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DDD Critical Issue

Sexuality and Individuals with Developmental Disabilities

The Board of Directors of the Council for Exceptional Children – Division on Developmental Disability believes that persons with Developmental Disabilities need and deserve sexuality education. Further, the notion that many with Developmental Disabilities are asexual is wrong and represents a significant barrier to sexuality education. If one is seen as asexual, it follows that sexuality education is unnecessary. This unfortunate but common belief, leads to increased vulnerability and a myriad of other negative consequences. Only through relevant sexuality education can this cycle be broken.

Sexual behavior is socially learned, shaped, and reinforced within the social contexts of family, community, school, and friends (Suris, Resnick, Cassuto, & Blum, 1996). Generally, people with developmental disabilities share the same sexual thoughts and feelings as their non-disabled peers. However, they are 1.7 times more likely to suffer from sexual abuse and the abuser is most frequently a member of the family or a familiar adult (American Academy of Pediatrics, 1996; Committee on Children with Disabilities, 1996; Mansell, Sobsey, Wilgosh, & Zawallich, 1997; Prevent Child Abuse America, 1994). To combat this increased risk, persons with developmental disabilities need information about sexuality, sexual abuse and what to do when it happens. Without such education, they remain vulnerable victims. The Committee on Children with Disabilities (1996) states that the best protection from abuse is effective education of children about sex and their rights. Inaccurate information is a major reason that

persons with developmental disabilities are more vulnerable where knowledge about sexual issues is sometimes learned from misinformed peers rather than reliable sources. Sexuality education will also prevent problems such as unwanted pregnancy, sexually transmitted diseases, dating, marriage, and so forth.

Sexuality Education

Sexuality education for persons with developmental disabilities requires a certain degree of individualization when it comes to delivery, information presented, and format (NICHCY, 1992). The specific disability should dictate the content of sexuality education for an individual. For school-age students, the IEP is a mechanism for tailoring the sexuality curriculum for each child. IEP's should be used for this purpose and should advocate for such services. If sexuality training is indicated in an IEP, it is likely to be planned and delivered around the unique needs of the child. It is also more likely to actually be delivered than a less formal process could guarantee. A team approach to developing sexuality education for an individual is important in that multiple perspectives are considered. Further, the person who is the recipient of sexuality education should have an opportunity to give input into its content. Sexuality is more than just sexual behavior, it includes self-image, emotions, values, etc. (Koller, 2000).

Sexuality education should begin in early childhood. Further, all people are social and sexual beings beginning at birth (Kupper, 1995). Parents teach their children the names of body parts by age 5 and children show tremendous curiosity toward their own bodies at a very young age (NICHCY, 1992). By providing age appropriate sexuality education, young children will be better prepared to deal with inappropriate sexual

advances by adults. The topics of sexuality education will change as needs demand but generally include; facts and data, feelings and values, and making responsible decisions.

The notion of tailoring the curriculum to the type of disability does not mean that students would not participate with other students or with others of the opposite sex. In general, advocates of sexuality education would prefer that the curriculum be delivered in a coed setting that allows for practice of many socio-sexual skills (Carter & Jade, 1999). However, there are persons whose developmental disability include a physical disability which presents a unique challenge to sexuality education. Many students with physical disabilities prefer to have sexuality education presented to them on an individual basis due to the unique nature of their disability (Berman, Harris, Enright, Gilpin, Cathers, & Buckovy, 1999). Those with cognitive disabilities would likewise need adaptations to accommodate their learning differences (i.e. concrete versus abstract presentation) and specific sexuality issues. Whether sexuality education is delivered individually or in a group, it should always reflect the type(s) of disability that is represented. Sexual information should be stated concretely, unambiguously, and repeatedly (Committee on Children with Disabilities, 1996).

Benefits of Sexuality Education

Sexuality education can benefit persons with developmental disabilities in many ways. Students who have appropriate sexuality educational experiences show increased social skills, improved assertiveness, greater independence, an ability to be responsible, reduced risk of sexual abuse and sexually transmitted diseases, and reduced unwanted pregnancies (Disability Online, 2003). There is ample evidence to suggest that without sexuality education, children and adults are at a significantly greater risk of sexual abuse,

unwanted pregnancies, sexually transmitted diseases, and poor relationships (Haight & Faching, 1986; Committee on Children with Disability, 1996; Bambara & Brantlinger, 2002). This outcome alone provides enough rationale for advocating for appropriate sexuality education. Of course, these benefits are not realized overnight and take considerable time to develop. Sexuality education must be an ongoing process over many years to fully realize maximum benefit (Kupper, 1995).

A side benefit to sexuality education is the lifestyle change that may occur. Besides being more prepared to deal with sexuality events, other social skills are learned as well. For instance, researchers report that a component of a sexuality program should include developing hobbies (NICHCY, 1992; Kupper, 1995). Through this activity, students find others who share a common interest and thus have the foundation for building a relationship. This is particularly pertinent for persons with developmental disabilities who may have trouble building such relationships in the traditional “dating” context. According to Walker-Hirsch (1995), empowerment is taught by creating the opportunity for the person to experience self-esteem.

Parents and Sexuality

An almost universal theme in the literature on sexuality and disability is the crucial role the family plays (Yohalem, 1995; American Academy of Pediatrics, 1996; Kupper, 1995; NICHCY, 1992; Carter & Jade, 1999; Berman, Harris, Enright, Gilpin, Cathers, & Bukovy, 1999; Koller, 2000). The home is a natural environment for learning and the social learning that occurs within families is a primary influence on one’s sexuality. The sexual values of the family are important for the child with developmental disabilities to learn and consider. Unfortunately, family members often feel

uncomfortable with the content of sexuality education and may not feel they are knowledgeable enough about their child's disability in the context of sexuality education. They may also have difficulty with the vocabulary of sexuality, embarrassment, and may feel it is the job of a school or agency to present this information (Perspectives on Sexual and Reproductive Health, 2003). Parents also fear that sexual knowledge will lead to sexual experimentation and they are uncomfortable with that outcome (Disability Online, 2003).

Special education professionals and parents of children with developmental disabilities need to work together to develop and deliver sexuality education. It is not the domain of either group exclusively but, the main emphasis should be on the home and family. Educators must also take an active role in advocating for and delivering sexuality education. Many issues of sexuality occur outside the home and some issues may be better explored in school or in some other out-of home setting. It is recognized however, that most special education professionals have not been prepared to be sexuality educators and do not expect to teach this content (Walker-Hirsch, 1995). This has implications for teacher and other professional training programs in what is presented to prepare these educators for delivering sexuality information. In the meantime, the current work force in developmental disabilities has the responsibility for setting up and delivering sexuality education. They need a solid professional support system so that appropriate content can be delivered in an appropriate manner.

Curriculum Considerations

When developing or choosing curricular materials and activities, a number of important considerations should be explored. The materials should reflect and be

designed for people with developmental disabilities. The reading, age, and ability levels must be appropriate for the learner and materials should be adaptable to many different disabilities. The notion of disability-specific materials and activities in sexuality education is critical to success. Considerable research suggests that sexuality education should be tailored to the individual and should always consider the type of disability (Wolfe & Blanchett, 2003; NICHCY, 1992; Committee on Children with Disabilities, 1996; Koller, 2000; Kupper, 1995).

The family values of the person with developmental disability are also an important consideration when choosing materials and activities for sexuality education. Materials should reflect the family system as much as possible. The notion of individualizing sexuality education requires a variety of suitable strategies and materials so that they can be adapted for students with different disabilities or needs (Wolfe & Blanchett, 2003). The content and presentation of the material should also match the disability. For instance, a person with cognitive disabilities could benefit from having social skills modeled or role-played. However, Walker-Hirsch (1995) notes that it isn't a good idea to model or role-play adult sexual activities. In that case, the next most concrete option might be appropriate; videos, photo's, or drawings. Koller (2000) notes the importance of concrete over abstract presentation for students with autism and adds that it is more effective if presented in a real-life setting and repeated often.

Haight & Faching (1986) point out a major problem with materials available for sexuality education today – they focus on anatomy, contraception, and venereal disease and treat love, maturity, and stress as peripheral issues. Sexuality education should not be limited to basic sex facts but should explore the human side of the equation. Intimacy

and love are critical components of sexuality and relationships and the more exposure to these topics in a sexuality education program will enhance the probability of satisfaction. How students view love and intimacy will depend somewhat on their gender, girls define these concepts differently than boys. By presenting these topics in coed settings, a greater understanding of the opposite sex will result.

Teaching appropriate behavior is an underlying foundation to any sexuality curriculum. Students must learn appropriate expressions of physical affection and should know the differences in private and public behavior (Committee on Children with Disabilities, 1996). It is not unusual to hear about the adult with developmental disabilities who greets strangers with a hug or extended handshake often scaring the other person. If sexuality education had been widely available to this adult when he or she was young, such an inappropriate public display probably would not occur. The consequences of such behavior include perpetuating myths about persons with developmental disabilities as being unable to conform to social rules and forgiveness of them because of their disabilities. Both outcomes serve to disable the person even more.

One area that is frequently mentioned as a strong influence in developing sexuality concepts is watching television. Images of sexuality are common in TV programming and mirror (or maybe shape) societal values regarding body image, relationships, and sexuality in general. This sort of informal education is going on constantly (Koller, 2000). Walker-Hirsch (1995) sees an opportunity to teach using the TV and notes that many “teachable moments” occur in TV programming. Indeed, parents and professionals would be wise to use this readily available technology to pose sexuality questions to children and adults who are learning social skills.

Masturbation

The self-pleasuring activity of masturbation is commonly used by persons with developmental disabilities who have been unsuccessful in finding an intimate partner or who have had unsatisfactory experiences with other forms of sexual expression.

Masturbation can be an uncomfortable topic for many parents (Kupper, 1995; NICHCY, 1992). However, it must be viewed as a natural event and not as deviant behavior so that guilt does not become associated with masturbation. Koller (2000) notes that for persons with Autism, masturbation may be the only means of appropriate sexual release. When comparing people with moderate and severe disabilities, they engage in masturbation with equal frequency (Wolfe, 1997).

The key elements about masturbation are how to do it safely, when to do it appropriately, and where it is appropriate. Generally, masturbation is a safe activity but excessive stimulation can lead to injured genitalia and thus the need for education and understanding. Common sense rules apply about when to masturbate as well. It would not be appropriate to engage in this activity in a public place or where others might observe. Instead, instruction on masturbation should highlight the need for privacy. Finally, the places where masturbation is appropriate are private places to the individual rather than such public settings as restrooms, etc. Of course, the residential situation of the person is a critical consideration. Many group homes and other multiple-resident dwellings offer little in the way of privacy and it becomes a challenge for them to provide such private accommodations.

Some persons may have physical disabilities that prevent them from masturbating independently. They may have insufficient motor strength to masturbate or to pleasure a

sexual partner (McCabe, Taleporos, & Dip, 2003). For those persons, assistive technology may offer a solution. There is an ever-increasing number of vendors who provide such assistive technology and these resources should be available to people who might need them. A search for such items on the internet will yield a broad array of such products.

Birth Control

Birth control and family planning are critical components of sexuality education (NICHCY, 1992). Many families have religious and other personal values against some birth control methods. Indeed, many see abstinence as the most desirable, and sometimes only, form of birth control. For those who live in positive environments with such values, abstinence is a relevant message. However, for many persons with developmental disabilities, it is not a viable option. For these persons, sexuality education must contain issues of birth control and disease prevention. Conception, contraception, and prevention of sexually transmitted diseases are topics that should be covered. Of course, abstinence should also be offered as an alternative method.

Researchers report that children with developmental disabilities are engaging in sex during their teenage years (Haight & Faching, 1986; Perspectives on Sexual and Reproductive Health, 2003). Further, it is believed that many of these teenagers are having sex without their parents' permission. As teenagers, these young people often do not have adequate knowledge of birth control and other fertility issues. An appropriate sexuality education program would help decrease these teenage sexuality concerns. Under most circumstances, obtain written parent permission on topics to be covered before implementing sexuality education.

Sexual Orientation

Many people with developmental disabilities have homosexual or bisexual preferences. One reason for this may be segregated residential settings where people with developmental disabilities may develop sexual values (Thompson, 2002). It's also been posited that sexual orientation is not something that a person can change (NICHCY News Digest, 1992). It is clear that this topic is relevant to a sexuality curriculum and should be included when dealing with persons with developmental disabilities.

Although sexual orientation should be included in the sexuality curriculum, that does not mean that a particular position is taken by the educator. Indeed, it is pointed out in the NICHCY News Digest (1992) that strong, emotional messages against homosexuality and bisexuality will not change a person's sexual orientation. The educator must first examine their own bias regarding this topic and make a decision whether or not they can deliver it in a fair fashion. If they are unable to suppress or change their bias, then another person should introduce and teach this part of the curriculum. One of the most important things that a young person who is gay or bisexual needs is an open, honest discussion with a caring adult in an accepting atmosphere.

Conclusion

When people with developmental disabilities are denied sexuality education, they are at risk suffer sexual abuse, inappropriate sexual behavior, and unsatisfactory social relationships. The notion that they are asexual and therefore do not need sexuality education is simply wrong. The home is the most natural place for sexuality education to occur but sexuality education must happen outside of the home as well. Likewise, parents are the most desirable sexuality teachers but professionals must be prepared to fill

this role. Sexuality education for persons with developmental disabilities should be tailored with the specific disability in mind and should begin in early childhood. Family values are an important component of any sexuality program and should guide content but that content should not be limited to sexual facts only. Feelings, emotions, relationships and many other social consequences of ones sexuality must be explored in sexuality education. The concept of appropriate sexual behavior guides sexuality education and helps to decrease unacceptable public behaviors in adults.

By providing a well thought out sexuality curriculum, persons with developmental disabilities can realize such important experiences as childbirth and marriage with greater success. Further, professionals have an opportunity to examine their own beliefs and values as a product of sexuality education. It seems clear that the benefits outweigh any negatives associated with this sensitive yet crucial human experience.

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