

**Best-Practice: Sexuality Education for Children  
and Youth with Physical Disabilities- Developing  
a Curriculum Based on Lived Experiences**

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## Executive Summary

### Best-Practice: Sexuality Education for Children and Youth with Physical Disabilities- Developing a Curriculum Based on Lived Experiences.

#### *Description of Project*

This project is a community-university research partnership that addressed the need for effective approaches to sexual health education for children and adolescents with physical disabilities. Presently, Canada has well-established guidelines for sexual health education which have been implemented by the Public Health Agency of Canada. Unfortunately despite best efforts, some relevant and essential information may be missing from the current guidelines. Although these guidelines do mention diversity, they do not provide specific strategies or meet the unique sexual health needs of people with physical disabilities. The general goal of this project is to understand and develop curriculum guidelines for teaching sexual health education to children and youth with physical disabilities, and disseminate it nationally and internationally, as appropriate.

#### *Purpose of the research*

The purpose of this project was to develop guidelines for teaching sexual health education to children and youth with physical disabilities in order to meet their unique needs.

#### *Research Questions*

Empowering children and youth 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 practices. Specifically, the research aims to understand the following:

1. Unique issues that children and youth with physical disabilities face in relation to sexuality education
2. Participants' experiences with sexuality education, development and associated issues as they relate to disability
3. What should be included in a sexual health education curriculum for children and youth with physical disabilities
4. Participants' primary source of sexual health education
5. How the sexual health education received by children and youth with physical disabilities influenced their sexual practices

Children and youth with physical disabilities often have many of the same interests and curiosities about sexuality as any other child. Due to the controversial and often uncomfortable nature of sexuality and disability, people with physical disabilities are seriously underrepresented and even stigmatized (i.e., people with disabilities are perceived as being asexual) leaving them uninformed and vulnerable to health risks. This population is known to be at an alarmingly high risk of sexual assault and can be targeted by sexual predators due to a lack of knowledge and/or being physically unable to protect themselves. Therefore, specific education and strategies to address sexuality unique to the situations experienced by this demographic are at an even greater necessity to administer.

#### *Design/Methods*

A participatory needs assessment was completed using a qualitative approach including one-to-one interviews and focus groups with adults with congenital physical disabilities and acquired physical disabilities (acquired pre-pubescence), as well as service providers who are experienced in working with children and youth with physical disabilities. This qualitative

project used a phenomenological approach in an attempt to understand the participants' experiences with the sexuality education, development and associated issues. The qualitative approach was ideal in obtaining the necessary information which can be used to develop sexual health programs that are sensitive to the needs of children and youth with physical disabilities.

### *Participants*

Volunteers for the study are referred to as participants rather than subjects to reflect the active nature of their participation throughout the study. All participants were eighteen years or older and either had a congenital disability or were diagnosed or injured before or during puberty. Participants from six cohorts were recruited through various community and healthcare facilities. The six cohorts included: individuals with cerebral palsy, spinal cord injuries, visual disability, as well as burn survivors, individuals who are Deaf or hard of hearing, and service providers. The selected cohorts were representative of individuals with congenital and acquired disabilities, those with a publicly visible and invisible disabilities, as well as those with progressive and stable disabilities. These participants also provided a good blend of physical and sensory limitations. It was important to for this study to include service providers who, at times, are responsible for the education of children and youth with disabilities.

### *Data Analysis*

Data analysis consisted of a thematic content analysis, which was used to analyze the transcribed one-to-one and group interviews.

### *Results*

Overall the findings of this study indicate that all the participants felt that sexual health education for children and youth with physical disabilities did not provide adequate information and that there are insufficient resources in place to assist service providers to deal with the topic

properly. There was a general feeling that children and youth with physical disabilities are systematically asexualized and not given the opportunity to discuss and learn about the topic of sexuality. It was felt that children and youths with physical disabilities should receive the same sexual health education as all the other students. However, it was felt they should also receive additional instruction that is specific to their disability and unique circumstances. This disability specific information should ideally be provided by a mentor or someone who the children or youth with physical disabilities feel comfortable with and who is able to empathize with their situation. Participants also talked about how the lack of sexuality education had a significant impact on their self-esteem, self-worth and identity. There was also a consistent feeling that individuals with disabilities do not receive the education and resources they require and that healthcare professional, specifically, did not adequately meet their sexual health education needs. Participants felt that it was healthcare professionals' responsibility to provide sexuality education for people with physical disabilities as part of their service.

Although there are many similarities in views between the different cohorts of participants, there were some unique differences in their views of effective strategies of teaching/learning sexual health education. Some interesting similarities were found when comparing data from participants with stable versus progressive conditions, visible versus invisible disabilities, and congenital versus acquired disabilities. Overall, suggestions and strategies were divided into three categories: content (what should be included in sexual health education curriculum), methods of delivery (how sexual health education should be taught), and environment (what is the most conducive environment to teach sexual health education to children and youth with physical disabilities).

In terms of content, each cohort very clearly stated that children and youth with physical disabilities require additional information that is specific to their disability. The participants felt it was important for children and youth to receive precise information regarding the unique features and impact of their disability on their present and future sexual functioning. In addition, the participants wanted to clearly send the message that even within the same disability there are many variations and unique manifestations. It was suggested that when content is developed for each type of disability, it should incorporate the large variations that are observed within the condition and must include content pertaining to self-esteem, acceptance, and physical concerns specific to their disability.

When looking at the methods of delivery there was again considerable variation which included specific examples as they relate to a specific disability, for example the use of tactile models for students with visual impairment and the use of physical demonstration for students with hearing impairments. It was felt that the methods of delivery must be sensitive to the functional limitations of the specific disability.

There was a lot of discussion around the type of environment that would be conducive for sexual health education for individuals with disabilities. In general, all participants felt that the disability specific information should be given either in one-to-one or small group situations where the individual has an opportunity to ask questions without feeling judged. It was felt that all children and youth able-bodied and with physical disabilities require a “safe” environment to be able to discuss and learn about these issues. All participants agreed that one of the biggest factors in creating a safe, conducive learning environment was dependent on the characteristics of the teacher or educator. All participants felt having a mentor or a trained educator carry out the sexual health education would be most appropriate. Although the use of a mentor was

considered ideal, most agreed that this would be unrealistic in most settings. They felt that it was critical to have somebody who could really empathize with their unique situation and that the children or youth felt comfortable with the educator. The educator should receive additional training to have a better understanding of the impact of disability on sexuality.

### *Conclusion*

The ultimate goal of this project is to provide information that can be used to develop sexual health education programs for children and youth with physical disabilities in order to help them make a positive sexual health transition into adulthood. This project will not only benefit individuals with physical disabilities within the cohorts studied, but can ultimately be used as a resource to assist students without physical disabilities, as well as parents, teachers, and service providers to appropriately deal with the topic of sexuality for various types of physical disabilities. The insightful information and strategies provided by the study participants can help these individuals address the unique sexual health needs of children and youth with disabilities.



## **Sex Education Guidelines for Children and Youth with Physical Disabilities**

### **Final Research Report**

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

#### Description of Project

This project is a community-university research partnership that addressed the need for effective approaches to sexual health education for children and youth with physical disabilities<sup>1</sup>. Presently, Canada has well established guidelines for sexual health education which have been implemented by the Public Health Agency of Canada. Unfortunately, despite best efforts, relevant and essential information may be missing from the current guidelines. Although these guidelines do mention the importance of addressing diversity of Canadian youth, they do not provide specific strategies or meet the unique sexual health needs for people with physical disabilities. The general goal of this project is to understand and develop curriculum guidelines for teaching sexual health education to children with physical disabilities, and to disseminate these guidelines nationally and internationally, as appropriate.

#### Purpose of the research

The purpose of this project was to develop guidelines for teaching sexual health education to children and youth with physical disabilities in order to meet their unique needs.

**Research Questions:** Empowering children and youth with the knowledge and understanding of various sexual issues that are relevant to their physical abilities will allow them

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<sup>1</sup> For this study children will be defined as a young human being below the age of full physical development or a son or daughter of any age and youth refers to the period between childhood and adult age (Oxford University Press, 2008).

to make safe and appropriate decisions regarding their sexuality and sexual practices.

Specifically, the research aims to understand the following:

1. Unique issues that children and youth with disabilities face in relation to sexuality education
2. Participants' experiences with sexuality education, development and associated issues as it relates to disability
3. What should be included in a sexual health education curriculum for children and youth with physical disabilities
4. Participants' primary source of sexual health education
5. How the sexual health education children and youth with physical disabilities has received influenced their sexual practices

Sexual health among children and youth is both a family issue and a community issue, but more importantly should be recognized on a larger scale. When sexual health is recognized on a larger scale, standards and legislation can be developed to appropriately and effectively teach *all* children about sexual health. In order to encourage this process, research needs to be conducted to explore topics on sexuality and the diversities people face that impact their sexuality.

Children and youth with physical disabilities often have many of the same interests and curiosities about sexuality as any other able-bodied child or youth. Due to the controversial and often uncomfortable nature of sexuality and disability, people with physical disabilities are seriously underrepresented and even stigmatized (i.e., people with disabilities are asexual) leaving them uninformed and vulnerable to health risks (Koller, 2000). This population is known to be at an alarmingly high risk of sexual assault and can be targeted by sexual predators.

Therefore, there is a greater need to administer specific education and strategies to address the unique sexual situations experienced by this demographic.

*Significance*

In *Goals and Elements of Sexual Health Education* (2003), the Population and Public Health Branch (PPHB) of the Canadian Government encourages the Canadian education system to: 1) aid in the development of positive sexual outcomes (e.g. self-respect, respect of others, positive functioning relationships, and rewarding sexual experiences); and 2) deter negative sexual outcomes (e.g. unwanted pregnancy, sexually transmitted infections (STIs), sexually assault and harassment). Furthermore, in *A Canada Fit for Children* (2004), the Ministers of Health and of Social Development, with the leadership of Senator Landon Pearson, prepared a policy document in response to the General Assembly of the United Nations. This document recognizes the diverse makeup and needs of Canadian children and youth and encourages the promotion of children and youth's emotional, sexual, and intellectual health. As part of the document's action plan, respect for the diversity of children and the insurance of social inclusion are essential for a successful future for children and can be accomplished through fostering multi-sector collaborations and the sharing of research and data. These values and goals are essential to this research project.

Over the past two decades, health and social issues related to sexual behaviour have become an important topic of study for professionals and academics in a wide range of fields (Gullotta, Hampton, Adams, Ryan, & Weissberg, 1999). Compared to three decades ago, a large number of youth are becoming sexually active at a younger age, engaging in sexual activities before they finish high school. Recent data indicates that approximately 25% of Canadians will have had sexual intercourse by the age of sixteen (McKay, 2000), with the majority of young

Canadians initiating sexual intercourse between 16-19 years (Crockett, Raffaelli, & Moilanen, 2003; Maticka-Tyndale, 1997; Miller, Bayley, Christensen, Leavitt, & Coyl, 2003).

As mentioned above, not only are more youth becoming sexually active at an early age, but they are also engaging in risky sexual intercourse. Researchers have defined risky sexual intercourse of youth as involving multiple partnering, no use of condom, and an early age at the time of first intercourse (Moore et al, 1998; Wellings, Field, Johnson & Wadsworth, 1994; Wellings & Mitchell, 1998). Having multiple sexual partners is a common phenomenon among young people and this behaviour increases their risk for contracting a sexually transmissible infection, such as HIV/AIDS (McKay, 2004). Multiple partnering can also have long-term repercussions on the physical and mental health of these youth (Concordia University Health Services, 2010; Government of New Brunswick, 2010). Furthermore, we speculate this practice has unknown effects on the development of one's sexual identity and effects on self-regulation of impulses and desires (Passey, 2009).

The Canadian Community Health Survey (2005) found that 40% of males 15-19 years of age had had more than one sexual partner in the 12 months prior to the survey. Females within the same age range had lower rates, with 27% reporting more than one sexual partner (Maticka-Tyndale, 1997; Barrett & McKay, 2000). Youths with multiple sexual partners appear to be compounding their risks because they are more likely to: 1) have had sex for the first time before the age of thirteen; 2) have not used a condom the last time they had sex; 3) have consumed alcohol or drugs before having sex when they last had sex (Kuortti & Kosunen, 2009). An increasing number of youth contract sexually transmitted infections (STIs), develop cancer, or experience early pregnancy and/or social and emotional problems as a result of this sexual behaviour (see Gullotta & Adams, 2005 for a comprehensive review of these issues).

We know that, while youth have information on sexual issues, they often do not have the skills to deal appropriately with sexually difficult situations (Gullotta, Adams, & Markstrom, 2000). To counteract these issues, youth are in need of programming that helps them construct a healthy sexual identity and develop positive self-regulation techniques along with skills for dealing appropriately and effectively with difficult sexual situations, such as setting specific boundaries with their partner. Research indicates that while the majority of teens in North America hold values consistent with responsible sexual conduct, many are unable to translate these attitudes into positive personal behaviours (Christopher & Cate, 1984; McCabe & Killackey, 2004; Zabin, Hirsch, Smith, & Hardy, 1984). Furthermore, most programs aimed specifically at reducing sexual activity are found to be ineffective (Franklin, Grant, Corcoran, Miller, & Bultman, 1997). However, research consistently indicates that positive outcomes are most likely to occur when programs effectively integrate knowledge, motivation, skill-building opportunities, and environmental supports for sexual health (Fischer & Fischer, 1992). The development of a curriculum based on principles of education that embrace participant ownership, exchange, reflection, and action offers such an experience.

The current lack of programs providing youth with information on sexuality and disability has led to the perpetuation of myths and stereotypes about individuals with disabilities and their sexuality. Children and youth with disabilities are often viewed as being asexual and therefore have no need of sexual education (DiGuilio, 2003; Sugar, 1990). On the contrary, these children are sexual beings who have the same experiences of pleasure, excitement and passion as their able-bodied peers (Tepper, 2000). Another common stereotype is that people with disabilities are unattractive, undesirable and attracted solely to others with disabilities (Medlar & Medlar, 1990). This stereotype, especially in adolescents, can be detrimental to the individual's

self-esteem and self-confidence (Teleporos & McCabe, 2005). Through proper sexual education the effects of these negative stereotypes can be counteracted by empowering youth with disabilities (McCabe, 1999). The myth that individuals with disabilities are incapable of engaging in sexual activity because they are infertile or they are physically unable to perform is also false as there are devices, medications, and positioning to assist these individual with their sexual needs (Earle, 2001). Education programs can help to discredit the myths and stereotypes that exist, encourage healthy sexual behaviours, and provide children and youth with physical disabilities accurate and positive perceptions of sexuality (Torisky, Torisky & Elgar, 1985). Children and youth with disabilities face the same issues and challenges as the able-bodied population, but also have to deal with additional issues specific to their disability. As mentioned above, a common myth exists that children and youth with disabilities are asexual and consequently do not need education about their sexuality (Murphy & Young, 2005; Sugar, 1990). However, the curiosities, drives and interests of youth with disabilities in themselves and others are much the same as their able-bodied peers (American Academy of Pediatrics (A.A.P), 2006). Youth with physical disabilities have the same likelihood of becoming sexually activity as their able-bodied peers (Cheng & Udry, 2002). For instance, the mean age for first intercourse is 13 years for boys with disabilities and 14 years for girls with disabilities (Neufeld, Klingbeil, Bryen, Silverman, & Thomas, 2002). Unfortunately, adolescents with disabilities have a higher incidence of contracting a sexually transmitted infection compared to their able-bodied peers (Suris, Resnick, Cassuto, & Blum, 1996) Another alarming fact is that children with disabilities may be twice as likely to be sexually abused as children without disabilities (Murphy & Young, 2005).

There is much controversy over providing sexual health education to typically developing children and providing sexual health education to children with disabilities bring about many more issues of concern (Koller, 2000). Fear, lack of knowledge, and embarrassment impede meaningful communication with the youth without disabilities and creates more difficulties when dealing with children and youth with disabilities. The prospect of teaching their child with a disability about sexuality is disturbing for parents (Ikeler, 1990). Parents report feeling uncomfortable educating their children with disabilities about sexuality, even if they had reported feeling comfortable teaching their children without disabilities about sexuality. This discomfort emerges as parents tend to focus on the disability of their child rather than their potential (Murphy & Young, 2005), therefore, they tend to avoid the whole issue (McCabe, Cummins, & Deeks, 2000). Most adolescents with physical disabilities report that they feel that they have not been provided with adequate information on sexual health issues (Murphy & Young, 2005). This coincides with the conclusions of Berman *et al.* (1999), who found that the majority of adolescents with physical disabilities are uninformed or misinformed about general sexual knowledge.

Children and youth with physical disabilities are faced with a number of unique educational barriers and physical limitations. Sexual education in schools has been found to be inadequate for educating youth with disabilities about sexual health due to educators being inadequately prepared and trained on the topic of sexuality and disability, as well as the students with disabilities avoiding being vocal participants in their own education (Berman *et al.*, 1999; Murphy & Young, 2005; Stevens *et al.*, 1996). Another barrier for youth with disabilities is the lack of accessible formal material specific to their unique needs, for example youth with a visual disability are faced with a lack of formal educational material in the format of Braille (Hicks,

1980; Shakespeare, Gillespie-Sells, & Davies, 1996). Sexual health education programs are often taught during physical education classes which can inadvertently exclude youth with physical disabilities as they do not participate in this class (Berman et al., 1999). These barriers and limitations can perpetuate negative feelings about sexuality held by youth with physical disabilities (McCabe et al., 2000).

Sexual health education at a young age is imperative as it allows individuals to construct a healthy sexual identity, fulfill desired needs with appropriate behaviours, understand methods of effective self-regulation, and develop skills for dealing appropriately and effectively with sexual situations. Sexuality education empowers children with physical disabilities to enjoy personal sexual fulfillment and to protect themselves from abuse, unintended pregnancies, and STIs (A.A.P., 2006; Murphy & Young, 2005).

The need for a sexual health education program that meets the unique needs of children and youth with disabilities is becoming increasingly important. These youth are dealing with the same issues and challenges surrounding sexuality as their able-bodied peers but are also faced with unique situations and challenges, such as stereotypes, educational barriers and physical limitations. With increasing rates of youth engaging in sexual activities, youth with disabilities are exposed to sexual experiences in which they are uninformed, putting them at an increased health risk. They are in great need for sexual health education programs that can help them develop a healthy sexual identity, empower them and allow them to learn self-regulation techniques. There has been little research done on youth with disabilities and sexual health education, therefore it has been difficult to develop guidelines for an effective sexual health education program that best meets the needs of students with disabilities (Berman et al., 1999).



This project aims to investigate the unique issues related to youth with disabilities and their sexuality in order to produce guidelines for an effective sexual health education program.

### Methods

The aim of qualitative sampling is to understand the phenomenon of interest as opposed to quantitative research where the aim is to generalize finding to the population from which the sample was taken (Mayan, 2001). Therefore, the task of phenomenological research and writing is to construct a possible interpretation of the nature of a certain human experience. The key is to call upon the experiences of several people as opposed to those of only one person (van Manen, 1997). Generally, the participants in this type of research study are selected because they best exemplify the phenomenon under study and offer the richest possible data (Moules, Simonson, Prins, Angus, & Bell, 2004). The participants recruited for this study were volunteers who felt they had a story to tell or felt strongly about the topic of sexual health education to be willing to participate.

A participatory needs assessment was completed using a qualitative approach that included one-on-one interviews and focus groups with adults with congenital physical disabilities and acquired physical disabilities (acquired pre-pubescence), as well as service providers who were experienced in working with children or youth with physical disabilities. This qualitative project used a phenomenological approach to understand the participants' experiences with their sexual health education as it related to their physical disability. The principles of participatory needs assessment were used to elicit the participants' perspective regarding what they felt were the sexual health education needs for children and youth growing up with a physical disability. This approach values the participants as experts, as their knowledge and understanding of the phenomena is invaluable (Wang & Burris, 1997). The

phenomenological method is ideal to achieve our stated objectives for this study as it involves the participants in the collection of information, data analysis and priority setting (Smith, Tang, & Nutbeam, 2006). This qualitative approach was ideal in obtaining the necessary information that could be used to develop sexual health education guidelines that are sensitive to the needs of children and youth with physical disabilities.

#### *Data Collection Plan*

Participants for the one-on-one interviews and focus groups were recruited using a variety of methods including:

1. Recruitment postings in community agencies, rehabilitation facilities, homecare offices, newsletters, and other similar public forums.
2. Recruitment information was given to service providers and professional contacts working with children with disabilities.
3. Recruitment information was also posted on the Edmonton Planned Parenthood and the Alberta Society for the Promotion of Sexual Health websites.

All participants were advised in writing and orally prior to the interview or focus group that their participation was voluntary, confidential, and that they could withdraw from participation at any time, without explanation.

#### *Participants*

The volunteers for the study are referred to as participants rather than subjects, to reflect the active nature of their participation throughout the study. All participants were eighteen years or older and had either a congenital disability or an acquired disability obtained following an injury or identified through a diagnosis prior to or during puberty. The selected cohorts provided

a representation of congenital and acquired disabilities, publicly visible and invisible disabilities, as well as progressive and stable disabilities. The cohorts also provided a good blend of different physical and sensory limitations. Participants from each of the following cohorts were recruited through various community and healthcare facilities:

- **Cohort #1-** participants had acquired the physical disability of a spinal cord injury (SCI)
- **Cohort #2-** participants had hearing loss and were Deaf or Hard of Hearing (D/HH)
- **Cohort #3-** participants had the visible disability of having scars from burns
- **Cohort #4-** participants had congenital or acquired visual disabilities (VD)
- **Cohort #5-** participants had the congenital disability Cerebral Palsy (CP)
- **Cohort #6-** participants were service providers experienced in working with children with physical disabilities. This group consisted of healthcare professionals such as occupational therapists, nurses, school teachers, and community sexual health educators.

The number of participants targeted for this study follows the general trend for a phenomenological study of this type, where information is collected using in-depth, one-on-one interviews with as many as ten individuals in each cohort (Creswell, 1998). Approximately seven to ten individuals from each cohort participated in one-on-one interviews and approximately six to eight individuals were recruited for each focus group (table #1). Focus group participants consisted of approximately 50% of participants who participated in the one-to-one interviews and 50% of new participants. The mix allowed for added discussion where the returning

participants had the opportunity to confirm or question themes that were presented previously and the new participants could comment on the themes having a fresh perspective.<sup>2</sup>

Table #1

Number of	Spinal Cord Injury	Deaf or Hard of Hearing	Burns	Visual Disability	Cerebral Palsy	Service Providers
<u>One-To-One Interviews</u>						
Males in one-on-one interviews	5	3	3	2	4	2
Females in one-on-one interviews	3	5	5	6	5	6
Total	8	8	8	8	8	8
<u>Participants In Focus Group</u>						
Males in focus group	5	2	1	4	3	0
Females in focus group	2	5	3	5	2	7
Participants in focus group	7	7	4	9	5	7

The average age of participants in the one-on-one interviews was 35.1 years (spinal cord injury), 34.7 years (cerebral palsy), 37.9 years (burn survivors), 38.4 years (Deaf and Hard of Hearing), 42.8 years (service providers), and 40.4 years (visual disabilities). Specific demographic data were not collected for focus group participants as each of the participants were asked to introduce themselves at the start of the focus groups and not asked to provide more specific information. The level of impairment was not formally assessed to ensure that the level of impairment would not interfere with the true goal of the study which was to understand the

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<sup>2</sup> It should be noted that the focus group for the burn survivors had only four participants. Two of the burn survivor participants who were scheduled to attend the focus group were unable to attend due to unforeseen circumstances. Furthermore, the focus group for the Deaf and Hard of Hearing participants took place using an online forum. Our intent for using an online forum was to enable participants of varying degrees of hearing the opportunity for unimpeded communication between each other and the investigators. Unfortunately, the response rate on the online forum was low and little new information was collected. In addition, one male and one female who participated in the SCI focus group did not have spinal cord injuries. These participants were married to individuals with spinal cord injuries and offered insightful ideas.

lived experience of these individuals. Due to the nature of a qualitative study, an attempt to quantify and compare levels of impairment to sexual health education needs would not have been valuable or may have lead to false conclusions due to the limited number of participants. The goal was not to generalize the finding but to gain some insight into the experiences of individuals with disabilities as it relates to sexual health education. However, for all our cohorts, the level of impairment and disability ranged from mild functional limitations to severe limitations<sup>3</sup>.

### *One-on-One Interviews*

A trained project member conducted the semi-structured one-on-one interviews in an appropriate environment selected by the participant (for example, the participant's home or a meeting room at the University of Alberta). Some interviews were also conducted over the telephone when one-on-one in person meetings were cumbersome to the participant or not possible. The interviews were recorded in two formats (audio-recorded and digitally-recorded) for later transcription. The focus of the interview was on the experiences of people with physical disabilities, their sexual health education experiences, and the associated issues they experienced. Responses were coded by themes, categorized, and finally analyzed. Analysis was conducted separately within cohorts, then between cohorts, as well as combined as a whole. Additional analysis was also done differentiating for sex and type of disability. The interviews took approximately one hour each. See interview guide appendix #A

### *Focus Groups*

Two trained project members conducted the focus groups at a designated location (i.e. a University of Alberta meeting room or a conference room at a service agency). A set of probes

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<sup>3</sup> All participants in the visual disabilities cohort were considered legally blind; 20/200 or less in the better eye after correction, a visual field of no greater than 20 degrees, or both (CNIB).

and activities for the focus groups were developed based on the results of the individual interview analysis. The goal of the group discussion was to obtain participant perceptions, experiences, and ideas regarding sexual health education and associated issues for individuals with disabilities. These meetings were also used to confirm themes generated during the one-on-one interviews and to gain participants' views regarding similarities and differences identified between the cohorts. Various activities and strategies were used during the focus group to ensure participants based their comments on personal experiences as opposed to providing what they thought were socially desirable responses. The strategies used included the use of scenarios and pencil and paper tasks in which participants had to brainstorm and work through based on personal experiences. The goal was to elicit the main themes and priorities that occur throughout the discussion, not necessarily to gain consensus. The focus groups took between 90 minutes and two hours. See focus group guide appendix #2

#### *Data Analysis Plan*

The analysis stage of this project was separated into five specific phases: Phase 1 - complete the analysis of individual, one-on-one interviews in each cohort; Phase 2 - compare and amalgamate data, from individual one-to-one interviews, between and within cohorts; Phase 3 - develop a set of probes and activities for use in the focus group sessions based on the results of the individual interview analysis; Phase 4 - conduct the focus groups, identify the main themes and priorities that emerged, and compare how these relate to findings from the individual interviews; and Phase 5 - amalgamate the findings from the one-on-one interviews and the focus groups and relate these to the project's original objectives.

### *Data Analysis*

A thematic content analysis (Burnard, 1991) was used to analyze the transcribed one-on-one and focus group interviews. A format combining a fourteen-stage approach described by Burnard (1991), as well as a six step guide to analysis as describe by Kvale (1996), was used to analyze the transcripts and a general approach described by Maykut and Morehouse (2001). This approach did not use one standard method of analysis, but instead, utilized a free interplay of techniques during the analysis. The new ten-stage process was used to analyze the transcripts and field-notes from both the one-to-one interviews and focus groups.

#### *Phase one Analysis: (Steps 1-4)*

The first phase of analysis involves four stages in which the data is filtered and categorized. During the first stage, notes were written immediately after the interviews or focus groups. After each interview/group, the audio-recording was replayed and more notes were made. Memos were also written about ways of categorizing the data (Burnard, 1991). During the second stage, the transcript was reviewed again and put in table format. The transcript was read while listening to the audio-recording of the interview to ensure accuracy as well as to gain a general “feel” for the interview and a better understanding of some of the larger themes (Beck, 1994; Finlay, 1999). Some quick notes were made using sticky notes and put in a column on the left side of the interview transcript. In the third stage, each transcript was reviewed again. Detailed notes on general themes and major categories were recorded in the right column of the table. In the fourth stage, open coding occurred where the transcripts were read again and as many headings and themes as necessary were written down. Any information that was deemed unrelated to the topic (“fillers”) (Burnard, 1991) were crossed out.

*Phase two Analysis: (stages 5-7)*

Stages five to seven involved condensing, organizing, and integrating the data. In the fifth stage, the headings and themes found in stage three were narrowed down and similar or repetitive ones were removed. During the sixth stage, the remaining headings and themes from stage five were grouped together under categories and higher order headings. For the seventh stage, the transcripts were reviewed again using the categories and higher order headings. Colored highlighters (one color for each category or higher order heading) were used to ensure all aspects of the transcripts were covered except for the fillers crossed out in stage four. Throughout the second phase of analysis a constant comparison method was used in which all data coded were simultaneously compared to each new unit of meaning and then compared to all other units and subsequently grouped (Maykut & Morehouse, 2001). This allowed all data to be compared to all categories and themes to eliminate overlap and repetition. Any unit of data that was found to be not related to a previous theme constituted a new category.

*Phase three Analysis: (stages 8-10)*

*Trustworthiness and Credibility*

Several strategies were used to ensure the trustworthiness and credibility of this study; they included a form of triangulation, partial saturation, member checks, peer debriefing, personal reflexivity, and an audit trail. A form of triangulation was used in which the data was collected and checked using several different sources including one-to-one interviews, focus groups, and field notes. True saturation was never achieved as it was not a goal for this study. However, semi-saturation was achieved through the use of a constant comparison method in which new data was added and compared to previous data until no new themes and categories



emerged. Peer debriefing was attained by having all transcriptions analyzed independently by the primary investigator and a member of the research team in order to ensure the analysis completed had good “truth value”. Member checking was achieved through the sharing of narratives and themes from the interviews with each participant and creating a discussion surrounding the shared themes during the focus group. Personal reflexivity was used to ensure no bias or personal ideas of the researchers would influence the data analysis. The individuals who completed the analysis accomplished this by keeping notes in the form of a reflexive journal. These notes were then reviewed for any bias or preconceived notions, emotions, and experiences that occurred during the various stages of the study to ensure that the true representation of the participants' lived experience was reported, not the investigator's perceptions. The final strategy used was to adhere to a set route for data collection and analysis. Adherence to a set path allowed the research team to back track and check various ideas and thoughts throughout the research process.

#### *Data Storage and Access*

Data was stored at the University of Alberta in a secure office and filing unit. Pseudonyms or code numbers were used to protect the identities of participants. All data was pooled to ensure anonymity. Identifying information was stored in a locked secure location that was only accessible by the principal investigator. The principal investigator had access to the raw data along with research assistants under supervision. It is expected that the information collected for this study will be destroyed after five years from the project end date.

#### Findings

Participants appeared excited and motivated to help develop sexual health education guidelines for children and youth with physical disabilities. There was general consensus that our topic of

research was important and the present is the appropriate time to address these issues in schools. Participants felt that, in general, sexual health education in school was poorly taught and that sexual health education pertaining to physical disabilities was non-existent. They were hopeful that the results of this study would open up discussion and influence educational systems in order to ensure that children and youth with physical disabilities receive the sexuality education they require.

When looking at all the cohorts together some common themes emerged. Selected quotes are provided to illustrate the major themes that emerged from the data analysis. Quotes that best represented the views of the entire cohort were used as a way to give words to the participants' thoughts and ideas.

All the participants felt that there is a lack of understanding and many misconceptions regarding sexuality and disability. Many felt that the general public has false perceptions and biases toward people with disabilities, especially surrounding the topic of sexuality, as one participant clearly stated.

**“At the moment there is not anything out there for young persons, male or female, to guide them with regards to sexuality”**

The common themes that emerged for all cohorts were:

- 1) Many participants felt that society views people with disabilities as asexual; as individuals who do not have a sexual future, and who should not be “allowed” to be in a relationship. This is illustrated by a female participant in the CP cohort.

**“I think for me that’s the biggest kind of myth or misconception or stereotype or you know [being asexual] , and that’s – I think that does the most harm.”**

- 2) The participants also felt the topic of sexuality was avoided and never talked about when they were children or even now as adults.
- 3) All participants believed that the best way to provide sexual health education would be the use of mentors or peers: however, they also acknowledged that this is not always possible or even appropriate. Participants indicated that the key element would be to have somebody they felt they could be comfortable with and that could actually empathize with their unique situation.
- 4) Participants discussed how the lack of sexual health education had a significant impact on their self-esteem, self-worth, and identity. All participants reported that they received no formal (school system) and minimal informal (parents and peers) sexual health education as it related to their disability.
- 5) Participants felt strongly that all children and youth with disabilities should get the same formal sexual health education provided to all students, regardless of physical abilities. This formal education should include diversity and an overview of the impact of disability on sexuality without highlighting specific children's disability in a given presentation. It was felt to be critical that children and youth with disabilities not be treated differently within the classroom. Specific or specialized information for children and youth with physical disability should take the form of additional resources delivered either individually, in a small group setting, or be accessible online.
- 6) There was a consistent feeling that healthcare professionals did not adequately meet the participant's sexual health education needs when they were either children or youths. Participants felt that it was healthcare professionals' responsibility to provide sexual health education for children and youth with physical disabilities as part of their service.

- 7) Sexual health education needs to cover some of the psychosocial areas in addition to the reproductive anatomy. All cohorts believed that the importance of the emotional impact of disability was greater than the physical impact. They felt that any sexual health education curriculum for all children and youth able-bodied or not must have a section on self-esteem and self-worth.

**“Issues of self-esteem self-worth, self-discovery, self-identity, and self-image need to be addressed as well as fears of rejection, emotions, negotiation, and communication.”**

Unique themes were also found when looking at each cohort separately and are briefly presented below. Although many of the themes regarding provision of sexual health education were similar for each cohort, they each described unique needs and circumstance. It would be impossible to give a detailed account in this report therefore separate publications have been submitted (Krupa & Esmail, in press 2009; Parrott & Esmail, in press 2009) or are planned for the future to address all the unique sexual health issues for each cohort.

*Cohort #1- Cerebral Palsy (CP)*

Individuals with CP were frustrated by the lack of information available regarding the impact of CP on sexual health. They felt this to be a major barrier to their sexual health education. A majority of this cohort reported that the small amount of sexual health education they received was from their mothers and included minimal to no information about their disability. In addition, several participants indicated receiving sexual health information from their friends and the media, however, this information was not relevant to their disability related issues. Many participants also expressed frustration regarding how the general society viewed

individuals with CP as asexual and incapable of having a family. Participants provided valuable insight and the following primary themes unique to their cohort were found:

- 1) **“We are not sexual beings.”** More than any other cohort the participants with CP described experiencing discrimination due to their disability which led to feelings of low self-confidence and self-esteem. For example, one participant commented on the discrimination she received from a health care professional viewing her as asexual.

**“Oh you don’t need to do that (sexual health education) - When will you be having sex?”**

This discrimination was also provided indirectly by peers.

**“Girls at parties would always come up to me and pat me on the head like a buddy or even a brother. Nobody looks at me that way.”**

- 2) Participants felt that sexual health education programs lack adequate information and that they should be designed to focus more on specific disabilities as opposed to generically covering disabilities as a whole. On the other hand, other cohorts wanted more general information on disability to be a part of the curriculum and for disability specific information to be available to students upon request. In addition, participants felt that supplemental sexual health resources that specifically target children and youth with CP should be available.

**“How do we use contraception? Given the fact that you don’t necessarily have the same use of our fingers that normal kids have, so here’s how you can put a condom on using alternative methods?”**

- 3) Sexual health education should be provided using an integrated approach as opposed to segregating children and youth with disabilities into their own group. This was further discussed by one of the participants during a one-to-one interview.

**“A lot of my peers just didn’t understand what was wrong with me. I would like for them to be more educated so they could better understand.”**

*Cohort #2 – Spinal Cord Injury (SCI)*

Participants with SCI recognized the importance of addressing sexual health with regards to their disabilities. In general, participants were in agreement that the emotional aspects of sexuality are extremely important to understand, especially considering that often physical response, such as erections and sensation, may no longer be functioning. They also felt that sexual identity is an important component to discuss in sexual health class as many individuals with SCI may feel differently about their sexuality after a spinal cord injury. Content analysis revealed the following primary themes:

- 1) They felt it was imperative to have sexual health education programs that focused on the specific issues faced by people with SCI. Due to the impairments in sensation and functioning, many people with SCI may need to learn and develop strategies for sex, as well as experiment with their bodies sexually. Also, as there is a large variation in types of SCI, participants felt it was important to provide information to the students that was specific to the level of spinal injury.

**“In 19XX it was still a little bit of a hush-hush thing. Since then, it’s like you know look you’re not gonna stop ‘em from doing it, they’re gonna have sex, you might as well inform ‘em on it.”**

**“Yes, plumbing issues should be discussed, but so should issues about feelings and fears that people with SCI may have.”**

- 2) This group also talked about the emotional trauma and loss they experienced due to their injury and how it was very important to also deal with the psychological and social aspects of sexuality. One male participant describes some of the issues he faced due to his injury.

**“It’s the whole psychological impact that it has on an individual too, in terms of losing that (sexual functioning), so your pride, your image, everything of yourself has been shot down, so you don’t have that self-confidence anymore”.**

- 3) More than any other cohort, with the exception of burn survivors, this cohort believed that the ideal source for sexual health education is peer mentoring and/or one-on-one sessions with a knowledgeable health professional. Participants also felt that having a safe private environment to learn about sexuality was more important than having an integrated program, as suggested by individuals with cerebral palsy.

**“Someone of the same gender with a similar level of spinal cord injury, who is living a fulfilling life would be most desirable.”**

- 4) Participants wanted information regarding assistive devices and medication as it pertains to sexuality and sexual functioning as directly stated by a male participant.

**“They give you the gun, but they do not teach you how to hunt.”**

### ***Cohort #3 – Visual Disability***

A detailed overview of the findings for this cohort can be found in – In press 2009 Krupa, C; Esmail, S. Sexual health education for children with visual disabilities: Talking about sex is not enough. *Journal of Visual Impairment and Blindness*.

Overall, participants with visual disabilities felt that either due to a lack of creativity by their teachers and/or the use of non-inclusive curriculum material, they did not adequately learn the presented information in sexual health class. This also led to students having to find alternative methods to retrieve sexual health information (i.e., peers). As well, the sexual health education received tended to leave the student with a visual disability feeling ill-equipped and insecure with regards to their understanding of sexual health. The notion of sex as “dangerous”

or “taboo” influenced many of the participants to not speak of, or express sexual or emotional urges. Some of the specific themes that emerged from the data analysis were as follows:

- 1) Participants felt there was a definite need for further education beyond what was provided to the general population. One participant described the inability of educators to adjust the class to meet their specific needs.

**“They (teachers) weren’t really able to tailor the course in any kind of way very easily...”**

- 2) Participants reported feeling lost during any sexual health education they received. Many of the concepts presented to them were delivered in a method that was difficult to comprehend through verbal or visual explanation alone, especially if they had no previous experience to compare it to.

**“I remember him trying to explain to me about what a condom was, I remember it being very difficult for me to actually understand how the hell this thing worked, ..., it wasn’t until I ‘looked’(felt) at the thing that I understood what it was, how it was supposed to be used.”**

**“I failed miserably when it came to sex ed... because it’s all on video and it made no sense because I couldn’t see it and so... and the anatomy was really hard to learn.”**

As youths with a visual disability, many of the participants reported using their sighted peers and people they trusted to help them translate the sexual health materials they could not access in the school systems.

**“I guess people out of class you know I would say oh you know I didn’t really get this diagram or this part of the video – what was going on there and they would – you know- tell me what was going on.”**

- 3) This cohort recommended tactile models and non-visual methods of teaching with the opportunity to ask questions.

**“Yeah! I would have jumped at that opportunity [of using tactile models]... but not in the same classroom (as the able-bodied students).”**



- 4) One very unique suggestion was the need for a new “language” that may convey their interest in others, which may allow them the ability to pick up on cues other than body language or visual cues.

**“difficulties in gauging a situation ...depending how little you can see who’s where and what’s the surroundings, what body language am I missing...”**

- 5) Personal safety was another significant theme reported by all participants. They felt they needed to learn how to be in control, in order to keep themselves safe in dating and social situation. This was particularly important to the female participants who felt they could easily be taken “advantage of”. All participants suggested having personal safety strategies incorporated into the sexual health education program. Two participants talk about their experiences which bring to life the reality of having a visual disability and its impact on their sexuality.

**“My first encounter with a sexual experience was not a good one. I was out with a so-called “girlfriend” who said she knew the two people who were giving us a ride. I wound up in some area of our city that I had NO idea where I was. At the time I was not using a white cane and it wound up being a really ugly experience all the way around.”**

**“I had friends who were a little older than me so hearing their experiences and seeing what they went through was kind of a form of birth control... you know abstinence like I abstained from having – or WANTING to have sex because I’m just thinking wow it’s not that much fun...”**

#### *Cohort #4 - Burn Survivors*

A detailed overview of the findings can be found in – In press 2009 Parrott, Y; Esmail, S. Burn survivors’ perceptions regarding relevant sexual education strategies. Journal of Health Education.

Overwhelmingly, all participants, but specifically burn survivors, perceived their sexual health education as deficient or nonexistent. They also emphasized that it was critical to provide a sexual health education program for child and youth burn survivors. Specifically, the following themes were found:

- 1) Sexuality education should be provided when it is meaningful to the child. As all the participants suffered their burns during or before puberty they strongly felt that they would have benefited from getting sexual health information earlier when they were just starting to think about these issues. Usually when sexuality becomes an issue, individuals who are burn survivors have already been negatively affected in terms of self-esteem, etc.

**“If you are burned or have a disability at a young age you don’t know what normal is, you can only rely on what other people tell you”**

**“By grade 6 it’s almost already too late because they are already picking up misconceptions. I think earlier is probably better.”**

- 2) This group most strongly voiced their opinion of wanting to receive sexual health education in a safe environment from an individual they trust and feel comfortable with – ideally another burn survivor. The following are examples of many comments made during interviews or focus groups regarding the need for an emotionally safe environment.

**“You know some really good mentoring. I think that is more important than anything - knowing that there is other people out there like you.”**

**“Groups of five people, I think would be good because then you can get people more involved and not kind of just like a big lecture.”**

- 3) With respect to content, the participants felt information on self-esteem, body image, and acceptance, as well as specific information on the type, location and functional limitations associated with their burn, would have been helpful.

**“[In my sex education] there [was] nothing specific to people with burn injuries”**

**“...plus information on self esteem, body image, acceptance and physical implications of burns on sexuality.”**

**“The thing with burns is that they will never go away and that’s why you take it so personally because you know you’re always gonna have them.”**

**“ he biggest impact for me was image. It was how other people would see me. If I look into a mirror I don’t see anything beautiful looking about my body I see scars and ugliness...I automatically assumed that’s how the opposite sex or whatever would perceive me as well.”**

*Cohort #5 – Deaf or hard of hearing*

The Deaf or Hard of Hearing cohort mentioned that sexual health education was learned through incidental learning, such as observations of peers and siblings. Participants felt that this type of learning may have led to unsafe sexual behaviours. They felt there are very few resources that are accessible that have been developed for the Deaf /Hard of Hearing individuals. Analysis of the interview and focus group transcripts revealed the following themes:

- 1) Supplemental sexual health education resources that specifically target people who are Deaf or Hard of Hearing need to be available.

**“There are lots of services out there but my question is always, where are the services for the deaf people?”**

- 2) Sexual health education resources need to be explicitly visual. When a discussion of using drama or theatre for sexuality education came up several participants were quite supportive of this approach.

**“I never thought of them doing some sort of play. That would actually...(visual demonstration) I wonder if that would have been good because it’s really visual.”**

- 3) This group felt the use of role playing as a method of education was advantageous as it would allow students to visually observe interactions and consequences.

**“Deaf people role playing just getting it out there as explicitly and clearly as they could and that to me was mind boggling it was amazing.”**

- 4) Participants felt that education that included information on how to establish respectful boundaries within relationships was essential.

**“...in my early years I had issues with establishing boundaries. I was too permissive when it came right down the line. I needed to know when to say “no” more often. Yeah, so again, that’s why I say establishing boundaries is really important.”**

#### *Cohort #6 - Service Providers*

Overall, service providers were sensitive to the need for sexual health education for people with disabilities and felt that sexual health was a basic human right for everyone.

Awareness and greater pools of resources for sexual health education, fitting the unique needs of individuals with disabilities, were thought to be essential for children and youth with a physical disability. Service providers felt that sexual health education should pay particular attention to debunking the misconceptions regarding sexuality and disability that tend to be prevalent.

Participants suggested that a sexual health education curriculum should include psychosocial aspects of sexuality in order to exemplify the important non-physical aspects of sexuality. Key themes revealed from the data they provided included:

- 1) This group admitted that the provision of sex education was inadequate and that they were partly to blame.

**“Easier to talk about the act of sex than it is to talk about all the issues associated with sex,... feelings.”**

- 2) The service providers also felt that the use of a mentor or peers is ideal, however not always realistic or practical as stated by a participant.

**“For some kids I think it’s a great thing to have it done in a group situation so they can hear other peers.”**

- 3) They believed that there were not enough resources available for service providers to do an adequate job.

**“There aren’t very many resources out there.”**

**“Those who attempt to address it, usually don’t have much guidance either with addressing it, they mostly just use their common sense and experience (both personal and professional).”**

They felt that for sexual health education to be meaningful to students with disabilities it has to be relevant, useful, and provided in a sex positive manner. In order to address sexual health education with children and youth with physical disabilities, an honest, open, sex positive discussion should be generated so that these youth understand that having a physical disability does not equate to a sexual disability. Using a sex positive manner allows educators to focus on both the life-enhancing aspects of sexuality and the negative aspects that may exist.

All participants in this study recognized the overwhelming need for an accessible and disability specific sexual health education programs for children and youth with disabilities. It was felt by the participants that there is currently still a lack of appropriate resources and education opportunities which has lead to the development of misconceptions and lack of understanding about sexuality issues. Educators and healthcare service providers must work

together in order to provide a sexual health education program that is accessible to all students and can fulfill the specific needs of children and youth with disabilities.

### **Discussion**

Valuable insight was gained from the participants explaining their experiences growing up with a disability and the lack of adequate sexual health education they received. The many barriers they were faced with included societal, parental, school system, and their own self-limiting attitudes and behaviours. When unique questions arose, their attempts to gain information about sexuality were met with limited or irrelevant advice from parents and educators. Learning about their own sexuality through personal experimenting was prevented due to their physical limitations. The area of sexuality was a significant cause of frustration for many participants. Their transition to adulthood was made even more difficult due to the overall lack of information that was accessible to them during adolescence.

Overall, all the participants felt that the delivery of sexual health education to children and youth was poor and they were not aware of any good resources available in which parents or educators could access. When it came to their own experiences, none of the participant reported receiving disability specific information in any sexual health education they received. Participants felt that effective sexual health education should teach *all* students (able-bodied and those with physical disabilities) that sex is multifaceted and takes into account both the biological aspects of sexual health along with the emotional aspects of sexual health (i.e., self-esteem, body image, relationships). An important lesson to be included in the sexual health curriculum was making *all* students aware that individuals with physical disabilities are not dissimilar in their sexual health needs as their able-bodied peers and are thus are not asexual. Sexual health education that explains to *all* students that physical disability does not equate with

sexual disability was an aspect that all participants hoped would be included in a sexual health education curriculum. Participants felt that educators should be knowledgeable on the topic of sexuality and disability and should be able to ensure their students have equal access to the sexual health resources presented in the classroom. It is important that students with disabilities should not be singled out in a classroom amongst peers. Educators should take subtle approaches that ensure students with physical disabilities are receiving the sexual health information being presented in class and that their needs in terms of their physical issues are being met.

Participants wanted educators to teach students that the physical aspects of sex are only one dimension of sexual health and that sexual health is multifaceted, with psychological dimensions being equally as important. For example, persons with a spinal cord injury may retain their psychological capacity for sexuality even though their physiological capacity was affected by their injury. Participants also felt that sexual health education for *all* children and youth should never be reduced to a single-solution approach.

All participating groups, including the service provider's cohort, felt that health care professionals were a valuable resource for educators and children and youths with physical disabilities. However, many healthcare professional avoid the topic or don't feel adequately prepared to deal with the topic. They felt there was a need for health care providers to become more familiar with their role in the sexual health education of children and youth with physical disabilities. Health care providers are the primary professionals that educators and children and youth with disabilities should access for reliable disability specific information on sexual health. Any sign of embarrassment or lack of ease regarding sexuality on part of the health care provider can breakdown the client and health educator relationship.

Finally, participants felt strongly that sexual health education needs to be customized to the particular physical disabilities that the children or youth are facing. For instance, any sensory disability (i.e., vision or hearing loss) that children or adolescents are experiencing must be taken into consideration in determining how to present sexual health information and what materials may be needed. For example, methods using videos with captioning or tactile models may be needed in order to ensure curricular messages are communicated. Educators would need to be cognizant of needed adaptations in the classroom. A burn survivor may face different challenges in the area of sexuality (i.e., body image) than a person with a spinal cord injury (i.e., erectile issues) and thus require disability specific information. Each cohort discussed specific issues they faced in terms of their sexual health education and their disability, as well as what methods could be used to better disseminate information.

When this study was first conceptualized, it was thought that through gathering data from various cohorts we would gain an overall perspective of the sexual health education needs of children and youths living with a disability. Our goal was to provide some common strategies that educators could use when working with children or youth with physical disability. As the study progressed, it became clear that each cohort had its own unique issues which were significantly different from other cohorts. Although many similar themes were described, how they manifested themselves for each cohort was quite different. The general themes and strategies gained from combining all the cohorts does not do justice to the unique experiences and issues that each participant has dealt with in regards to their own disability.

Through discussions and stories the participant clearly demonstrated how each disability has its own unique manifestation with regard to its impact on the individual and sexual functioning. Even individuals with very similar disabilities appeared to be impacted differently



regarding sexual functioning and adjustment. In addition, the way each person responds to their own disability in terms of coping and management was quite different.

Specific information on the impact that various disabilities have on sexuality can be found in the literature and through appropriate associations and organizations for people with disabilities. To fully understand the impact of disability on a person's sexuality one must consider the type of disability and their personal characteristics (Sipki & Alexander, 1997). In addition, understanding whether the type of disability is stable or progressive, visible or invisible, and congenital or acquired will assist service providers in their understand of how the specific disability will impact the child or youth (Esmail, Dairy, Walter, & Knupp, in press 2009; Sipki & Alexander, 1997).

Data analysis revealed some interesting differences between the various cohorts in terms of the suggestions they made for sexual health education programs and what their specific needs and wants were. For example, the cohorts with acquired disabilities, such as SCI and burns, were very clear in their demands for separate sexual health education programs or resources in addition to main stream programs. They strongly advocated for the use of mentors, a safe and comfortable environment, and the need to deal with more of the psychological aspects of sexual health education. This group experienced a loss from being able-bodied to being someone with a disability. They felt that able-bodied individuals would never understand the experience they have gone through having lived in an able body and now are living in one that is disabled. The lack of attention paid to the psychological aspects of sexuality was viewed as a major concern. The participants with acquired disabilities tend to compare their present circumstance of functioning to their previous level of functioning (Kedde & van Berlo 2006; Mona, Gardos & Brown, 1994). For example, after a burn or spinal cord injury, one of the most frequently asked

questions concerned the change from pre- to post-injury, was how a person could remain physically attractive or sexually desirable in the aftermath of such injuries.

On the other hand, the cohorts with congenital disabilities, such as CP, and the majority of the participants in the visual and hearing disability groups were more inclined to want integrated programming with less emphasis on having a safe, private opportunity to discuss issues. They also did not put great emphasis on being taught by a mentor. They discussed how they have only known themselves as the way they are and they have a right to get educated just like everyone else. Being disabled was the norm for these participants (Mona et al., 1994) and they didn't want to be treated any differently from their peers. These suggestions are in line with research conducted by Kedde & van Berlo (2006) who found that self-esteem and adjustment was higher for individual with congenital disabilities as opposed to acquired disabilities.

Other interesting observations that were made between the different cohorts were based on whether their disability was stable or progressive in nature. There was a mix of participants in each cohort who had conditions that were medically stable or slowly worsening. The participants who had progressive conditions tended to put greater emphasize on the inclusion of the psychological impact that disability has on sexual functioning. Individuals with progressive conditions discussed having the added stress of how and when their condition will worsen. They described how, as they got older, their condition worsened causing them to continually adapt to their changing environment, and how their decreased physical functioning lead to subsequent changes in their sexual functioning (Sipki & Alexander, 1997). This may result in children and youth with progressive conditions taking on a fatalistic view or even a "why bother" attitude regarding sexuality. Therefore, these youth would benefit from receiving a sexual health education program that addresses these issues.

Unique perspectives were also given by individuals who had visible disabilities as opposed to those with an invisible disability. A distinctive difference has been found in the literature among the experiences of those with visible disabilities and those with invisible disabilities (Dale, 2005; Galvin 2005). Visible disabilities are defined as a disability related to functional limitations that are visually obvious to the general public. Examples of visible disabilities in our cohorts include participants with SCI, CP, burns and visual disabilities (i.e., the use of a cane to identify them). Invisible disabilities, on the other hand, may not be obvious to the general public but encompass having functional limitations. This category includes participants in our cohort with hearing and visual disabilities, burns that are under clothing, and individuals with CP where only one segment of their body was affected, making it a less obvious disability. Participants with visible disabilities described how they were often patronized, pitied, stared at, or treated as invisible. These negative attitudes from others often lead to the development of negative self-perceptions and low self-confidence (Galvin 2005). However, those with invisible disabilities described how they wanted to be seen as normal and worked to hide their limitations and actively avoided situations in which they knew they would encounter difficulties (Dale, 2005). This avoidance leads to self-exclusion from social opportunities and reluctance to engage in the development of their sexuality. Usually, people with invisible disabilities are not stigmatized as those with visible disabilities may be. However, they are still subject to forms of rejection, degradation, and social disapproval due to their self-limiting or avoidant behaviours (Davis, 2005). The participants with visible disabilities wanted more general education on disability for all students to increase public awareness in the hopes of dispelling some of the myths and biases they experience. They also emphasized the need for specific content relating to self-esteem and body image within the sexual health education curriculum.

All participants stated that they did not want to be singled out in class regarding sexual health education. Participants with invisible disabilities, in particular, insisted on having additional resources that children and youth can access independently, in order for them to remain “invisible.”

### Clinical implications

Overall, the findings of this study indicate that participants felt it was critical that children and youth with disabilities receive mainstream sexual health education. There was a general feeling that individuals with disabilities are systematically asexualized and not given the opportunity to discuss and learn about the topic of sexuality (Gannon, 1998; Kroll, Barbour, & Harris, 2007; Neufeld et al., 2002). It was felt that children and youth with physical disabilities should receive the same sexual health education as their able-bodied peers, but that they should also receive additional instructions that are specific to their disability and unique circumstances. Although there were many similarities between the different cohorts of individuals with disabilities that participated in the study, there were some unique differences in terms of what they felt were effective methods of teaching/learning sexual health education. These differences can be divided into three categories which include content, methods of delivery, and environment.

#### *Content*

Content refers to the information that should be included in a sexual health curriculum. Each cohort very clearly stated that in addition to the standard sexual health curriculum children and youth with disabilities must receive or have access to additional information that is specific to their disability. The participants felt it was important that the students with disabilities receive precise information regarding the unique features and impact of their disability on their present

and future sexual functioning. In addition, participants wanted to clearly send the message that the same disability might have many variations and unique manifestations. For example, SCIs are associated with important variation in the impact of the disability on general and sexual functioning. It was suggested that content developed for each type of disability should incorporate the large variations that are observed within the condition. All cohorts also mentioned that sexual health education programs for individuals with disabilities must include specific psychological content pertaining to self-esteem and acceptance, as well as physical concerns specific to their disability.

#### *Methods of delivery*

Delivery method refers to how sexual health information could be provided; the most appropriate and effective *means* to teach sexual health education to children and youth with physical disabilities. When looking at the methods of delivery there was again considerable variation which included specific examples as they relate to a specific disability, for example the use of tactile models for students with visual impairment or physical demonstration for student with hearing impairments. Individuals from the cohorts with sensory impairments, such as visual or auditory impairments, strongly felt that present methods used in classrooms are inadequate and at times inappropriate for their functioning. All participants believed that the methods of delivery should be sensitive to the functional limitations of their specific disability. Participants also suggested online resources may be an effective method to provide additional content that children and youth with physical disabilities can access independently. It was suggested that the educators could use careful, subtle adaptations and a variety of delivery methods to ensure that the sexual health program was user-friendly to all students.

When looking at methods of delivery, it is also important to consider when is the best time that children and youths should receive sexual health education. Generally, it was felt that sexual health education should be provided when it is meaningful to the child. In other words, a developmental approach should be used. For example, young children should learn early that sexuality is an appropriate and “normal” subject to talk about where they learn the proper vocabulary and immediately receive education on topics that include acceptance, self-esteem, and body image. As the child achieves various developmental milestones they would receive more detailed information that would include disability specific information. Also, if a child or youth asks a question about sexuality, it should not be avoided and should be dealt with in an open, honest manner. It was felt that there was no set “magic” age or time, but that sexuality should be integrated into the day-to-day education a child receives growing up.

### *Environment*

Environment refers to the physical and emotional setting that would be most conducive to providing sexual health education. As discussed previously, there were significant variations between the cohorts with regard to they type of environment they felt would be most suitable. For example, the individuals with congenital disabilities such as cerebral palsy tended to want more integrated education within the classroom, while individuals with acquired disabilities tended to want more separate, safe environments. All participants felt that the disability specific information should be given either in one-to-one or small group situations where the students could have an opportunity to ask questions without feeling self-conscious. Generally, it was felt that children and adolescents with physical disabilities require a safe environment to be able to discuss and learn about these issues.

Participants all agreed that one of the biggest factors in creating a safe, conducive learning environment was the teacher or educator's personal characteristics. All participants felt having a mentor or a trained educator to carry out the sexual health education program would be most appropriate. Although the use of a mentor was considered ideal, most agreed that this would be unrealistic in most settings. They felt that it was critical to have somebody who could truly empathize with the children or youth's unique situation and that they could feel comfortable with this educator. The educator should receive additional training in order to have a better understanding of the impact of disability on sexuality.

#### Limitations

This investigation had several apparent limitations. First, the private and sensitive nature of the topic of sexuality may cause increased apprehension when discussed (Thorn-Gray & Kern, 1983). This may have influenced those who were willing to participate in the study by possibly attracting individuals who feel strongly about the topic or have a personal agenda to meet.

Second, although our sample follows traditional numbers for a qualitative study of this type, to ensure more credible findings, a larger sample using both adults and adolescents would be beneficial and would allow for comparisons across age groups (Creswell, 1998). Furthermore, undertaking quantitative research could provide a more comprehensive comparison of the issues faced by children and youth with disabilities as it relates to sexuality education.

Third, although the focus groups have provided valuable insight, only one focus group was conducted with each cohort, limiting the value of the conversations. Additional focus groups that consisted of a mix of participants from various cohorts would prove valuable conversations between the various cohorts. The findings of this study may not be generalizable to all children

and youth with physical disabilities, however they have provided us with some unique issues needing to be addressed for this population in terms of sexual health education.

### Conclusion

Helping children and youth to construct a healthy sexual identity, increase enjoyment, effectively self-regulate, and develop skills for dealing appropriately and effectively with difficult sexual situations are essential when providing them with sexual health education programs. An appropriate sexual health education program will empower youth with disabilities to enjoy personal sexual fulfillment and to protect themselves from abuse, unplanned pregnancies, and sexually transmitted diseases (Murphy and Young 2005; A.A.P 1996).

Currently, sexual health education programs for youth use a medical model approach. These programs are designed and implemented based on societal expectations and taboos, imposing restrictions on content and limiting the areas of discussions. By paying attention to the content, methods of delivery, and environment of the sexual health experience of students, we can help children and youth with physical disabilities make a positive sexual health transition into adulthood. Participants in this study felt that they did not receive adequate sexual health education as children. In their view, a more thorough and in-depth sexual health education is needed that looks specifically at the needs of students with physical disabilities. Each cohort discussed specific issues they faced in terms of their sexual health education and their disability. They also suggested methods which could be used to better educate children and youth with physical disabilities. While each cohort tended to have unique issues when compared to one another there were also similarities between cohorts in terms of the potential methods educators could use in sexual health class.



The ultimate goal of this project is to use the findings to develop sexual health education programs for children and youth with physical disabilities. This project will not only benefit children and youth with physical disabilities within the cohorts studied, but can ultimately be used as a resource to assist able-bodied students, parents, teachers, and service providers to appropriately approach the topic of sexuality for various types of physical disabilities. Based on the lived experiences of our participants', we have been provided with valuable insight and specific strategies which educators and other service providers can utilize to address the issue of sexuality in a manner that is sensitive to the needs of the children and youth with physical disabilities. More effective sexual health education programs can assist children and youth with physical disabilities to better deal with issues they face and allow for a healthy transition into adulthood.

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## **Appendix A – Interview guide In-depth semi-structured interview**

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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.

### **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:

- A. As a child did anyone discuss sexuality with you?
- B. When do you remember about being taught about sexuality
- C. What was the primary source of sex education for you when you were growing up?
- D. What unique issues did you face in relation to sex education?
- E. Thinking back how you have liked to learn about sex?
- F. What experiences do you have with sex education?
- G. Where did you learn about sex?
- H. What do you think should be included in a sex education curriculum for individuals with physical disability?
- I. How did the sex education that you received influence your participation in sexual activities?

### **Wrap Up**

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

## Appendix B – Focus Group Guide

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- Introduction
- Thanks & welcome
- Introductions
- Purpose of the focus group, in relation to the research – looking for spectrum of opinions, diversity of responses
- How questions were derived:
- Outline of the session
- Timing of the session
- Domestic arrangements (toilets, tea/coffee, etcetera)
- Confidentiality
  1. As members of the Focus group your identity is confidential – who owns what opinions remains in this room
  2. However information that you provide will be shared with members of the research team and used in further reports, presentations, publications, etc.
  3. Your identity will not be known
  4. Obviously we need to speak frankly with one another and we would ask you to keep the knowledge you gain about each other s’ perceptions and views confidential as well
  
- Tape recorder and notes – turn on tape recorder
- Why you were invited
- Invite clarifying questions during introduction
- Stress this session as a focus group interview (dynamic process of group work)
- Rules about agreeing, disagreeing, changing one’s mind, respecting the opinion of others:
  1. everyone’s experiences are important
  2. there are no good or bad opinions
  3. we expect opinions and experiences will differ
  4. we are interested in hearing and understanding each person’s perspective, and
  5. we welcome all input
  
- How the session will be organised
- Questions from group members
- Brief two minute biography from each member: focus on:
  - community/institution; rural/urban; types of clients - acute/enduring conditions
- Questions and activities based on data analysis from the one-to-one interviews

### Wrap up

Summarise the main points

Reports emanating from the research, etc.

Thanks