidance because they are uncomfortable discussing the subject matter. Research has documented difficulties by nurses in accepting and dealing with the sexuality of homosexuals and other client groups [11,12], and preparing nurses to be comfortable with addressing the sexuality concerns of clients from many backgrounds is identified as a serious concern in nursing education [13].

Individuals with physical disabilities and individuals with I/DD often acquire sexual knowledge, experience, and feelings from different sources than do their nondisabled peers [14]. Although people in the general population receive their sex education from a variety of sources, including parents and friends, individuals with physical and I/DD are more likely to receive their knowledge only from formal educational programs and the media [14]. Furthermore, individuals with I/DD are much less likely to discuss their thoughts, feelings, and experiences with family and friends [14]. According to McCabe [14], "the whole topic of sexuality is less likely to be normalized, because it is not discussed" (p. 167). For persons with I/DD, attitudes of parents, teachers, and staff present significant barriers to developing a healthy sexual identity, which in turn serves to deny them of their humanity.

Sexuality as a human right

Historically, in the United States, individuals with I/DD have been portrayed as sexually threatening and requiring professional management and control [15]. During much of the twentieth century, extreme methods of social control were employed in the United States and Europe to reduce perceived threats to the social order from marginalized individuals [16]. Individuals stigmatized by disability status, gender, race, and socioeconomic status were the most vulnerable victims of practices aimed at improving social order and societal conditions. Although a variety of policies were enacted by policy makers, the institutionalization and compulsory sterilization of individuals with I/DD has had pervasive effects on suppressing the development of healthy sexuality. For persons with I/DD who were institutionalized, sterilization served as a means to ignore issues related to sexuality and sexual abuse [16]. Sex and rape became invisible for sterilized "patients" living in institutions.

The eugenics movement (the science of genetically improving the human race) was another crucial component that was used to control sexuality and

fertility among individuals with I/DD (especially women). While less prevalent today, sterilization of individuals with I/DD continues to be discussed and performed under the guise that it will prevent expressions of sexuality and reproduction, diminish the chances of sexual exploitation, or reduce the likelihood of acquiring sexually transmitted diseases at the onset of puberty [17]. Moreover, the attitudes and beliefs that supported these practices provided a foundation for many of the services that exist today and continue to marginalize people with I/DD [16]. Even in the late 1990s, Wolfe [5] reported that a majority of special education teachers and administrators thought that sterilization should be encouraged for individuals with I/DD.

The infantilization of adults with I/DD—that is, viewing these individuals as "childlike" and asexual—continues to provide a framework that excludes and isolates them from sexual expression [16]. While this belief is slowly dissipating, many existing policies that control and repress individuals with I/DD remain in effect at residential and work-site settings [16]. Persons with I/DD report having the same dreams and sexual desires as do their nondisabled peers. Nevertheless, they continue to be held to rigid standards of sexual morality and receive messages from families, professionals, and society that marriage, children, and an active sexual life are forbidden.

Case example

Carlos is an 11-year-old student with physical disabilities— including poor manual dexterity—and severe cognitive disabilities. Carlos is now experiencing erections and has made attempts to masturbate. Carlos' mother has reacted to this by making sure that his diaper is placed securely on Carlos and at times placing mitts on his hands. She has instructed the teachers and staff where Carlos goes to school to do the same.

By 1981, people with physical disabilities were viewing sexuality as a human rights issue and were advocating for their rights to obtain information, education, and training and to marry and have children [16]. Unfortunately, these beliefs have been slow to include persons with I/DD. Currently, people are acknowledging that the denial of sexuality for individuals with I/DD is a violation of human rights, and are recognizing that, with information, education and training, and opportunity, individuals with I/DD are capable of fulfilling sexual relationships.

Paradigm shifts promoting sexuality development

Understanding the philosophical underpinnings of sexuality development is important because it impacts individuals' perception of themselves. In a seminal article, Johnson and Johnson [19] outlined three approaches that have been used to develop sexuality among individuals with I/DD. One early philosophy that guided sex education was based on the belief that any form of sexuality expression should be eliminated. A second philosophy accepted

expressions of sexuality; however, proponents believed that control and responsibility should be emphasized, especially with respect to time and place. The third viewpoint suggested that sexuality and sexual gratification are major life resources and individuals with I/DD need to be taught. The Western New York Association for Sexuality and Disability expands this perspective to include the rights of individuals with I/DD to develop their potential in relation to sexuality. This organization—which represents educational, residential, vocational, and day programs serving individuals with I/DD—developed a philosophy statement that serves as a mission statement for promoting sexuality for persons with I/DD [18].

> In regard to the sexuality of persons with developmental disabilities, we hold that every person with special developmental needs has the right to achieve her/his potential on the continuum of maturity. Social and sexual development begins in infancy and continues throughout life. Persons with developmental disabilities are entitled to move toward social and sexual maturity and need related opportunities to develop friendships and relationships. (p. 287)

Promoting sexuality across the life span

Sexual lives of individuals with I/DD

Limited qualitative research among women with I/DD has documented that only a small minority of women reported positive experiences in their sexual lives [20]. In a qualitative study among sexually active women with I/DD, most of the women noted that they lacked control and choice as to what they wanted to do, with whom, when, and how [20]. They also predominantly experienced penetrative sex with a lack of sexual pleasure. High levels of sexual abuse were reported by many of the women. One disconcerting finding from McCarthy's research [20] was that the experiences of women who lived in community settings were essentially the same as those of women who lived or had lived in institutional settings [20]. The quality of the women's experiences was related to the nature of their relationships with men, the level of their self-esteem and assertiveness, and the availability of sex education and support.

Recent studies [14,20] demonstrated that people with I/DD, compared with their peers with physical disabilities, experienced lower levels of sexual knowledge and experience, more negative attitudes toward sex, and stronger sexual needs in all areas of sexuality. Moreover, compared with the general population without disabilities, people with physical disability demonstrated a similar trend. For women with I/DD, according to McCarthy [21], they often receive education about sex in the form of abuse. Unfortunately, because individuals are less likely to discuss their thoughts, feelings, and experiences with family and friends, educational efforts must be provided to individuals with I/DD. Further, parents and caregivers need to receive information on how to foster healthy sexuality among persons with I/DD.

Sexuality education programs across the life span

Similar to their nondisabled peers, individuals with I/DD must receive education and training around sexuality issues, beginning in infancy and extending throughout their life span. Learning to enjoy their sexuality requires the presence of several factors: developing a positive self-esteem, making choices, giving consent, receiving information, experiencing mutuality, experiencing pleasure, and having legal recourse if they are abused [21]. McCarthy [21] stressed that sexuality education must ensure that coercion, oppression, and guilt and shame are absent.

Although sexuality education programs have developed and been extended over the last 20 years, many of the programs taught to individuals with I/DD have focused on increasing knowledge, but not on developing positive attitudes toward sexuality [22,23]. To enhance sexuality as a positive life force, McCabe and Schreck [22] state that education should be broad based and help individuals with I/DD make informed choices. Based on the literature, a number of content areas for sexuality education for individuals with I/DD are recommended for teaching, including sex and sexuality, current relationships, body part identification, menstruation, pregnancy, childbirth and abortion, sexually transmitted diseases, masturbation, marriage, homosexuality, sexual interaction, dating and intimacy, and sexual abuse. Other authors and programs [18,24] have also suggested that sexuality education programs should have content on consent, self-esteem, attitudes and values, and sexual responsibility and privileges. Current literature [14,20] also notes that the voices of individuals with I/DD need to be heard and taken into account when developing sexuality education programs. Tables 1 through 6 list proposed content areas and detail how the content areas can be taught at different age levels. The following sections discuss literature regarding some of the proposed content areas.

Sex and sexuality

Individuals with I/DD have a human right to sexuality and sexual expression. Key to overall sexuality education is an education regarding basic human rights and the right to sexual expression. The sexuality of individuals with I/DD should be supported in ways that assist them to feel accepted, comfortable, and safe and in ways that do not compromise the rights or vulnerability of others [25]. Among individuals with I/DD, many differences exist in class, family, and racial and cultural backgrounds, and in the impact of the disability on their lives and the lives of those around them. No one means of sexual expression is right for everyone, but it should be understood that sexuality and sexual expression are important and basic human rights.

The sexual expression of individuals with I/DD is, at times, subjected to restrictions that are extreme. To prevent individuals with I/DD from engaging in sexual relations, caregivers have punished them through

Table 1
Content areas health education activities—infancy to 3 years of age

Content area	Health education actvities
Sex and sexuality	Teach parent(s)/caregiver(s) that curiosity about genitals is a part of normal development Instruct parent(s)/caregiver(s) to teach child: Certain body parts are private Behaviors that need to be done in private and what can be done in public (eg, pull down pants only in bathroom) Self-pleasuring is a normal part of self-exploration
Body part identification	Ask parent(s)/caregiver(s) if they are comfortable discussing correct names for body parts with their child Instruct parent(s)/caregiver(s) to begin teaching child the appropriate names of all body parts in play with the child
Sexual abuse	Ask parent(s)/caregiver(s) if: They are comfortable discussing stranger safety with their child Someone has hurt their son/daughter They are worried that someone is or may hurt their son/daughter Instruct parent(s)/caregiver(s) to: Teach child good touching versus bad touching Listen to their son/daughter when they try tell them something Evaluate child for signs and symptoms of abuse

beatings, to limit their access to social relationships [16]. Block [16] reported that a mother placed a hot hard-boiled egg in her daughter's vagina upon learning that she had been sexually active. These actions often result in long-term consequences on psychological well-being and sexuality.

If healthy sexuality is not promoted and supported, unhealthy and abusive forms of sexuality may prevail. The inability to develop healthy sexuality can lead to mental disorders such as anxiety, depression, and adjustment disorders, as well as impaired self-esteem [26]; and can put individuals at risk for sexual abuse and exploitation, AIDS and other STDs, and unplanned and unwanted pregnancies. Thus, the discussion and promotion of sexual expression and the basic human right to sexuality needs to be developed in childhood and continue across the life span to promote healthy sexual development.

Case example

George is a 22-year-old young man with Down syndrome who participates in a city-sponsored recreation program for individuals with disabilities. George reports to his mother that Dave, another individual in the program, asked him to touch his (Dave's) penis in the shower. Dave is both older and has less severe disabilities than does George. George's mother asked him if this interaction made him uncomfortable, which George indicated it did. George's mother worked with recreation staff to talk with Dave about appropriate behavior and also worked with staff about

Table 2
Content areas health education activities—3 to 5 years of age

Content area	Health education actvities
Sex and sexuality	Instruct parent(s)/caregiver(s) to: Answer child's questions truthfully and directly Discuss issues in language that the child understands
Body part identification	Instruct parent(s)/caregiver(s) to: Continue teaching child the correct names of all body parts that are visible with appropriate terms (eg, penis, vagina, breast) Use age-appropriate books to teach child names of body parts Avoid cute names that may confuse child Help child to differentiate between boys and girls
Sexual abuse	Continue asking parent(s)/caregiver(s) if they have any questions or concerns about sexual abuse and sexual abuse prevention Instruct parent(s)/caregiver(s) to: Identify signs of abuse Continue listening to their son/daughter when they try tell them something Ask child if: Anyone ever touched him/her in a way that he/she didn't like Anyone ever tried to hurt him/her Teach child: Concepts of stranger safety His/her body belongs to him/her He/she has a right to tell others not to touch his/her body if they do not want to be touched Evaluate child for signs and symptoms of abuse
Relationships	Instruct parent(s)/caregiver(s) to: Demonstrate qualities of healthy relationships, such as love, respect, communication, friendship, and affection between adults Teach about the different kinds of families that children have Concretely discuss various sexual orientations and other differences

developing policies for increased supervision in vulnerable areas such as showers.

Consent

Kennedy and Niederbuhl [27] identified basic knowledge of sexual behavior and its consequences and abilities to protect oneself as integral components in a person's ability to have sexual consent capacity. Steele and Cato [28] observed that skills such as interacting with peers, observing

Table 3
Content areas health education activities—5 to 8 years of age

Content area	Health education actvities
Sex and sexuality	Teach parent(s)/caregiver(s) that sexuality: Exists in children with disabilities Develops in children with disabilities Includes physical expressions of love, affection, and desires Consists of gender identity, friendships, self-esteem, and body image Encourage child to ask trusted adults questions about sex and sexuality Teach child basic health and safety, cleanliness, and hygiene Remind child that masturbation should be done in private
Body part identification/ Bodily changes	Instruct parent(s)/caregiver(s) to: Discuss information given to child at school Answer child's questions Continue teaching the correct names for all body parts using age-appropriate books Begin talking about the occurrence of changes during adolescence as questions arise Discuss menstruation as situation arises
Sexual abuse	Continue to ask child if he/she has been: Touched in a way that he/she didn't like Hurt by anyone Ask parent(s)/caregiver(s) if they have any concerns or questions Reinforce with child: Concepts of stranger safety His/her body belongs to him/her Good touching versus bad touching No one has a right to touch him/her without permission
Childbirth	Teach basic concepts of where babies come
Relationships	Demonstrate qualities of healthy relationships, such as love, respect, communication, friendship, and affection between adults Teach about the different kinds of families that children have
Sexually transmitted diseases (STDs)	Teach child: Basic information regarding STDs Concepts of avoiding contact with blood and other body fluids

appropriate public and private activity limits, and establishing meaningful relationships are an important subset of social interaction skills. Children and adults with I/DD frequently have problems determining safe, effective, and appropriate sociosexual interactions.

Wolfe [5] interviewed teachers and administrators regarding the sexual practices and relationships of individuals with I/DD. The second most

Table 4
Content areas health education activities—8 to 11 years of age

Content area	Health education actvities
Sex and sexuality	Teach parent(s)/caregiver(s) and child that information is power and lack of information puts children at risk for abuse Instruct parent(s)/caregiver(s) and child about: Physical and emotional changes that occur during puberty Menses for girls and "wet dreams" for boys The normalcy of sexual feelings Teach child to discuss sexual issues with appropriate family members or other identified adults Teach parent(s)/caregiver(s) the need to: Provide accurate information about sex, sexual relationships, reproduction, sexually transmitted diseases (STDs), and sex abuse Discuss information that child learned at school Provide clarification as needed
Body part identification/ bodily changes	Teach child to continue discussing sexual issues with appropriate family members or other identified adults Instruct parent(s)/caregiver(s) to: Continue talking about the occurrence of changes during adolescence Discuss menstruation as situation arises
Sexual abuse	Teach parent(s)/caregiver(s) and child how to avoid sexual abuse and the need to report any sexual abuse or exploitation
Self-esteem	Teach child: To focus on his/her strengths and not on his/her weaknesses That all people have some things that make them different from others
Pregnancy, contraceptives, and STDs	Instruct parent(s)/caregiver(s) and child about: Safe sex and contraception The consequences related to decision making in that unprotected sex may lead to pregnancy and STDs Basic information regarding STDs Reinforce concepts of avoiding contact with blood and other body fluids
Relationships, dating, and intimacy	Reinforce teaching about families and acceptance of various sexual orientations and other differences Discuss dating and relationship issues

frequently cited problem was inability to distinguish between consenting and nonconsenting partners. One aspect of consent is an individual's ability to say "yes" or "no" to a sexual encounter. In her seminal work, McCarthy [20] interviewed 17 women with I/DD and noted that most of the women

Table 5
Content areas health education activities—12 to 18 years of age

Content area	Health education actvities
Sex and sexuality	Ask adolescent if he/she has concerns about sex or sexuality Give adolescent permission to discuss issues regarding safe sex and contraception with a parent or other identified adult, such as a nurse or physician Teach adolescent: How to say "no" to sex Delay having sex until he/she is mature enough to handle responsibilities
Body part identification/ bodily changes	Reinforce with adolescent girls: If sexually active, the need, for annual pelvic exam and Pap smear sexuality transmitted disease (STD) screening The need for monthly breast self-exam Reinforce with adolescent males testicular self-exam
Sexual abuse	Continue teaching strategies to avoid sexual abuse and the need to report any sexual abuse or exploitation Reinforce teaching regarding sexual exploitation and the adolescent's right to say "no" to unwanted sex
Self-esteem	Teach adolescent: Our feelings about ourselves influence the activities that we engage in and these activities affect maintain, improve, or harm our health To engage in sex when he/she is able to handle responsibilities
Pregnancy, contraceptives, abortion, and STDs	Ask adolescent if he/she: Is having sex Uses contraceptives Has ever been pregnant Has had an STD Has ever had sex with anyone who had an STD Discuss with adolescent in a frank, open, nonthreatening manner: Information about contraception, safe sex, pregnancy, abortion, and STDs Basic childcare and development, as well as the responsibilities of being a parent If he/she is planning to have a baby, discuss taking a daily folic acid supplement before and during pregnancy Information about STDs
Relationships, dating, intimacy, and marriage	Ask adolescent if he/she: Is having sex Is dating Dates more than one person Teach adolescent about: Peer pressure and resisting when necessary Importance of interpersonal relationships Importance of communication in an adult relationship including the ability to discuss sexual behaviors with that person Reinforce the values of the family, culture, or religion that the adolescent is a part of, and help them to define their own values

Table 6
Content areas health education activities—adults

Content area	Health education actvities
Sex and sexuality	Ask adult if he/she has concerns about sex or sexuality Provide opportunity for adult to discuss issues regarding safe sex and contraception with appropriate individuals
Body part identification/ bodily changes	Reinforce with women the need for: Pelvic exam, Pap smear, and sexually transmitted disease (STD) screening, if necessary Breast self-exam Reinforce with men the need for testicular self-exam
Sexual abuse	Continue teaching strategies to avoid sexual abuse and the need to report any sexual abuse or exploitation Reinforce teaching regarding sexual exploitation and the adult's right to say "no" to unwanted sex
Self-esteem	Teach adult: Our feelings about ourselves influence the activities that we engage in and these activities affect, maintain, improve, or harm our health We have high self-esteem when we feel competent and lovable We have low self-esteem, when we feel incompetent and unloveable That with high self-esteem, people generally have good relationships People with low self-esteem may be overally influenced by others instead of making their own decisions
Pregnancy, contraceptives, abortion, and STDs	Ask adult if he/she: Needs to practice safer sex (why or why not) Negotiates safe sex with his/her partners Is planning on becoming pregnant Uses contraceptives Has an STD, herpes, HIV, hepatitis C, or human papilloma virus (HPV) Ever had sex with anyone who had an STD If adult has an STD, ask if he/she tells new sexual partners about these STDs If planning to become pregnant, discuss the need to: Eat a balanced diet of healthy foods Engage in regular physical activity Avoid tobacco, alcohol, and drugs before and during pregnancy
Relationships, dating, intimacy, and marriage	Discuss with adult: Importance of interpersonal relationships Importance of communication in an adult relationship including the ability to discuss sexual behaviors with that person Concerns about dating

with sexual experience noted many encounters in which they had not given full consent.

Issues of consent concerning individuals with I/DD are not easy for professionals. Parker and Abramson [29] found that the perceived ability of women with I/DD to consent affected the assessment of professionals—including law enforcement officers, licensing personnel, and sex educators/counselors—to utilize legally relevant criteria when assessing sexual abuse of individuals with I/DD. The authors advocated for the development of explicit standardized criteria to use when assessing consent if possible abuse is an issue.

Case example

Robert, a 16-year-old high school student, spends part of his day in regular classrooms and part of the day in a special education classroom. Despite being in regular classrooms part of the day, Robert has little interaction with those classmates outside class hours. Robert has expressed a desire to date and have sex. On a few occasions, Robert fondled young women on the school bus coming to school. The young women whom he fondled were all young women he knew from his special education class. After a suspension from school and discussions between school staff, Robert, and his parents, this behavior stopped. On a school outing, however, Robert followed a young woman from his class into a washroom and assaulted and attempted to rape her. Police were called and charges filed. Charges were later dropped due to concerns that the young woman would not be able to testify. However, the police and courts worked with the school to place Robert in a restricted special education school for students with behavioral problems.

The literature suggests that a variety of issues around consent including self-esteem; determining safe, effective, and appropriate sociosexual interaction, the ability to identify what consent means; and how to give consent or deny it need to be addressed in sexuality education. Education for individuals with I/DD regarding issues of consent can begin in childhood, in ways that are age appropriate and take into account particular learning needs. For instance, one can teach toddlers about good touching versus bad touching and teach older children about not allowing anyone to touch them without permission (see Table 2).

Sexual abuse and exploitation

Individuals with I/DD are more susceptible to sexual abuse than is the general population [30,31]. Individuals with I/DD may have experienced incest, abuse by caregivers or persons in authority, and abuse from other individuals with I/DD. Aspects of their lives and lack of sexual knowledge and experience may put them at risk for abuse. Betz [6] proposed that adolescents with a disability are at greater risk of being victimized and

suffering long-term consequences of low self-esteem due to their belief that they are bad and somehow deserve to be exploited because they have mental retardation or developmentally disabilities. For adults with I/DD, employment and housing in the community mean that they may be in contact with some people in the community who may abuse and exploit them [32]. Aylott [33] noted several features of the lives of individuals with I/DD that make them vulnerable to sexual abuse and exploitation. The features include a culture of obeisance and compliance, many different caretakers, the need for help with personal body care, an inability to defend and speak up for themselves, and a lack of sex education and knowledge of normal social and sexual limits. McCabe et al [34] interviewed a group of individuals with mild I/DD and a group of college students regarding their sexual knowledge and experiences. The individuals with mild I/DD had lower levels of sexual knowledge and experience, were more likely to believe that others had the right to decide about their sexual experiences, and were less negative about sexual abuse than were the college students [34].

McCarthy and Thompson [35] looked at the prevalence of sexual abuse among individuals with I/DD in the United Kingdom and found that 61% of women and 25% of men were likely to be victims of sexual abuse. A qualitative study in the United States [36] that studied women with I/DD found that 79% were likely to be victims of sexual abuse. In interviews with 17 women with I/DD regarding their sexual experiences and practices, McCarthy [20] found that 14 of 17 indicated experiences that they perceived as sexually abusive, including experiences of sexual abuse from men with I/DD.

The issue of abuse among persons with I/DD, including abuses by men with I/DD of women with I/DD, cannot be ignored. Brown and Stien [37] found "peer abuse" to be a problem—one that is inadequately addressed by service agencies. Klein, Wawrok, and Fegert [38] interviewed women and young girls with I/DD living in 26 residential institutions in Germany and found nearly one third of the subjects reported problems of sexualized violence within those institutions.

One aim of sexuality education is to provide individuals with I/DD the tools to avoid and defend themselves from abuse. Education also needs to target parents, staff, and agencies regarding ways to prevent sexual abuse. Initial attempts have been made to develop sexual abuse prevention programs among individuals with I/DD [21,39,40] and to address the knowledge needs of staff in preventing sexual abuse [41,42]. Teaching for sexual abuse prevention can begin in childhood. Children can be taught to inform parents or other trusted adults about unwanted touching (see Tables 2–5).

Self-esteem

In the general population, sexual satisfaction is linked to self-esteem [43]. Although there is no known literature with regard to the impact of sexuality

on the self-esteem of individuals with I/DD, there are indications in the literature that individuals with physical disabilities perceive many social and sexual barriers related to their physical impairments, and that this leads to increased feelings of negativity about themselves, including a belief that they are less sexually desirable [44].

Little literature exists on the impact of barriers to positive sexuality on self-esteem and the impact of self-esteem on sexual abuse and exploitation of individuals with I/DD. Currently available sexuality education programs for individuals with I/DD, however, generally contain components on increasing self-esteem. Parents, teachers, and others can start at infancy and continue across the life span to foster self-esteem around sexuality that is integral to the person's larger sense of self-esteem.

Body part identification

The literature regarding the knowledge and education of individuals with I/DD in body part identification is extremely limited and is contradictory. McCabe and Cummins [45] found no significant differences in body part identification between a group of college students and a group of individuals with mild I/DD. In contrast, in interviews with 17 I/DD women, McCarthy [20] found that all 17 had had sexual experience with at least one other person; however, only 2 of the 17 knew what or where the clitoris was. As well, none of the women had experienced orgasm and 14 of the 17 indicated that sex hurt them [20]. Interestingly, Tepper [46] noted that sexual pleasure is absent in most educational discussions regarding sexuality and disability. The paucity of data indicates the need for further research regarding knowledge and the importance of knowledge of body parts—especially body parts involved in sexual pleasure—for individuals with I/DD. As with self-esteem, teaching about body parts and assisting individuals with I/DD to feel comfortable with their own bodies can begin in early childhood. From infancy, children should be taught the correct names of body parts; cute names can be confusing (see Tables 1, 2). Parents, teachers, and nurses can build upon the basic knowledge to assist individuals to understand healthy sexual expression.

Masturbation

Masturbation is a normal part of sexuality. For example, all infants, whether disabled or able bodied, explore their own bodies and discover that touching and stroking the genital area causes a sense of pleasure. The topic of masturbation in the general population is controversial. The sensitivity of this topic was noted when former Surgeon General Jocelyn Elders resigned her position as Surgeon General in December 1994 following her comments regarding masturbation being a part of normal sexuality that should be taught.

Kaeser [47] surveyed agencies that provide services to individuals with severe and profound I/DD with regard to the sexual practices of their clients. Twenty-three agencies responded and all indicated that clients had masturbation behaviors. Twenty-two of the 23 agencies indicated that clients either did not reach orgasm or had difficulty doing so when masturbating. Approximate percentages of persons with difficulty were given as 1% to 52% and 17 agencies reported clients who became frustrated after such an episode. The author noted the potential need for therapeutic treatment programs that would provide education in techniques to overcome difficulties with masturbation [47]. Some individuals believe that nurses should be involved in masturbation training for individuals with I/DD and that those nurses should be protected from any attempts at censure or loss of licensure [48].

Issues surrounding masturbation are critical components of sexuality education programs for individuals with ID and their families, staff, and caregivers. If parents or staff react too strongly to masturbation or condemn this type of exploration in childhood or at any age, then children receive a negative message regarding their sexuality [49]. Beginning in childhood, individuals with I/DD need assistance in feeling comfortable with their sexuality.

Sexual interaction, dating, and intimacy

Only 2 of the 17 women in McCarthy's study [20], all of whom were sexually active, were generally positive about their experiences. Most said that the men chose them as partners, initiated the sexual experiences, and wanted the sex more than they did. Their most preferred sexual interaction was cuddling and hugging, and none of the 17 women reported experiencing orgasm. Further, all women in this study who had lived in institutions had received payment for sex (usually money or cigarettes), whereas none of the women in community-based living arrangements had received what they perceived as payment for sex [20]. Results from McCarthy's study indicated the need for education regarding a range of issues related to sexual interaction and intimacy.

Pregnancy, childbirth, and parenting

Individuals with I/DD can and do become successful parents. McCabe and Cummins [45] interviewed individuals with mild I/DD and college students regarding their sexuality and found that the individuals with I/DD had a higher percentage of pregnancy. Unlike for any other group, however, disability status is sufficient justification in some states to terminate the parental rights of individuals with I/DD [50]. Opposition to parenting by persons with I/DD was historically rooted in the concern for transmitting faulty genetic material on to their children. Today, concern has shifted to issues related to the ability of persons with I/DD to provide appropriate

parenting, based on the perceptions that their children are at greater risk for child abuse or neglect. Although research among parents with I/DD is limited, mothers with I/DD are significantly less likely to abuse their children than are their nondisabled peers [51], and neglect is frequently related to inadequate training and supports [52]. The literature indicates the need for education regarding contraception and parenting with this population.

Sexually transmitted disease

Individuals with I/DD may be at increased risk of sexually transmitted diseases including AIDS. In the same study referred to previously, McCabe and Cummins [45] found that individuals with mild I/DD had a higher percentage of experience with sexually transmitted disease than did a group of college students, indicating the need for education on prevention of sexually transmitted diseases. McGillivray [53] conducted a study that assessed the knowledge levels and risks of contracting HIV in a group of adults with mild I/DD and a group of undergraduate college students. The adults with I/DD had less knowledge of HIV and the means of prevention, less confidence in their ability to use safe-sex practices, and were more likely to choose unsafe sexual solutions when presented with hypothetical risk situations.

Sexual orientation

Determining sexual preference begins in childhood and is part of developing a sexual identity, but individuals with I/DD may not have the same opportunities as do others to develop their sexual identities. As adults, many individuals with I/DD live in sex-segregated housing and the only outlet for sexual relations that they have may be with same-sex peers. Same-sex relationships for individuals with I/DD may not be due to choice or development of sexual identity, but rather opportunity [54–56]. McCabe and Cummins [38] found that only about half of the individuals with I/DD in their study had positive views toward homosexuality. The literature indicates the need for sexuality education for individuals with I/DD to discuss this topic.

Including the voices of individuals with I/DD

Intrinsic to sexuality education and training is the inclusion of the voices of individuals with I/DD. Although some literature does exist, a paucity of information is available to provide an understanding as to how men and women feel about their sexuality and what they want in terms of intimate relationships [57]. Increased understanding of the lives and needs of individuals with I/DD would greatly assist in developing sexuality education programs and improving organizational policies and professional standards.

Implementing sexuality education programs

Sexuality education programs need to be directed at the needs of the individuals involved. The content and the teaching methods are important [28,56]. The specific needs of the population should help to determine the content of the programs [22,28,56]. Low literacy and other learning deficits are common for persons with I/DD; thus, teaching methods need to take their abilities into account. Although the need for alternative learning methods is recognized, little research exists on the effectiveness of various methods [14,58,59].

Campbell and Huff [60] highlight the need for educators to be aware of the learning needs of the learner. Sexuality information needs to be presented concretely, simply, matter of factly, and repeatedly. All information needs to be presented in language that the learner is able to understand easily [61]. Age and learning abilities need to be considered in sexuality teaching with children, adolescents, and adults with I/DD. Multiple teaching methods can be used and the type of disability can be considered when doing sexuality education. For example, children with a combination of physical disabilities and I/DD may have different teaching needs than do children with I/DD and no physical disabilities. A child with autism—who has more difficulty with social interactions—may benefit more from teaching the concepts of privacy and appropriate social behaviors than from a lengthy discussion of sex itself. Because individuals with Williams syndrome often have extreme uninhibited behaviors and hypersociability [62], they may need reinforced teaching on engaging in only wanted sexual opportunities and avoiding sexual abuse. Special considerations may need to be made for those children who have sensory impairments as well as developmental disability [28]. An interpreter familiar with medical terms would be appropriate for children with a hearing impairment or for children who are unable to communicate verbally. Braille materials and anatomically correct dolls would be appropriate for classes with blind or visually impaired participants and others who may need more concrete methods of learning.

Kupper [63] points out that "it's important to realize that discussing sexuality will not create sexual feelings in young people. Those feelings are already there, because sexuality is a part of each human throughout the entire life cycle" (p. 9). Popovich [64] calls for recognition that all children are sexual beings and to anticipate the threats to the self-concept and self-esteem of each child that may begin in infancy. Sexuality teaching should begin in infancy and be based on developmental level. A number of resources are available to parents, teachers, and staff that give useful information on how to give information to infants and children with I/DD and support healthy sexuality beginning in early childhood. Resources such as *Sexuality: Your Sons And Daughters ith Intellectual Disabilities* [65], *The Guidelines For Comprehensive Sexuality Education, Kindergarten—12th Grade* [66], and *Sexuality and the Person with Spina Bifida* [67] provide some

excellent guidelines for providing sexuality education for children with developmental disabilities. They also list information and assistance that is available to make sexuality education more comfortable for those who teach. Other resources are available from Planned Parenthood [68], the Sexuality Information and Education Council of the United States (SIECUS) [69], and the National Information Center for Children and Youth with Disabilities [3]. Tables 1 through 6 compile suggestions from these sources regarding how a parent or other support persons can teach and support healthy sexuality beginning in early childhood through adulthood, and organizes the suggestions by content areas.

Nursing implications

Promoting and developing sexuality education for individuals with I/DD has practice, education, and research implications for nursing. Nurses can be involved in sexuality education for individuals with I/DD in a variety of settings, including schools, churches, health clinics, and early intervention programs. Sexuality education should begin in infancy and continue across the life span and account for the particular needs and developmental level of the individuals involved. For individuals with I/DD, sexuality education needs to address their lives and experiences. Teaching skills such as interacting with peers, observing appropriate public and private activity limits, and establishing relationships is an important subset of sexuality education.

Sexuality education for teachers and school, agency, and workplace staff is also important to increase comfort in discussion sexuality. Nurses can work to reduce or eliminate organizational and attitudinal barriers that restrict the development of healthy sexuality of individuals with I/DD. Schools, community agencies, and work sites can develop organizational and institutional policies that do not restrict healthy sexual expression an important area. Furthermore, nurses need training to assist them in taking on the role of sexuality educators. Education can begin with nursing students in basic nursing education and graduate and continuing education programs. To enhance the educational experience, programs need to provide more opportunities for nurses to interact with individuals with I/DD across the life span, which will increase the level of comfort among nurses who engage in practice with individuals in a variety of settings.

Nursing practice standards related to sexuality education, prevention of sexual abuse and exploitation, and promotion of sexual development and healthy sexual expression are needed. Nurse researchers can make positive contributions to knowledge and practice in sexuality education for individuals with I/DD. The literature indicates a number of areas in which further research is needed. Research regarding sexuality for particular disabilities such as traumatic brain injury and spina bifida are ongoing, but research about sexuality for persons with other disabilities such as autism, fragile X, and Down syndrome is needed. Another area for research would

be alternative lifestyles and sexual orientation in persons with disabilities. Assessing the long-term effect of sexuality teaching on self-concept, identity development, and sexual behavior is important. Another area in need of development and research is the establishment of criteria for sexual consent at its most basic level. This would also enable practitioners and the judicial system to have improved legal definitions of sexual consent capacity.

Summary

Sexuality is a human right that is important to all individuals regardless of age, gender, orientation, or developmental level. Sexuality is closely related to a person's self-concept and self-esteem. Individuals with I/DD have a right to sexuality and sexual expression. Nevertheless, persons with I/DD have historically been denied this right, and many structural and attitudinal barriers exist to their healthy sexuality. Paradigms in sexuality education have shifted toward recognizing sexuality as a human right, a major life resource, and an integral part of one's makeup. To broadly address the development of healthy sexuality for individuals with I/DD, the issue needs to be normalized, not ignored or avoided; which means involving parents, staff, and professionals. Working with parents to overcome parental overprotection and social isolation is critical. Parents can provide opportunities for their sons and daughters to network and form meaningful personal relationships, with peers including encouraging association with peers outside of school or work hours.

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