Review of Issues Related to Sexuality of Individuals with Developmental Disabilities

Perceptions of Sexuality and Individuals with Developmental Disabilities

Historically, mental retardation was closely linked with having an uncontrollable sex drive and perverse practice (Tregold, 1920). A multitude of techniques were used to 'control' individuals with developmental disabilities. Confinement was commonly used for the restriction of sexual expression, and later on, sterilization techniques were implemented (Landman, 1932). Because homosexual activity and masturbation were considered perverse, castration was often practiced to halt these activities (Robitscher, 1973).

Deinstitutionalization, the civil rights movement, and the normalization principle have created the need to more fully understand people with developmental disabilities. According to Ludlow (1991), society is becoming more accepting of people with developmental disabilities, and with this acceptance, multifaceted and exigent concerns are topics of conversation. These issues involve:

(a) the attitudes of families and professionals as caregivers,
(b) attitudes of the community,
(c) policy impacting individuals with developmental disabilities, and
(d) education initiatives (e.g., curriculum development, instructional methodology, and staff training)

Perceptions of the Public

The general population has varied attitudes about the issue of human sexuality, and when coupled with the issue of individuals with developmental disabilities, the attitudes and misunderstandings are intensified. Contradicting identities include that individuals with developmental disabilities are sexually repressed or sexually uncontrollable (Ludlow, 1991). Although these individuals should be expected to have sexual impulses and desires, they are often restricted by policies and isolated settings with the intent of retraining and containing their sexuality (Thompson et al., 2001). Education and encouragement are considered necessary in order to develop appropriate social and sexual behaviors.

Perceptions of Caregivers

Research indicates that individuals with developmental disabilities and professional caregivers report conflicting information regarding sexuality issues. Support staff report that they are supportive of the individuals being sexually active, while the individuals report that their support staff are not supportive (Johnson & Davies, 1989). Individuals of this population have reported that professional caregivers rarely ask about their sexual needs (Thompson et al.,
Another problem is that the support staff may view the sexual needs of individuals with developmental disabilities as being different from other human beings. More specifically, 94% of the support staff report that they view masturbation as a normal activity, yet 39% reported they would stop an individual with a developmental disability from masturbating (Deishier, 1973).

In regard to parental attitudes, some parents may deny that their children have sexual needs (Heyman & Huckle, 1995). According to Poyadue (1993), parents may regard sexuality as hazardous for individuals with developmental disabilities, and thus, inhibit or restrict their learning environment. Parents also may fear that if their child does have sexual needs, their community would not accept the onset of a sexual relationship (Pueschel & Scola, 1988). Although the parents seem motivated by fear, these fears are not irrational because many individuals with developmental disabilities have been the victims of sexual abuse and some have even been the perpetrators. Other concerns for the parents are how their offspring will deal with the breakdown of a relationship, the responsibilities of parenthood, or the loss of a loved one. These are concerns that many parents have for adult children who do not have developmental disabilities, and these concerns are multiplied exponentially when the child has developmental disabilities.

Perceptions of Individuals with Developmental Disabilities

Interestingly, individuals with developmental disabilities are often not asked how they feel about their sexuality (Garwood & McCabe, 2000). Within the limited scope of research about their attitudes, it has been suggested that individuals with developmental disabilities have traditional attitudes toward sexual activities such as masturbation, nudity, and talking about sex (Hall, Morris, & Baker, 1973). Szollos and McCabe (1995) suggested that they lack sexuality education, and therefore express negative attitudes regarding the expression of sexuality.

In one study, teachers reported that the majority of their students with developmental disabilities desired social intimacy and sexual relationships (Brantlinger, 1988). Based on staff and parental interviews, Heshusius (1982) states that intimacy and sexuality are considered a perplexing but crucial part of the lives of adults with developmental disabilities.

Besides being denied sexuality education, individuals with developmental disabilities are often denied privacy. Intimacy between males and females is so closely scrutinized that true affection may be tempered. This, according to Heshusius (1982), becomes pervasive in the bigger picture because the individuals have not had experience with compassion, affection, and amiability articulated through touch. This lack of development in social skills often has to be addressed when social problems and concerns about sexuality become apparent. Therefore, sexuality education is warranted.

Potential Harms of not Providing Sexuality Education to Individuals with Developmental Disabilities

Sexual Abuse of Individuals with Developmental Disabilities
High levels of sexual victimization, exploitation, and abuse of and by individuals with developmental disabilities have been documented in numerous studies (Sobsey, 1988). However, detection and disclosure of sexual abuse of individuals with developmental disabilities often goes undetected, consequently underestimating the problem (Burke et al., 1998). Discovery of abuse may be inhibited because the individual may not be aware that the actions that have taken place are in actuality abusive (Furey & Niesen, 1994). Also, the individual may have feelings of confusion, guilt, and denial which would inhibit disclosure (Ludwig, 1998).

A study by McCarthy and Thomson (1997) divided abuse into two categories: (a) acts which would be defined as illegal and (b) acts which are not defined by law, such as undue pressure or abuse of power. According to Burke et al (1998), individuals with developmental disabilities who understand that abuse has taken place frequently have feelings of confusion, guilt, or denial especially if the perpetrator was a caregiver or friend. McCarthy and Thomson (1997) state that women are victimized most in their own place of residence.

Furey and Niesen (1994) suggest that when institutionalized, neglect of the individual with a developmental disability arises if the individual experiences a ban on sexual expression, gender segregation, lack of sexuality education, or abuse by staff and other residents. Risk of sexual abuse and abuse of this population is multiplied when there is an insufficiency in their social skills (Lumley et al 1998). As Sobsey (1988) states, if there are deficits in communication then the predator may identify the individual as being more vulnerable because of the decreased ability to disclose effectively.

Sexual Perpetration by Individuals with Developmental Disabilities

Literature has noted that individuals with developmental disabilities are excessively represented in correctional agencies for sexual perpetration (Petersilia, 1997). According to Petersilia (1997), the rates of crimes committed by this population are consistent with the rates of crimes committed by persons without developmental disabilities, however, there are factors that contribute to the greater rates of incarceration. First, perpetration and sexual abuse are closely linked by studies demonstrating that children who are sexually abused are more likely to become criminal perpetrators later in life (Demetrat, 1994; Hayes, 1991; Hingsburger 1987). Also, perpetration of sexual abuse by individuals with developmental disabilities may be attributed to a lack of sexuality education.

According to McCarthy and Thomson (1997), of the group that they sampled, 63% of the abused female subjects with developmental disabilities had perpetrators who also had developmental disabilities and little was done to rectify the situation. Police were generally not involved if the perpetrators also had developmental disabilities because the act was considered less serious; hence, the most common response to these perpetrators was to do nothing.

Sexuality Education Instruction for Individuals with Developmental Disabilities

The development of sexuality in the population of persons with developmental disabilities is
often seen in the non-disabled community (e.g., caregivers, parents, and educators) as problem-causing instead of being a positive human attribute (McCabe, 1993). This negative attitude is quite frequently found within the disabled community as well. Therefore, it is the duty of the health educator to change attitudes and provide sexuality education to both the disabled community and their support persons.

In an effort to successfully dispense information, the educator should possess certain skills that will enable individuals with developmental disabilities to comprehend and retain the information given (Monat-Haller, 1992). It is imperative that the facilitator has an extensive knowledge base about sexuality education in order to impart information on the biological function, formation and maintenance of relationships, expression of sexual urges, consequences of sexual expression, conception, and STD's.

Along with this knowledge, the ability to communicate the information in developmentally appropriately ways and in great detail is needed (Monat-Haller, 1992). Individuals with developmental disabilities need to have abstract concepts translated into detailed, concrete information in order to grasp the meaning and preserve it for future use. Therefore, the educator should demonstrate patience and the ability to clarify information while continuing to focus on the initial objective of the prepared lesson plan. The educator also needs to be able to discriminate between his or her own personal opinion and fact. This is important so as to address the needs of those with developmental disabilities and not to impose the values of the non-disabled culture. According to Whitehouse (1997), it is imperative that we not try to impose an idea of typical sexual behavior on individuals with disabilities because there is no such normalization.

According to McCabe (1993), many programs focus on some sexuality issues while disregarding others. In order for a sexuality education program for persons with developmental disabilities to be considered ample, all areas of sexuality have to be acknowledged (Monat-Haller, 1992). Knowledge, attitude, and behavior should be addressed in order to have synergy within a curriculum. Program lessons should incorporate information on social skills (e.g., differentiating between public and private information, dating, establishing relationships, eye contact, social distance, listening, posture, voice modulation); reproduction (e.g., anatomy, biological function, menstruation, birth control); STD's (e.g., how they are transmitted, how to avoid them, safer sex, abstinence, and how to find out if one has the virus); prevention of sexual abuse (e.g., saying "No", running away, and reporting instances); and evaluation of one's actions.

The program materials, techniques, and attitudes used by the facilitators to disseminate this information may be equally as important as the information itself. The techniques used to impart this knowledge should incorporate visual, auditory, and tactile methods (Monat-Haller, 1992). For example, anatomically correct dolls could be used to initiate conversation about the anatomy of males and females, allowing the teacher to assess the knowledge base of the students in regard to the names of body parts. Other techniques include role-playing, modeling, group lecture, and videos. Also, repetition offers the students a chance to hear the information a few times over the course of the lecture. A question and answer section allows the educator
to assess if the information is being understood, and if so, at what level of comprehension. The question and answer period also permits the educator to become aware of the knowledge that the students may have garnered prior to the course, and if the material is indeed factual and applied correctly. Within the group sessions, the educator may also work as a facilitator in a negotiation game that consists of group members collaborating with each other about a particular issue, while processing ongoing commentary (Whitehouse, 1997). The accomplishments and socialization of group work are important components of an effective program and increase imitative skills (Storm & Willis, 1978). All individuals benefit when sufficient tools are utilized that include a combination of these methods.

References


