Sex Life and Sexuality of Individuals with Developmental Disabilities; A Critical Review of the Literature

by

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A Research Paper
Submitted in Partial Fulfillment of the
Requirements for the
Master of Science Degree
in

Family Studies and Human Development

Approved: 2 Semester Credits

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December, 2006

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Title: ***Sex Life and Sexuality of Individuals with Developmental Disabilities; A Critical Review of the Literature***

Graduate Degree/ Major: **MS Family Studies and Human Development**

Research Adviser: **Denise Zirkle Brouillard, Ph.D.**

Month/Year: **December, 2006**

Number of Pages: **26**

Style Manual Used: **American Psychological Association, 5th edition**

ABSTRACT

Individuals with developmental disabilities are increasingly being integrated into community living settings where their educational and habilitative needs are moving beyond the traditional focus on daily living skills, for example, dressing and grooming, to include a greater range of social and vocational activities. Research shows that a central issue in this expanded focus is sexuality and the rights of individuals with developmental disabilities to sexual expression and sexual education. Unfortunately, service providers, counselors, teachers, social workers, parents, and other members of society hold many stereotypes about individuals with developmental disabilities, particularly about their sexual behavior.

The purpose of this paper is to review current literature and research on the attitudes that individuals have in regards to the sexuality of those with developmental disabilities, the barriers that individuals with developmental

disabilities face in regards to their sexuality, and the recommended components for sex education programs for individuals with developmental disabilities. An analysis of the literature, limitations of current research, implications for future research, implications for practice, and a summary are also included.

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Acknowledgments

There are a number of people whom I would like to take this opportunity to thank for all of their help throughout Graduate School and the process of writing this thesis.

Dr. Dale Hawley, Dr. Judy Rommel, Dr. Susan Wolfgram, and Dr. Denise Zirkle Brouillard, you have all been amazing professors and you have each provided me with the inspiration to keep on learning!

My dear friend, Becky, I couldn't have done this without you! I will never forget our walk that we took, when I decided that I would apply to Graduate School. Thank you for your endless words of encouragement and constant motivation to just get this done!

My parents, Rick and Pam, after my first semester of college (you both know how well that went), can you believe I have made it through Graduate School? It is because of your ongoing love and support that I have made it this far. Thank you for believing in me.

My husband, Dan, I love you. Thank you for being so patient with me and for listening to me through my triumphs and struggles. You have provided me with so much love and support – I am forever grateful.

My son, Conner, you are the light of my life. Thank you for being there, ready to snuggle, when I needed a break from writing. Mama loves you.

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Chapter I: Introduction

Only in the past two decades have the topics of sex education and support for sexual expression of individuals with developmental disabilities become important to researchers and professionals (Stinson, Christian & Dotson, 2002). As a society, we are gradually increasing our recognition of the basic human rights of people with developmental disabilities; however, there continues to be a high level of anxiety and uncertainty concerning the sexuality of people with developmental disabilities. Sexuality plays a significant role in the lives of people with developmental disabilities as it has direct implications for the mental, physical, and social aspects of their lives. People with developmental disabilities, like the rest of society, have varying degrees of reproductive ability, sexual interest, and sexual response. It is crucial that, though often denied or forgotten, we acknowledge that individuals with developmental disabilities have the same requirements for love, affection, and fulfilling interpersonal relationships as any other member of society.

Although we have begun to pay attention to the sexual needs of individuals with developmental disabilities, there is still so much to learn. In order to educate and instill healthy attitudes towards sexuality among individuals with developmental disabilities, it is essential to first understand the existing attitudes. The interplay of sexuality and disability is much too complex and cannot be understood without paying further attention to the various barriers that exist. Appropriate attention to this topic is further compounded by the complexities of human sexuality and the unique needs of subgroups of individuals. When issues

of disability are added, opinions may change depending on the severity and type of the disability, age, gender, and race of the individual.

Purpose of the Study

The purpose of this paper is to review current literature and research on: the attitudes on sexuality of those who are developmentally disabled, current barriers that individuals with developmental disabilities face in regards to their sexuality, and components necessary for sex education programs for individuals with developmental disabilities. Understanding staffs attitudes and beliefs is an important step in understanding the climate in which services are provided to individuals with developmental disabilities. An agency's policies and procedures can either provide guidance to staff with attitudes and beliefs that are incongruent with that agency's mission, or validation to those that are in agreement. An analysis of the literature, limitations of current research, implications for future research, implications for practice, and a summary are also included.

Definition of Terms

In order to completely understand the research that follows, it is important that the following terms be defined. For this study, the definitions for the terms developmental disability and sexuality will be listed.

> *Developmental Disability:* A diverse group of severe, chronic conditions that are due to mental and/or physical impairments. People with developmental disabilities have problems with major life activities, for example, language, mobility, learning, self-help, and independent living.

Developmental disabilities begin anytime during development up to 22 years of age and typically last throughout one's lifetime.

Sexuality: Refers to the person as a whole; includes one's thoughts, feelings, attitudes, and behavior toward oneself and others.

Chapter II: Literature Review

Although attitudes are beginning to change, American culture continues to react with discomfort to the recognition that individuals with developmental disabilities are indeed sexual beings with needs for affection, intimacy, and sexual gratification. The literature review has been organized into three different sections: 1.) attitudes on sexuality of those who are developmentally disabled, 2.) current barriers that people with developmental disabilities face in regards to their sexuality, and 3.) recommended components of sex education programs for individuals with developmental disabilities.

Attitudes on Sexuality of the Developmentally Disabled

There are a number of studies that have examined attitudes towards the sexual behavior of people with developmental disabilities and found that support staff, doctors, parents, and other members of society, in general, disapprove of developmentally disabled individuals engaging in specific sexual behaviors but are comfortable with non-disabled individuals engaging in those same behaviors. Scotti, Slack, Bowman, and Morris (1996) found that among their study of college students, participants were less accepting of public and private displays of affection and vaginal intercourse among the developmentally disabled, compared to their acceptance of these same behaviors for those who were not developmentally disabled. Wolfe (1997) conducted a study to examine how special education administrators and teachers felt about issues of sexuality and relationships for individuals with moderate and sever disabilities. The study concluded that there was more disapproval of sexual acts and behaviors among

students who had severe cognitive impairment (this was defined by IQs of 40 or below) as opposed to moderate (defined by IQs of 40-55) cognitive impairment. Respondents held negative attitudes toward the right of individuals with developmental disabilities to have children and differentiated this right based on the level of disability.

All of these findings support the notion, which is held by many, that individuals with developmental disabilities lack the capacity to have responsible sexual relationships. These attitudes not only isolate and marginalize the disabled, they also lead to the internalization of negative attitudes and beliefs by the disabled themselves.

Barriers that People with Developmental Disabilities Face in Regards to their Sexuality

As mentioned earlier, people with developmental disabilities have the same needs for love and affection, just as any other person; however, individuals with developmental disabilities must face a large number of barriers in regards to their sexuality. According to DiGiulio (2003), individuals with developmental disabilities often lack access to information, specific to their individual circumstances, about appropriate expression of sexuality and effective sexual communication skills. Not only do these individuals not have access to accurate information, they are often deliberately misinformed about sexuality in order to discourage their interest.

The lack of privacy for sexual expression is another barrier for people with developmental disabilities, particularly for those living in group homes or other

institutional settings (Hingsberger & Tough, 2002). Shared living accommodations make obtaining privacy, which is necessary for appropriate sexual expression, extremely difficult. Coincidentally, such individuals are then pushed, by conditions in which they live, to engage in the inappropriate sexual behavior. As a result, these individuals face negative stereotyping from society.

Another important barrier to the sexual health of individuals with developmental disabilities is their reduced access to sexuality related health care (DiGiulio, 2003). Women with developmental disabilities may have special needs that are poorly understood by healthcare professionals. For example, a woman with a developmental disability may be afraid of medical instruments used for gynecologic examinations due to a lack of knowledge of what is happening or from past experiences with a doctor. Stinson, Christian, and Dotson (2002) discusses the idea that when doctors do treat women with disabilities, that the doctors may use language that is intimidating or difficult for a woman with a developmental disability to understand. Furthermore, they may address comments and questions to accompanying family members or service providers instead of directly to the woman, whom is their patient. This is a barrier that may continue to keep individuals uninvolved in their healthcare. Often times, because of the assumption that disabled individuals are unlikely to have sex, parents, caretakers, or doctors may not encourage or discuss with the disabled to access sexually transmitted disease testing or to receive contraceptive counseling. For individuals who have been deemed incapable of giving consent, family members, doctors, service providers, or other professionals may have the power to make

important reproductive decisions on their behalf (Stinson, Christian & Dotson, 2002).

There is also the stereotype that individuals with developmental disabilities are asexual. This stereotype stems from the past, when disabled adolescents were often ignored even in hospitals where they received medical treatment, for example, boys and girls being placed in adjoining beds.

People with developmental disabilities are often forced to move several times during their life and their established relationships do not appear to be considered. Individuals with developmental disabilities have little or no say in choosing their own living conditions; instead, legal and structural factors determine the nature of their social and residential lives. Coincidentally, multiple moves of housemates and/or caregivers can result in feelings of loss and sorrow, thus contributing to a potential unwillingness to commit to future emotional attachments (Lesseliers & Van Hove, 2002).

Staffs' values and attitudes also impact the ability of individuals with developmental disabilities to make their own decisions regarding their sexuality (Christian, Stinson & Dotson, 2001). Agencies that do not have a policy on sexuality leave the decision making to untrained staff. Staff are then left to rely on their own views of sexuality and disability, on their own values in regards to the expression of sexuality, and on their own personal experiences when providing support to individuals who are developmentally disabled. Sexuality, which is already an uncomfortable topic for most people, the lack of a comprehensive policy, the lack of staff training, or a lack of knowledge about staffs' values and

attitudes can lead to inconsistencies in how support is provided to their clients. A survey was conducted by Christian, Stinson, and Dotson (2001) to determine the attitudes and knowledge of support staff at an agency serving individuals with developmental disabilities. Results indicated that a majority of staff felt comfortable supporting individuals in expressing their sexuality, but few were trained in this area. Findings also suggested that staff were guided more by their personal values than by agency policy. Supporting individuals in expressing their sexuality is an important job responsibility and staff need training in this area just as they need training in dispensing medications or in implementing individual support plans.

Components for Sex Education Programs for Individuals with Developmental Disabilities

Research shows that providing sex education to people with developmental disabilities is a vital route to enhancing their sexual well being. Christian et al. (2001) conducted a study and most of their respondents agreed that women with developmental disabilities should be given the opportunity to receive sex education (93%) and more than half said they would feel comfortable implementing such training (61.9%). In contrast, only 7.1% said they had received training in how to implement a sex education program.

Sex education should recognize and should teach that sexuality is an important component of human relationships. According to a study by Lesseliers and Van Hove (2002), a great deal of attention should be given on learning how to communicate desires, learning about the meaning of sexual actions, and

learning about pleasant and appropriate times and places for sexual expression. Lesseliers and Van Hove are also in favor of sex education since most of the participants in their study were unable to name their sexual organs in either casual terms, their own jargon, or in biological terminology. Sexuality education for youth with developmental disabilities must, in addition to including the information that would be included in effective programming for all youth, also include information and skills relevant to their specific disability (Di Giulio, 2003). This may include addressing issues such as how a certain disability may impact on sexual function, the suitability of particular contraceptive methods for different disabilities, prevention of sexual exploitation and abuse, and lastly, place an emphasis on social skills and relationship training. Stinson et al. (2002) emphasize the importance of comprehensive socio-sexual education curriculum, suggesting topics related to self-awareness, self-esteem, self-protection, relationships, and intimacy. Limiting sex education to basic information about male and female body parts, the act of sex, and the process of reproduction is a potential barrier to sexual growth and expression as it fails to address the important emotional and interpersonal components of sexuality (Christian, Stinson & Dotson, 2001). One last key component to sex education is addressing the issues of abuse. Unfortunately, sex education programs cannot eliminate the threat of abuse; however, they can assist the disabled in learning skills in personal safety. These skills may include: the ability to identify inappropriate verses appropriate behavior, the ability to clearly and effectively say no to

unwanted sexual activity, and the ability to report abusive behavior to the necessary parties (Di Giulio, 2003).

Stinson et al. (2002) suggest that in addition to the discomfort teachers, family members, or support staff may face when discussing topics of sexuality, several other factors may hinder the appropriate presentation of sex education materials. Values and attitudes of trainers may influence the variety of topics that are presented. For example, information about masturbation or homosexual practices may be omitted from the training. Training materials may not include effective teaching methods, such as models, pictures, role-plays, or videos. Most importantly, specific characteristics of the learner may not be taken into account, for example, language ability, physical limitations, or behavioral issues.

Chapter III: Summary and Discussion

This chapter discusses the results from the literature review. Limitations of the current research, implications for future research, and implications for practice are discussed. The chapter concludes with a summary of the literature review.

Analysis of Literature Review

After reviewing the literature on the sexuality of individuals with developmental disabilities, three main findings were identified. Studies show that society generally disapproves of individuals with developmental disabilities engaging in sexual acts. Interestingly, society approves of these same sexual acts for individuals who do not have disabilities. The second finding was the large number of barriers that individuals with developmental disabilities must face in regards to their sexuality. Most people meet potential partners at college, at work, or in social spaces. Unfortunately, individuals with developmental disabilities often don't get to go to college, to work, or to social spaces, because of physical and social barriers. Being sexual demands having positive self-esteem. Individuals with developmental disabilities, devalued and excluded by our society, are often not in the right place to begin the task of self-love and self-worth. Lastly, research shows that providing sex education to individuals with developmental disabilities enhances their sexual well being. Providing sex education will enable individuals with developmental disabilities to make responsible decisions regarding their sexuality that will enhance their overall quality of life.

Limitations of Current Research

The biggest limitation of current research is that there have only been a few studies that examine the attitudes towards sexuality of people with developmental disabilities. Lunsky and Konstantareas (1998) believe there are several factors as to why there is limited research in this area. First, misconceptions regarding sexuality and disability may have resulted in researchers placing little value on the sexual attitudes of people with developmental disabilities. Research shows that individuals with developmental disabilities have previously been perceived as asexual, sexually immature, or sexually deviant; therefore, their attitudes have not been directly sought out or considered legitimate or worthy of study. A second factor contributing to the limited research appears to be the perceived and likely overmagnified difficulty of collecting valid data from individuals with developmental disabilities. Researchers argue that participants may not be able to understand the questions asked of them. Researchers also indicate that the responses of many individuals with developmental disabilities may sometimes be the result of echolalia.

A shortcoming of current research is that the majority of research focuses on individuals with mild mental retardation. Much less is known about the attitudes of individuals with moderate to severe mental retardation. The attitudes of individuals with mild mental retardation are the most frequently examined because they are easiest to access reliably. The attitudes of individuals with autistic disorder, at least 75% of whom also have mental retardation, have never been studied (Lunsky & Konstantareas, 1998). Most of what is known about their

sexuality has been derived from parental or staff interview studies. Dotson, Stinson, and Christian (2003) note that women with more severe disabilities are routinely absent from sexuality research studies due to a lack of appropriate tools and research designs. Unfortunately, these might be the women whose needs and experiences are least understood, yet most requiring of attention. Future studies to include individuals with more sever disabilities may include utilizing sign language, photos, role-plays, or developing interactive computer programs as communication devices (Dotson, Stinson & Christian, 2003).

Implications for Future Research

It is obvious that researchers want to better the lives of individuals with developmental disabilities. They do this by highlighting the difficulties individuals with developmental disabilities face. The hope is that research will bring about a needed change for individuals with developmental disabilities in regards to their sexuality.

While many barriers continue to exist for the sexual expression of individuals with developmental disabilities, it is encouraging that they are being increasingly recognized and discussed. However, studies are usually presented from the perspectives of service providers, parents, or advocates (Dotson, Stinson & Christian, 2003). First-hand accounts and opinions from individuals with developmental disabilities are largely absent from the literature. McCarthy (1998) interviewed several women with developmental disabilities, asking questions about their feelings towards their bodies, health and reproduction, and how much control they had over choices concerning their bodies. Her findings

indicated that women had a lot to say about their experiences when given the opportunity. Her study demonstrates a need to set aside theories and assumption and listen to the actual experiences of women with developmental disabilities.

Lastly, homosexuality, and sexual acts such as anal intercourse and oral sex are often ignored or mentioned only superficially in the literature (Williams & Nind, 1999). From a lesbian feminist's perspective, Williams and Nind research the "oppressive nature of sex education in a culture that places a premium on normality" (pg. 659). A study of the attitudes of service providers indicates that these activities continue to be met with discomfort or disapproval from support staff (Scotti, Slack, Bowman, & Morris, 1996).

Implications for Practice

DiGiulio (2003) suggests that professionals recognize that individuals with a developmental disability often suffer from a low self-esteem, especially a low sexual self-esteem. It is important for professionals working with clients who have a developmental disability to help them affirm their status as a fully sexual human being. It is necessary to help them develop confidence in their ability to enjoy their sexuality. Confidence is especially important to individuals with developmental disabilities as they may feel dehumanized by societal attitudes and by negative stereotypes in regards to the sexuality of people with developmental disabilities. It is also important for professionals to not automatically assume that an individual's sexual difficulty is related to a disability. While the onset of a disability may complicate one's sexuality, it may also be true

that the sexual difficulty is rooted in one of the same causes as an individual without a disability.

According to Hingsburger and Tough (2002), professionals should help individuals with developmental disabilities integrate "disability" and "pride" into a healthy personality, through the means of learning about prejudice and self-advocacy. They use the following example to show the benefits of this approach:

> A woman had been told that if she ever had sex with her boyfriend she would get caught because "retarded people stick together like dogs do" and that the staff would have to help them get "unstuck." She and her boyfriend were terrified. Her boyfriend reported that once when he was touching her with his hand he felt her vulva move and so was convinced that her vulva was trying to grab him and hold him there. When they learned that this misinformation was a lie, they were able to discuss why others would lie to them. At a later point after the couple married and decided they wanted to have a baby, a gynecologist told them that the woman's eggs had all dried up because she had not drunk enough water. In addition, her mother suggested that then she did not need to have a period anymore so that a hysterectomy would be a good idea. Something rang untrue in this woman's mind, and she used the techniques of self-advocacy that she learned. She double-checked the facts. She called her sex educator to find out accurate information. "Can not drinking enough water dry up your eggs?" Her healthy suspicion and skepticism about the connection between drinking water and infertility helped her analyze the

> information as well as the motives of the doctor and her mother. Her husband said, "I thought the doctor was prejudiced because he told us that if she could have babies we should only have one – what business is it for the doctor to tell us that? I bet he doesn't tell normal people how many babies to have!" (pg. 15).

Knowing about prejudice is a good thing for individuals with developmental disabilities because they learn that many people are afraid of them being sexual so they are sometimes told false information.

Gynecological healthcare is an important component of sexuality, especially for women. Inadequate gynecological healthcare not only places women at risk of developing reproductive health problems, but also devalues their sexual and reproductive needs. It is essential that we provide education about the importance of such care and support through uncomfortable medical procedures for women with developmental disabilities. Without the appropriate healthcare, education, and support, increased risks to reproductive health represent a significant barrier to one's sexuality (Christian, Stinson & Dotson, 2001).

Lesseliers and Van Hove's (2002) study made it very clear that relationships matter to individuals with disabilities. Their study also showed that most people with developmental disabilities currently have limited opportunities to develop their relationships. In order to help individuals with developmental disabilities develop relationships of their own choosing, we need to meet their personal wants and needs. This may include allowing self-determination in one's

selection of where they live and who they live with; creating space for privacy in all residential settings; providing adequate and continuous sexuality education and relationship training; and training staff, parents, and other influential people in society so that they develop a respectful and supportive attitude toward the potential of people with developmental disabilities to have fulfilling relationships and appropriate kinds of sexual expression (Lesseliers & Van Hove, 2002).

Enhancing the quality of life for individuals is one of the major tasks of social workers. Many social workers help youths with gaining developmental competence, assist their parents or caregivers with education, offer emotional and social support, and attempt to influence society to be more caring to the needs of individuals with disabilities. As Zajicek-Farber (1998) suggests, although these interventions target youths with disabilities, they also need to include youth's sexuality. For example, social workers may specifically need to actively encourage youth's mastery of age-appropriate socialization skills with an open discussion about sexuality, and the increased need for personal intimacy while creating a supportive atmosphere for confidential self-expression.

Summary

People with developmental disabilities often face obstacles to maximizing their potential as fully sexual human beings. These individuals often internalize negative societal assumptions and attitudes regarding the sexuality of people with disabilities. With similar focused efforts and persistent incremental changes within our society and agencies that work with individuals who are developmentally disabled, it is the researchers hope that the barriers discussed

in this paper will continue to erode and that individuals with developmental disabilities will have increased opportunities for sexual growth and fulfillment. Agencies policies and procedures can greatly impact the lives of the individuals they serve only if staff are both aware and trained regarding the agency's core values, beliefs, and their expectations regarding the support of sexual expression. Moving beyond the barriers discussed throughout this paper includes recognizing and challenging harmful beliefs and power imbalances that exist between individuals with developmental disabilities and the important people in their lives. Lastly, it is imperative that we begin listening to the voices of individuals with developmental disabilities, not only to witness their experiences, but to begin meeting their needs.

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