University of Alberta

Best-Practice: Developing Guidelines for Sexuality Education for Children with Cerebral Palsy

by

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Dedication

To Ma
You are truly a legend

Abstract

Research has documented what needs to be included in a sex education program for the disabled population. However none of the researchers have elicited information directly from the individuals in question. The purpose of this phenomenological study was to develop guidelines for a sex education program made specifically for the CP population through understanding their lived experiences with regards to the sexuality education they received. Semi structured interviews and a focus group session was conducted with adults with CP. Thematic content analysis of data suggested that health care professionals need to work towards fostering positive attitudes towards sex and dispelling myths such as '*the disabled are asexual'*. The traditional curriculum should be altered to include essential topics like self esteem and body image. A comprehensive sex education program would empower individuals with CP to attain sexual fulfillment and simultaneously be able to protect themselves from unwanted sexual encounters.

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CHAPTER 1

INTRODUCTION

> "Children and adolescents who have a physically or intellectual disability have the same concerns about sexuality as do other children. They must learn to cope with generally the same biological changes as other children, as well as the new sexual feelings and desires that come in early adolescence. However individual disabilities can complicate these tasks of growing up. Quality family life education can benefit disabled children in this process." (Thornton, 1981, p. 229)

The need to provide accurate sex information to individuals with a disability is immense. "A comprehensive sexuality education should address the biological, socio cultural, psychological and spiritual dimensions of sexuality" (Haffner, 1990). Inadequate education results in the inability to develop social and sexual relationships. This prevents individuals, regardless of whether they have a disability or not, from functioning effectively within a society (Couwenhoven, 2001).

What is Cerebral Palsy?

Cerebral palsy (CP) refers to a "non progressive disturbance of the nervous system function characterized by an abnormality of motor function and posture or an aberrant movement disorder" (Eiben & Crocker, 1983). Depending on its etiology, it can be congenital or acquired (Scherzer & Tscharnuter, 1990). The symptoms range from mild to severe and the condition gets worse as the child grows older. With treatment most children can significantly improve their abilities.

In addition to the motor deficits, other associated disabilities/impairments are frequently present. These include abnormalities of vision, hearing and speech, seizure disorders, mental retardation, learning disabilities and frequent social and emotional problems (Eiben & Crocker, 1983). Many times, CP may be confused with other non progressive central nervous system disorders. However the primary motor nature of the condition can be used as an indicator to differentiate it from other disorders like mental retardation, organic brain deficits, attention deficit disorder and autism (Scherzer & Tscharnuter, 1990).

Types of Cerebral Palsy

CP can be classified according to the motor types, distribution and severity. The different motor patterns exhibited are dependant on the site of the lesion. The most common is the spastic variety which is due to a fixed lesion in the motor portion of the cerebral cortex and pyramidal tract dysfunction. Other forms, such as athetosis or dystonia, are associated with lesions in the extrapyramidal pathways, while ataxia results from cerebellar lesions. Rigidity suggests a severe decerebrate lesion (Scherzer & Tscharnuter, 1990).

The effect of the lesion is also seen in the variable distribution pattern. In monoplegia, one extremity is affected, whereas in hemiplegia one half of the body is affected. Both the lower extremities are affected in paraplegia while quadriplegia indicates equal involvement of the upper and lower extremities. Lastly, diplegia is a form of quadriplegia with mild upper limb involvement (Scherzer & Tscharnuter, 1990).

CP can also be categorized on the basis of severity as mild, moderate or severe (Scherzer & Tscharnuter, 1990). These classifications are essential aspects of the CP diagnosis because they give meaning and direction to treatment and management of the patient. See Appendix A for a brief summary of factors that cause CP.

Sexuality

Sexual health is integration of the somatic, emotional, intellectual and social aspects of sexual being, in ways that are positively enriching and that enhance personality, communication and love (World Health Organization (WHO), 2004).

According to Littner, Littner and Shah (2001) describe sexuality as a composite term that includes the biological, sociological and spiritual aspects of a person. Sexuality is made up of bodily changes, gender identification, and a collection of behavioural manifestations. The authors go on to say that the extent of sexual maturity has an impact on quality of personality development as well as interpersonal relations.

“Sexuality should be considered in a context that extends beyond genital sex to include gender-role socialization, physical maturation and body image, social relationships, and future social aspirations. Like all adolescents, teens with disabilities may express desires and hopes for marriage, children, and normal adult sex lives. In fact, adolescents with physical disabilities are as sexually experienced as their peers without disabilities.” (Murphy & Elias, 2006)

Integration of these aspects of sexuality contributes to the overall health of individuals (WHO, 2004). Imparting comprehensive sexuality education holds as much importance as integration of various aspects of sexuality with regards to the overall health of person (Sweeney, 2007).

Disability

Impairment refers to a loss or abnormality of physical or psychological structures or functions. When impairment is severe enough to limit a person's ability to perform the activities of daily living, work and productive activities, or play and leisure activities, the individual has a disability. When an impairment or disability interferes with the person's ability to complete activities that fulfill the essential responsibilities and duties of a social role, he or she is defined as being handicapped (WHO, 2004).

According to the World Health Organization (2004), disability can also be thought of as an umbrella term, covering impairments, activity limitations, and participation restrictions. Impairment is a term used to describe a deficiency either in body functioning or structure. Activity limitation occurs when an individual has trouble executing a task or action. Participation restriction is a problem encountered by an individual in involvement in life situations. Disability therefore is complex and reflects the interplay between an individual's functioning and elements of the surrounding society

The number of children and adolescents in North America with chronic, disabling conditions has multiplied significantly (Hallum, 1995; Wolman & Basco, 1994). The Health of Canada's Children: A CICH Profile has documented approximately 564 575 children and youth between birth and 19 years of age that had disabilities in the year

1996-97 (The Health of Canada's Children, 2001). This figure represented 7.7% of that population. According to the 1991-92 U.S. Bureau of the Census Current Population Report, there were 48.9 million Americans with a disability. This number was 19.4% of the total population (US disability statistics).

Sexual Dysfunction

Masters and Johnson (1966) identified four phases of normal human sexual response cycle. An impairment or disturbance in any of these four stages is viewed as a sexual dysfunction (Wincze & Carey, 2001). Sexual dysfunction of any kind is almost a disability in itself (Stewart, 1979) Sexual dysfunction in children with CP is usually a result of physical impairments and psychogenic factors like low self esteem, lack of confidence and most importantly lack of sexual information (Thornton, 1981) This is worsened by the attitudes of people without disabilities. Individuals with disabilities are thought of as one single unit wherein all of them have similar notions about sexuality and sexual health (Sexuality Committee of Bloorview Childrens Hospital (SCBCH), 1985). This is completely false because depending on the physical and cognitive limitations each person with a disability has his or her own unique definition of their sexuality. These attitudes prevent people with disabilities from expressing their true sexual sense thereby compromising sexual health (Stewart, 1979).

Cerebral Palsy and Sexuality

"I walked around with my head in the clouds most of my early life because I was trying to avoid my body and I did not associate sexuality with my body. I associated it with my emotions and with my spirit. The sexual feeling I had, I saw others having also, but they were not disabled. I thought, "I have these feelings too, but I am ashamed because am not supposed to have them. So I walked around with a lot of emotional pain." (Thornton, 1981, p 229)

The above statement is from an individual with CP and it aptly sums up the feelings sexuality evokes in the lives of these individuals. Sexuality is an unexplored territory simply because they don't have the necessary tools to help them do so. Lack of knowledge is one of the greatest barriers. Individuals with CP deem themselves as being asexual right from the time they begin to understand what sexuality is all about. This is because being sexual is equated to the ability to have sexual intercourse and not being able to do so is the same as being asexual! (SCBCH, 1985)

Sexuality in these individuals generally revolves around two axes. The first is dissatisfaction with body image and the second is social isolation due to disability (Thornton, 1981). A sexually healthy adolescent needs to be able to appreciate their own body. This is difficult to achieve by an individual with a disability and thus sexuality is once again hampered. Additionally, absence of peer group interaction results in lack of informal discussions on sexuality. For instance, traditional sex education programs do not cover topics like masturbation or wet dreams. These are uncovered when friends interact informally within a group. Since people with disabilities do not have the opportunities for such interactions, this valuable source of knowledge is lost to them (Stevens et al., 1996). Also social skills that are of utmost importance in adolescence, remain underdeveloped due to lack of opportunities to observe, learn and practice them (Couwenhoven, 2001).

There are also the physical limitations due to the disability itself. For instance an individual with spastic CP may not be able to have intercourse in the male on top position. Sexual excitement tends to bring on or augment spasms and heighten reflexes (Stewart, 1979). A person with athetoid type CP will have difficulty controlling movements during lovemaking. Furthermore problems such as spasms, muscular weakness, and incontinence diminish whatever sensual pleasure is experienced (SCBCH, 1985). Sadly the literature doesn't have material on specific techniques which can be utilized by these individuals.

Problem statement

It has been found that individuals with disabilities have to confront issues and challenges which are very similar to those of the able bodied population, as well as a variety of additional issues that arise solely as result of their disability. The myth most prevalent in today's society is that children with disabilities are asexual and consequently do not need education about their sexuality (Sugar, 1990). However, it has been found that person's with disabilities have similar curiosities, drives and interests in their own bodies and those of others (American Academy of Paediatrics, 1996). Even more critical is the issue that children with disabilities may be more vulnerable to sexual abuse, as it is reported that children with disabilities are more than twice as likely to be sexually abused as children without disabilities (Murphy & Young, 2005). This is clearly an issue that needs to be addressed in order to inform and protect our children.

Empowering children and adolescents with the knowledge and understanding of various sexual issues that are relevant to their physical abilities will allow them to make safe and appropriate decisions regarding their sexuality and sexual practice (Murphy & Young, 2005). The purpose of this phenomenological study is to better understand the lived experiences of children and adolescents with CP with regards to the sexual health education they received and its impact on their personal views and perceptions of sexual health.

CHAPTER 2

REVIEW OF LITERATURE

Sexual and Social Development

Sexuality and how it develops is very much dependant on ones social and sexual maturity. Both these aspects play key roles in development of each other as well as the overall self. Sexuality does not develop independently from other parts of self (Edwards & Elkins, 1988).

The term adolescence is used to describe the period of time between 12 to 19 years of age (National Information Center for Children and Youth with Disabilities (NICHCY), 1992). During this period the child experiences biological, psychological as well as social changes. At the end of this transitional period the child matures into an adult who has a greater sense of independence, autonomy and personal identity (Kelly, 2008).

Puberty is characterized by enormous physical change brought about by the changes in hormonal production (NICHCY, 1992). The physical changes are accompanied with emotional changes, mood swings, obsession with ones appearance, varying degrees of self consciousness and extreme sensitivity (Dacey, 1986).

Adolescence is a strenuous period not only for the teenager but also for the parents, more so for parents of children with disabilities. Parents find it difficult to find a balance between making decisions for their children and letting the children do it for themselves. More often, parents have strong urges to protect their adolescents from engaging in behaviour for which they are not emotionally or cognitively ready

(Tharinger, 1987). On the other hand, teenagers strive to develop an identity separate from their parents (Dacey, 1986).

This period of time marks the formation of important social relationships (Murphy, 2005). Through these relationships, adolescents learn about social norms and expectations. The manner in which they respond to these expectations serves to mould their personality, self esteem and confidence (Kelly, 2008). Sexuality and sexual desire begin to play an important role from the onset of puberty. The most prevalent form of sexual activity during this time is masturbation (DeLamater & Friedrich, 2002). An important characteristic seen during this period is the formation of sexual preferences or sexual identity. During this time, most adolescents are able to categorize themselves as being heterosexual, homosexual or bisexual (DeLamater & Friedrich, 2002). Values and morals play an important part in development of sexual attitudes as do interaction with peers and media (Wolfe, 1997). They are also able to set personal limits regarding sexual behaviour and can therefore comprehend what is openly acceptable and what should be done privately (Kelly, 2008). In order to become comfortable with one's own sexuality it is essential for every child to go through all the steps that contribute to a healthy social development (NICHCY, 1992).

These years are crucial for the development of sexuality in individuals with disabilities as well. Unfortunately their disability may impact the transition from childhood to adulthood to such an extent that the development of sexuality is sidelined and parents, therapists and everyone working with the child put extra efforts in other areas like enabling communication with peers etc (Tepper, 2001). Adolescents with disabilities usually go through the same biological changes as their able bodied peers (NICHCY, 1992).

Societal Attitudes

Our society today seems to have a sex negative approach as opposed to a sex positive one (Kelly, 2008). Sex and sexuality are seen as dirty and unhealthy and something that should be brought up only within the privacy of one's home. There are however cultural differences in terms of the extent to which this topic is taboo (Stockdale, 2003). Whatever the case, most adolescents get mixed signals regarding how best to deal with anything sexual. Consequently, they are not adequately educated on the topic of sexuality. This coupled with the fact that adolescence comes with "I can never be wrong attitude", makes them increasingly susceptible to serious problems like sexually transmitted infections and unwanted pregnancies (Kempner, 2003).

It is has been found that societies that accept sexual interaction as normal and healthy part of adolescent development have lower rates of teen pregnancies and sexually transmitted infections (Lottes, 2002). The journey from sex negative to sex positive approach needs to be expedited if adolescents are to acquire sexual attitudes and behaviours that will help them transform into sexually healthy and happy adults (Kelly, 2008).

The need for sexual education is therefore immense. Most programs teach students about condom use, sexual decisions and transmission of sexually transmitted disease (Chipouras et al., 1979). They neglect to bring up topics which adolescents end up learning from their peers or the media. Both these sources are laden with misinformation and exaggeration (Landry et al., 2003)

Sex Education Today

Sex education occurs both formally and informally. Informal sources include information provided at home, through the media, in conversation with friends etc. The formal programs are what are taught at the school level. These programs include topics like anatomy of sexual organs, sexual response cycle, typical sexual development, contraception and sexually transmitted diseases (Chipouras et al., 1979).

The goals of a typical sex education program are to help people "achieve positive outcomes" and to "avoid negative outcomes" (Health Canada, 2003). Self esteem, respect for others etc are considered as positive outcomes whereas as unwanted pregnancies, STIs are considered negative outcomes (Health Canada, 2003).

Sexuality in People with Disabilities and its Implications for Sex Education

Sexuality in people with disabilities continues to be an abstract concept owing to cultural barriers, societal frameworks and misplaced notions of how too much information might encourage sex (Kelly, 2008). Despite that, the niche sexuality holds in defining who we are can't be undermined. Sexuality and our personal definition of what it means to us form an important aspect of our personalities (Chipouras et al., 1979).

Unfortunately, this doesn't seem to hold true for individuals with disabilities. These individuals seem to have to abide by a different set of rules in comparison to the rest of the society (Sweeney, 2007). They have to constantly face up to a variety of myths created by the rest of the population. One of the most common myths they face time and again is that "they are asexual and consequently don't need any education about their sexuality (Sugar, 1990). It is assumed that the only kind of relationship that might interest them is that of friendship. Even in cases when they are found attractive by the opposite sex, nobody ever approaches them because it is assumed that the person already has so many problems that sex is the last thing on their minds (SCBCH, 1985). As teenagers' people with disabilities find they constantly endeavour to make peers realise that it is their bodies which are impaired and not their sexual feelings. In certain instances it is thought that people with disabilities don't have sensations hence commencing anything remotely sexual is futile (Stewart, 1979).

These myths are never clarified for various reasons. The most obvious reason seems to be limited understanding of disability and how it impacts various areas in the life of the person with a disability. Also the general societal attitude towards people with disabilities is that of pity or sympathy. Therefore people hesitate to broach sensitive issues for fear of causing more pain than necessary. Sometimes they are sheltered from these topics just for convenience sake! (Chipouras et al., 1979)

However, research during the past decade has proven that on the contrary, issues of sexuality are as important to children and adolescents with disabilities as they are to able bodied kids (American Academy of Paediatrics, 1996). Children with disabilities have normal curiosities, drives and interests in their bodies and in the bodies of others (Tepper, 2001). A study conducted at the University of Minnesota showed that adolescents with chronic disabilities exhibit sexual behaviour and have a sexual orientation which is similar to that of adolescents without disabilities. Also they are at a significantly higher risk of contracting STDs' (Suris et al., 1996).

Sexual behaviour is one which is learnt when an individual interacts within the society (Blum, 1984). Unfortunately children with CP are faced with greater social isolation in comparison to their healthy peers, thereby significantly restricting opportunities for normal sexual experimentation (Blum et al., 1991). This interferes with a normal social development. In addition to this, overprotection by parents and lack of awareness about their own sexual and reproductive capabilities further limits their sexual expression (Zeltzer, 1985). The combination of insufficient sexual education and poor social interaction results in children engaging in "acting out" behaviours such as having multiple partners or not using contraception (Zeltzer, 1985). It is therefore a vicious cycle which can only be interrupted by using a clear and straightforward approach towards sexuality.

Literature proves that parental concern about possible sexual abuse is very much a real issue and not a figment of their imagination (American Academy of Paediatrics, 1996). A recent report from the National Center on Child Abuse and Neglect found that for a representative sample of maltreated children studied, 36 of 1000 children with disabilities were maltreated, which is a rate 1.7 times higher than that for children without disabilities (Crosse et al., 1992).

Parents do not bring up the topic of sexuality not only because they feel their child is asexual but also because they feel this might result in them getting sexually exploited or becoming pregnant (Murphy & Young, 2005).They don't realize the best means of protecting their children is providing a comprehensive sex education and making it clear that they possess the rights to refuse unwanted sexual advances (American Academy of Paediatrics, 1996).

Research shows that another factor that plays a role is parental over protectiveness (Guest, 2000). Parents often firmly believe that their child with a disability does not have what it takes to be able to initiate or sustain a romantic relationship with anyone (Zeltzer, 1985). They end up shielding their child from any such social interaction thinking it is in the best interest of the child when infact it is the converse which is true! Sometimes it is cultural barriers which prevent adequate sexuality education. Moral and value systems play a role in sexuality education leading to lack of open and straightforward discussions (Berman et al., 1999).

Like able bodied children, children with disabilities also begin to respond to hormonal changes and sexual feelings once they attain puberty (Murphy, 2005). These children have been known to occasionally engage in socially inappropriate sexual behaviour like rubbing himself or herself in public, touching the genital region etc (Dennis, 2004). The most common response from parents and health care professionals to this sort of behaviour is embarrassment. Lack of awareness, and the uncomfortable nature of the topic of sexuality, results in parents and teachers wondering how best to confront such situations (Littner et al., 2001).

It is apparent that children with disabilities who have had the opportunity to be sexually educated have a more optimal transition into adulthood as compared to those who are not exposed to sexuality education. They have positive socials skills, are more assertive and independent and most importantly are at a reduced risk of sexually transmitted diseases and unwanted pregnancies (Sweeney, 2007).

These issues need to be resolved thereby enabling children with disabilities to fully explore and experience their own unique sexuality. As Berman et al., (1999) puts it health care workers, parents and teachers need to work together to come up with a holistic approach that can be employed when dealing with adolescents with special needs. It needs to be understood that no one profession can be designated the responsibility of imparting sex education since attempting to do so had resulted in a situation where no knowledge is imparted at all.

"It is essential that all those who work and live with individuals with special needs guard against making inaccurate assumptions. By avoiding misinformation and a restrictive attitude towards sexuality of developmentally delayed individuals, and by recognizing sexuality as a multidimensional process that crosses the lifespan, healthy sexuality can be championed and celebrated" (Sweeney, 2007).

Cerebral Palsy and Sex Education

Like most adolescents, children and teenagers with CP have dreams about marriage, and attaining satisfying sex lives (Berman et al., 1999). However, they are faced with a misplaced notion that they are asexual or have different sexual desires than the able bodied population. In contrast, some members of the society view them as aggressively sexual with uncontrollable urges (Neufeld et al., 2002). Even the people willing to interact with individuals with physical and/or mental disabilities hesitate to view them as dating or life partners. This brings up an important point that it is not only people with CP who need education on sex and disability but also the able bodied people so they can better understand the needs of this population.

It appears that sex education for children with CP is more often reactive than proactive. Inappropriate acts and behaviours occur more out of ignorance and are checked only after they occur (Couwenhoven, 2001). It's important to be aware of the various sexuality issues likely to arise at different times in the child's life so as to be proactive in handling the problem. This underscores the need for a sex education program that specifically targets the CP population.

Parents play a primary role in sexuality education of their children (Couwenhoven, 2001). However this is not usually the case. A study by Alcorn (1974) indicated that 80% of the parents felt that they should bear the primary responsibility for the sex educating their children yet more than half were unsure of their ability to do this. This is worsened by the fact that adolescents with CP are presumed to be asexual. Guest (2000) talks about how his father thought he would never be able to engage in sexual activity and so didn't need to be sexually educated. He went on to say that sexual education "is not simply a matter of imparting facts about biological sex, but the knowledge of sexuality is crucial for a child's personal development" (Guest, 2000, p. 138). It therefore comes as no surprise that adolescents with CP have limited knowledge to make informed decisions regarding their sexuality.

Most authors agree that sex education is an ongoing process and that it should begin as early as possible (Couwenhoven, 2001; Kelly, 2008; Gordon et al., 2001). A variety of views on what should be included in a sex education program for individuals with disabilities can be found in the literature. Marshak and Seligman (1993) identified several areas that should be taken into account when working with children with disabilities: a) emphasize on self image as an important aspect of sexuality; b) encourage development of social skills required for dating; c) educate clients on the side effects if any, of the medications they are on; d) educate clients on different adaptive techniques for sexual expression.

To summarize, sex education for the persons with a disability should encourage the shift of sexuality from being limited just to sexual intercourse and more towards a social phenomenon (Way, 1982) for regardless of our abilities, we are all social animals who require “friendship, warmth, approval, affection and social outlets” (Edwards & Elkins, 1988).

CHAPTER 3

METHODS

Ethics approval was received through the Health Research Ethics Board, Panel B (See Appendix B). A qualitative approach was used seeing that as Creswell (1998) wrote, it focuses on "how" and "what" of the study in contrast to "why". It aims to study the phenomenon in its natural surroundings and then interpret the phenomenon in terms of the meaning it brings to the people involved in the study. There has been some research on what should be included in a sex education program for persons with disability. However none of the researchers have had a specific target population in mind or elicited information directly from the individuals going through the lived experience. Through this study, we wanted to hear from the individuals who had true insight into the situation thereby giving us a perspective we have never heard before.

Among the five traditions of qualitative enquiries, phenomenology is therefore best suited to this study. As Patton (1990) and Creswell (1998) put it, phenomenology attempts to give meaning to the experiences individuals have with regards to a particular phenomena in a context specific setting. In this study, our goal was to understand and develop guidelines for sex education based on the lived experiences of the participants with regards to how the sexuality education information they received or lack of it, influenced their growing up with a disability.

Creswell (1998) notes that a phenomenological approach is one that suspends all judgments about what is real. This suspension is called epoche and is the central concept in phenomenology (Morse & Field, 1995). To best understand the phenomenon being studied, it is of paramount importance that the researcher brackets his thoughts and views i.e. put aside all preconceived notions thereby eliminating as much bias as possible (Moustakas, 1994).

As the researcher, I had to bracket my personal thoughts and experiences making it challenging to use phenomenology. Also, I had to be cognizant about the fact that the participants for the study needed to be chosen carefully to ensure that they had in fact experienced or were experiencing the phenomenon being studied (Creswell, 1998).

Sampling

The sampling technique employed in the study was purposive sampling. The researcher handpicked participants thereby ensuring that they had "lived" the phenomenon being studied. Since the study utilized a phenomenological approach, purposive sampling was the method of choice.

Sample Size

In keeping with the tradition of phenomenological study, the target sample size was as many as 10 individuals (Creswell, 1998). Participants were recruited till new data was emerging and theoretical saturation had not been achieved. The study sample comprised of nine individuals.

Recruitment strategies

Participants for the semi structured interviews and focus group were recruited using the following methods:

- Recruitment information was given to service providers and professional contacts working with individuals with CP.
- A mail out was done through the Cerebral Palsy Association of Alberta.

Inclusion/ Exclusion criteria:

- The participants were diagnosed with CP.
- The participants were eighteen years or older.
- The participants were required to have minimum communication skills and the ability to reflect and articulate abstract thoughts.
- No associated co morbidities for example head injury suffered during childhood.

Prior to the interviews, all participants were advised orally and in writing that their participation was voluntary and confidential and they could withdraw from the study at any time and without the need for an explanation.

Data Collection

This study was exploratory and descriptive in nature. It used the phenomenological approach to help gain insight into the meaning sexuality held for children and adolescents with CP. The two methods used for data collection were semi structured interviews and focus group. The participants received information sheets and consent forms prior to beginning the interviews and focus group. (See Appendix C for information sheet and Appendix D for consent form).

Demographic Data

The study sample consisted of five females and four males. The ages ranged from 27 to 62 with the mean age being 34.7 years. Four participants had or were pursuing college education whereas the remaining five had post secondary education. Three of the participants were married and one was engaged. Two participants had children.

Semi Structured Interviews

One to one, semi structured interviews were conducted with the participants. The location was selected by the participants as per their convenience. Before beginning the interview, consent was taken to digitally record the interview as well as take field notes. Field notes were taken to record observations and note the emerging themes. The interviews were transcribed as soon as possible after they were conducted, to ensure validity and accuracy (Morse & Field, 1995). During the interview the spotlight was on the lived experiences of participants with respect to sexual health education and associated issues. The interviews took approximately an hour each. See Appendix E for the interview guide. Transcription was done by an appropriate service provider to ensure confidentiality. After reviewing the transcriptions as well as the field notes, a concise summary of each interview was written. All the material from the interviews and focus groups was stored in a safe place accessible only to the researcher.

Focus group

The focus group had five participants and was conducted by the researchers at a designated location. Out of the five, three participants had also been part of the semi structured interviews. As with the interviews, the focus of the session centered on the experiences with sexual health education and associated issues. This meeting was used to gather new information and also confirm themes generated during the one to one interviews. This approach of member checking also helped reinforce the rigor of the study (Tuckett, 2005). The focus group lasted approximately 90 minutes. See Appendix F for the focus group guide.

CHAPTER 4

DATA ANALYSIS AND RESULTS

Analysis of the interviews was done using a format which combined a fourteen-stage approach described by Burnard (1991), and a six step guide to analysis described by Kvale (1996) (See Appendix G). The steps were categorization, condensation, narratives and interpretation. During categorization, the data was reviewed and detailed notes were made on general themes and categories discovered. Condensation involved narrowing down the categories and removing repetitive themes. Following this brief narratives were written describing the primary points under each category. In the final stage, the narrative under each category were linked up and compared to what has already been described in the literature about the impact disability due to CP had on sexuality and sexual relations of these individuals.

Analysis of the transcribed interviews uncovered the following themes regarding sex education of individuals with CP: 1) "We are not sexual beings." 2) "We might have non functional limbs but we have a brain!" 3) "Nobody wants to tell us anything." 4) "Sex education programs do not have adequate information." 5) "What we want our sex education program to look like." The focus group confirmed and clarified these themes. Additional themes that emerged were 6) "Are our parents protecting us or themselves?" and 7) "Sex education programs are a joke irrespective of whether they are targeting the able bodied population or persons with a disability!"

Theme one: "We are not sexual beings."

The participants felt they were viewed as asexual beings by the society including doctors, therapists and teachers. Health care professionals tended to refrain from providing any information pertaining to sexuality and sexual health. Participants felt that maybe one of the reasons why they were not provided with sexual health information was healthcare professionals felt that this information was not required. A bigger factor however seemed to be the fact that they didn't have the information required to adequately answer some of the questions that might arise. It's almost like there were set criteria of what the person with a disability could and couldn't do. One participant recalled an incident during her driving test where she was asked if she had been in an accident. She explained that she had a condition called CP. The response she got to that was, ***"too bad you are so beautiful."*** The participant thought to herself, ***"Really what does that have to do with anything!"*** In most cases family proved to be the one source of unconditional support. Sometimes family was reported to be not very encouraging when it came to sexuality partly because they felt they were saving the child from disappointments; for example, in one case the father told the child ***"you have to find somebody who has a disability."***

A subtheme of females facing a reproductive bias was also found. Attempts made by participants, to gather information on how best to deal with pregnancy and related issues were met with responses like ***"I would advise you not to have children".*** They found there was no objectivity in the counselling they received from health care professionals. One of the participants said, ***"So as a society, it's a weakness to be disabled, so I shouldn't be allowed to marry and have sex and have kids!"*** Another participant asked her doctor about the birth control pill and was told ***"oh you don't need to do that because you wouldn't like....when will you be having sex?'***

Most members of the society including friends, parents and doctors discouraged the idea of reproduction. This was partly because the physical limitations were thought to cause complications and partly because the mother was not thought to be fit enough to cater to the needs of the baby. Some reasons clearly reflected the lack of understanding of CP itself; for instance, some people discouraged reproduction for fear that the babies had chances of ending up with the condition too!

Theme two: "We might have non functional limbs but we have a brain!"

Having a milder form of CP increased societal perception of the individual as a sexual being. As one participant reported, ***"disabled people are hushed away and therefore don't make friends easily."*** This discrimination had a huge impact on self confidence and self esteem. The one thing they seemed to repeatedly ask themselves was, ***"how do I find someone who is ok with this?"*** It appeared that the lesser the level of disability, the easier it was to integrate with the able bodied population. If parents didn't discuss sexuality with them effectively then nobody did. This was further compounded by the fact that virtually no information was available on the subject.

Theme three: "Nobody wants to tell us anything."

All the participants agreed unanimously that there was almost no information available on sexuality and how to deal with it when one had CP. Books and TV shows that talked about sexuality and issues related to it provide information keeping the able bodied population in mind. Although television shows were pretty explicit they remained a relevant resource only for the able bodied. There was not even a small subsection that included persons with a disability. One of the participant quoted, ***"I love listening to Oprah or Dr. Phil about sexuality. I'm going like that's ok but how about the disabled? We are trying to cope with our sexuality and disability and there is no doctor who we can contact or who can wrote a book for us. Somebody should be out there teaching disabled sex."*** Another said ***"you never see anybody struggling to find a sexual position that is comfortable, that isn't going to mean that they fall on their head because they can't quite balance that way. It would be nice if somebody acknowledged that the sexual acrobatics you see on TV is just not an option when you have physical limitations."***

Theme four: "Sex education programs do not have adequate information."

The sex education programs attended by the participants as part of the school curriculum were not useful apart from providing a basic knowledge on issues common between people with and without disabilities; e.g. safe sex. Issues specific to disability were not addressed even with the presence of an individual with a disability in the classroom. There were no opportunities for asking private or intimate questions partly because of the teacher having inadequate knowledge required to answer the questions that might arise and partly because the classes were held with boys. The focus was more on the physiological and anatomical changes during puberty. As one participant said, ***"it doesn't even get remotely close to erections or the various physiological changes before during and after intercourse."*** The programs don't acknowledge the role of feelings and there is no discussion on associated morals and values. Almost all participants received sex education from their parents, specifically their mothers. Although highly criticised for sidelining the people with disabilities, television shows were the next best source of information.

The participants agreed that this was not to say that children with CP should be whisked off to another room to be taught a separate sex education program when the rest of the kids are attending the program incorporated in the school curriculum. All the kids should attend the same program to avoid the feeling of being isolated and yet the programs should be able to have the ability to answer questions specifically related to the impact CP would have on sexuality. One participant said ***"whenever I see a person with a disability portrayed in a television show it's almost always a paraplegic from a spinal cord injury or are blind or deaf. I have never seen anyone with CP ever!"*** Another went on to say, ***"a lot of my peers just didn't understand what was wrong with me. They thought I was from another planet or something! I would have liked for them to be more educated just so they could understand better."***

Theme five: "What we want our sex education program to look like."

Mostly participants felt that sex education for children with CP refers to a subset of information that would be specific to children with CP. The content is similar to that an able bodied would be exposed to but at the same time it should be disability specific. One of the participants went on to say ***"how do we use contraception given the fact that you don't necessarily have the same use of your fingers that normal kids have, so here's how you can put a condom on using alternative methods."*** It is extremely important for the program to point out that it is ok for people with CP to feel sexual. Depending on the degree of severity it is possible to reproduce and have healthy babies. Another important message is that people with disabilities shouldn't be scared to ask questions. One participant added to this point by saying, ***"people with disabilities need to understand and accommodate for the changes that occur in their body. They should acknowledge that even with their disability they ARE people! They have a heart, a brain and urges. It's normal to have these urges."*** Sex education should be taught to boys and girls at the same time because both should be familiar with the anatomy and physiology of each other. Similarly most of the participants feel that both the able bodied and people with disabilities should attend the same sex education program because this will not only help to mitigate the sense of isolation but also increase awareness regarding the issues the people with disabilities face. The ideal sex education program should have the ability to answer a question as soon as it comes up. As one participant emphasize, ***"the response shouldn't be why do you need that information? Who cares why they need that information. They asked a question and it is their right to have an answer."*** Most participants were more comfortable learning about sex within the security of their own home. As one participant puts it, ***"you cant stick your hand up in class and say Nurse Smith, as you know I have this small disability thing and I was wondering if I was going to be able to hold a boy's cock in my hand!!"*** Just because a person has CP doesn't mean they can't have a normal, loving, sexual relationship! It just might not look like what we see on TV.

The ideal sex education program should include not only all that which is talked about already but also additional topics like self esteem and body image. Both these aspects have been a problem at one point or another in the lives of all the participants. None of the participants thought of themselves as attractive just because no body took the effort to explain to them that body image went beyond what the physical body looked like. One participant reported, ***"in the summertime, everyone likes to suntan wear shorts and all that. I absolutely refuse to go and sit out and wear shorts because I don't like to show off my legs because they're kind of bent and a little bit twisted and I don't really want other people looking at them."*** All the participants also felt that the need to address self esteem is immense and it is surprising that it is not on the curriculum already! One participant said, ***"I suppose the reason why I was a little stunned was because self-esteem should be taught regardless of able-bodied or disabled. It should be across the board. Teaching kids self-esteem is the best way to protect them from negative consequences of bad decisions, and I don't think it's any different regardless of whether you're disabled or able-bodied because my experience is that yeah they picked on me because of my disability, but they picked on my neighbour because he had to do chores in a pig barn and he came to school smelling like a pig barn! He was perfectly able-bodied but they still found something to pick on."***

Theme six "Are our parents protecting us or themselves?"

All the participants had received sex education at home by one of their parents, usually the mother. It was agreed unanimously that the knowledge parents imparted regarding sex was clearly inadequate. It generally skimmed topics that were easiest to talk about and these were not too different from the ones addressed at school. Some thought that parents didn't broach the subject more than necessary because they felt their child wouldn't be having sex anyway so why educate them about anything irrelevant. Others thought it was attributed to parental concerns of hurting their child's feelings because talking about sex will portray it as important and yet another thing the child can't do due to his/her disability. Others say that this topic is not addressed just for convenience sake. Some parent's don't take responsibility of talking about sex and sexuality because they feel this is the job of the doctors. Sometimes the value and moral systems come into play. Parents think of sex as sinful and dirty and therefore refrain from talking about it irrespective of whether the child is able bodied or has a disability. When asked how best to correct these issues, all the participants talked about the need and importance of family support groups.

Theme seven: "Sex education programs are a joke irrespective of whether they are targeting the able bodied population or disabled!"

Most participants agreed that the content of the sex education programs was clearly lacking. One participant went on to say, ***"the sex education I received at school was more of a joke!"*** The program discussed the basic topics like normal anatomical and physiological changes during puberty, safe sex etc. There were absolutely no opportunities for the people with disabilities to ask private or intimate questions. It appeared that it wasn't just the basic structure of the program that was faulty but also lack of knowledge on the part of the instructor. The dearth of information not only decreased awareness but also served to reinforce myths like the individuals with disabilities are asexual. The issue most of the times was not what was said but that which was not said. By not acknowledging or talking about the sexual needs of persons with disability, the society was silently conveying that these individuals were not or could not be sexually active. The people with disabilities always made good friends or good brothers/sisters but could never be thought of in the role of a partner.

CHAPTER 5

DISCUSSION AND CONCLUSION

Discussion

The findings from the study reflect the need for a sex education program designed specifically for the CP population. “Children need to be provided with sexuality education to help them attain a life with more personal fulfillment and to protect them from exploitation, unplanned pregnancy, and sexually transmitted diseases” (American Academy of Paediatrics, 1996, p. 275). The participants agreed that sexuality is an issue that is important to them and they expressed dissatisfaction with how it was taught to them. They felt unsure about what the society in general expected from them and the lack of resources available added to the ambiguity of the issue. Kempton (1978) disputed the fact that society cannot demand sexually responsible behaviour from people with disabilities if they have never been taught what constitutes sexually responsible behaviour.

One of the many purposes served by a sex education program developed specifically for people with CP would be shattering myths such as these individuals are asexual. “The truth is that all children are social and sexual beings from the day they are born” (Sugar, 1990). Having a disability does not mean the individual is banished to a life where there is no role of sexual fulfillment. It should be remembered that they are humans too and that they have normal biological functioning and sex drives (American Academy of Paediatrics, 1996). The need for empowering these children with education and counselling regarding sexuality cannot be emphasized enough. Health care professionals need to work towards fostering positive attitudes towards sex and dispelling myths like people with disabilities are asexual (Murphy & Young, 2005). The people with disabilities are sexual beings just like the able bodied. Knowledge and confidence about individual sexuality is as important to them for facilitating optimal character development as it is for the rest of their peers (Guest, 2000).

The participants felt very strongly that provision of these facts should extend not just to them but also to the general public. If doctors, parents, teachers and peers can acknowledge the fact that although individuals with CP might function differently, they have desires just like everyone else and that it will prove to be invaluable in allowing them to exist holistically.

The study also reveals the importance of positive parental intervention. As Graham (2000) puts it, parents and the therapists need to work together, providing information as and when the child's curiosity is aroused. The moment of truth will come when the informants will have to summon the courage to tell the children how the extent of their disability could restrict their physical sexual activity and the compromises they would likely have to adopt. Once that is over, the therapist plays an invaluable role in assisting the child in coming to terms with physical limitations and then discovering means of overcoming them.

The content of the sex education program should include the traditional curriculum as well as educate them on additional areas that are of great relevance to them. The findings of this study are similar to what has been found and stated previously in the literature. Marshak and Seligman (1993) for instance empahize on areas like self image and social skills to be incorporated in the content, a statement clearly evident throughout the data analysis in the study. For sex education to be relevant and effective, it is vital to provide it within the context of their lives and what information they require to live successfully. It is important to asses the needs of the children before sex educating them. For instance a separate section could elaborate on how body image goes deeper than what you see in the mirror. Self esteem and its enhancement is also a very important area that needs to be included in the curriculum. This finding relates again to what researchers have described in the literature. Thornton (1981) places enormous importance on educating people with disability about body image and self esteem. Among persons with disabilities itself children have different views and priorities when it comes to sex. What maybe important to one may not be to another.

The findings also suggest that the modified sex education program which incorporates information specific information for children with CP should not be taught to them separately. This reinforces the fact that they are "different" and consequently impacts self esteem and confidence. It is therefore recommended that the additional information be included in the program already taught at schools. It may also help to have opportunities for one on one interaction with an adequately qualified professional at the end of the session.

Children with CP do not get very many opportunities to participate in appropriate social and sexual behaviour (Sweeney, 2007). Sexual health instructors can therefore utilize techniques such as role playing social situations so the child understands what acceptable behaviour is and what is not. There can also be exercises that will help encourage positive self image. Couwenhoven (2001) talks about using techniques such as modelling social skills during play time. The sex education program should also emphasize that sex is not limited to orgasm and is not purely a function of the sexual organs.

Almost all participants reported health care professionals as having preconceived notions on matters relating to sexuality. It is critical for the therapists to come to terms with their own biases before treating children with disabilities. Personal biases and societal barriers make it difficult for health care providers and related individuals to promote and advocate rights of these individuals (Murphy & Young, 2005). The more often this topic will be raised during therapy, the easier it will become to address this issue. Waiting for the client to take incentive will result in him continuing to live with "misinformation" which could be dangerous while the health care provider wrongly believes that the client has no qualms regarding sexuality.

To summarize, the curriculum utilized by the sex education program should give additional importance to areas relating to affective domains such as social skills training, positive self esteem and relationships training. Several investigators have found lack of sexual knowledge among individuals with disabilities (Börjeson & Lagergren, 1990; Hayden et al., 1979; Nelson, 1995; Rothernberg et al., 1979). Consequently it is important to include information the rest of the kids gain through peer interaction; for example, masturbation is normal.

Conclusion

A sex education program appropriately modified to meet the needs and challenges faced by individuals with CP should be incorporated early on in small but concrete steps. It should provide information about self esteem, confidence, body image and social competence thereby building healthy attitudes towards sexuality. These changes should be incorporated into the mainstream program so as to raise awareness not just in individuals with CP but also their peers. Often the myth that sex is only for the able bodied is more of a hindrance to optimal sexual development of individuals with disabilities than any other limitations arising from the condition itself (Berman et al., 1999).

In conclusion, "the presence of a developmental disability does not override the rights of children and adolescents to develop and express their sexuality or to have access to accurate information that permits safe and healthy choices to be made" (Murphy & Young, 2005, p. 643). Sex education would empower individuals with CP to attain sexual fulfillment and simultaneously be able to protect themselves from unwanted sexual encounters (American Academy of Paediatrics, 1996).

The present study correlates the lived experiences of children and adolescents with CP and the sexual health education they received as well as its impact on their personal views and perceptions of sexual health. A comprehensive sexuality education program developed specifically for children and adolescents with CP should utilize the themes uncovered throughout this study. The information obtained was utilized to propose the guidelines to base an individualised sexuality education program on.

Proposed Guidelines

1. Based on the findings of the study, a major recommendation is that a sexuality education program should shatter myths such as individuals with disabilities are asexual. It should be able to put across to both the individuals with and without

disabilities that it is erroneous to assume that if an individual has a disability he or she ceases to be a sexual being. It is essential for the program to be altered to include the needs of individuals with CP. Consequently, apart from the traditional curriculum the content should also focus on positive self esteem and body image. Self esteem is an integral part of sexuality and all that it entails. A section of the program should therefore be devoted to describing what factors make up self esteem and their importance in acquiring an optimal persona. Of equal importance is the need to educate these individuals on how body image goes deeper than physical appearance and that it is the feeling of being comfortable within ones body which is what should be desired and achieved by each individual. Additionally, it should be able to tackle the sexual concerns that arise as a result of functional limitations from having a disability.

2. It is critical to impart knowledge in an environment conducive to learning. The participants show a strong inclination towards learning within the privacy of their home. The environment should be free of anxiety as well as be able to foster trust thus encouraging the audience to inquire unhesitatingly about uncertainties however insignificant they might be. Such an environment would be most likely achieved through employing sex positive as opposed to sex negative attitudes.
3. It is suggested that the sex education program be taught in small groups which includes individuals with CP as well as the able bodied population. If need be, this can be supported by providing opportunities for the instructor and child with CP to have a one to one interaction. It is also important to include both males and

females in the same group as this will improve awareness of concerns which are unique to each gender.

4. The data collected from the participants mirrors the fact that no one individual in the life of the child with CP is willing to take on the responsibility of provision of sexuality education. It is clearly evident that individuals with CP want their primary sex education from parents and later, during the course of their adolescence be able to turn to doctors and therapists for further clarifications. Based on the findings of the study, it is proposed that parents, doctors and therapists equally share the duty of providing an ample sexuality education to the child.
5. The study demonstrates that elementary school continues to remain the apt time to introduce sexuality education within the school system. However as mentioned above, the content should be vaster than it is at present.
6. It is also suggested the sex education program utilize a variety of media like audio visual materials, interactive group sessions, use of anatomical models etc.
7. The program can also include a list of resources which would prove to be invaluable to the audience it targets. Resources could comprise of relevant audio visual media like TV shows, movies etc and books. It is important to note that audio visual media is preferred to written material.
8. The instructor should keep in mind that each individual with CP is unique in their abilities based on factors like tonal variations, physical deformities, balance problems etc. A comprehensive sexuality education therefore, is made more substantial by providing each individual with an amalgamation of group

interaction as well opportunities to ask one on one questions based on his/her unique needs.

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APPENDICES

Appendix A- Etiological Factors

Congenital Cerebral Palsy

Maternal and Environmental Factors

It is a well established fact that prenatal conditions in the mother have an important effect on CNS development in the fetus. Maternal infections such as congenital rubella, toxoplasmosis, herpes etc can cause significant motor and neurological dysfunctions. Effects of drugs, tobacco and alcohol consumption, Exposure to radiation and effects of consumption of alcohol, tobacco and drugs by the mother are all known to have some bearing on fetal development.

Prematurity

Studies show intracranial hemorrhage among premature babies is a causal factor for cerebral palsy. Intrauterine malnutrition and the presence of an intrinsic developmental disability are also thought to be related to cerebral palsy.

Perinatal Events

Neonatal asphyxia due to obstetrical accident, anesthesia, nuchal cord etc is a very significant perinatal event that can lead to cerebral palsy. Infections resulting in sepsis or meningitis during the perinatal period may also result in the child having cerebral palsy.

Acquired Cerebral Palsy

The major cause for acquired cerebral palsy has been attributed to a late onset or inadequately treated hydrocephalus. Other important causes include CNS infections, intracranial hemorrhage due to primary vascular accident.

Genetic Cerebral Palsy

Studies have shown several instances where there are multiple cases within a family. Silver (1966), notes that a pattern of autosomal dominance has been established and is traceable through several generations.

Appendix B- Ethics Approval

Health Research Ethics Board

213 Heritage Medical Research Centre
University of Alberta, Edmonton, Alberta T6G 2S2
p.780.492.9724 (Biomedical Panel)
p.780.492.0302 (Health Panel)
p.780.492.0459
p.780.492.0839
f.780.492.7808

January 16, 2007

Dr. Shaniff Esmail
Occupational Therapy
3-04 Corbett Hall

File #B-140107

Re: **Best Practice: Sexuality Education for Children with Physical Disabilities – Developing a Curriculum Based on Lived Experiences**

Dear Dr. Esmail;

Thank you for your recent submission of the above mentioned study. Dr. Griener has reviewed and approved your application on behalf of the Research Ethics Board. However, before I can release the approval, please respond to the following:

1. Dr. Vivien Hollis cannot be listed as both a co-investigator and the authorizing signature. Please forward a copy of the application with the appropriate authorizing signature.
2. Modify the Informed Consent Documents as follows:
    - Ensure that they are on the appropriate letterhead.
    - The information letter should be in the required HREB format, with the inclusion of all the appropriate headings. Please see our website at www.hreb.ualberta.ca for guidelines and a template.
    - Include the contact information for an uninvolved third party should there by any questions regarding one's rights as a research participant. Typically, Dr. Paul Hagler's contact information is provided for your department.

Please forward one revised copy to me, with changes either highlighted or underlined. Please feel free to contact me at 492-0302 or ckabatoff@med.ualberta.ca should you have any questions.

Sincerely,

Charmaine N. Kabatoff
Senior Administrative Coordinator
Health Research Ethics Board (Health Panel)

Health Research Ethics Board

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January 17, 2007

Dr. Shaniff Esmail
Occupational Therapy
3-04 Corbett Hall

File# B-140107

Re: **Best Practices: Sexuality Education for Children with Physical Disabilities – Developing a Curriculum Based on Lived Experiences**

Dear Dr. Esmail:

Thank you for your correspondence dated January 17, 2007, which addressed the requested revisions to the above-mentioned study. These changes have been reviewed and approved on behalf of the Research Ethics Board. Your approval letter is attached.

Next year, a few weeks prior to the expiration of your approval, a Progress Report will be sent to you for completion. If there have been no major changes in the protocol, your approval will be renewed for another year. All protocols may be subject to re-evaluation after three years.

For studies where investigators must obtain informed consent, signed copies of the consent form must be retained, and be available on request. They should be kept for the duration of the project and for a full calendar year following its completion.

Approval by the Health Research Ethics Board does not encompass authorization to access the patients, staff or resources of Capital Health or other local health care institutions for the purposes of research. Enquiries regarding Capital Health administrative approval, and operational approval for areas impacted by research, should be directed to the Capital Health Regional Research Administration office, #1800 College Plaza, phone 407-6041.

Sincerely,

Charmaine N. Kabatoff
Administrative Coordinator
Health Research Ethics Board (Panel B)

UNIVERSITY OF ALBERTA
Capital Health
Edmonton and area
CARITAS HEALTH GROUP

Health Research Ethics Board

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HEALTH RESEARCH ETHICS APPROVAL FORM

Date: January 2007

Name of Applicant: **Shaniff Esmail**

Organization: **U of A**

Department: **Occupational Therapy**

Project Title: **Best-Practice: Sexuality Education for Children with Physical Disabilities - Developing a Curriculum Based on Lived Experiences.**

The Health Research Ethics Board (HREB) has reviewed the protocol for this project and found it to be acceptable within the limitations of human experimentation. The HREB has also reviewed and approved the subject information letter and consent form.

The approval for the study as presented is valid for one year. It may be extended following completion of the yearly report form. Any proposed changes to the study must be submitted to the Health Research Ethics Board for approval. Written notification must be sent to the HREB when the project is complete or terminated.

Special Comments:

Dr. Glenn Griener, PhD
Chair of the Health Research Ethics Board
(B: Health Research)

JAN 17 2007
Date of Approval Release

File Number: B-140107

UNIVERSITY OF ALBERTA

Capital Health
Edmonton and area

CARITAS HEALTH GROUP

UNIVERSITY OF
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Appendix C- Information Sheet for Prospective Participants

Title of Research: Best-Practice: Developing guidelines for Sexuality Education for Children with Cerebral Palsy

Principal Investigator:	Co -Investigator
Dr. Shaniff Esmail Associate Professor Dept of Occupational Therapy, Faculty of Rehab. Medicine Phone: 492-0397 Email: shaniff.esmail@ualberta.ca	Arpita Srivastava MSc OT (Thesis) Department of Occupational Therapy Faculty of Rehab. Medicine Phone: 935-9898 Email: arpita@ualberta.ca

Dear Sir/Madam:

Back ground: It has been found that people with disabilities face the same issues and challenges as those of the typical population, but also have to deal with additional issues specific to their disability. A common myth exists that children with disabilities are asexual and consequently do not need education about their sexuality. A review of the literature shows that adolescents with disabilities seem to be participating in sexual relationships without adequate knowledge and skills to keep them healthy, safe, and satisfied.

Purpose of this study: is to develop guidelines for teaching sexual health education to children with Cerebral Palsy. Specifically, with regard to persons with disabilities:

- What unique issues do they face in relation to sex education?
- What experiences do they have with sex education?

- What should be included in a sex education curriculum for them?
- What are some of the primary sources of sex education for them when they were growing up?
- How did the sex education that they received influence their sexual activities?

Procedures: You are asked to participate in an interview at a location of your choice. It will take approximately one hour. The interview will be tape recorded, allowing transcription of the interview for data analysis.

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Benefits and Risks: Your input may improve sex education programs for children with disabilities. There is no perceived risk or benefit from participating in this study. If any questions or issues come up, I may be able to answer some basic questions. I can also provide you with a list of resources where you may seek further support.

Confidentiality: all information collected will be kept confidential. Your name will be replaced with a number to protect your identity. Although some quotes from your interview may be published, you will not be identified.

Voluntary Participation: *You don't have to take part in the study at all, and you can quit at any time.*

Right to refuse to answer a question: You are not expected to answer any question that you do not want to answer

Reimbursement of Expenses: You will not be reimbursed for participation in the study however incidental expenses such as parking will be covere

Outcome: Results of the study will be shared in several ways:

- Findings will be published in various newsletters.
- They will also be published in a research journal.
- They will be presented at appropriate conference and workshops.
- The findings will be used in the sexuality courses for both medical students and occupational therapy students.

***Contacts**: If you have any questions or concerns about any part of this study, you may contact Shaniff Esmail (780) 492-0397, Arpita Srivastava (780) 935-9898 or Dr. Paul Hagler, Associate Dean Research, Faculty of Rehabilitation Medicine, at (780) 492-9674. Dr Hagler is not part of this study.*

Thank you for your interest in our study.

Sincerely,
Arpita Srivastava,
Shaniff Esmail.

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Appendix D- Informed Consent Form

Title of Research- Best-Practice: Developing guidelines for Sexuality Education for Children with Cerebral Palsy

Principal Investigator:	Co -Investigator
Dr. Shaniff Esmail Associate Professor Dept of Occupational Therapy, Faculty of Rehab. Medicine Phone: 492-0397 Email: shaniff.esmail@ualberta.ca	Arpita Srivastava MscOT (Thesis), Department of Occupational Therapy Faculty of Rehab. Medicine Phone: 935-9898 Email: arpita@ualberta.ca

Do you understand that you have been asked to be in a research study?	Yes	No
Have you read and received a copy of the attached Information Sheet?	Yes	No
Do you understand the benefits and risks involved in taking part in this research study?	Yes	No
Have you had an opportunity to ask questions and discuss this study?	Yes	No
Do you understand that you are free to refuse to participate or withdraw from the study at any time? You can also stop your information from being used.	Yes	No

You do not have to give a reason and it will not affect you in any way.
To withdraw, ask the interviewer to stop the interview and the tape-recorder. Then, if you wish, tell the interviewer that you do not want your information to be used in any way.

Has the issue of confidentiality been explained to you? Do you understand who will have access to your information and what will the data be used for?	Yes	No

This study was explained to me by: ____________________

I agree to take part in this study.

Signature of Research Participant ____________________ Date ____________ Witness ____________________

Printed Name ____________________ Printed Name ____________________

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Investigator or Designee ____________________ Date ____________________

Appendix E – Interview guide In-depth Semi-Structured Interview

1. Small Talk – rapport building

2. Some basic introduction questions to enhance comfort and get basic demographic information.
    - Age
    - Education
    - Interests
    - Date of onset of disability
    - Basic impairments caused by the disability
    - Anything else they would like to add before getting into the interview

3. Define sexuality using the SIECCUS definition (Sexual Information and Education Council of the US)

    "Human sexuality encompasses the sexual knowledge, beliefs, attitudes, values and behaviours of individuals. It deals with anatomy, physiology and biochemistry of the sexual response system, with roles, identity and personality, with individual thoughts, feelings, behaviours, and relationships. It addresses ethical, spiritual, and moral concerns and group and cultural variations".

    Sexuality is a broad area but basically covers basically all aspects of being male and female. Sexuality is part of who we are.

    As you know the goal of this research is to develop guidelines for sex education program for children wit disabilities. So when I say sex education for children with Cerebral Palsy, what is the first thing that comes to mind?

4. Open-ended introductory statement/question:

    As you know, the purpose of this project is to develop guidelines for teaching sexual health education to children with physical disabilities, in order to meet their unique needs.
    Basically what I would like to understand is what we call your "lived experience". You decide what is important – what would you like me to know about this topic.

    Example of prompts/questions used if / as necessary:

    - As a child was did anyone discuss sexuality with you?
    - When do you remember about being taught about sexuality
    - What was the primary source of sex education for you when you were growing up?
    - What unique issues did you face in relation to sex education?
    - Thinking back how would you have liked to learn about sex?
    - What experiences do you have with sex education?

- Where did you learn about sex?
- What do you think should be included in a sex education curriculum for individuals with physical disability?
- How did the sex education that you receive/or lack of influence your participation in sexual activities?
- What do you think of the quality of sex education today?
- Do you feel the information you were given was adequate?
- Do you think that sexuality education should be treated differently for girls than it is for boys?
- If you knew then what you know now, what would you do differently?
- If you were to design the perfect sex education program for yourself, as a child, how would it look and what one thing would you make sure is included?

5. Wrap Up

- Any other comments about the sexuality education?
- Thank you for your help.
- Any questions?

Appendix F- Focus Group Probe

1. Small talk- rapport building.
2. Get consent forms filled out. Remind them of confidentiality.
3. Introductions- thank you for making time to attend our focus group. The purpose of this meeting is to obtain feedback on the findings of the study so far and also to obtain further information on what are the most appropriate guidelines based on which we can develop a sex education program.
4. **Shaniff** gives an overview of the project.
5. **Arpita**- the focus group should take about an hour to an hour and a half. If any of you are uncomfortable at any point feel free to drop out. No explanation required. Any questions?
   Define sexuality using the SIECCUS definition (Sexual Information and Education Council of the US)

   "Human sexuality encompasses the sexual knowledge, beliefs, attitudes, values and behaviours of individuals. It deals with anatomy, physiology and biochemistry of the sexual response system, with roles, identity and personality, with individual thoughts, feelings, behaviours, and relationships. It addresses ethical, spiritual, and moral concerns and group and cultural variations".

   Sexuality is a broad area but basically covers basically all aspects of being male and female. Sexuality is part of who we are.

6. The primary theme that emerged from the preliminary data was that people with CP had a hard time coming across as being sexual beings. They were perceived as being asexual by the doctors, therapists, teachers and sometimes even parents. Some didn't feel the requirement to impart the information while others didn't have any information that could adequately answer the questions that came up. How do you feel about that? Do you feel it's accurate?
7. A subtheme that also came up was that the females faced a reproductive bias. By that I mean doctors automatically assumed they wouldn't be having kids…not because they couldn't but because they shouldn't.
   What feedback can you give us on that?
8. We also found that the lesser the disability, or at least the visible bit of it, the easier it was to integrate with the rest of the society. As the level of disability worsened so did the discrimination. Do you think this comment can be generalized to the entire CP population? Does it affect self confidence etc resulting in further isolation as sexual beings? What steps do you think can be taken to correct these attitudes? **FLIP CHART**
9. There is a distinct lack of information on sexuality and disability let alone CP. There are no books, TV shows etc. What would you like to be done in terms of resources?
10. Another bit of information that the study revealed was that the sex education programs attended as part of the school curriculum were extremely basic. There were no opportunities to ask intimate questions. What would you like to be

modified during these programs? **FLIP CHART** Should there be a separate program for people with disabilities?

11. To conclude our discussion for today lets end with your thoughts on what an ideal sex education program for children with CP should look like. **FLIP CHART**
12. Thank you for coming.

Appendix G- Data Analysis Format

Phase	**Stage**	**Process**
1 **Filtering and Categorizing**	1	- Notes are written immediately following the interview. - Memos are written about ways of categorizing data.
	2	- Each transcription is read to gain a better understanding of some of the larger themes.
	3	- Each transcript is re-read and detailed notes on general themes and major categories are made.
	4	Open coding - Transcriptions are read again and as many headings and themes are recorded. - Fillers are then deleted.
2 **Condensing and Integrating**	5	- Headings and themes are narrowed down and repetitious ones are removed
	6	- Heading and themes are grouped under higher order headings
	7	- Transcriptions are reviewed again using the categories and higher order headings
3 **Understanding and Interpretation**	8	- Short narrations briefly describing the primary points are written - Comparisons are made between interviews
	9	- Narratives are shared with participants
	10	- Narratives are linked up to what is found in the literature and how it relates to the research questions

(Adapted from Burnard, 1991; Kvale, 1996)