

Sexuality and developmental disability: Obstacles to healthy sexuality throughout the lifespan

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This paper presents a lifespan perspective of sexuality issues for individuals with developmental disabilities. Individuals with developmental disabilities are human beings who have historically been denied the right to express their sexuality or engage in sexual relationships due to misconceptions or negative attitudes. Using a hypothetical case to illustrate the challenges experienced by individuals with disabilities, human rights violations and the need for education and appropriate sexual information are highlighted. Issues such as eugenics, vulnerability to abuse, self-esteem, and individual differences are also discussed. Recommendations for practice are provided.

There has been little acknowledgement of sexuality as a natural experience throughout the life span for individuals who have developmental disabilities. Such a disregard has resulted in imposing unfair limits and expectations on the sexuality of such individuals. From a historical perspective, the Eugenics movement spanning from 1880 – 1940 led to forced mass sterilization and the segregation of people with developmental disabilities from mainstream society (King & Richards, 2002; Löfgren-Mårtenson, 2004). As a prime example, in 1927, during the case of *Buck v Bell*, 274 U.S 2000 (1927), the United States Supreme Court upheld the constitutionality of involuntary sterilization on individuals with mental retardation. Oliver Wendel Holmes, a Supreme Court judge, found in his judgment that

[I]t is better for all the world if instead of waiting to execute degenerate offspring for crime or to let them starve for their

imbecility, society can prevent those who are manifestly unfit from continuing their kind...Three generations of imbeciles are enough. (Buck v Bell, 274 U.S. 2000, 1927)

Not only have individuals with developmental disabilities been viewed as sexually deviant (Di Giulio, 2003), but they have also been seen as irrelevant, prone to criminality, asexual, and problematic to society (Karellou, 2003; King & Richards, 2002). However, Wolfensberger's normalization movement of the 1960s and 1970s emerged with great force in North America, helping individuals with developmental disabilities lead normal, natural, and ordinary lives (Karellou, 2003; Kempton & Kahn, 1991; Watson, Venema, Molloy, & Reich, 2002). Signs of growth began with groups advocating for individual choices and desires of people with developmental disabilities along with their right to live with, work with, and love people of both sexes. A major progression occurred in 1971 when the United Nations declared in its declaration of rights for persons with mental retardation "[t]hat every member of a given society should enjoy the same rights regardless of disability" (Karellou, 2003, p. 66). Despite this progress, the sexuality of individuals with developmental disabilities was still feared and grossly misunderstood by society at large (Karellou, 2003). Sexual needs were completely ignored; sexual behaviour was punished; basic human rights were being violated; reproduction was forbidden and prevented via segregation by sex; and the perception that people with developmental disabilities were perpetual children, irrespective of their age, still lingered (Di Giulio, 2003; Karellou, 2003; King & Richards, 2002).

The normalization movement prevailed well into the 1980s. It created an atmosphere for families, caregivers, educators, and professional health care workers to critically examine their personal and professional attitudes toward the sexuality of their clients and children with developmental disabilities (Kempton & Kahn, 1991). In 1986, following the U.N's declaration, the Supreme Court of Canada ruled that "[n]on-therapeutic sterilization without consent is not justifiable" (Di Giulio, 2003, p. 58). Marked advancement occurred in 1997 at an international conference held by the World Congress of Sexology exclusively addressing developmental disability and sexuality. The end result was

the production of the *Valencia Declaration on Sexual Rights* delineating nine sexual rights for persons with disabilities. These included the right to: (1) freedom; (2) autonomy, integration, and safety of the body; (3) sexual equality; (4) sexual health; (5) wide, objective, and factual information on human sexuality; (6) comprehensive sexuality education; (7) associate freely; (8) make free and responsible choices, and (9) privacy (Instituto de Sexologia Y Psicoterapia Espill, 1997).

At present, society is gradually more tolerant and accepting of individuals with developmental disabilities as a result of their increased presence in leisure, work, and community activities. Thus, the recognition of the significance of quality of life for all persons, regardless of level of functioning, is well underway (Löfgren-Mårtenson, 2004; Seltzer & Krauss, 2001). Staff and caregivers have become more open-minded and liberal with respect to their attitudes and practices related to the sexuality of people with developmental disabilities (Di Giulio, 2003). There appear to be trends toward providing opportunities for people with developmental disabilities to be sexual beings throughout their lives, although many obstacles and myths still remain (Griffiths & Lunsky, 2000; Karellou, 2003).

Negative attitudes toward sexuality are a significant obstacle for individuals with developmental disabilities. This is due largely to negative experiences with intercourse. Thus, McCarthy (1996) reports that less than a third of the women who had had intercourse with men reported a desire for it. Vansteenwegen, Jans, and Revell (2003) found that women with physical disabilities had a more rejecting attitude toward sexuality when compared to women without disabilities. Furthermore, they are also less satisfied with their sexual experiences, in spite of a typical level of sexual desire and fantasy.

This article discusses a host of sexuality issues that can arise for people with developmental disabilities as seen through the life span development of Samantha. She is a fictitious woman with a developmental disability who faces various barriers throughout her life that directly impact on her sexuality. Although fictional, Samantha's life

reflects many of the life experiences of actual individuals encountered by the authors.

The Life Span

The early years: Birth to adolescence

When Samantha was born, she experienced difficulties with her health and spent a great deal of the first 6 months of life under constant medical care. Apart from having breathing difficulties, Samantha's parents discovered shortly thereafter that their daughter had Cerebral Palsy and a developmental disability. For the first few formative years of Samantha's life, her parents frequented numerous medical appointments and became involved in gaining proper evaluations through psychological assessments in order to meet the unique needs' of their daughter. Samantha's also had two older siblings who required their parents' attention. As Samantha grew, she appeared well-adjusted, and developed into a sociable child who enjoyed the company of family and peers. However, this would prove to be the difficult years for the family; the furthest thing on their mind was providing Samantha with information about her sexuality. Still, Samantha's parents would make efforts to teach her about respecting other individuals' privacy, as they often found her invading privacy by opening the bathroom and bedroom door when her siblings occupied the rooms. Overall, her parents felt that Samantha's school provided her with appropriate and specialized provisions for education.

Samantha is quite similar to most children who have a developmental disability. Research clearly indicates that, regardless of the disability, children and adolescents are sexual beings and have similar curiosities, drives, and interests about their own bodies and that of others (American Academy of Pediatrics, 1996; Cole & Cole, 1993). Early on, children need to be taught about privacy and boundary acceptability not only of others but for themselves as well (Cole & Cole, 1993). Bradley and Burke (2002) contend that, due to inadequately developed social boundaries, individuals are at risk for sexual exploitation and abuse. Basic social and sexuality education within schools and community systems needs to

include topics such as respect for the body, privacy, and boundary issues that begin in the primary years so as to decrease the potential for sexual abuse. The understanding and utilization of such topics can also help enhance opportunities to develop meaningful friendships during these formative years.

Current cultural ideology bombards us with beautiful body images that are virtually impossible for someone with a physical disability to attain (Cole & Cole, 1993). Such messages, in turn, cultivate a negative self-image and low self-esteem (Bradley & Burke, 2002). Potgieter and Khan (2005) interviewed adolescents with spinal cord injuries who discussed the battle they face about not meeting conventional standards of beauty. In this regard, some individuals perceived themselves as doubly disabled—that is, disabled and unattractive. To assist children with developmental disabilities in understanding their self-worth, sex education programs are the most optimal way to teach about self-esteem building (McCabe, 1993; 1999). Sexual self-esteem is so vital that Mayer, Heller, and Heller (1993) have even cited damages to sexual self-esteem as a kind of disability in and of itself. Such a low self-esteem detracts from the individual's self-image and ultimately satisfaction with life.

Parents are often apprehensive about teaching their child with a developmental disability about sexuality for fear of abuse. According to Ballan (2001), the fear of their child being sexually abused or behaving in socially and sexually inappropriate ways becomes a deterrent to teaching and preparing their child about sexuality issues. In the end, anxiety and overprotection prevail and deprive the children of knowledge about basic and important sexual issues. These barriers suppress fundamental social and sexual rights and freedoms for children with developmental disabilities (Ballan, 2001). Early childhood is an opportune time for parents to introduce sexuality as a natural part of life. Cole and Cole (1993) suggest that this sexual information increases an individual's feelings of self-worth and can help prevent sexual abuse.

The Formative years: Adolescence to adulthood

The adolescent years are filled with a myriad of obstacles, challenges, and difficulties for most “typically” developing teens. Individuals with developmental disabilities such as Samantha are severely challenged. During these changing years, Samantha experiences an array of emotions including confusion, frustration, and uncertainty, particularly about her relationships with significant others. Samantha desires a boyfriend just as much as her friends at school. Unfortunately, none of the teenage boys appear interested. She begins to think she is not worthy of a boyfriend, and even questions the authenticity of her friendships. She can’t engage in most activities of her friends such as driving a car around the city, or going camping on the weekends. Even her brother and sister begin to ignore her as they too begin to experience “teenage hood” and all its fun. Samantha’s mother and father hesitate to let her go out by herself for fear that something “bad” might happen to her. As a result, Samantha feels angry and overwhelmed due to isolation, loneliness, and a bad self-concept.

On the whole, human beings feel isolated and alone when their need to belong is not met. Such isolation makes a person more likely to experience mental health problems such as depression or anxiety (Bradley & Burke, 2002). The social and sexual needs of young persons with disabilities are typically similar to those of individuals who do not have a disability (Gilby, 1993). Yet Muccigrosso (1991) contends that society will need to learn about developmental disabilities and promote integration within schools in order to facilitate the understanding and appreciation of the sameness of those who are disabled and those who are not. This could promote discussion and ultimately potential friendships between individuals who have a developmental disability and those who do not (Katz, 1998).

Unfortunately, for some children with physical disabilities, normative social experiences with peers - such as going to the movies or having sleepover parties - present major challenges. These often keep individuals with disabilities from learning and experiencing “typical” teenage experiences such as dating and kissing (Cole & Cole, 1993; Di

Giulio, 2003). In a recent study of adolescents with spinal cord injuries, Potgieter and Khan (2005) found that it is society's entrenched attitudes, rather than the limitations imposed by their disabilities, that limit opportunities for adolescents to express their sexuality. Adolescents with disabilities in this study reported that "typical" opposite sex peers held negative and rejecting attitudes towards them and as a result avoided romantic involvement.

However, parents, educators, and caregivers should take note that youth with developmental disabilities express the same sexual needs and desires as their peers and, indeed, often act upon these needs and desires. For example, Cheng and Udry (2002) suggest that between 36% and 52% of adolescents with physical disabilities in the United States have had sexual intercourse. Such numbers are disconcerting because sexuality education curricula created for adolescents without disabilities rarely address the needs or match the level of cognitive comprehension of individuals with developmental disabilities (Schwier & Hingsburger, 2000).

Löfgren-Mårtenson (2004) conducted a study to identify, describe, and understand sexuality and love for young people with developmental disabilities, looking at both the barriers and possibilities for love relationships and the expression of their sexuality. Participants included youth with developmental disabilities who attended social dances in their native Sweden. Parents and staff were also interviewed. Overall, Löfgren-Mårtenson (2004) found that a more independent new generation of youth with developmental disabilities is emerging. Their caregivers stated that they were hesitant and anxious about dealing with the topic of sexuality because they feared their loved one would become pregnant or sexually abused. On the other hand, they expressed the desire to support the sexual health needs of their child/client by providing them with skills in self-determination and independence. Overall, it has been suggested that staff members in particular need to increase their knowledge about sexuality for this new and ever-changing progressive group who seem to be embracing their sexuality with full force (Löfgren-Mårtenson, 2004).

Another potential risk to consider during adolescence is sexual abuse. According to Sobsey (1994), individuals who have developmental disabilities are at 150% more risk for abuse than their same sex peers. Carmody (1991) contends that community agencies that are supposed to protect these young people from sexual abuse are failing to recognize their specialized needs.

Sobsey (1994) argues that it is not the disability per say that increases the risk for abuse and exploitation, but rather *society's treatment* of persons with developmental disabilities. Cole and Cole (1993) note that an adolescent with a disability lives in a society that is not sensitive to his or her needs and may thus be at risk for stigma or humiliation. Keeping this in mind, parents are also hesitant about their children being unsupervised in social type settings. This strongly suggests that effective, comprehensive, and on-going sexuality education with a distinct sexual abuse prevention component is *imperative* within home and educational settings (Cole & Cole, 1993).

Topics that should not be overlooked in any sexual abuse prevention program include personal safety, inappropriate versus appropriate social and sexual behaviour, saying NO, and effectively reporting cases of abuse, assault, and exploitation (Di Giulio, 2003). In a recent study, Murphy (2003) found that an educationally based curriculum was effective at enhancing sexual abuse knowledge in a population of people with developmental disabilities. This is consistent with previous research showing that sexuality education programs are a catalyst for helping foster knowledge and skills in abuse prevention (Blanchett & Wolfe, 2002; Lee & Tang, 1998; Sobsey, 1994; Whitehouse & McCabe, 1997).

Such programs must be evaluated in order to assess their efficacy (Blanchett & Wolfe, 2002; Griffiths, Watson, Lewis, & Stoner, 2004; Muccigrosso, 1991). As well, in order to be effective, sexuality training must be continuous and persistent from the early formative years, through adolescence, and into adulthood.

The Adult years: 21 – 55 years old

As a 28 year old, Samantha has recently moved into a group home with three other individuals who also have various developmental disabilities. Her parents feel that she needs to be more involved socially with people her own age in the community. Her parents are getting older and it has become increasingly difficult for them to provide adequate care for their daughter.

In the community, there is a man named Ray that Samantha has grown quite fond of. Ray works with her at her workplace where they see each other weekly. He too, has expressed an interest in Samantha and has told her so. Eventually, their friendship developed into something more, and for the past several years, they refer to each other as “boyfriend and girlfriend.” Naturally, they would like to see each other more than just at work, however this usually depends on staff and what is happening (e.g., appointments) in their group homes. They would like to take the next step in their relationship and become intimate. A few times they have been caught at work embracing and kissing. Their supervisor informed them that this behaviour was inappropriate and that they needed to do it in private. Samantha and Ray talk openly about being intimate; they would like to find a space where it would be appropriate to have sexual intercourse. Often, they discuss the possibility of marriage one day. Samantha and Ray realize that they too are getting older and, as such, discuss having children. Although they are uncertain about children, they have not ruled it out; in considering this, they often think about the long-term ramifications.

McConkey and Ryan (2001) stress the powerful role that professionals play in the lives of people with developmental disabilities. For example, the attitudes of support staff in residential and day programs toward sexuality greatly influence the sexual and social behaviour of their clients (Wolfe, 1997). People with developmental disabilities may often find themselves adjusting to the attitudes of different staff, thereby experiencing additional confusion (McConkey & Ryan, 2001).

The results of Yool, Langdon, and Garner (2003) suggest that attitudinal change toward the liberal viewpoint of staff was more apparent over time when comparisons were made in the 1970s, early 1980s, and the late 1980s to early 1990s. The attitudes of staff are seen in a survey by Christian, Stinson, and Dotson (2001). Ninety-one percent of the respondents felt that sexuality was a vital component in the lives of women with developmental disabilities and almost 96% felt that freedom of expression of sexuality should be encouraged. A majority of respondents reported that health care, reproductive rights, marriage, and having children were all relevant issues in the lives of their clients, albeit 44% of respondents stated that there were other more critical issues to focus on (Christian et al., 2001). Staff are clearly sensitive to the sexuality issues of their clients. However, although staff felt competent in providing their clients with sex education (93%), only a small number were actually trained to adequately do so (7.1%).

Similarly, McConkey and Ryan (2001) revealed, from their self-completed staff questionnaire, that only 22% of respondents had had previous training or course work in sexuality, "with only 11% of *direct care staff* having taken a course" (p. 86). Forty-six percent of surveyed staff revealed a preference for additional sexuality training with the intention of feeling more confident in dealing with such issues (Christian et al., 2001). Thus, staff training in areas such as gynecological care and supporting the expression of sexuality is paramount so that women with developmental disabilities can face the unique barriers that often hinder their ability to lead a sexually and socially fulfilling life (Christian et al., 2001).

The attitudes and perceptions of the public on the sexuality of those with disabilities are just as consequential as the attitudes of staff. Karellou (2003) investigated the attitudes of laypeople in Greece with respect to the sexuality of individuals with developmental disabilities. Age and level of education had a main effect on attitudes. Younger respondents reported more liberal and contemporary attitudes than those over 45 years of age. Also, a positive correlation was found between level of education and liberal attitudes. In general, respondents were accepting of masturbation in private and the provision of sexual education. In

contrast, homosexuality among people with developmental disabilities was viewed negatively (Karellou, 2003). The general public's attitudes about sexuality for people with developmental disabilities affects the way they are treated and their human rights.

Experts such as Hingsburger (1995) declare that the sexual needs of people with developmental needs are similar to those of other human beings, yet it is common to see people's needs as different simply because of their disability. Similarly, Shakespeare (2000) states that intimacy, relationship building, warmth, validation, and a sense of connection to others is just as critical to people with developmental disabilities as it is to typically developed adults. They also need and desire feelings of love and companionship, perhaps more than the need sexual intercourse. There is no validity to popular beliefs that people with disabilities are over-sexed and sexually promiscuous (Di Giulio, 2003; Griffiths, 1999; Shakespeare, 2000).

It is clearly important that people's needs are met and that their concerns are addressed. This must include the right to a homosexual or bisexual orientation (McCarthy, 1996; Thompson, 1994), and to accommodations for the unique sexual needs associated with particular disabilities (Griffiths, Richards, Fedoroff, & Watson, 2002). It is imperative that opportunities are made available upon the request of individuals, and that the appropriate skills are taught to create personal successes in the intimate and sexual lives of persons with disabilities.

The senior years: 55 years and older

Samantha is now 55 years old and is living with a roommate in a supervised apartment. Her father passed away a few years ago and her mother resides in a home for the aged. Throughout her adult years, Samantha has maintained her relationship with Ray and the couple is still "boyfriend and girlfriend." Over the years, they have grown to love each other deeply and care for one another's personal wellbeing. Regrettably, they no longer work together—it has become increasingly more difficult for them to spend time alone together. A support worker takes Samantha and Ray out on a "date" each Thursday night and they

also have opportunities to talk on the phone everyday. However, as any couple in a long-term monogamous relationship, they want to share their lives completely. Samantha and Ray have high hopes of one day becoming husband and wife and they tell everyone around them that this is their lifelong dream.

According to Cole and Cole (1993), “[w]e are sexual until our death” (p. 202). How long should people with developmental disabilities be obliged to wait to prove their commitment and love, and be granted the life they so long for? The implementation of social and sexuality education, staff training, parent training, attitude evaluation, policy statements, advocacy groups, and the positive shift of mainstream society’s attitudes, is not meaningful unless it is *truly* believed that all people are equal. Although the United Nations proclaimed in 1988 that “All human beings are born free and equal in dignity and rights,” Traustadottir (1990) states that people with developmental disabilities rarely have the same options and access to traditional roles as people without disabilities. This is clearly a failure in providing the most basic of human rights related to sexuality—love and marriage.

Conclusion

Sexuality is a fundamental need for human beings (Watson, Venema, et al., 2002). It is an integral part of being human and is a part of one’s personality that cannot be denied. In order to fully express their sexuality in a successful manner, individuals with developmental disabilities require the opportunity for social and sexuality training (Held, 1992; Watson, Griffiths, Richards, & Dykstra, 2002). Typically, this can be achieved through sex education in schools and community agencies. However, much of what is learned about sexuality is derived from mass media and formal classes that are either sensationalized or not tailored to the developmental needs of these individuals (Watson, Griffiths, et al., 2002).

It is important to realize that acquiring knowledge of sexuality is only useful once it is put into practice. Educators should bear in mind individual and group needs assessment, their level of functioning, and

appropriate instructional design when designing curricula. This, coupled with the support of family and staff, will enable successful transitions from childhood to adulthood; it will also ensure that people with developmental disabilities enjoy the rights and responsibilities as active members of society (Watson, Griffiths, et al., 2002) and a healthy and enriched quality of life (McCabe & Schreck, 1992).

Griffiths et al. (2002) draw attention to some of the unique sexual needs faced by individuals with disabilities. They are more likely to experience physical and medical challenges that interfere with their reproduction and sexual experience. For example, individuals with Down syndrome and Turner's syndrome are often infertile. This should be respected and dealt with sensitively when teaching sex education. Some specific disabilities such as Prader-Willi and Klinefelter syndrome are also related to the physical sexual difference of hypogonadism that makes individuals look physically different and affects their sexual self-esteem. Educators and staff members should be responsive to specific sexual needs and challenges faced by the individuals they support.

McCarthy (1996; 1999) and Thompson (1994) have also drawn attention to the unique needs of individuals with disabilities who have a homosexual orientation—an area often overlooked or altogether ignored in sex education programs. Many men with disabilities have sex with both men and women, although usually only their relationships with women are publicly acknowledged (Thompson, 1994). In fact, in McCarthy's (1996) study, only 24% of the men with disabilities said that they had not had sex with another man. McCarthy (1999) also draws attention to the unique needs of lesbian women with disabilities, asserting that this population is almost entirely disregarded.

Only recently, society has begun to recognize that people with developmental disabilities are sexual beings who have the same needs for affection, intimacy, and sexual gratification as those without disabilities (Shakespeare, 2000). Society has evolved significantly since the days of sexually segregated institutions, mass involuntary sterilization, and debilitating misconceptions and myths of people with disabilities as sexually deviant and crazed (Christian et al., 2001;

Karellou, 2004; Di Giulio, 2004; King & Richards, 2002). Although much progress has been made since the late 19th century, society still needs to take responsibility to remove the remaining barriers that are placed upon the sexual lives of people with disabilities.

Davis (2002) claims that the primary barrier to sexual health is societal values that hinder the sexual development and overall positive sexuality of this population (Giulio, 2003; Karellou, 2004). Parents, educators, support staff, and health care professionals need to consistently provide advocacy and support so that negative, prevailing myths and dehumanizing misconceptions can be completely eliminated.

People with developmental disabilities are sexual at all stages of life and face many obstacles regarding their sexuality. In childhood, they require early intervention in areas of privacy and boundary acceptability, appropriate versus inappropriate sexual behaviour, and knowledge about socialization and friendship building. Parents play a large role in teaching about self-worth that enhances their self-esteem and their perceptions of themselves as social and sexual beings. In adolescence and early adulthood, people with developmental disabilities face typical young adulthood experiences such as social interactions with peers and the opposite sex, but not without the added barrier of overprotected and fearful parents. Sexual abuse becomes more of a concern to parents as children develop physically, emotionally and sexually.

In adulthood, people with developmental disabilities often face more independence as they begin residing in supervised group home settings. They may experience negative attitudes held by support staff and systemic barriers to sexual health such as policies that do not allow access to sexual partners or privacy and less access to current and relevant sexual health information (Di Giulio, 2003). Those fortunate enough to find a significant other, like Samantha, are not without difficulties. Issues of wanting to marry, take birth control, have children, or go for relationship counselling may present as uphill hurdles (Di Giulio, 2003).

Finally, the aging years can be just as taxing with respect to achieving a healthy sexual life as compared to earlier stages of life. Samantha clearly struggled with trying to achieve her lifelong dream of marriage—this was still prominent in the senior years of her life. Stated eloquently by Langfeldt and Porter (1986), “sexuality is an integral part of the personality of everyone: man, woman, and child. It is a basic need and an aspect of being human that cannot be separated from other aspects of human life” (p. 5). All beings must work toward this philosophy a little every day.

References

- American Academy of Pediatrics. (1999). Sexuality education of children and adolescents with developmental disabilities. *Pediatrics, 97*, 275-278.
- Ballan, M. (2001). Parents as sexuality educators for their children with developmental disabilities. *SIECUS Report, 29*, 14-19.
- Blanchett, W. J., & Wolfe, P. S. (2002). A review of sexuality education curricula: Meeting the sexuality education needs of individuals with moderate and severe intellectual disabilities. *Research & Practice for Persons with Severe Disabilities, 27*, 43-57.
- Buck v. Bell, 274 U.S. 200 (1927).
- Bradley, E., & Burke, L. (2002). The mental health needs of persons with Developmental disabilities. In D. Griffiths., C. Stavrakaki, & J. Summers (Eds.), *Dual Diagnosis*, (pp. 45-79). Toronto, ON: Habilitative Mental Health Resource Network.
- Carmody, M. (1991). Invisible victims: Sexual assault of people with an intellectual disability. *Australia and New Zealand Journal of Developmental Disabilities, 17*, 229-236.
- Cheng, M. M., & Udry, J. R. (2002). Sexual behaviors of physically disabled adolescents in the United States. *Journal of Adolescent Health, 31*, 48-58.
- Chivers, J., & Mathieson, S. (2000). Training in sexuality and relationships: An Australian model. *Sexuality and Disability, 18*, 73-80.
- Christian, L., Stinson, J., & Dotson, L. A. (2001). Staff values regarding the sexual expression of women with developmental disabilities. *Sexuality and Disability, 19*, 283-291.

- Cole, S., & Cole, T. (1993). Sexuality, disability, and reproductive issues through the lifespan. *Sexuality and Disability, 11*, 189-203.
- Cuskelly,, M. & Bryde, R. (2004). Attitudes towards the sexuality of adults with an intellectual disability: Parents, support staff, and a community sample. *Journal of Intellectual & Developmental Disability, 29*, 255-264.
- Davis, L. A. (2002). People with cognitive, intellectual and developmental disabilities & sexual offenses. *The Arc*: Author.
- Di Giulio, G. (2003). Sexuality and people living with physical or developmental disabilities: A review of key issues. *The Canadian Journal of Human Sexuality, 12*, 53-68.
- Dotson, L. A., Stinson, J., & Christian, L. (2003). "People tell me I can't have sex": Women with disabilities share their personal perspectives on health care, sexuality, and reproductive rights. *Women & Therapy, 26*, 195-209.
- Gilby, R. (1993). Parental concerns around sexuality education for their developmentally disabled children. *Sexuality & Developmental Disability: Sicann Newsletter, 28*, 9-13.
- Griffiths, D. M. (1999). Sexuality and people with developmental disabilities: Misconceptions and facts. In I. Brown., & M. Percy (Eds.), *Developmental disabilities in Ontario* (pp. 443-452). Toronto, ON: Front Porch.
- Griffiths, D. M., & Lunskey, Y. (2000). Changing attitudes towards the nature of socio-sexual assessment and education for persons with developmental disabilities: A Twenty-year comparison. *Journal on Developmental Disability, 7*, 16-33.
- Griffiths, D. M., Richards, D., Fedoroff, P., & Watson, S. L. (2002). Sexuality and mental health issues. In D. M. Griffiths., C. Stavrakaki, & J. Summers (Eds.), *Dual diagnosis: An introduction to the mental health needs of persons with developmental disabilities* (pp. 419-454). Sudbury, ON: Habilitative Mental Health Resource Network.
- Griffiths, D. M., Watson, S. L., Lewis, T., & Stoner, K. (2004). Sexuality research and persons with intellectual disabilities. In E. Emerson., C. Hatton, T. Thompson, & T. Parmenter (Eds.), *International handbook of methods or research and evaluation in intellectual disabilities* (pp. 311-334). London: John Wiley and Sons.

- Held, K. R. (1992). Ethical aspects of sexuality of persons with mental retardation. *Sexuality and Disability, 10*, 237-243.
- Hingsburger, D. (1990). *"I" contact: Sexuality and people with developmental disabilities*. Mountville, PA: Vida Publishing. Instituto de Sexologia Y Psicoterapia Espill. (1997). *Valencia declaration on sexual rights*. Valencia, Spain: Author.
- Karellou, J. (2003). Laypeople's attitudes towards the sexuality of people with learning disabilities in Greece. *Sexuality and Disability, 21*, 65-84.
- Katz, G. (1998). Sexuality groups for adolescents with developmental disabilities. *Journal on Developmental Disabilities, 6*, 73-88.
- Kempton, W., & Kahn, E. (1991). Sexuality and people with intellectual disabilities: An historical perspective. *Sexuality and Disability, 9*, 93-111.
- King, R. & Richards, D. (2002) Sterilization and birth control. In D. Griffiths., D. Richards, P. Fedoroff, & S. L. Watson (Eds.), *Ethical dilemmas: Sexuality and developmental disability* (pp. 227-254). Kingston, NY: NADD Press.
- Langfeldt, T. & Porter, M. (1986). *Sexuality and family planning: Report of a consultation and research findings*. Copenhagen, Denmark: World Health Organization.
- Lee, Y. K., & Tang, S. C. (1998). Evaluation of a sexual abuse prevention program for female Chinese adolescents with mild mental retardation. *American Association on Mental Retardation, 103*, 105-116.
- Löfgren-Mårtenson, L. (2004). "May I?" About sexuality and love in the new generation with intellectual disabilities. *Sexuality and Disability, 22*, 197-207.
- Mayers, K. S., Heller, D. K., & Heller, J. A. (2003). Damaged sexual self-esteem. A kind of disability. *Sexuality and Disability, 21*, 269-282.
- McCabe, M. P. (1993). Sex education programs for people with mental retardation. *Mental Retardation, 31*, 377-387.
- McCabe, M., & Schreck, A. (1992). Before sex education: An evaluation of the sexual knowledge, experience, feelings, and needs of people with mild intellectual disabilities. *Australia and New Zealand Journal of Developmental Disabilities, 18*, 75-82.
- McCarthy, M. (1996). The sexual support needs of people with learning disabilities: A profile of those referred for sex education. *Sexuality and Disability, 14*, 265-279.

- McCarthy, M. (1999). *Sexuality and women with learning disabilities*. London: Jessica Kingsley.
- McConkey, R., & Ryan, D. (2001). Experiences of staff in dealing with client sexuality in services for teenagers and adults with intellectual disability. *Journal of Intellectual Disability Research*, 45, 83-87.
- Muccigrosso, L. (1991). Sexual abuse prevention strategies and programs for persons with developmental disabilities. *Sexuality and Disability*, 9, 261-271.
- Murphy, G. H. (2003). Capacity to consent to sexual relationships in adults with learning disabilities. *Journal of Family Planning and Reproductive Health Care*, 29, 148-149.
- Potgieter, C., & Khan, G. (2005). Sexual self-esteem and body image of South African spinal cord injured adolescents. *Sexuality and Disability*, 23, 1-20.
- Seltzer, M. M., & Krauss, M. W. (2001). Quality of life of adults with mental retardation/developmental disabilities that live with family. *Mental Retardation and Developmental Disabilities*, 7, 105-114.
- Schwier, K. M., & Hingsburger, D. (2000). *Sexuality: Your sons and daughters with intellectual disabilities*. Baltimore: Paul H. Brookes Publishing.
- Shakespeare, T. (2000). Disabled sexuality: Towards rights and recognition. *Sexuality and Disability*, 18, 263-282.
- Sobsey, D. (1994). Sexual abuse of individuals with intellectual disability. In A. Craft (Ed.), *Practice issues in sexuality and learning disabilities* (pp. 93-115). London: Routledge.
- Thompson, D. (1994). Sexual experience and sexual identity for men with learning disabilities who have sex with men. *Changes*, 12, 254-263.
- Traustadottir, R. (1990). *Obstacles to equality: The double discrimination of women with disabilities*. Retrieved on September 29th, 2005 from <http://dawn.thot.net/disability.html>.
- Vansteenwegen, A., Jans, I., & Revell, A. T. (2003). Sexual experience of women with a physical disability: A comparative study. *Sexuality and Disability*, 21, 283-290.
- Watson, S., Griffiths, D., Richards, D., & Dykstra, L. (2002). Sex education. In D. Griffiths, D. Richards, P. Fedoroff, & S. L. Watson (Eds.), *Ethical dilemmas: Sexuality and developmental disability* (pp. 175-225). New York: NADD Press.

- Watson, S. L., Venema, T., Molloy, W., & Reich, M. (2002). Sexual rights and individuals who have a developmental disability. In D. Griffiths., D. Richards, P. Fedoroff, & S. L. Watson (Eds.), *Ethical dilemmas: Sexuality and developmental disability* (pp. 175-225). New York: NADD Press.
- Whitehouse, M. A., & McCabe, M. P. (1997). Sex education for people with intellectual disability: How effective are they? *Education and Training in Mental Retardation and Developmental Disabilities*, 229-240.
- Wolfe, P. S. (1997). The influence of personal values on issues of sexuality and disability. *Sexuality and Disability*, 15, 69-89.
- Yool, L., Langdon, P. E., & Garner, K. (2003). The attitudes of medium-secure unit staff toward the sexuality of adults with learning disabilities. *Sexuality and Disability*, 21, 137-150.

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