Sexuality and the Developmentally Disabled:

Literature Review and Sexuality Knowledge Assessment

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Abstract

The developmentally disabled are a segment of the population which is too often forgotten. This is due to a variety of cultural norms, biases and misconceptions. This paper will examine the history and culture of the developmentally disabled as well as provide an adapted sexuality knowledge assessment to be used with this population for health professionals to get a deeper understanding of an individual’s beliefs and attitudes regarding sexuality.
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Sexuality and the Developmentally Disabled

Each human being emerges from the mother’s womb as a sexual being and remains one until death. This statement is true regardless of race, gender, age or intellectual ability. Each person learns to interact with others through social cues from parents, friends and the media. We learn what is public and what is private. We learn how and who to trust and what level of personal touch is appropriate. Sexuality education is an important part of a person’s development and sexual maturation. It can, however, be a misunderstood concept. Sexuality is a lifelong process of learning, experiencing and understanding appropriate interactions with others. It is a process of forming beliefs, attitudes and values about sexual development, intimacy and affection.

BT is a 26 year-old female with Down syndrome. BT lives in an assisted living apartment which is staffed 24 hours per day. She is under the care of a professional guardian. BT has a history of focusing her thoughts and feelings on one specific person in an overt and obsessive manner. For the past year, BT has centered her thoughts on another female of the same age whom she met at camp 10 years ago. Last summer, BT and this other woman had a handful of sexual encounters which caused the other woman’s parents to place a restraining order against BT. Since that time, BT has continued to insist that she is in a dating relationship. BT reports that she wakes up in the middle of the night thinking about this other woman and has trouble going back to sleep. If allowed, BT would verbally relive the sexual encounters of the previous summer. BT speaks as if the encounters occurred yesterday. BT displays signs of sadness when discussing this other woman, but she will not admit that they are not currently in a romantic relationship. Questions to consider include: Who decides who BT can date? How can
BT properly express her own individual sexuality? Are there changes that need to be made to the way society views vulnerable adults and their sexuality?

**Background on Developmental Disabilities**

Health professionals agree that there are four main causes of developmental disabilities: (1) genetic abnormalities; (2) problems during pregnancy; (3) problems during birth; and (4) various health problems. First, a developmental disability could stem from abnormal genes from parents, problems when certain genes combine, or other reasons. Examples of genetic abnormalities include Down syndrome, fragile X syndrome, and phenylketonuria (PKU).

Developmental disabilities may also be associated with problems during pregnancy. An intellectual disability can result when a baby does not properly develop inside the womb. For example, there may be a problem with the way the baby’s cells divide as the baby grows. A woman who consumes alcohol or gets an infection like rubella during pregnancy may also have a baby with an intellectual disability. Alternatively, problems during birth may result in developmental disabilities. If a baby has problems during labor and birth, such as oxygen deficiency, he or she may develop an intellectual disability. Finally, various health problems can be responsible for the occurrence of developmental disabilities. Diseases like whooping cough, the measles, or meningitis can cause intellectual disabilities. Developmental disabilities can also stem from extreme malnutrition, insufficient medical care, or exposure to poisons like lead or mercury.

Many individuals with developmental disabilities live in the general community, either with family members, in supervised group homes or in their own homes that they rent or own, alone or with housemates. At-home and community supports range from one-on-one assistance from a support worker with identified aspects of daily living, such as budgeting, shopping or
paying bills, to full 24-hour support. The need for full 24-hour support is usually associated with difficulties recognizing safety issues, such as responding to an emergency situation or using a telephone, or handling potentially dangerous medical conditions like asthma or diabetes who are unable to manage their conditions without assistance.

In the United States, a support worker is known as a Direct Support Professional (DSP). The DSP assists the developmentally disabled individual with activities of daily living and also acts as an advocate for the individual in communicating the individual’s needs, self-expression and goals. Supports of this type also include assistance to identify and undertake new hobbies, access community services like education, learn appropriate behaviors or recognize community norms, develop relationships and expand circles of friends. Most programs offering at-home and community support are designed to increase the individual’s independence, although it is recognized that individuals with more severe disabilities may never be able to achieve full independence in some areas of daily life.

Adolescence may be the most critical of the developmental stages that impact the social, physical, and emotional aspects of one’s life (Koller, 2003). A phenomenon known as the hierarchy of attraction can demonstrate that those individuals with a moderate developmental disability would prefer to be with someone who has a mild developmental disability. Likewise, an individual with a mild developmental disability would prefer to be with a person who is not developmentally disabled (Lofgren-Martenson, 2004).

**Sexuality**

Sex and sexuality are seen by many as integral to a healthy relationship. Extensive research exists on the development of a healthy sexuality for people without developmental disabilities. Yet, minimal research exists on the developmentally disabled individual’s sexuality.
Sexuality begins at birth and evolves throughout childhood without regard to ability. Sexual drive does not diminish as physical or mental abilities diminish. Sexuality is not simply sex—it is an essential aspect of one’s personality and sense of self and it offers a gateway to intimacy that includes feelings of comfort, security, support, love, and affection. Persons with intellectual disabilities have the same sexual needs as the average person (Isler, Tas, Beytut & Conk, 2009). Accordingly, sexuality is of crucial importance to the developmentally disabled population.

Sexuality encompasses self-image, emotions, values, attitudes, beliefs, behaviors, relationships, and other areas in a person’s life (Koller, 2000). Sexuality cannot be simply defined. When it comes to research in the area of sexuality, most of the information is related to sexual education and abuse (Bedard, Zhang, & Zucker, 2010).

Individuals with developmental disabilities, including autism and/or mental retardation, face barriers to expressing their sexuality. Such barriers include social myths, insufficient knowledge and training opportunities, personal discomfort, and limited access to available and appropriate educational resources. Research on the sexual behavior of people with a developmental disability demonstrates that sexuality is as much a part of their lives as it is for everyone else (Karellou, 2003).

History

The beginning of the nineteenth century marked the commencement of the Enlightenment in Europe and the United States. The main idea that evolved was that all people are capable of reasoning and that our similarities are more central than our differences. The ideas of the Enlightenment Movement cleared the way for the first state schools for the education of individuals with disabilities. Schools for the deaf and blind were also established. The goal of the state schools was to prepare individuals with disabilities for employment and
independence. However, aside from education, jobs and other opportunities were not developed for people with disabilities.

For a long time, it was believed that individuals with developmental disabilities were not capable of falling in and out of love, did not seek emotional satisfaction, and were not interested in marriage or having children. Additionally, several researchers reported a general concern that unless the sexuality of the developmentally disabled person was not suppressed, he or she would reproduce prolifically and sexual impulses would emerge in uncontrollable spurts of sexual violence (Karellou, 2003). The developing sexuality of the developmentally disabled was often associated with a number of myths, including that the developmentally disabled have no sexual needs or desires, or that they are sexually dangerous or incapable of dealing with sex responsibly (Karellou, 2003).

Towards the end of the nineteenth century and into the twentieth century, schools began to adopt a medical model in the school curriculum. The focus of the curriculum in the schools eventually moved from education and independence to custodial care. Younger children were placed in the care of state schools. According to Kempton and Kahn (1991), poorly designed research in the late nineteenth century carried out in the United States linked developmental disabilities to heredity and to criminal and sexually promiscuous behaviors and, as such, developmental disabilities were viewed as posing serious problems for American society. The proposed solution was selective breeding or eugenics (Karellou, 2003). The eugenics movement prevented individuals with disabilities from moving to the United States, marrying, or having children. In many instances, the movement led to the institutionalization and forced sterilization of persons with disabilities, including children. During the Great Depression, the disabled were viewed as financial burdens. Infants were routinely left in the care of the state schools. Schools
became grossly overcrowded and underfunded. Life expectancy for the developmentally disabled fell to age 18.

The late President John F. Kennedy raised awareness of the status of people with developmental disabilities. He appointed the President’s Panel on Mental Retardation to improve and reform existing services and to develop new programs for people with developmental disabilities. The civil rights movement also inspired additional advancement of the disability rights movement. By 1965, Willowbrook, a state mental institution, housed over 6,000 mentally disabled children notwithstanding its maximum capacity of 4,000.

Senator Robert Kennedy toured the institution in 1965 and proclaimed that individuals in the overcrowded facility were “living in filth and dirt, their clothing in rags, in rooms less comfortable and cheerful than the cages in which we put animals in a zoo” and offered a series of recommendations for improving conditions. Although the hepatitis study had been discontinued, the residential school’s reputation was that of a warehouse for New York City’s mentally disabled children, many of whom were presumably abandoned by their families, foster care agencies or other systems designed to care for them. Donna J. Stone, an advocate for mentally disabled children and victims of child abuse, gained access to the school by posing as a recent social work graduate. She then shared her observations with members of the press. A series of articles in local newspapers, including the Staten Island Advance and the Staten Island Register, described the crowded, filthy living conditions at Willowbrook and the negligent treatment of some of its residents. Shortly thereafter, in early 1972, Geraldo Rivera, then an investigative reporter for WABC-TV in New York, conducted a series of investigations at Willowbrook uncovering a host of deplorable conditions, including overcrowding, inadequate sanitary facilities, and physical and sexual abuse of residents by members of the school’s staff. The
exposé, entitled *Willowbrook: The Last Disgrace*, gained national attention and won Rivera a Peabody Award. Rivera later appeared on the nationally televised *Dick Cavett Show* with a film of patients at the school. Willowbrook was a clear picture of the depravity that can consume individuals when there is an extreme lack in oversight.

As a result of the overcrowding, a class-action lawsuit was filed against the State of New York in federal court on March 17, 1972. A settlement in the case was reached on May 5, 1975, mandating reforms at the site, but several years would pass before the numerous violations were corrected. The publicity generated by the case was a major contributing factor to the passage of the Civil Rights of Institutionalized Persons Act of 1980. During the 1970s, a series of newspaper articles and a televised exposé of the deplorable conditions at the Willowbrook State School of New York created enormous public outcry. The movement to deinstitutionalize people with developmental disabilities started to gain momentum. In 1972, the world’s first Center for Independent Living opened in Berkeley, California. Section 504 of the Rehabilitation Act of 1973, which addressed the discrimination of people with disabilities, was passed. In 1975, the Education for All Handicapped Children Act (PL 94-142) was passed, guaranteeing the right of children with disabilities to be educated in public schools with non-disabled peers.

In 1971, the United Nations in its Declaration of Rights of Retarded Persons, stated that every member of a given society should enjoy the same rights regardless of disability. In a series of publications, Craft (1985, 1987) identified six main rights related to the sexuality of people with developmental disabilities: (1) the right to grow up; (2) the right to know; (3) the right to their sexuality; (4) the right to be protected from sexual abuse; (5) the right to express their sexuality; and (6) the right to live in humane environments (Karellou, 2003).
During the 1970s, individuals with developmental disabilities transitioned from institutions into the community. This movement into the community created the need to accommodate both societal and individual goals. These goals often conflicted (Swango-Wilson, 2009). Wolfensberger (1972) wrote that the individual with a profound developmental disability had a reduced sex drive. Reid (1995) later wrote that sex drive even in the individual with a profound developmental disability was not uncommon (Swango-Wilson, 2009).

Today with the closing of the institutions and advancements in modern medicine, 90% of people with developmental disabilities live to adulthood. The life expectancy of most people with developmental disabilities approaches that of the general population. The need for trained medical providers is paramount because communication within the developmentally disabled population can be extremely varied. With properly trained medical providers, the developmentally disabled will be able to receive the utmost care and respect.

In 1995, the case of Sandra Jensen raised a public debate on this issue. Jensen was a 34-year-old woman with Down syndrome who was affected by a severe congestive heart failure. She maintained a good level of autonomy in her daily activities. Her family physician indicated that she needed a heart-lung transplant—a decision approved by her health insurance. However, the two transplantation centers suggested by the health insurance company denied the transplantation. They justified their decision on the basis that Down syndrome represents an absolute exclusion criterion for transplantation. After much public outcry and exhausting opposition, one of the transplantation centers eventually decided to perform the transplantation (Panocchia, Bossola, & Vivanti, 2010).

Many individuals with developmental disabilities are under the care of a private or professional guardian. There are three types of guardianship: person, property and limited
property. Guardianship of the person allows the guardian to be the decision-maker for the developmentally disabled individual. Guardianship of property allows the guardian to control the assets of this individual. In order to protect the individual’s rights, the assets are held jointly with the Surrogate, and the guardian must have the Surrogate’s permission before any resources are withdrawn from the bank account.

Misinformation and lack of understanding about the varying degrees of sexuality in the developmentally disabled population has led to severe injustice being perpetrated against this population. Sexuality, for persons with developmental disabilities, has often been an area of distress, exclusion, and self-doubt for so long, rendering it easier not to consider it as compared to the alternative of engaging in everything from which so many were excluded (Shakespeare, 2000).

**Current Attitudes**

The developmentally disabled population is frequently forgotten and neglected. Society often does not acknowledge the sexuality of individuals with developmental disabilities and even worse, perceives them as eternal children who cannot have sexual feelings (Karellou, 2003). It is this belief that perpetuates the negative stigma regarding sexuality and the developmentally disabled. Beliefs and attitudes vary on sexuality in this population. A relationship was found between level of education and attitudes about sexuality, suggesting that the higher the education, the more contemporary or liberal the attitudes are about the sexuality of the developmentally disabled (Karellou, 2003).

Sexuality is an area often overlooked in the development of social skill learning plans for this population. A mistaken belief held by many caregivers is that the individual with a developmental disability is child-like and incapable of sexual feelings (Swango-Wilson, 2008).
Recent research, of course, reinforces that this notion is false. Every human being has the capacity for sexual feelings—with variations only in degree. Caregivers concede the importance of relationships and sexual roles of individuals who are developmentally disabled. Younger caregivers typically are more accepting of sexual behaviors of individuals with developmental disabilities (Swango-Wilson, 2008). However, caregivers generally do not encourage skill development necessary for the individual with a developmental disability to define sexual roles.

Individuals with disabilities often describe themselves as being perceived as asexual, child-like, and in need of protection by society and by their physicians. In contrast, some view persons with disabilities as aggressively sexual with uncontrollable urges (Isler, Tas, Dilek & Conk, 2009). It is because of these extreme viewpoints that many people in this population are marginalized and often treated as subhuman. The rights of the disabled are inevitably governed by the feelings and behaviors of others. Even service providers maintain stereotypes regarding the sexual behavior of individuals with developmental disabilities and, as often happens with stereotypes, they reflect a negative view (Karellou, 2003).

It is often difficult to fully understand the goals and desires of individuals with developmental disabilities because of their limited social abilities, but it is up to the service providers and caregivers to take the time to understand their needs and desires. Developmentally disabled parents face an entirely new set of challenges as a result of having children. A disabled parent stated, if we do have a child we get asked if it is ours. “Who is the parent?” “Where is the parent?” or “Why are you holding it?” (O’Tool & Doe, 2002). Being a disabled parent with a disabled child can be a very isolating experience.

When it comes to sexual relationships between individuals with developmental disabilities, different sexes were generally perceived as normal and acceptable by both staff and
students. Nevertheless, acceptability decreased as the degree of physical contact intensified (Karellou, 2003). Parents identified a common theme of denial. “Sex is important for them to learn . . . but my child is not interested.” A theme of fear also emerged: “[I]f she had a baby I don’t think I could raise another one;” “I fear sexual abuse . . . he is so trusting.” Health professionals identified a theme of concern regarding general health issues (Di Giulio, 2003).

Today, more than 30 years after the movement to deinstitute individuals with developmental disabilities, these individuals are still not encouraged to participate in most decisions. Current research related to decision-making abilities of the developmentally disabled population focuses on food and leisure activities, and then within the confines of the agency by whose rules they live (Swango-Wilson, 2008).

Some professionals may deem persons who have severe or profound intellectual disabilities, along with the inability to verbally participate in a capacity assessment, to be incapable of sexual consent (Lyden, 2007). The idea that a third-party individual can measure the ability of consent in another person is highly controversial. It is unknown exactly what a person with severe or profound intellectual disabilities is capable of until you give them the opportunity to prove whether or not they can consent to having a healthy sexual relationship with another person.

What constitutes consent can be difficult to discern. Ames and Samowitz (1995) have suggested the following criteria for inferring sexual consent capacity: (1) Voluntariness: a person must have the ability to voluntarily decide, without coercion, with whom he or she wants to have sexual relations; (2) Safety: both participants in the sexual relationship must be reasonably protected from physical or psychological harm; (3) No exploitation: a person should not be taken advantage of or used by another in a way that is inconsistent with voluntariness; (4) No abuse:
psychological or physical abuse must not be present in the relationship; (5) Ability to say “no”: a person must be able to communicate “no” verbally or non-verbally, and remove himself or herself from the situation at hand, indicating a wish to discontinue the interaction; and (6) Socially appropriate time and place: either the person must be able to choose a socially acceptable time and place, or the person must be responsive to directives toward that end. It is helpful for the criteria of sexual consent to be written in a way that is clear and concise. The six rules for consent that Ames and Samowitz have laid out are not necessarily only for those individuals who are able to communicate verbally. It is important to recognize those individuals who communicate nonverbally. Being unable to speak verbally does not disqualify someone from the right to a healthy sexuality. Communication can be achieved through sign language, writing, or verbal forms.

The commonly used method for determining sexual consent capacity involves an assessment by a qualified health care professional, i.e. psychiatrists, psychologists, social workers, and physicians. The assessment process involves two general methods of obtaining information: (1) a review of relevant records; (2) discussions with selected people who know or work with the individual being assessed, like parents, staff members at a residential provider agency, and family members (Lyden, 2007). Even a person with a legal guardian can have sexual consent capacity.

**Sexuality Culture**

Culture has been defined as the system of shared beliefs, values, customs, behaviors, and artifacts that the members of society use to cope with their worlds and with one another, transmitted through learning from generation to generation (Greenwell & Hough, 2008). For most people, sexuality and its expression are a natural and important component of self-concept,
emotional well-being and overall quality of life. Disability impacts people across all demographic groups, creating multiculturalism within the culture of disability. Some have criticized existing empirical research for ignoring the diversity inherent in populations with disabilities and for assuming that disability status eclipses other types of culture variations (Greenwell & Hough, 2008).

Nearly two decades ago, the Disability Culture Movement began, leading to a heated discussion on the concept of a separate disability culture. Scholars debated whether a unified cultural group existed, given the tremendous within group variation (i.e. someone with autism varies significantly to someone with Down syndrome). (Greenwell & Hough, 2008). There has been a call for increased attention to cultural factors. There may be environments in which it is inappropriate to ask questions of culture and sexuality, or circumstances in which it is unsafe to ask these questions. Also, race and ethnic status are particularly significant variables in a country as diverse as the United States. Yet, internationally, other cultural variables may have greater significance (Greenwell & Hough, 2008).

**LGBT Sexuality**

Homosexuality is another area to consider when discussing sexuality in this population. Attitudes towards homosexual behaviors between two developmentally disabled individuals were mainly negative and certainly more restrictive that attitudes referring to heterosexual behaviors (Karellou, 2003). The vast majority of studies did not report data on the sexual orientation of their sample. This finding mirrors the results of Boehmer who examined the inclusion of LGBT participants over the last 20 years and found that LGBT issues are largely neglected in the research, represented in 0.1% of 3,777 Medline articles (Greenwell & Hough, 2008). This neglect can be seen in the LGBT community. Whitney states that many women
Sexuality and the developmentally disabled report a splitting of oneself, and rejection by both communities with which they may identify. “We are seen, and see ourselves, as different, as outsiders—outside the mainstream, rejected by the disability community, excluded by the lesbian world. We have no community of our own.”

One community that has been established is called The Rainbow Support Group. The Rainbow Support Group was the nation’s first support group focusing on the needs of LGBT individuals with developmental disabilities (Whitney, 2006).

**Sexual Abuse Risks**

Individuals with developmental disabilities not only think about engaging in sexual activity—they participate in it far more often that many would expect. As a result, people with developmental disabilities are at a higher risk for sexual abuse. Many parents with developmentally disabled children attempt to shield them from the outside world. Although this may limit their contact with strangers, it does not protect them from friends, family or caregivers. The risk factors for sexual abuse can never be eliminated (Bowman, Scotti, & Morris, 2010). However, educating individuals with developmental disabilities to recognize abuse and value themselves as not just human beings, but also as sexual beings, can be beneficial.

Many individuals with developmental disabilities are accustomed to the assistance of others in daily hygiene and other routines. This can inhibit the proper understanding of privacy and of self. Unfortunately, as a result, many individuals are not even aware that they are being exploited. Without appropriate education as children, these individuals will grow up to continue to put themselves in vulnerable situations in which they will be exploited. The reaction of the general public, medical professionals and disability-related service providers to information about abuse of women with disabilities is often one of shock and disbelief, suggesting a
misconceived notion that disability is somehow a “protective” factor against this epidemic social problem (Nosek, Foley, Hughes, & Howland, 2001).

Nosek, Foley, Hughes & Howland (2001) list eight reasons for increased vulnerability to sexual abuse victimization among persons with disabilities: (1) increased dependency on others for long-term care; (2) denial of human rights that results in perceptions of powerlessness; (3) lower risk of discovery as perceived by the perpetrator; (4) difficulty some survivors have in being believed; (5) less education about appropriate and inappropriate sexuality; (6) social isolation and increased risk of manipulation; (7) physical helplessness and vulnerability in public places; and (8) “values and attitudes within the field of disabilities toward mainstreaming and integration without consideration for each individual’s capacity for self-protection.” It is reported that 20-25% of children without disabilities are sexually abused, and estimated that children with disabilities will experience significantly higher percentages of sexual abuse (Koller, 2000).

Koller also states that education regarding sexual abuse should be a component of responsible sexuality education. Without proper education in the areas of sex, health, and physical education, people with moderate and severe disabilities risk exposure to sexual exploitation, poor health, abuse and neglect (Koller, 2000). Curiously, the literature on sexual abuse of adults with mental retardation, while still growing, rarely addresses abuse between two people with mental retardation (Furey, Granfield, & Karan, 1994).

**DD Sexual Offenders**

There is another subgroup that must be addressed when discussing sexual abuse in the developmentally disabled population: developmentally disabled sexual offenders. Forty-two percent of the 171 cases of sexual abuse substantiated over a 5-year study involved another adult with a developmental disability as the offender (Furey et al., 1994). Furey states that 44% of the
victims of consumer-to-consumer sexual abuse were male, while only 15% of those sexually abused by staff, family and others were male. This finding is consistent with the theory that institutional segregation of sexes results in same gender sexual behavior and/or assault since the majority of the perpetrators in both groups were male. The sexual assault that occurs because of the segregation of the sexes may be the result of isolation and opportunity.

**Sexuality Education for the DD population**

The sexuality of the disabled has been turned into a taboo pushed into the background as an issue of importance in understanding and assisting the developmentally disabled population. Very often, the only sources of knowledge about sexuality for them are pornographic magazines, the Internet, and films that are coarse and imbrued with sex and erotic games (Kijak, 2010).

Sex education for individuals with developmental disabilities continues to be debated among educators and mental health providers. Devereux Centers for children and adults with autism in Massachusetts, New York, New Jersey Pennsylvania, Florida, Texas, and California follow two fundamental precepts before beginning sexuality instruction: (1) Parents are the best sex educators. If, for whatever reason, parents are unable to complete this task, teachers and other staff attempt to fill this role; and (2) It is normal and natural for every person with a body to express sexuality regardless of handicap condition or level of functional ability. Further, it is normal and natural to express sexuality within the confines of the individual’s social contacts (Koller). This model can be very beneficial to an individual with a developmental disability because it places the responsibility first and foremost on the parents to provide sex education. It also accounts for the fact that some parents will not do an adequate job of educating their children, in which case teachers and other staff are able to fill in any gaps in their instruction.
Those who want to provide sexuality education for this population must first examine their own attitudes, values, and motives (Koller, 2000). Understanding issues of sexuality and developing mutual and satisfying relationships can be difficult for individuals with autism and other developmental disabilities without some interventions. However, typical sexuality education programs for persons with disabilities may lack components that address the unique social skills needs for persons with autism (Tarnai & Wolfe, 2008). Just like special education in school, there needs to be special education in sexuality to accompany the other areas of study. As Tarnai and Wolfe point out, there should be some form of adaptation that takes into account verbal, emotional and physical functions for those students with special needs.

Social Stories are one such adaptation. Social Stories were originally developed by Gray to teach children with autism how to play games with peers, with the aim to increase their ability to socially interact with others (Tarnai & Wolfe, 2008). In one study, 51.7% stated that they did not receive any sexuality education (Isler et al., 2009). Similar to findings in United States studies, results from the current study highlight that participants showed some knowledge about sexuality, but at an insufficient level. Leutar & Mihokovic (2007) suggest that there need to be more programs to engage individuals about the topic of sexual education for mentally disabled persons.

A task force of leading health, education, and sexuality professionals researching sex education for all children determined: (a) 9 out of 10 parents favored sex education; (b) 23 states required sex education; (c) 13 other states encouraged its teaching; (d) over 90 national organizations believed that all children and youth should have sex education; and yet (e) only 5% of children in America received sex education (Koller, 2007). The goal of sexuality education should be to protect individuals from sexual exploitation, teach healthy sex habits, and increase
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self-esteem through systematic, individualized approaches. Education needs to be provided with consistency and common-sense (Koller, 2007).

One thing I do not claim is to be an expert within the developmentally disabled community. My experience with this population has taught me many things, such as patience, empathy and creativity. Because therapeutic movement can be extremely slow, it is often hard to see change week by week. When movement is slow, you must adjust your expectations or you run the risk of burning out very quickly. Without patience, it can be very difficult to allow the client to move at their own pace (which is often much slower than the therapist or the insurance company may want). As documented in this paper, the developmentally disabled have experienced their fair share of injustices. I have been able to practice using empathy with a population that is very different from me. Understanding how they see the world by hearing it from their own words, has allowed me to experience a piece of their world. I came into this field with a fair amount of artistic creativity and over the past year have gained therapeutic creativity. By therapeutic creativity I mean thinking outside the box during the therapy sessions. Because many techniques cannot be used with this population, it is important for the therapist to be able to adapt what a typical session may look like in order to benefit the client.

One thing I admire about this population as a whole is their honesty. Many do not hold back and often say exactly what they are thinking; completely unfiltered. It is because of this seemingly uninhibited lifestyle that many people feel more comfortable saying “no” to someone with a developmental disability rather than taking it case by case and brainstorming the best possible way to allow a person with disabilities to thrive. While services to the developmentally disabled population have increased over the last two decades, gaps in service continue to plague those who need extra help in living their lives. One thing is clear: individuals with
developmental disabilities continue to thrive despite the ladders they have to climb to reach their goals in life. Adapted and personal sexuality education is the agreed-upon method by many health professionals to allow individuals with any mental impairment to fully embrace and love their own individual sexuality.
APPENDIX

Introduction

Assessment plays an important role in the therapeutic process as it keeps track of the progress achieved with the clients, which then permits future goal-setting with them. It also helps motivate the clients through feedback and constructive criticism where required. The therapist can also provide appropriate information on the clients' progress through doing regular reviews. The specific feedback by the therapist helps the clients demonstrate their understanding and development of skills, thereby helping the clients prove their competence. The assessment processes used in a program will directly affect how and what the clients do and learn. Assessment should serve to focus a therapist’s attention on client learning. It should create links and enhance consistency of subject matter within the clients' therapeutic goals.

A sexuality assessment for this specific population can be useful for measuring the level of knowledge the clients have towards sexuality. This can be beneficial for the therapist in developing specific interventions to demonstrate skills according to their knowledge of sexuality. It is important for the therapist to understand the clients' current knowledge to help establish a baseline to begin therapy.

Sexuality is a part of each person regardless of their IQ level. Sexuality manifests itself in each person in a unique way, yet the basic needs remain consistent. This assessment can not only be a useful tool for evaluation, but it also can serve as a focal point for the clients to begin to explore and understand how their sexuality uniquely affects them. It is then up to the therapist to guide the clients to a better understanding of their sexual nature.
Initial Sexuality Knowledge Assessment for the Developmentally Disabled

Part I

What does it mean to date?
What does it mean to be married?
What does it mean to get divorced?
Who gets to decide whether or not you have sex?
Is sexual activity a choice?
What is masturbation?
Do you know the difference between appropriate and inappropriate touch?
Has anyone ever touched you where you did not want them to?
Who do you tell if someone is hurting you?
Have you ever had a sexual relationship?
How can you show someone that you care about them without sexual contact?

Part II (To be completed by the therapist during 1-3 sessions)

Is the individual able to consent (auditory or visually) to a sexual relationship?
Is the individual under the care of a legal guardian that does not consent to a sexual relationship?
Does sexual activity threaten the health and safety of the individual?
Can the individual distinguish between appropriate private and public behavior?
Does the individual understand the concept of privacy?
Is it okay for family members to touch you in private areas?
Does the individual have the ability to say “no” to unwanted sexual contact?
Is the client able to report abuse of any kind?

*For use with persons 14 years and older*

**Assessment can be completed with the aid of a guardian or caregiver for a more accurate report

***Note to the assessor: You may need to use a variety of words appropriate to the age/functional level of the client.
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