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# Education, Exploration and the Elephant in the Room: A Narrative Inquiry of Sexuality and Sex Education among Adolescents with Physical Disabilities

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# Education, Exploration and the Elephant in the Room:

# A Narrative Inquiry of Sexuality and Sex Education among Adolescents with Physical Disabilities

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by

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# Abstract

Guided by a constructivist paradigm, this qualitative research study used a multidimensional form of narrative inquiry in order to understand the experiences of learning about sexuality among adolescents with physical disabilities, and in turn, how these experiences influence the way they view themselves as sexual beings.

For the purposes of this research, in-depth narrative interviews were conducted with adolescents who have physical disabilities and parents of youth with physical disabilities, as well as a focus group with health professionals. The findings from this study demonstrate that these adolescents often face challenges in accessing disability-specific sex information due to a lack of appropriate resources, discomfort with the topic among educators, health professionals and parents, as well as the pervasive social myth that views people with disabilities as asexual. The data from this study contributes to the literature about sexuality among adolescents with physical disabilities by drawing attention to this important but often overlooked issue, as well as offering recommendations for future resource development that could help empower these youth with the knowledge and skills needed to engage in safe, healthy and fulfilling relationships.

Keywords: Sex education, sexuality, sexual health education, physical disability, disability, adolescence, narrative inquiry, qualitative research

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# Chapter 1: Introduction

*"To be human is to be sexual."* (Winder, 1983)

The desire for love, intimacy and sexual expression is seen as an innate part of human nature (Boyle, 1994; WHO, 2007). However, certain groups in society who are perceived as deviating from the culturally defined norms in terms of appearance, function or behaviour, such as people living with physical disabilities, are often viewed as not being capable of possessing this fundamental aspect of the human experience. Societal views towards sexuality among those with physical disabilities are often driven by the widespread misconceptions related to people with disabilities being seen as asexual, as incapable of forming relationships or lacking the basic drives for intimacy and sexual satisfaction (Berman et al., 1999). This pervasive myth of asexuality can be particularly detrimental to youth living with physical disabilities, since the formative adolescent years are vital to one's psychosexual development, as well as their identity formation. Receiving incorrect or stigmatizing societal messages related to their own sexual and reproductive capabilities can exacerbate challenges already facing many of these youth, such as low self-esteem, poor body image, social isolation and the fear of not finding a partner (Milligan & Neufeldt, 2001).

Research indicates that young people with physical disabilities require the same basic sexual health education as their able bodied peers, combined with specialized sexuality information and skill development related to their disability (DiGiulio, 2003). This type of comprehensive education not only provides youth who have physical disabilities with the knowledge and skills needed to make informed choices about their own sexual health, it also teaches them to view themselves as sexual beings. Research has shown that accepting and embracing one's status as a sexual being is essential to the development of a positive self-image and sexual identity (Guest, 2000). The information currently available on the topic of adolescent sexuality and physical disability is rather limited and outdated, with specific gaps in the research pertaining to the use of qualitative methods, research with Canadian youth, sex education, and studies involving several different members of the disability community.

The number of people living with disabilities in Canada has been steadily rising over the past several years. According to the Government of Canada (2011), there are approximately 3.6 million people, or one in every eight Canadians, living with some form of physical, mental, cognitive or sensory disability. Among children between the ages of 5-14, Statistics Canada (2003) estimates that 3.1% have some type of diagnosed physical disability. It is evident that people living with disabilities make up a sizable portion of the Canadian population, yet their needs and rights are often overlooked, especially in terms of sexual health education and resources. Health Canada (2003) states that sexual health education should be available to all Canadians, as it plays an important role in promoting a healthy lifestyle by providing us with the necessary knowledge and skills needed to make safe and informed decisions regarding our sexual activity and intimate relationships. The Public Health Agency of Canada (2008) goes on to state that for sexual health education to be effective, it must be delivered in an open and nondiscriminatory manner that respects individual beliefs and is sensitive to the diverse needs of individuals, regardless of their age, race, religion, gender identity, sexual orientation, socioeconomic background or level of ability. Despite government agencies affirming the importance of sexual health education to the overall health and wellbeing of the entire population, sexuality and disability is an aspect of health and development that is often overlooked, particularly among young people with physical disabilities. These youth are often perceived to be innocent and naïve by their parents, educators and health professionals and as a result, they are not always provided with adequate information related to their own sexuality and sexual health (Neufeld, Klingbeil, Bryen, Silverman, & Thomas, 2002; Suris, Resnick, Cassuto, & Blum, 1996). A lack of sexual knowledge and inadequate sex education puts these youth at a high risk for sexual abuse and exploitation, sexually transmitted infections, teen pregnancy and HIV/AIDS (Moglia, 1986; Shoveller, Johnson, Prkachin, & Patrick, 2007).

An aim of this study is to understand what the experience of learning about sexuality is like for adolescents with physical disabilities, in terms of formal sex education at school, discussing sexuality issues with health professionals, and talking about sex with parents and peers. I am interesting in looking at how these experiences influence the way these youth see themselves as sexual beings within society. This study also aims to gain a greater understanding of the types of sex education resources and services that are currently available for youth with physical disabilities and their families, as well as the kinds of resources that need to be developed in order to improve sexual knowledge and competency among this population. While this study takes an in depth look into the area of sexuality and sex education among adolescents with physical disabilities, several other issues that are pertinent to these youth's lives are also explored, including dating, self-esteem, body image, social challenges, acceptance, independence, expectations, media influences and societal views on disability.

## Defining Key Terms

### *Adolescence*

Erikson (1950) described adolescence as a transitory phase between childhood and adulthood spanning from the ages of 13-19, often characterized by the challenge of identity development versus role confusion. The Oxford Dictionary (2011) uses a similar definition for this stage, describing adolescence as the period following the onset of puberty during which a young person develops from a child into an adult. While Erikson's classic definition may be prevalent in the literature on human development, this study recognizes the complex, multifaceted nature of adolescence as encompassing far more intricacies and challenges than the sole identity dichotomy proposed in Erikson's theory. Throughout this thesis the terms adolescent, youth and young person are used to describe the study population. Although these terms each have their own distinctive associations, they will be used interchangeably throughout the study in order to avoid repetition. For the purposes of this study, the term adolescence is used to describe the age bracket of 12-21, a broader definition than that proposed by Erikson. Although the ages of 18-19 are generally viewed as the transition between adolescence and adulthood, young people with disabilities may experience an extended adolescence (Stevens et al., 1996) due to limitations with independence or the fact that they are allowed to stay in high school until the age of 21.

### *Physical Disability*

The terms physical disability, physical limitation and physical impairment are used interchangeably throughout this thesis in order to describe the youth demographic being explored, as well as to avoid repetition within the study. The World Health Organization (WHO) (2010) describes the word "disability" as an umbrella term, which includes physical impairments, activity limitations, and participation restrictions. The WHO (2010) explain that an impairment is a problem in the structure or function of the body; an activity limitation is a difficulty encountered by an individual while performing an action or task; and a participation restriction is a challenge experienced by an individual in the involvement of social activities or life situations. The WHO (2010) also describes disability as the interaction between features of a person's body and aspects of the society in which he or she lives. The way in which this topic is discussed throughout the study is based on the WHO's complex view of disability as being something that is interrelated to and influenced by the social context in which people live. The word "disability" is generally used as a broad term to describe cognitive, physical and sensory impairments; however, since this study only included youth who have disabilities that affect their mobility and physical function, without limiting their cognitive or sensory abilities, the term "disability" will refer only to a physical disability unless otherwise specified.

### ***Sexuality***

Sexuality is a central aspect of being human and encompasses biological sex, gender identity, sexual orientation, intimate relationships and reproduction (WHO, 2007). According to the WHO (2007), sexuality is a complex, multifaceted phenomenon that is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, historical, and religious factors. As a result of these multiple influences, the Public Health Agency of Canada's (PHAC) Guidelines for Sexual Health Education (2008) suggest that "sexuality is best understood as a complex, fluid and dynamic set of forces that are an integral aspect of an individual's sense of identity, social well-being and personal health" (p.5). Along with the definitions of sexuality given by the WHO and PHAC, this study is also using the term to encompass psychological and emotional aspects of sexuality, such as the way we feel about our bodies, who we are attracted to, how we derive pleasure, how and why we form relationships, and what makes us feel attractive or desirable. This study looked at the interaction of various individual, interpersonal, societal and environmental factors in the lives of adolescents with physical disabilities, in order to explore how these factors influence the experience of learning about sexuality and developing a sense of sexual identity among these youth.

### *Sex Education*

The term "sexual health education" is often used by health care organizations or agencies and generally refers to education related specifically to sexual health and reproduction, whereas the term "sex education" is most often used to refer to broad-based, comprehensive education related to all aspects of sexuality. In order to limit repetition and confusion, both of these terms will be used interchangeably throughout this study. The PHAC (2008) describes sexual health education as "the process of equipping individuals, couples, families and communities with the information, motivation and behavioural skills needed to enhance sexual health and avoid negative sexual health outcomes" (p.5). They believe that sexual health education should encompass a broadly based, community-supported process, requiring the full participation of educational, medical, public health, social welfare and legal institutions within our society. Many educational organizations, including the PHAC, recognize the complexity of sexuality and sexual health, and consider access to timely, relevant and broadly based sexual health information and services to be a basic human right. The WHO (2011) believes that providing culturally relevant sex education is essential for ensuring that the sexual health needs of a community are met and maintained. This study uses the term sex education to describe the formal, comprehensive sex education provided in the mainstream school curriculum, the sexual health information delivered by health practitioners, and the informal sex education provided by family, peers and the media.

## Organization of the Thesis

Following this chapter, which provides background information on the topic of sex education among adolescents with physical disabilities, as well as an outline of the study and the definition of key terms, the organization of this thesis is as follows:

*Chapter Two:* This chapter presents a literature review covering a variety of areas related to sexuality and sex education among adolescents with physical disabilities. Firstly, information on the social characteristics of adolescence, as well as the current data on adolescent sexuality and sexual health in North America is presented. This is followed by a summary of the three main social theories related to sexuality and disability that have been used to develop the theoretical framework for this study, including the social model of disability, Goffman's notion of stigma, and the theory of sexual citizenship. I then address some of the prominent issues related to sex education among adolescents with physical disabilities, as well as the topics of body image and self-esteem within this population.

*Chapter Three:* The methodology chapter begins by providing a detailed outline of the main research questions and objectives of this study, as well as a description of my paradigmatic stance as a constructivist researcher. This is followed by information about narrative inquiry, the type of qualitative research design used in this project. This chapter goes on to discuss the research methods used in this study, including the recruitment, data collection and analysis processes. Finally, issues related to quality criteria and ethical procedures are addressed.

*Chapter Four:* Part one of the findings chapter outlines two of the major themes that developed through analyzing the narrative interviews and focus groups that were conducted during this study. These include discussions about the type of sex education adolescents with physical disabilities receive from their school, parents, peers and health professionals, as well as the issues of sexuality and self-image among this population. Quotations from the narrative interviews with youth and parents, as well as from the focus group conducted with health professionals are used throughout this chapter, in order to capture the main ideas relating to each theme. This chapter concludes with a discussion of how these findings relate to, extend or contradict existing research related to sexuality and sex education among adolescents with physical disabilities.

*Chapter Five:* Part two of the findings section is organized in the same format as chapter four, except that it features the two secondary themes of the study. While these themes are not directly related to sex education among adolescents with physical disabilities, they still play a significant role in the general lives of the youth and the development of their overall sense of self. Specifically this chapter explores the significance of the youth's relationships with their peers, parents and health professionals, as well as addressing some of the prominent views and perceptions society holds towards people with disabilities. This chapter concludes with a theme summary and discussion of how the findings from this study in terms of peer and parent relationships, as well as societal views of disability relate to the prominent literature currently available in these areas.

*Chapter Six:* This chapter begins with a discussion on some of the main findings of this research project and how they relate to the primary goals of the study. It then goes on to discuss some of the challenges and surprises encountered during the research process, and how the research findings compare to the literature that is currently available in the area of adolescent sexuality and physical disability. This chapter then highlights the strengths and limitations of the study, and how these may have positively or negatively influenced the outcome of the research. Recommendations for future resources and services aimed at improving sex education opportunities for youth with physical disabilities are then presented, followed by a discussion on possible areas of future research that would be beneficial to explore. This chapter ends with a conclusion that revisits the notion of stigma, expands on our current notions of adolescence and sexuality, discusses the significance of the title metaphor "the elephant in the room", and finally highlights some of the educational, societal and interpersonal implications that this research could have in the lives of youth living with physical disabilities.

# Chapter Two: Review of Literature

## Introduction

Historically, individuals with disabilities have faced numerous challenges in their efforts to be accepted as equal members of society. From injustice, discrimination and prejudice to institutionalization and forced sterilization, society has often thought of people with disabilities as less deserving of the same human rights that their able bodied counterparts have inherent access to, such as the freedom to choose what to do, where to live, who to live with, and when and if to have children (Johnson, 1982). With the initiation of the disability rights movement in the 1970's and the inclusion of people with disabilities into the Charter of Rights and Freedoms in 1981, the attitude towards those living with a disability began to shift towards a more egalitarian, ability-based viewpoint (Prince, 2004). However, as a result of decades of marginalization, there are certain aspects of daily life in which people with disabilities are still highly stigmatized, as Lamb and Layzell (1994) so poignantly state:

> There is an unspoken taboo about relationships and disabled people. Disabled people's sexual and relationship needs are rarely included in any representation [of] everyday life. This reinforces the public's attitudes and expectations towards disabled people, seeing them as 'sick and sexless'. It is perhaps the most pernicious way in which society has blanked out disabled people from a fundamental area of social life (p.22).

The pervasive misconceptions that suggest people living with disabilities are considered undesirable and asexual can be particularly damaging to the emergent sexuality of youth who have physical disabilities. Since adolescence is a time where young people are highly influenced by their social environments and desire to be accepted by their peers, these widespread misconceptions can negatively impact the youths' ability to confidently view themselves as sexual beings and desirable dating partners within society.

## Theories related to Sexuality and Disability

In order to understand the issues and challenges facing adolescents who have physical disabilities with regard to sexuality and sex education, it is important to explore the underlying theoretical frameworks upon which our current understandings of disability and sexuality are based on. The theoretical perspectives that provide the framework for this study are the social model of disability, Goffman's notion of stigma and the theory of sexual citizenship.

The social model of disability was included in this study as a means of understanding the way disability is currently viewed within society, how this model has changed the notion of disability over time and what sort of impact this model has had on the inclusion, acceptance and quality of life for people living with physical disabilities. The presence of disability-related stigma within society is an issue that is discussed several times throughout the thesis, as it poses a significant barrier towards people with disabilities being viewed and respected as sexual beings. In order to eliminate this negative stigma from society, we must first understand what stigma is, why it exists, how it develops, and what type of impact it can have on the people it affects. It is for this reason that Goffman's notion of stigma was chosen as the second theoretical framework for this study. The theory of sexual citizenship was included in this study as a means of understanding why it is that people with physical disabilities are not always viewed as being equally entitled to the same sexual rights and choices as the rest of able bodied society, and what kind of influence does sexual citizenship, or a lack thereof, have on a person's sexual health, sexual knowledge and overall sense of self.

## Social Model of Disability

Until fairly recently, research and discourse related to disability has been dominated by the western biomedical model. This perspective proposes a dichotomy between what is considered "normal" versus "pathological", where someone with a disability is seen as inherently damaged, flawed, and in need of repair because they do not represent the culturally accepted ideals of how a body should look and function (Hughes, 2007). As the rights of marginalized populations became increasingly recognized during the social and political movements of the 1960's and 1970's, a new way of thinking about disability, known as the social model or social constructionist theory, began to gain recognition. This model, rooted in the idea that dominant groups in society set the rules that define normality and deviance, frames disability as a public or social issue rather than a matter of individual deficits and corporeal shortcomings (Oliver, 1998). The social model of disability places an emphasis on how the environment, both physical and socio-political, includes or excludes certain people from fully participating in society (Mays, 2006).

The concept of disability being connected with and influenced by one's physical and social environments is evident in such frameworks as the World Health Organization's International Classification of Functioning, Disability and Health (ICF), which emphasizes the impact that body functioning as well as activities, participation and the environment have on the level or degree of disability that a person experiences. The IFC also makes a distinction between disability, impairment and "handicap" (WHO, 2010). For example, a person with a disability such as muscular dystrophy may not be able to walk independently, which would be considered an impairment. However, the fact that this person is unable to enter a pub that has a set of stairs out front instead of a ramp is not because this individual has muscular dystrophy and is physically unable to walk, but rather because the environment was built in such a way that excludes people who use mobility devices as their main form of transportation. The social model stresses that a person's participation in activities, such as going to a pub, are hindered not by one's individual disability but rather by the "handicaps" put in place by an unaccommodating, ableist society.

In order to create a more positive social attitude towards those living with physical disabilities, theorists in this field suggest a need for more strengths-based interventions, which embrace a people's unique talents and abilities, rather than focusing solely on their physical limitations (Greene, 1999). There is also a need for more positive images of disability in the media in order to attempt to break down some of the pervasive stereotypes that have caused much of the segregation and misconceptions that people with disabilities have had to face, including myths about asexuality, dependence, vulnerability and undesirability (Anderson & Kitchin, 2000). Until disability is viewed as an issue requiring social responsibility and attention, rather than a matter of individual tragedy, people with disabilities will continue to be excluded from fully participating in society. The social model has begun to dominate a large portion of the non-medical disability research; however, as a result of western society's obsession with "fixing" what is different rather than accepting and embracing it, the majority of medical literature related to people with physical disabilities still tends to emphasize functional deviation, deficiency and dependency on others for care. This allows negative stereotypes about people with disabilities to be continually reinforced, and often internalized by those living with physical limitations (Oliver, 1998).

This theory is useful in understanding some of the challenges adolescents with physical disabilities face in regard to learning about sexuality, being accepted by their peers or being viewed as desirable dating partners, since it frames disability as a social issue rather than a matter of physical inadequacy or deviation from the norm. For example, according to the social model of disability, the challenges that youth with physical disabilities may face in terms of finding a dating partner or engaging in intimate relationships are not due to their specific physical limitations, instead they are the result of society's perceptions towards people with physical disabilities as being undesirable or incapable of sexual expression. The notion of disability being a socially constructed phenomenon is congruent with much of the current literature on sexuality and disability, as Shakespeare (2000) states that "the barriers to sexual expression that people with disabilities face are primarily to do with the society in which we live, not the bodies in which we are endowed" (p.161).

## Goffman's Notion of Stigma

Stigma is defined as "a mark of disgrace associated with a particular circumstance, quality, or person " (Oxford English Dictionary, 2011), a term that was first coined by sociologist Erving Goffman in 1963 to describe any person who, due to some form of physical or social deviation from the culturally defined norm, was considered to be undesirable, unworthy and an outcast. Goffman (1963) described stigma as the relationship between an attribute and a stereotype, explaining how the link between a socially undesirable trait and a negative assumption changed the social view of "a whole and usual person to a tainted, discounted one" (p. 3). He described three types of stigma related to various physical, social and cultural norms present in society. These included: "abominations of the body", which he used to describe visible physical differences and limitations related to one's appearance or functioning; "blemishes of individual character" pertaining to actions or behaviours which at the time were believed to be immoral or sinister, such as addiction, imprisonment, mental illness and homosexuality; and finally "tribal stigma of race, nation and religion", a type of stigma that Goffman describes as "contaminating all members of a family" or group sharing a common characteristic. (Goffman, 1963, p.4).

While the concept of stigma operates within and is perpetuated against many groups in society, it has a particular relevance to the treatment and perception of people who have physical, cognitive or sensory impairments. Researchers explain that societal stigma is common towards people with disabilities due to the numerous misconceptions and assumptions that are presently associated with this population (Fine & Asch, 1988; Link & Phelan, 2001). Fine and Asch (1988) identify the five main assumptions that perpetuate the negative views towards people with disabilities, which include the belief that disability is located solely within the realm of biology; that the challenges facing people with disabilities are due to their own physical or cognitive impairment rather than societal views and practices; that the person with a disability is a 'victim'; that the disability is central to the person's self-concept, self-definition and social comparisons; and that having a disability is synonymous with needing help and social support.

The widespread belief of these largely incorrect assumptions can have a very negative impact on those living with a disability, and can lead to such conditions as poor self-image, limited confidence and internalized feelings of worthlessness (McDermott & Herve, 1995; Shuttleworth & Kasnitz, 2004). Researchers have expressed a variety of opinions on why this stigma developed and how it works to marginalize people with disabilities from the rest of society. Socio-cultural researchers have looked at the link between stigma and deviance, exploring how these concepts influence the social experiences of people with physical disabilities (Devlieger, 1999). They describe the stigma associated with physical disability in relation to western society's view of "non-normative bodies" or the perception that able-bodied individuals have towards people who for example cannot walk on their own, cannot control their movements, sounds or facial expressions and general speaking, those whose bodies look and function in a different way to the medically and socially accepted norm (Shuttleworth & Kasnitz, 2004). Some experts believe that the stigma associated with "non-normative bodies" stems from the knowledge, fear and resentment that anyone can become disabled at any point in time. This negative societal attitude towards disability can lead to discrimination and marginalization, by creating a stereotyped view of anyone with a physical limitation or difference as being perceived to be incapable, dependent and thus discredited from mainstream society (McDermott & Herve, 1995).

According to Link and Phelan (2001), stigma related to minority groups, such as those living with physical disabilities, exists when four interrelated components converge. In the first component, stigma occurs when people distinguish and label human differences. The second element relates to dominant cultural beliefs linking labeled persons to undesirable characteristics, ultimately developing into negative stereotypes. In the third aspect of this process, labeled persons are placed in distinct categories, creating a degree of separation between "us" and "them." Finally, labeled persons experience status loss and discrimination, leading to oppression and unequal outcomes for the stigmatized population (Link & Phelan, 2001).

The "us versus them" dichotomy addressed by Link and Phelan (2001) in their work on the development of stigma has also been explored by other researchers who examine the processes involved with labeling and marginalizing people who are perceived to be different from those deemed "normal" members of society; which is sometimes referred to as "othering". Wendell (1996) discusses "othering" in relation to people with disabilities, and explains that it is sometimes done in order to separate them from the well-established bounds of normative bodily, social, and sexual behaviours and identities. She also raises the idea that persons living with a disability may embody certain qualities that have been deemed dangerous and are things to avoid, namely imperfection, failure to control the body, and vulnerability to weakness, illness and death. This is another reason why these individuals commonly experience different forms of exclusion via "othering". Wendell (1996) argues that this aspect of identity politics and boundary maintenance is very problematic because it lowers people with disabilities to the category of "other" based solely on their deviation from normative ways of being and not in relation to their own particular individual and/or group characteristics and experiences.

In many ways, the traditional approach to doing research with people who have disabilities has also operated through certain processes that result in the "othering" of these individuals. In decades past the issue of disability was often understood through the lens of biomedicine, which upheld particular notions of health, the body, and identity that were based on certain ideas about productivity, being able-bodied, and the absence of disease or disablement (Oliver, 1998). Through this framework, people with disabilities were perceived to be inherently flawed, incomplete and separate from the rest of able bodied society on account of their 'deficient' bodies and differing abilities to contribute to society.

Importantly, "othering" is not just a labeling process applied by 'dominant' or 'mainstream' individuals to those with physical disabilities. It is also something that can be internalized, such that the "othered" often incorporate larger societal standards of what is considered "normal" or "desirable" into their own personal beliefs and values associated with their bodies, lives, and relationships (Eisenberg,1982). In order to eliminate the negative form of "othering" that can occur as a result of research conducted with people who have disabilities, modern disability researchers are pushing for more representative and socially-specific work that reflects the complexity of these individuals lives, not only in relation to the negative aspects associated with having a disability but also the positive things relating to their lives as people first and foremost (Shuttleworth & Kasnitz, 2004).

I would not have been able to complete this research project without incorporating the notion of stigma into the initial theoretical frameworks of this study, as it played a significant role in the research development, the participants' responses, the analysis of the data and the recommendations for improving sexuality and sex education resources and services for youth with physical disabilities. Researchers have suggested that one of the most important ways to improve sexual health education and sexual self-esteem among young people with physical disabilities is to reduce the societal stigma currently surrounding sexuality within the disability community (Berman et al. 1999; Taleporos & McCabe). Educating teachers, health professionals, parents and the rest of the able bodied community about the misconceptions surrounding sexuality among people with physical disabilities is imperative in order to begin breaking down some of the stigmatizing perceptions that have excluded and marginalized this population for so many years.

## Sexual Citizenship

The World Health Organization (WHO, 2007) states that having access to sexual health education and services is an important human right that should be available to all people, regardless of their race, gender, sexual orientation or physical and intellectual capabilities. The WHO (2007) also states that for sexual health to be attained or maintained, the sexual rights of all people must be respected, protected and fulfilled. Although organizations such as the WHO state that sexuality should be accepted and respected as a fundamental human right, they sometimes fail to recognize that certain groups of people, such as those living with physical disabilities, are not always accepted as equal members of society, particularly in regard to their sexual and reproductive rights. Due to the widespread misconception that people with physical disabilities are innocent, childlike and unable to engage in sexual activity, this group is far less likely to receive the same sexual health information, services and reproductive freedom as their able-bodied counterparts (Milligan & Neufeldt, 2001; Shakespeare, 2000). A recent push towards understanding and critically appraising sexual rights as they relate to issues of inequality has led to the development of a concept known as sexual citizenship.

Sexual citizenship encompasses three dimensions; first, a demand for control, such as control over one's body, emotions and relationships; second, a demand for access, including access to representations, information, services, partners and public spaces; and third, a demand for choice, particularly regarding identity, lifestyle and gender experience (Weeks, 1998). The concept of sexual citizenship is derived in part by the general idea of what it means to be a citizen within society. While a citizen generally refers to a person belonging to a particular nation or geographical community, political theorist Benedict Anderson (1991) extended our understandings of this concept by creating the term "imagined communities", in order to describe the notion of belonging to a certain community based on a group's shared personal experiences or circumstances, rather than their physical proximity to one another. This theory is particularly useful when trying to understand the experiences of marginalized populations, particularly those who belong to sexual minorities, as they often define themselves in terms of both personal and collective identities irrespective of shared nationality or geographic residence (Richardson, 2000; Weeks, 1998).

While the social model of disability and Goffman's notion of stigma focus primarily on the way in which society views people living with disabilities, I felt it was important to incorporate a theory that was based primarily around sexuality and the human rights associated with being a sexual person within society. The topic of reproductive capabilities and choices came up repeatedly during my interviews with the female youth participants, most of whom were largely unaware of their own reproductive capabilities, and felt very strongly about the fact that they did not want to have biological children of their own. This issue has particular significance to the concept of sexual citizenship, as it pertains to a person's right to be fully informed about their reproductive rights and capabilities, in order to make educated decisions regarding their future plans to raise a family if they so choose.

Sexual citizenship is a theory that has been primarily used in research to describe the issue of sexual (in)equality among members of the lesbian, gay, bisexual, transgendered and queer/questioning (LGBTQ) community; however, the challenges of being accepted and respected as an equal sexual citizen also have significant relevance to other minority groups, such as those living with physical disabilities. Although it can be difficult to label a group as a minority without reverting to an 'othering' type of mentality, it is also important to recognize that some groups within society have specific needs and challenges in terms of the intimate relationships they pursue and the sexual health information and services they require. For people with physical disabilities, these specific needs and challenges must be identified in order to ensure that they are viewed as sexual citizens within society. This means having an equal opportunity to receive accessible and relevant sexual health information and services, which is considered by the WHO (2011) to be a basic human right for all people.

## Adolescent Sexuality and Sex Education in North America

Sexuality and sexual identity have been described as basic and profound elements of one's overall identity and sense of self, as they are intricately connected to and influenced by one's cognitive, emotional, psychological, physical and social state of being (Boyle, 1994; Neufeld et al., 2002). For adolescents, gaining an understanding and acceptance of their sexuality plays a significant role in the development of identity and positive self-image, which researchers have described as key developmental milestones during this time of life (Rousso, 1996; Schachter, 2004).

While certain aspects of adolescent sexuality, such as sexual behaviour patterns and the age of first intercourse, have remained relatively consistent over time, an aspect of sexuality that has changed dramatically in the past few decades is the increased time between the first sexual experience and the marriage and childbearing stages of life (Maticka-Tyndale, 2008). In the past it was not uncommon to marry soon after graduating high school, which for many meant sharing their first sexual experience with their spouse. However, since the average age for first sexual intercourse in Canada is 16.5 (Rotermann, 2005) and the average age of marriage for males and females is 34 and 32, respectively (United Nations, 2008), young adults are experiencing many more years as sexually active singles, increasing the opportunity for sexual exploration, multiple partners and other forms of relationships (Statistics Canada, 2006). Although today's young people are engaging in safer sexual practices than that of previous generations, the dominant societal view towards adolescence does not seem to reflect these positive changes in teenage behaviour.

In North America, there is an overarching understanding that adolescence is a turbulent time filled with rebellion, angst, and conflict, a notion which has been prevalent since G. Stanley Hall (1904) first conceptualized this life stage as a period of "storm and stress", dominated by parent-child conflict, uncontrollable mood swings and risk taking behaviour. Due to this long standing association between adolescence and destructive or irrational behaviour, the view towards this stage of life as being something that is inherently negative or dangerous has been embedded in many forms of academic research, pop culture and the social imagination for over a century. This perception of adolescents being troubled and out of control is often applied universally, and is somewhat "expected" in North American culture, even though research has shown that only a small percentage of youth actually exhibit these sorts of behaviours (Holmbeck, 1996). As a result of this pervasive stereotype, fundamental aspects of adolescent development, such as sexuality, are also seen as inherently negative and dangerous. This is evident in the vast majority of sex education programs which are based on the prevention of pregnancy, sexually transmitted infections (STIs), sexual abuse and other "dangers" associated with adolescent sexuality (Maticka-Tyndale, 2008). Although there is a common misconception that adolescents are becoming increasingly promiscuous and partaking in more risky sexual behaviour than ever before, research shows this is not necessarily the case. While the age of first intercourse has stayed relatively stable, the rates of teenage pregnancy and some STIs have steadily decreased over the past three decades (McKay, 2006). This improvement is thought to be the result of better-quality comprehensive sex education that provides adolescents with relevant information about their own sexual rights, responsibilities and choices, along with greater access to birth control (Saewyc, Taylor, Homma, & Ogilvie, 2008).

Schools are often the primary sex education providers for young people; however, adolescents also learn about sexuality from a variety of other sources, including friends, parents (primarily mothers), siblings and the media (Bleakley, Hennessy, Fishbein, &

Jordan, 2009; DiCenso et al., 2001). Unfortunately, not all adolescents receive an equal opportunity to access accurate information and sexual health services. Young people who face particular challenges in accessing these services include youth living in rural or remote areas, very young adolescents, Aboriginal youth, youth who live in low socioeconomic communities, LGBTQ youth and adolescents with disabilities. The interaction of geographic, economic and social factors creates an environment where these youth are poorly served by sexual health services, which increases the risk of teen pregnancy, STI/HIV transmission and sexual abuse and exploitation (Canadian Federation for Sexual Health, 2007; Shoveller et al., 2007).

## Sexuality and Adolescents with Physical Disabilities

### Myths and Misconceptions

Although having a physical disability may cause several limitations and impairments to a person's functioning, it does not necessarily affect one's basic physiological and sexual drives or one's desire for love, intimacy and affection (Milligan & Neufeldt, 2001). However, the myths linking asexuality and disability are ubiquitous and stem largely from the fact that in the media, young people with physical disabilities are often portrayed as dependent, childlike and in need of protection (Neufeld et al., 2002; Suris et al. 1996). These stereotypes are particularly evident in the way charitable organizations use innocent, angelic looking images of children and adolescents in wheelchairs as a means to invoke heartfelt emotion and pity from their potential donors, which only perpetuates the myths associating these youth with being naïve, childlike and asexual (M. Kaufman, personal communication, Oct 2, 2009).

While the myth of asexuality may be very prevalent within society, several studies have found that the rates of sexual activity among adolescents with mild to moderate physical disabilities are equal to that of their able bodied counterparts (Cheng & Udry, 2002; Suris et al., 1996), and in some cases may even be higher (Brunnberg, Linden- Bostrom, & Berglund, 2009; Choquet, Du Pasquier-Fediavsky, & Manfredi, 1997). However, research also indicates that many adolescents with physical disabilities show considerably lower levels of sexual knowledge and inadequate sex education compared to their peers without disabilities (Berman et al. 1999). This issue of low sexual knowledge combined with other factors such as dependence on adults for personal care, social isolation and low self-esteem put youth with physical disabilities at a higher risk for sexual abuse (Schor, 1987). Since young people with physical disabilities are seen as more vulnerable than able bodied youth, parents and educators tend to place a greater emphasis on protection from sexual abuse and unwanted pregnancy, which means that aspects of healthy sexual developments such as the importance of touch, intimacy and exploration are often overlooked (Berman et al., 1999; Shapland, 1993).

## Sex Education

The process by which a person acquires sexual knowledge and values through both formal and informal measures is known as sexual socialization (Ward, 2003). This process is vitally important for children and adolescents as it not only improves their sexual knowledge and competency, it also plays a crucial role in their self-development by increasing awareness and understanding of their own sexual feelings, capabilities and identity (Guest, 2000). However, as a result of the widespread stigma and lack of appropriate resources related to sexuality and disability, parents and caregivers of youth with physical disabilities often feel uncomfortable or ill equipped to discuss issues of sexuality if and when they do arise (Berman et al., 1999). This lack of communication can result in negative implications for these youth, such as lower self-esteem, sexual identity confusion and doubt regarding their status as a sexual being (Greydanus, Rimsza, & Newhouse, 2002; Milligan & Neufeldt, 2001).

Along with parents and caregivers, health professionals are another group who often find it challenging to address sexuality issues with adolescents who have physical disabilities, particularly in a healthcare or rehabilitation environment. The reasons why health professionals may have a difficult time discussing sexuality issues with these youth often include their lack of disability specific knowledge, personal discomfort related to sexuality, inadequate training on the subject, or the fear of negative reactions from parents and colleagues (Cole & Cole, 1993; Neufeld et al., 2006). A recent Dutch study found that 90% of youth with cerebral palsy did not receive any sexuality information from their health care providers (Wiegerink, Roebroeck, Bender, Stam, & Cohen-Kettenis, 2010). Wiegerink et al. (2010) explains that since youth with physical disabilities are often uncomfortable bringing up sexuality during a medical or rehabilitation appointment, it is the responsibility of the health professional to bring up these issues with their young clients. However, despite this recommendation, research indicates that discussions about sexuality and sexual health rarely occur between health professionals and youth with physical disabilities within a pediatric rehabilitation setting causing many of these adolescents to remain largely unaware of the implications that their disability has on their own sexual functioning and reproductive capacity (Erikson & Erikson, 1992; Neufeld et al, 2002).

While most able-bodied adolescents learn about sexuality informally from their families, friends and the media, as well as formally from the sex education they receive at school (DiCenso et al., 2001; Maticka-Tyndale, 2008), many youth with physical disabilities reported that issues related to sexuality and sex education were rarely discussed with their family or friends (McCabe, 1999). Along with lacking these informal sex education opportunities, adolescents with physical disabilities are also sometimes excluded from formal sex education, since students with severe physical limitations may not participate in physical education courses at school (the course where sexual health education is generally taught) (Berman et al., 1999). Due to the lack of formal sex education, adolescents with physical disabilities often show significantly lower levels of sexual knowledge with regard to topics such as sexual behaviour, contraception, STIs, HIV (Cheng & Udry, 2002), pregnancy and sexual abuse when compared to their able bodied peers (Borjeson & Lagergrenm, 1990; Stevens et al., 1996). A lack of sexual knowledge is not only a problem during adolescence; it can also have implications into adulthood, as Pendergrass, Nosek and Holcomb (2001) found that many adult women with physical disabilities showed lower levels of sexual knowledge and held more erroneous beliefs regarding sexual health compared to able bodied women with the same level of education. In order to break this cycle of low sexual knowledge over the lifespan, research shows that it is beneficial for adolescents with physical disabilities to receive a combination of general comprehensive sexual education and skill development, as well as specific information that is tailored towards their individual needs (DiGiulio, 2003; Greydanus et al., 2002).

## Self-Image

### Self-Esteem and Sexuality

Developing an identity as a sexual being and learning to express one's sexual feelings are major cognitive, emotional and psychological milestones of adolescence. (Neufeld et al., 2002; Rousso, 1996). However, youth with physical disabilities often face challenges that limit their ability to discover and express their sexuality, such as a lack of privacy, dependence on others for personal care and reduced mobility (Greydanus et al., 2002; Neufeld et al., 2002). All of these obstacles can have significant implications on their sexual self-esteem, which Taleporos and McCabe (2003) describe as a sense of confidence and self-efficacy towards experiencing sexuality in a pleasurable and fulfilling way.

Researchers have found that people with physical disabilities are more likely to experience poor sexual self-esteem and self-image compared to their able-bodied counterparts, as a result of the pervasive societal assumptions which posit that they are less sexually attractive or capable than those who do not have a disability (Taleporos & McCabe, 2002, 2003). Sexual self-esteem also tends to have a greater impact on the desire and ability to form intimate relationships among people with physical disabilities (Taleporos & McCabe, 2002), since they face considerably more challenges towards being viewed and accepted as desirable intimate partners compared to those who are able bodied (Stevens et al., 1996). Some researchers also believe that these challenges stem from the fact that people with physical disabilities are rarely portrayed as desirable dating partners in the popular media (Taleporos & McCabe, 2002, 2003).

Taleporos and McCabe (2002) found that gender also has an impact on the way sexual self-esteem affects people living with physical disabilities. They noted that in men, sexual self-esteem was generally associating with overall self-esteem and psychological wellbeing whereas in females, sexual self-esteem was closely related to self-image and how they felt about their bodies. These differences are believed to be the result of the gender normative stereotypes present in our society, where men are seen as powerful, dominant providers and women are viewed as beautiful, nurturing caregivers. However, having a disability may disrupt one's capacity to embody traditional gender roles, leading some men with physical disabilities to feel emasculated due to their inability to perform in a dominant sexual manner and causing some females to experience feelings of inadequacy, since they may be unable to care for others or have children of their own (Teal & Athelstan, 1975; Tepper, 2000).

## Body Image and Physical Disability

The development of body image has been described as a psychological process focused on the feelings and attitudes one experiences towards his or her own body (Teal & Athelstan, 1975). Other researchers have expanded on this definition, stating that body image also encompasses conscious and unconscious feelings about the size, function, appearance and potential of one's body, as they are experienced within a particular socio-cultural context (Slade, 1994; Smith, 1984). While body image is an issue that affects virtually all adolescents, regardless of their physical appearance or capabilities, many youth with physical disabilities experience more negative views towards their bodies compared to their able bodied peers (Rousso, 1996). This is likely due to the fact that adolescents with physical disabilities may feel self-conscious, embarrassed or ashamed about characteristics of their body over which they have no control over, such as drooling, body disfigurement and uncontrolled muscle movements (Greydanus et al., 2002), compared to the somewhat modifiable body image challenges that most able bodied adolescents face, such as managing their weight or the appearance of their skin.

Body image is not just an issue of physical appearance. It is also very much tied to the concept of the self and how adolescents construct their identity (Bronheim, 1996). This link between body image and self-concept is particularly significant among those whose appearance tends to deviate from the socially accepted norm, such as young people with physical disabilities (Taleporos & McCabe, 2002). For these youth, the inability to match society's view of the ideal body with their physical appearance can be a very problematic experience, often resulting in lowered self-esteem, poor body image and a constant desire to fit in with the cultural ideals that govern what it means to be attractive and desirable to others (Rousso, 1996). Howland and Rintala (2001) state that body image has a powerful influence on how adolescents with physical disabilities see themselves as sexual beings, since body image encompasses both the emotion and cognition that governs self-image and self-esteem (Taleporos and McCabe, 2002). As a result, youth with physical disabilities who experience unsatisfactory body image and lowered self-esteem often perceive themselves as less attractive, making it difficult to develop strong intimate relationship with others (Greydanus et al., 2002).

While having a positive self-image plays a significant role in the development of confidence, self-esteem and overall well-being during adolescence, little is known about the way this issue affects the sexual and emotional development of youth living with physical disabilities (Slade, 1994; Taleporos & McCabe, 2002). It would be beneficial for further research to be conducted in this area, in order to deepen our understandings of the factors that influence body image, sexual self-esteem and self-concept among these adolescents, and in turn, how these influences impact the way in which they perceive themselves as sexual beings and desirable intimate partners.

# Chapter Three: Methodology

## Introduction

### Research Questions and Objective

A primary objective of this research study is to address and critically reflect upon some of the knowledge gaps related to sex education, sexuality, dating, peer relationships, independence and societal expectations among adolescents with physical disabilities. In doing so I have adopted a multidimensional, qualitative approach which allows for a rich, culturally relevant examination of what learning about sexuality is like for adolescents with physical disabilities from the perspective of their lived experiences, as well as those with whom they interact, mainly parents and health professionals. I discussed my research goals, objectives and data collection strategies with several people who have physical disabilities, including older peers, colleagues, athletes and motivational speakers, and took their feedback into account as I formulated my research methods and questions, in order to ensure that the study was appropriate and culturally relevant to the participants. Using a combination of narrative interviews conducted with adolescents who have physical disabilities, parents of youth living with physical disabilities and a focus group of health professionals working with this population, this study explored the following research questions:

1. What is the experience of learning about sexuality like for adolescents with physical disabilities and how does this experience influence the way they see themselves as sexual beings?

2. What kinds of resources and services are needed to help develop sexuality education and knowledge within this population?

## Role of the Researcher

Ballinger (2006) explains that identifying the role of the researcher is an important quality criterion for qualitative research, particularly related to the transparency of the researcher's background, intentions and the use of reflexivity. I am a graduate student in the Child and Youth Heath field of the Health and Rehabilitation Sciences program at the University of Western Ontario. I have over nine years of experience as a personal support worker for children and adolescents with physical and developmental disabilities. I have also worked as a sexuality educator for many years, facilitating sex education classes and peer support programs for high school and university students. Through this experience, I have gained an intimate understanding of the many issues and challenges that may arise when discussing sensitive topics like sexuality with adolescents who have a physical disability. This insight has enabled me to conduct this study in a manner that has been well informed, culturally appropriate and sensitive to the needs and experiences of young people within this population.

I am situated within a constructivist paradigm, where my values and perceptions are seen as equally valid to those of the participants (Schwandt, 1994). By conducting a narrative inquiry within this constructivist paradigm, I was able to incorporate the significant experiences, perspectives and opinions brought forth by the participants into my own observations, perspectives and beliefs about the topic of adolescent sexuality and disability. This was accomplished through the use of reflexivity, which is discussed in detail during the analysis portion of this thesis. The experience of participating in this narrative study and engaging in in-depth dialogues with youth who have physical disabilities, parents and health professionals has helped increase my understanding of sexuality in many profound ways. In particular, I have become more aware of the significant interactions that occur between various personal, societal, environmental and cultural factors, in relation to the development of one's sexuality and sexual identity. This has allowed me to think more critically about the impact that these interactions can have on an individual's expression of intimacy, self-image and identity as a sexual being.

## Introduction to Narrative Inquiry

Narrative inquiry is a broad, interdisciplinary approach within qualitative research that uses in-depth interviews, along with focus groups, field notes, journal writing and social observation, in order to understand the perception and significance given to one's life experience within a particular social or cultural context (Chase, 2005). Gubrium and Holstein (1997) describe narrative inquiry as a form retrospective meaning making, using stories to organize actions and events that are pertinent to one's life into a meaningful whole. This in turn, leads to a clearer understanding of the consequences and implications these actions and events have had in a person's life. Narrative interviews use skillfully crafted storytelling to depict the personal, intimate details of one's lived experience in a way that other research methods cannot, such as surveys and assessment tools which focus primarily on the collection and objective quantification of data (Gubrium & Holstein, 2009).

An important aspect of narrative inquiry to realize is that narratives are not always true, historically accurate depictions of one's life experience, but rather personal interpretations of the meaning one gives experiences based on emotions, environment, imagination and interaction with the researcher (Gubrium & Holstein, 1997). Chase (2005) explains that narrative participants often share the experiences which they believe to be "story-worthy", rather than the fact based reality of what truly occurred. The concept of finding truth within narrative inquiry can be a particularly complicated and subjective process for the researcher, especially since the story a person shares about an experience may not have occurred exactly as they describe it; however, their depiction may be completely true to the way they interpreted the situation within the particular context in which they are retelling it. Riessman (2005) states that "narratives do not mirror, they refract the past" (p.6), referring to the interpretive process of narrative inquiry that she believes offers storytellers a way to re-imagine their lives.

Narrative inquiry is an interactional, interpretive method of qualitative research. The findings that develop from narrative interviews are often seen as a joint production, where the narrator's story is shaped by the listener, and the listener's interpretation is influenced by the way the story is told (Bauman, 1986; Bruner, 1986). This co-construction of meaning between the story-teller and the listener is a key concept of narrative inquiry, particularly within the context of a constructivist paradigm. While the significance of the participant or storyteller within narrative inquiry is evident, the researcher's interpretation of what is said during the narrative interview and how it is presented is a crucial aspect of the co-construction of meaning that occurs within this type of study. During a constructivist guided study, the co-construction of meaning is developed through open, interactional dialogue between the participant and the researcher, where both members of the conversation are free to share stories and ask questions to one another in order to better understand the other person's experience or stance on a particular issue or event. The process of co-constructing meaning specifically occurs as a result of this 'back and forth' or dialogic interaction between the researcher and the participant, which includes the interactions that take place both formally during the interview, as well as informally during casual conversation before and after the interview. Word by word, story by story the researcher begins to incorporate what they have seen, heard, noticed, perceived and experienced from the participant into their own personal understanding of a topic, both deliberately and subconsciously. The participant is also involved in this co-construction of meaning, since the way in which they tell their story and the details they choose to include or leave out are influenced by their interaction with the researcher, specifically through the responses, reactions and non-verbal cues they receive.

## Narratives and Disability

Narrative inquiry is a useful and coherent choice for research with those who may be misunderstood by society or at risk of marginalization, such as people living with physical disabilities. This is due in part to the open-ended, intimate and respectful approach of narrative inquiry, as well as the fact that this type of research design focuses on the uniqueness of each individual and their experiences, rather than being concerned with making generalizations about the entire population (Bruner, 1986; Riessman, 2003). Goodall (2004) states that narratives have the ability to challenge the existing ways of thinking, writing and speaking about a particular issue or group within society by exposing others to the intimate and often overlooked details of another person's lived experience. Challenging the way society thinks about disability through narrative inquiry is especially important for young people living with physical limitations, as they are particularly impacted by the negative societal myths and stereotypes associated with having a disability; however, they are not often given the opportunity to voice their opinions and dispel some of these negative misconceptions.

Conducting narrative studies with youth who have physical disabilities can benefit several groups connected to the disability community, including researchers, parents, health professionals and the youth themselves. Since the majority of research conducted with adolescents who have physical disabilities is quantitative, the "true" voices and opinions of these youth are rarely heard from their point of view (Berman et al., 1999). Participating in in-depth narrative interviews can be a very positive and cathartic experience for the adolescents involved, by providing these often marginalized and misunderstood youth a safe outlet to express themselves (Martin, 1998). Giving these adolescents the opportunity to express their feelings through narrative inquiry may also help to improve the communication that takes place between them and their families, by empowering the youth to speak openly and feel as though their opinions and experiences are truly valued by others.

Disseminating the results of these types of narrative studies with other researchers and health professionals can help to inform the academic world, as well as the medical community about the more sensitive, personal and misunderstood issues facing adolescents living with physical disabilities.

## Narratives and Sexuality

Sexuality is a topic that poses several challenges for researchers, due to personal and societal discomforts related to the stigma and taboos that continue to surround the topic, as well as the deeply complex, culturally diverse and immensely value laden nature of sexuality. As with the study of disability, the intimate and in-depth approach of narrative inquiry can be seen as an appropriate and beneficial method for exploring the multifaceted and often misunderstood issue of sexuality; however, few researchers have used narrative inquiry as a means of gaining insight into the sexual lives and identity of young people living with physical disabilities. Instead, many of the narrative studies exploring sexuality have focused on the identity development of sexual or gender minorities, such as those who identify as gay, lesbian, bisexual or transgendered (Hammock et al., 2009).

Hammock et al. (2009) explain that the development of sexuality and sexual identity in youth, particularly among those belonging to a minority group, is fundamentally linked to the construction of a narrative which aims to integrate desire and behavior into a meaningful and feasible configuration. By using personal narratives to enact this configuration, youth are able to make meaning of their desire and create a sexual identity of their own (Diamond, 2006). Although this study is not focused on youth who are considered to be sexual minorities, understanding the utility of narratives may provide useful insight into how youth with physical disabilities develop their identity as sexual beings. Schachter (2004) describes this process as "the ways in which individuals configure the relationship among potentially conflicting identifications in the process of identity formation" (p.167). In other words, individuals create an identity through a process of integrating at times conflicting values, beliefs, and experiences (Hammock et al, 2009). This idea is particularly pertinent to the sexuality development process of youth who have physical disabilities, due to the conflicting and often stigmatizing messages they receive from school, peers, family and the media regarding the ubiquitous myth that people with disabilities are thought to be asexual.

## Triangulation in Narrative Inquiry

Qualitative researchers use the term triangulation to describe the use of multiple strategies to study the same phenomenon (Denzin, 1989). This is an important concept when studying complicated or multifaceted issues, such as sexuality among youth with physical disabilities, as it allows researchers to understand the breadth and complexity of the issue by exploring it from a variety of different perspectives. The use of triangulation is particularly important for this study as it allows for the development of a more holistic understanding of the topic at hand by exploring the perspectives and experiences of different groups of people within the disability community. Following Denzin (1989), this study used two types of triangulation, known as methodological triangulation and data triangulation. Methodological triangulation entails the use of a variety of different data collection strategies, such as narrative interviews, focus groups and participant observation, in order to gain a broader, more multidimensional perspective on the topic of study. Data triangulation involves the comparison of different data sources using the same research method in order to explore similarities and differences between subjects. Examples of this would be when a researcher compares the transcripts of different participants who were asked about the same topic during their interviews, or when interviews are conducted with different participant groups, as was done in this study with youth, parents and health professionals.

While traditional narrative inquiries use mainly in-depth, one on one interviews, it is becoming more common for contemporary narrative researchers to utilize a multimodal approach, which may incorporate focus groups, observation, field notes and discourse analysis into a narrative study, in order to gain a broader, contextual understanding about the topic of interest (Chase, 2005). Methods which involve group settings and social interaction, such as focus groups and social observation, can be particularly useful in gaining an understanding of the discourse surrounding a particular issue or population, by allowing the researcher to compare the perspectives of several different members of a group simultaneously. For example, conducting a focus group which involves a variety of individuals who are associated with, but not necessarily part of the particular group of interest, allows the researcher to gain insight into the underlying societal, cultural and interactional factors that influence why and how a story is told, which is known as the narrative environment (Gubrium & Holstein, 2008).

## Sexuality through a Constructivist Paradigm

Constructivists believe in the existence of multiple constructed realities, and dispute the notion of reality as a single, generalizable entity (Schwandt, 1994). Constructivist theory also posits that the beliefs of the researcher and participant are inextricably linked, putting a strong emphasis on the co-construction of meaning through hermeneutic interaction (Guba & Lincoln, 1994; Ponterotto, 2005). From this perspective, individuals do not exist independently; rather the nature of human reality is shaped through one's interaction with family, peers, environment, community, the media and other aspects of one's social and cultural world (Holloway, 2005).

Researchers have described the complex nature of sexuality as the expression of one's sexual thoughts, emotions and acts within the context of personal identity, which is influenced by cultural learning, self-image and the expectations of others (Rousso,1996; Trieschmann,1988). Through a constructivist viewpoint sexuality, a fundamental aspect of the human experience (Neufeld et al., 2002), is also seen as a socially constructed phenomenon which develops and evolves through the social interactions and experiences of one's life within the contexts of family, friends, school, community and culture (Blum, 1984; Longimore, 1998). For adolescents, and in particular youth with physical disabilities, the nature of these interactions can greatly influence their development as a sexual being. For instance, dependence and overprotection by parents and caregivers of youth with physical disabilities, a commonly cited issue in the literature on adolescence and disability, can severely limit a young person's opportunities for sexual expression, dating and personal exploration (Cole & Cole, 1993).

Sexual subjectivity is another important factor influencing sexual development during adolescence. This relates to the perception of pleasure from the body and the overall understandings of experiences with being a sexual person (Martin, 1996). Martin (1996) describes the importance of sexual subjectivity as "a necessary component of agency and thus of self-esteem. That is, one's sexuality affects her/his ability to act in the world, and to feel like she/he can will things and make them happen" (p. 10). Tolman (2002) states that among adolescent girls, sexual subjectivity is linked to the understanding and experience of entitlement for both sexual safety as well as sexual pleasure. However, this concept also relates to the awareness of the social influences that may prevent young girls from possessing these entitlements, such as cultural taboos surrounding female self-satisfaction or the risk of sexual assault (Tolman, 2002). While her work does not examine the sexual subjectivity of youth with disabilities directly, it is an important concept for my work because it helps to draw attention to the importance of pleasure, self-satisfaction and sexual agency rather than a people's physiological functioning and reproductive health, which is often the focus in studies on physical disability and issues relating to sexuality.

## Methods

### Inclusion Criteria and Recruitment

The original inclusion criteria for the youth participants in this study was as follows; they had to be between the ages of 14 and 19 and have a permanent physical disability, one that is either congenital or acquired in early childhood, that requires the use of a mobility device such as a wheelchair. The reason for choosing this criterion is that an adolescent who acquires his/her disability later on in life would have already developed an understanding of sexuality from the point of view of an able bodied person. Additionally, the extent to which a person's disability is visible and immediately apparent to the public plays a significant role in the social interactions they experience (Kewman, Warschausky, Engel, & Warzak, 1997). As a result, the socialization process of an adolescent with a mild or "hidden" disability may be very different to that of an adolescent who uses a wheelchair. The exclusion criteria for this study relates to adolescents with additional cognitive or developmental disabilities. This is because adolescents with cognitive impairments face their own unique challenges when dealing with sexuality issues, which are beyond the scope of this particular study. Adolescents with severe speech impairments or major verbal communication barriers were also excluded. Since narratives rely on a rich, detailed expression of one's lived experience, the ability to communicate verbally and use comprehensive diction is vital in capturing the true meaning of one's life story. Narrative inquiry is concerned with not only what is said but also how and why it is said. As a result, the use of alternative communication devices would not allow for these other dimensions of storytelling to be explored due to their limited verbal skills and lack of expressive range. In order to include youth with severe speech or language impairments, an alternate technique for collecting information would need to be developed, which is not feasible for this study. For the parents participating in the study, they had to have children between the ages of 10-21 with the same inclusion and exclusion criteria as the youth participants. A broader age range was chosen for the parent participants in order to capture differing perspectives on sexuality and sex education throughout the entire sexual development process, starting in pre-puberty right through to early adulthood. For the focus group, the participants had to be currently working as a health professional with youth who have physical disabilities.

The only aspect of the criteria that changed during the process of the study was that one of the youth participants had turned 20 a few weeks before the interviews had begun. I decided to include her in the study, even though she was over 19, because she offered very insightful and interesting perspectives on the topics under investigation and was very keen to participate. All other aspects of the inclusion criteria for the narrative interviews and focus group remained consistent with what was originally proposed.

recruit within my local community, so I contacted numerous disability organizations and described my study to them. However, this did not lead to me making contact with any potential participants for the parent or youth interviews. Eventually I was put in contact with a group of youth who all had physical disabilities and were active leaders at the CRC, as well as in the community. Not only did they introduce me to a number of their peers who also had physical disabilities, one of the leaders herself fit the study criteria and was able to participate, along with her mother. Through word of mouth I was invited to attend a sledge hockey practice where I was introduced to several families who had youth with physical disabilities. The rest of the youth and parent participants were recruited through this strategy.

## Participants

*Narrative interviews*: Four youth between the ages of 15-20 participated in the study. The youth consisted of three females, two of whom had cerebral palsy and one who had spina bifida and one male who had spina bifida. Four parents participated in the study, including three mothers and one father. Their children ranged in age from 18-21, and had a variety of different disabilities including spina bifida, muscular dystrophy, cerebral palsy and other neurological disorders.

Table 1. *Narrative Interview Participants*

| **Parent** | **Youth** |
|---|---|
| Tessa | Olivia - Age 18 |
| Catherine | Grace* - Age 20 |
| Patrick | Tyler* - Age 19 and Megan* - Age 21 |
| Marie | Elena - Age 20 |
| ---- | Justin - Age 15** |
| ---- | Lilly - Age 19** |

*Note.* * = Youth did not participate in the study

**= Parent did not participate in the study

*Focus Group*: Four health professionals from the CRC participated in a focus group. The group consisted of an occupational therapist, a teacher who also worked as a counselor, a nurse and a social worker. The group was made up of an equal number of male and female participants.

### *Description of Participants:* Youth

### ***Justin***

Justin is a 15 year old high school student who currently lives at home with his parents and siblings, one of whom also has special needs. Justin was born with spina bifida and uses a wheelchair as well as crutches to get around. He is independent with most of his personal care, including eating, dressing and catheterization, but does use attendant care for showering and some physical therapy. He enjoys playing sports, video games, going on Facebook and mentioned that he is starting a band with one of his friends. Justin has missed a substantial amount of school due to illness and a recent surgery. At the time of the interviews he had not been to school in over six weeks. Justin spoke about the frustration he has over missing so much school, saying that it made him feel very isolated and that his friends were beginning to forget about him.

Justin said that he was comfortable discussing dating and sexuality, although he always spoke in very general terms and did not divulge much in the way of personal or intimate information. When asked about some of the more complex topics that were explored in the study, such as stigma and the myth of asexuality that is commonly associated with people who have disabilities, he stated that he had not thought about these issues before. This was very different to the responses of the older female participants, who were well-aware of these societal myths and expressed strong opinions about them. Justin often brought up his ex-girlfriend, who lives in another city and also has spina bifida, but he never mentioned anything regarding sexual experiences they may have had. In the first interview, Justin stated that he was a happy, confident person who was accepting of his disability. However, during the second interview he began to share some of the more negative emotions that he was experiencing, including loneliness, depression and social isolation.

### *Elena*

Elena is a 20 year old university student who currently lives at home with her family, but is hoping to move out on her own sometime in the next year. Due to a lack of oxygen at birth, Elena developed a severe form of cerebral palsy that makes her dependent upon attendant care for all of her personal needs including feeding, dressing, showering and toileting. As well as having a very active social life, which includes going to bars and parties, playing in a band and working out with her friends at an adapted fitness centre, Elena is also involved with many groups and organizations at the university she attends and within the disability community. Elena has had a few short term boyfriends who also had disabilities but has never been in a serious relationship, although she said that it is something she has been thinking about and is becoming more important to her as she gets older.

Elena is very intelligent and, according to her mother, has excelled in university both socially and academically; however, Elena spoke about her frustration with the fact that many people assume she has a cognitive impairment due to her appearance and difficulty with speech. She discussed the challenges she faced during high school with other youth not wanting to be friends with her anymore because it was not considered "cool", explaining to me that this was a very difficult and lonely time in her life. Elena told me that the transition to university has been an extremely positive experience for her, feeling like she has finally made true friends who accept her for who she is. Elena explained that despite her physical limitations, she is very grateful for the abilities that she does have, such as being able to express herself verbally. She told me that she tries not to let her disability stop her from doing whatever she wants to do and said that it is frustrating to see other youth with disabilities give up too easily on their goals. When I asked her if she felt like an inspiration, she modestly explained that she feels like she is just doing what everyone else is doing and does not really see what the big deal is.

### *Lilly*

Lilly is a 19 year old college student who has recently moved out on her own. She was born three months premature, which she believes is what caused her to develop spastic cerebral palsy. As a result of her disability, Lilly relies on attendants for most of her personal care including showering, meal preparation and toileting; however, she can eat and use the computer and telephone independently. Lilly enjoys writing, playing video games, going to bars with her friends and having "girls nights". She was the most forthcoming of all the participants about her experience with sexuality, and was the only one to explicitly discuss sensitive topics like being a virgin, exploring masturbation and the fear of not finding a partner. She spoke very candidly about having low self-esteem and poor body image, due to her inability to engage in physical activity and subsequent larger body size. Lilly explained that she was currently going through a period of self-discovery and personal transition at the time of the interviews, which was evident in her ambivalent and often conflicting views on sexuality, disability and self-esteem. At one point she explained how accepting she was of her disability and that she was very proud of her accomplishments, and then moments later described how uncomfortable she was with her body and how she wished to be "normal" like everyone else, which she described as wanting to look and act like her able bodied peers. Lilly told me that participating in the study was a very positive and cathartic experience for her and that she had never been able to speak so frankly about sexuality with anyone before. She said that discussing these issues in a relaxed yet engaging way made her feel much better about the sexual frustration that she had been experiencing. Lilly also said that participating in the interviews helped to put a lot of things into perspective and made her realize that sexuality was an area of her life that she had been trying to ignore for quite some time.

### ***Olivia***

Olivia is an 18 year old high school student who is planning to go to university in the fall. She lives at home with her family and is currently juggling school and a part time job, while playing on two different sports teams. Olivia has a moderate form of spina bifida that allows her to get around the house on her crutches, while using a wheelchair for longer distances. She is completely independent with all of her personal care including catheterization, changing, showering and performing chores around the house. At the time of the interviews Olivia had never had a boyfriend, and after facing some rejection from male friends she explained that she was not particularly interested in dating at that time. Almost all of Olivia's friends had some kind of physical disability as well, so she often played somewhat of a caregiver role, helping to feed her friends who were less independent than she was. Olivia explained that she was very accepting of her disability and other than some issues with accessibility and transportation, she felt that having spina bifida did not pose any major limitations in her life. Similar to Justin, Olivia spoke more generally when it came to personal issues related to sexuality; however, she became more candid when discussing some of her insecurities regarding the way her body looked and her desire to find a partner in the future.

## Parents

### ***Tessa***

Tessa lives at home with her husband and two daughters, one of whom is Olivia. Tessa explained that she had a close relationship with her children and always tried to be very open about discussing issues related to sexuality with them. Interestingly, Olivia and Tessa's responses were very similar on a variety of issues. Tessa spoke a lot about her willingness to discuss sexuality with her daughters, as well as her frustration with society's ignorance and low expectations towards disability. Although Olivia had not yet been in a serious relationship, Tessa said that she felt hopeful and optimistic about her daughter finding a partner at some point. Tessa believed that many of Olivia's classmates were quite immature and superficial, and felt that her daughter would have a much more positive experience with dating once she left high school and had the opportunity to meet more independent, open-minded and less judgmental people.

### ***Catherine***

Catherine is the mother of Grace, a 20 year old college student who has a neurological disorder similar to cerebral palsy. I was surprised by Catherine's knowledge of her daughter's sex life and her openness to share this sensitive information. She explained that Grace had engaged in numerous sexual relationships during adolescence, which Catherine believed was a way for her daughter to feel accepted by her peers. Grace was the only youth who was explicitly sexually active (according to Catherine, as Grace did not participate in the study). This introduced important and unique data regarding access to sexual health services and birth control.

### ***Patrick***

Patrick is the father and full time caregiver to his son Tyler and daughter Megan, both of whom have degenerative disabilities and require assistance with all of their personal care. Patrick was quite possibly the most heartbreaking participant to interview as he spoke very candidly about the fact that both of his children have no friends and are completely socially isolated. According to Patrick, Tyler refused to participate in the study due to immense shyness and low self-esteem, and Megan was not eligible to participate due to her age and degree of cognitive impairment. This made Patrick the gatekeeper to his children's lives, as he discussed many sensitive and emotional issues, such as the imminent mortality of his son, an episode of sexual assault his daughter faced, and the guilt he felt about his children's lack of meaningful social relationships. Patrick desperately hoped that one day his children would be able to experience emotional and sexual intimacy and said that he had thought about the idea of looking into obtaining the services of a prostitute for his dying son.

### ***Marie***

Marie is the mother of Elena and has always been of the mindset that her daughter could do anything. As a result, she has encouraged Elena to participate in numerous activities, such as karate and music lessons, many of which were not geared towards children with disabilities. Marie spoke about how she often did the opposite of what the health professionals told her to do with Elena, such as rarely using her wheelchair and refusing to put her on any medication. Both Marie and Elena believed that this type of upbringing was the main reason for Elena's accomplishments and success in life, such as her stellar academic record, her highly active social life and her strong will and determination. While Marie described the difficulty she has had with letting go and allowing her daughter to be independent, she said that she knows it is important for Elena's adult development and is supportive of her eventually moving out on her own.

### *Health Professionals*

The health professionals who participated in the focus group came from a wide range of backgrounds and experiences working with youth who have physical disabilities. While the nurse, teacher and social worker had been involved with this population for well over twenty years, the occupational therapist was fairly young and new to the field. Although they dealt with different areas of disability, they shared similar experiences related to discussing sexuality with their clients. The health professionals explained that they had not received adequate training in this area and often felt unsure about their ability and competency to comfortably talk about sexuality issues with their clients. Another challenge they mentioned frequently was the fear of backlash from parents after discussing sexuality with their young clients, particularly when it came to the male professionals. The male occupational therapist felt that there was already a negative stigma related to male professionals working one-on-one with children, alluding to the notion of sexual molestation or exploitation within institutional environments. He felt that discussing sexuality with youth may jeopardize his reputation and career, particularly if the information or his intentions were communicated incorrectly to parents or other professionals. The health professionals all felt that sexuality was an area of development that was rarely discussed and often overlooked due to discomfort or lack of appropriate resources, particularly in a pediatric setting such as the CRC.

## Data Collection Process

Table 1. *Data Collection Summary*

| | **Youth** *(n =4)* | **Parents** *(n = 4)* | **Health Professionals** *(n=4).* |
|---|---|---|---|
| **Narrative Interviews** | *Yes*** | *Yes** | *No* |
| **Focus Group** | *No* | *No* | *Yes* |

*Note.* * = Participated in 1 interview each

** = Participated in 2 interviews each

The data collection process for this study consisted of narrative interviews with youth and parents, as well as a focus group with health professionals who worked at the CRC. The interview guides that I developed for this study were used as a template in order to help navigate the interviews in a direction that allowed me to gain the information that would help answer the research questions for this study, such as what the experience of sex education is like for youth with physical disabilities, how they feel about their own sexuality and what types of resources need to be developed in order to improve sex education among these youth. These guides were designed to be able to accommodate both narrative style interviews as well as semi-structured interviews, depending on the particular participant that was being interviewed. A semi-structured interview differs from a narrative interview in that the direction of a narrative interview is generally driven by the participant's interests and opinions through their retelling of long, in-depth stories or life events. Conversely, a semi-structured interview follows somewhat of a formal guideline that includes open ended questions and prompts set by the researcher. While a semi-structured interview does not allow for the same degree of flexibility as a narrative interview in terms of the direction of the dialogue and the variety of topics which are discussed, it is a useful strategy to use for participants who are not overly talkative or for those who do not easily partake in unprompted, detailed story-telling. Some of the participants in this study were very talkative and easily engaged in open ended, narrative or "story-telling" type dialogue, whereas other participants (particularly the younger adolescents) tended to offer only one word answers and often needed prompting in order to progress the conversation. In these situations I tended to engage in more of a semi-structured interview rather than a narrative style interview, since I only had a limited opportunity to converse with each participant and this seemed to be the best way to illicit the most relevant and useful information for my study.

## Narrative Interviews with Youth

*Interview #1:* For the first interview I used the same interview guide for all of the youth. The questions asked were fairly general and covered the main areas that I was interested in exploring, including how they describe their personality and how they thought others would described them; what it is like to be an adolescent with a physical disability; what their experience with sex education was like in terms of formal sex education at school, talking to their parents and peers about sexuality and what they had learned from the media and online resources; and their perspective on dating and peer relationships. I also asked them how they believed sex education could be changed or improved for youth with physical disabilities.

The interviews generally took place in the youth's home, either in their bedroom or in a common area such as the living room or at the kitchen table. Being in a familiar home environment seemed to be where the youth felt most comfortable; however, it did pose certain challenges. These included distractions like the telephone ringing or younger siblings screaming, as well as privacy issues, such as parents and siblings being in earshot of the interview. Although the other family members were distracting at times, none of them ever interrupted the youth's interviews or tried to take part in them. Conducting these interviews in a home setting allowed me to better understand who the participants were by seeing their bedroom, meeting other family members and looking around the house. Through these intimate interactions, I was able to gain insight into the youth's hobbies and interests, social life, family structure as well as the neighbourhood and community in which they lived. The interviews lasted between 30-75 minutes, depending on the youth's attention span and eagerness to share information. All of the interviews were audio-recorded and then later transcribed verbatim by myself. After going through the first interview's transcripts, I was able to pick out interesting or important themes that I wanted to expand on during the second interviews.

*Interview #2:* Each youth received a different set of questions for the second interview based on what they had discussed (or in some cases not discussed) during the first interview. This was a way for me to clarify issues or experiences that I was unsure about, to get the youth to elaborate on something that they may have alluded to in the first interview and to ask about aspects of their lives that I had reflected on after their first interview had been conducted. The second interview also gave the youth an opportunity to reflect on what their experience of being interviewed was like, if there was anything that they thought of later and wanted to share, and in some cases it was a time for them to give me ideas of questions that they felt I should be asking other youth in the future. At the end of all the interviews I generally stayed and chatted to the youth once the recorder had been turned off. It was often during these casual, unstructured conversations where they really opened up to me, so I made sure to write about these conversations in my journal after I left the interview to include them in the analysis. The participants were all informed that any information they shared with me before, during or after the interview could be used in the study.

### Narrative Interviews with Parents

Each parent was interviewed using the same interview guide; however, the questions asked were often altered or adapted to fit with the specific issues that the different parents were dealing with in relation to their child's disability, sexuality and social life, such as how they felt about their child entering the dating world or whose responsibility it was to provide sex education to youth with physical disabilities. Originally the plan was to run a focus group for 5-7 parents in a similar style to the focus group for health professionals. However, as recruitment went on, the logistics of trying to organize different parents from all over the city into a single focus group with little incentive other than complimentary parking and refreshments proved too difficult. I decided it would be less challenging and much more beneficial to conduct individual interviews with the parents, in order to gain more insight into issues related to adolescent sexuality and physical disability from a parent's point of view. In addition, the public nature of a focus group is not always conducive to participants sharing sensitive or personal information and it was decided that private, one-on-one interviews would be the best setting in which parents could feel comfortable opening up about potentially emotional or uncomfortable topics . The interviews generally took place in the parent's home, with the exception of one that occurred at a coffee shop. The interviews ranged from 30 - 75 minutes, with most lasting about 1 hour. The interviews were audio recorded and transcribed in the same way as the youth interviews; however, a second interview guide was not developed since the parents were only asked to participate in one interview.

Many of the parents told me that I had chosen a very important issue to study and were eager to share their opinions with me, since the topic of sexuality was rarely brought up during their child's medical appointments or parental workshops. All of the parents believed that talking to their children about sexuality was critical, as it not only provided an opportunity to discuss the family's morals and values related to sexuality and relationships, but it also helped to validate their children's status as sexual beings. The parents explained that there was a great need for information and resources related to sex education that both youth with physical disabilities and their parents could easily and confidentially access. Although the parental participants were aware of the negative stereotypes and misconceptions related to asexuality and disability, they still felt very strongly about wanting their children to have healthy and fulfilling intimate relationships in the future.

## Focus Group with Health Professionals

The focus group took place in a boardroom at the CRC. It lasted 90 minutes and a few of the participants stayed afterwards to speak more informally about their experiences related to discussing sexuality with their young clients. The main issues that were brought up during the focus group were the challenges health professionals have with accessing relevant disability-specific sex education information, the difficulty and discomfort they experience when discussing sexuality in front of parents, and the lack of sexuality training and education offered to health professionals. They all felt that the myths about young people with physical disabilities being naive, dependent and asexual were very apparent in society, often seeing this reflected and perhaps reproduced through the interactions they witnessed among parents being somewhat overprotective and infantilizing with their children who have disabilities. The health professionals felt that this form of overprotective parenting was one of the main reasons for the lack of independence and subsequent social isolation apparent among many of their youth clients. In addition, these participants discussed the importance of incorporating sex education into many levels of the rehabilitation environment, including the development of training programs, workshops and access to online and printed resources for health professionals, parents and youth.

## Data Analysis

Data analysis was performed using two types of qualitative analysis methods - thematic and interactional. Thematic analysis focuses primarily on the context of the dialogue, looking at what is said rather than how it is said. Riessman (2005) describes this as the "told" rather than the "telling". A thematic approach to analysis is useful when the researcher is comparing several narratives in order to find common themes or events reported by different research participants. Compared to thematic analysis, interactional analysis focuses primarily on the dialogic "back and forth" process between the listener and the storyteller (Riessman, 2005). During the interactional analysis process, I took into account pauses, hesitations, topic chaining, interruptions and other non-verbal aspects of the interview as a way to read between the lines and see if there was anything important that the participant was attempting to say by his or her actions. Mishler (1999) describes this process of analyzing what is not said by stating, "we speak our identities, but much remains unspoken, inferred, shown and performed in gesture, association, and action. What narrators show, without language, constitutes ways of making claims about the self" (p.19).

Interactional analysis does take into account the content and structure of what is being said during an interview; however, this approach places particular importance on the co-construction of meaning created through the interaction and collaboration of ideas between the researcher and the participant. A co-construction of meaning related to the experience of learning about sexuality among youth with physical disabilities occurred through my dialogic interactions with each participant. I made a point to use the terms and vocabulary that the participants used in order to connect with them and show that I understood what they were saying. In return, I noticed that the participants often used specific words or expressions that I had brought up earlier in the interview. This type of interactional exchange of meaning seemed to occur most prominently with the youth participants. I also tried to incorporate responses from other participants into my interview questions, in order to familiarize the participants with the kind of knowledge I had been exposed to and how these previous interactions had led me to my current understandings of the topics being studied. Another way in which a co-construction of meaning occurred between myself and the participants was through the evolution of the interview guide and the development of new interview questions based on previous participants' responses. This was to ensure that the knowledge I gained from one interview could be incorporated into my own understanding of the topic that I was studying and then in turn, could be introduced to a new participant in order to understand their perspective on the topic. By the end of the study, the questions asked and information gained from the interviews and focus group was an amalgamation of my own previous knowledge, new knowledge that I had gained from the participants, the experiences of other people in the disability community that I spoke with, as well as suggestions that I took from the participants about the types of questions they believed I should be asking others.

I chose to incorporate both thematic and interactional techniques into the analysis process in order to capture the dominant ideas and themes brought forth by the participants, while still keeping true to the constructivist paradigm that I have situated myself in for this study. The data obtained in this study was analyzed in two main stages:

*Stage #1*:

The first stage of formal data analysis began once the focus group and narrative interviews were transcribed; however, the reflexive activities which helped to guide my analysis were performed throughout the data collection process and are described in detail later in this section. I began by reading and re-reading the transcripts from the narrative interviews and focus group multiple times in order to look at the most significant and relevant data that informed my understanding of the issues that were most pertinent to this study, such as sex education, sexuality, dating, self-image, independence, relationships and societal perceptions of disability. These main themes were colour coded and numbered so that the transcripts could be thematically analyzed and coded, all of which was done by hand. As the coding process continued, several sub themes began to develop under each main theme and these were represented by letters. Further thematic analysis continued until a set of secondary sub themes was created, represented by roman numerals. In total there were 9 main themes, 81 subthemes and 122 secondary subthemes. For example, theme #2 was entitled “Sexuality and Dating”, subtheme #2f was “Challenges for Dating” and a secondary subtheme of that (2f-iv) was “Accessibility as a Challenge for Dating”.

*Stage #2*:

Once I had coded all of the transcripts, the second stage of the analysis process took place using Microsoft Word. Here the data was organized by theme rather than by interview, which was achieved through cutting and pasting all of the significant quotes from the transcripts, along with my own reflexive notes, into one single document. The analyzed data were then categorized into the appropriate themes and subthemes from stage 1 and colour coded to differentiate between the information given by the youth, parents and health professionals. Once this stage of the analysis was complete, I began to extract the most significant themes and quotes as a way to decide which aspects of the data I wanted to incorporate into the findings chapters of the thesis. This was done by examining which themes were not only brought up most often, but also which one's contained the most significant and meaningful information that related to my study objectives and aims. Eventually the analyzed data were narrowed down to create four final themes; Experiences with Sex Education, Sexuality and Self-image, Relationships, and Societal Views of Disability.

### *Reflexive Activities*:

Throughout the recruitment and data collection process, several forms of reflexive and observational notes were recorded. These included journal entries made immediately following a meeting or interview; field notes about the participants' environment, appearance and demeanor; as well as observations of the social interaction I witnessed between the youth and their family, peers and health professionals. These notes were incorporated into the analysis process as a way to further contextualize the transcribed interviews with the data that was collected through informal interaction and observation of the participants and other members of the disability community.

Specifically, the reflexive and observational notes were incorporated into the coding process using interactional analysis, after the initial data coding and sorting was complete. Ochberg (1996) discusses the important role that non-verbal communication plays in interpretation and analysis during narrative interviews, since the gestures, hesitations, repetitions, pauses and facial expressions that the narrator displays during the interview allows the researcher to gain a deeper insight into not only what the participant is saying, but also what he or she may not be saying in so many words. During the interactional aspect of the process, I made note of any significant hesitations, outbursts, pauses, interruptions and body language cues, in order to explore what these non-verbal responses might be saying about the participant's experience or perspective that may not have been articulated by the participant out loud.

It was during this stage that I was also able to incorporate my own perspectives regarding any surprises, hesitations or incongruences that may have arisen during the interviews. These were incorporated into the analysis process as a way to further contextualize the transcribed interviews with the data that was collected through informal interaction and observation of the participants and other members of the disability community.

## Quality Criteria

### Coherence and Reflexivity

One of the most important aspects of quality criteria in qualitative research is the presence of coherence. Ballinger (2006) defines coherence as a type of quality criteria which examines how well the methodology of the research is suited to the particular epistemological approach the author has chosen to adopt. This study was developed in such a way that all aspects of the research design, data collection and analysis were carefully aligned with the constructivist methodology that guided the project from the beginning. The choice to use narrative inquiry for this study fits in very well with a constructivist ideology, as these types of interviews are focused largely on the interactional, co-construction of meaning that occurs between the storyteller and the listener. Narrative interviews offer another advantage, particularly when working with an often stigmatized and misunderstood population, like young people with physical disabilities, given that one of the primary goals of narrative inquiry is to give a voice to the often silenced lives of marginalized people (McLaughlin & Tierney, 1993).

The use of reflexivity is an aspect of quality criteria that some researchers feel so strongly about they believe it should be a prerequisite to all research (Finlay, 1998). The researcher's reflexive voice is described by Gubrium and Holstein (2002), who make special reference to the technique as being the who, what, where, why and how of communicating one's findings and drawing conclusions about the meanings within each narrative. Reflexivity was an important feature of this study and included the use of field notes, observation, journal writing and other forms of self-reflection. These reflexive activities allowed me to consider and think about how my decisions regarding the study design, information collection and analysis of this study may have influenced the research process and outcome, while allowing me to keep my own feelings, bias and opinions in check. Ballinger (2006) argues that maintaining reflexivity throughout the entire research process is essential to ensure that the paradigmatic stance of the researcher fits with the choices made during the study. This type of coherence or "goodness of fit" between the methodology chosen and the researcher's own epistemological stance is something I endeavored to do over the course of my project.

One way I developed coherence throughout the study was by ensuring that the way in which I viewed sexuality and disability were aligned with my theoretical framework. In particular, I made sure that the questions I asked and the way I analyzed the data focused on framing both sexuality and disability as socially constructed phenomena. For example, I asked questions related to the way in which peers, school, society and the media influenced the participant's views towards topics such as dating, sexuality and body image. This was done in order to explore the type of impact these socio-environmental influences have on their lives and how these factors interact and shape the way the youth feel about their own sexuality, as well as their disability.

Keeping in line with my theoretical framework I also had to be cognizant about my decisions and the way in which I conducted the study as not to "other" the participants who had disabilities in any way. "Othering" refers to the labeling, exclusion and subsequent marginalization of a group deemed to be different from the culturally or socially defined majority. For this study, I felt it was important to recognize that people living with physical disabilities do have different needs and face unique challenges compared to those who are able bodied; however, the differences between the youth who had disabilities and their able bodied peers was not the main focus of my study. In fact, I made a conscious effort to note the many similarities I found between the challenges these youth faced compared to those experienced by the majority of adolescents, particularly in terms of gaining independence, fitting in with their peers and dealing with body image issues.

## Ethical Procedures

Ethical considerations are important for any study and particular attention must be paid to the ethical implications involved in working with vulnerable groups such as minors, people with disabilities and those at high risk for sexual abuse and exploitation. This study was approved by both the University's Research Ethics Board (REB), as well as the CRC's Research Advisory Committee prior to commencement of the project. These approvals ensured that confidentiality, security of information, free and informed consent, and the safety and wellbeing of the participants were addressed and accounted for.

Anonymity was one of the main ethical challenges of this study due to the sensitive and personal nature of the study topic, along with the fact that youth with disabilities are considered to be a vulnerable population according to the REB. However, true anonymity can sometimes pose a challenge for the researcher, since narratives are saturated with identifying characteristics of the participant due to the rich, descriptive nature of telling one's life story (McLeod, 1996). Researchers often walk a fine line between removing enough identifiable markers and still maintaining the detail and integrity of the original narrative. I took this into consideration by using several strategies to minimize the chance of the participants' identities being revealed, such as omitting the name of any groups, schools or sports teams that the participants belonged to, along with any unique identifying features they may have mentioned during their interview. Also, some of the youth participants had fairly rare disabilities which could have made them easily identifiable within the community, so the names of these conditions were either not used or rather changed to broader, more generic disabilities.

Pseudonyms were used for all of the participants from the very beginning of the recruitment process. Youth participants were given the opportunity to choose their own pseudonyms, while I selected the pseudonyms that would be used for the parents. The purpose of allowing the youth to choose their own pseudonyms was to give them a sense of pride and ownership in the research process, in the way they were represented, and to make them feel as though their opinions mattered on many different levels. The health professionals were identified only by their occupation. There were, however, several challenges related to anonymity that I had not necessarily foreseen prior to the start of the study. Since the disability community that I was recruiting from was quite small and well connected, many of the youth and parents that I interviewed knew each other and were often friends. This meant that some of the participants did discuss their involvement in the study with their friends, which made total anonymity virtually impossible.

There were several ethical and moral challenges that I faced throughout this study, not necessarily in terms of the formal ethical guidelines outlined by the REB, but rather in terms of the sensitivity of the subject that I was studying and the emotional vulnerability of some of the participants. In order to find youth who were willing to participate in the study I told them from the very beginning of the research process that I would not ask them any personal questions related to the types of sexual behaviour they had engaged in and that if they did feel uncomfortable with a question they could refuse to answer it at any point. At times it was difficult not to ask certain questions, since there were moments when I was very curious and eager to delve deeper into a particularly personal topic we were discussing, especially in terms of past (potentially sexual) relationships they had been a part of. However, I also knew that I had to keep my word about not asking these types of personal questions as not to destroy the trust or rapport I had built with the youth throughout their time in the study. This is an example of the fine balance that researchers must navigate between gaining rich, detailed information from the participants and at the same time respecting them as human beings and honouring the agreement and conditions that were made in terms of participating in the project in the first place.

Prior to the interview, I went over the letter of information and consent form with each participant to fully inform them about the research project and what participating in the study entailed. All of the participants signed the consent form before any of the interviews took place. Since Justin was the only participant who was under 18, he signed an assent form while his mother signed a consent form to allow her son to take part in the study. One of the participants was not able to write due to her disability, so with her verbal permission I took a name stamp out of her bag and stamped her signature on the consent form.

As mentioned earlier, part of the initial plan this study was to conduct a focus group with parents. However, as the design of the study progressed I decided it would be more beneficial to conduct several individual narrative interviews with the parents rather than have them participate in one single focus group. Since the research ethics board approved the original proposal of this study, the consent forms used for the parent participants described their participation in a focus group rather than the narrative interview they actually ended up taking part in (see Appendix D). While meeting with potential parental participants, I explained this situation to them and made sure that they were fully informed about this change in the methods prior to obtaining their consent for participating in this study.

Due to the sensitive and taboo nature of sexuality, there was a possibility that asking the youth about this topic may have caused them to divulge challenges and struggles regarding issues such as sexual abuse, sexual orientation, social isolation or depression. It was for this reason that I provided each participant with a resource form that included information on several disability friendly sexual and mental health services in the area, as well as the contact information of a social worker who works at the CRC and has extensive experience in dealing with sensitive issues facing children and youth with disabilities. The health professionals were given the contact information for a counseling service provided by their employee assistance program (EAP) in case they felt the need to speak to somebody after the focus group was completed. If instances of sexual exploitation or other forms of child abuse or neglect were disclosed during the interviews, I would be required by law to report these in the appropriate manner; however, nothing of the sort was brought up during any of the interviews.

# Chapter Four: Findings – Part 1

This chapter outlines two of the main themes that emerged during the narrative interviews with youth and parents, as well as the focus groups with health professionals. The first theme explores the experience of learning about sexuality for adolescents with physical disabilities by looking at their perspectives on formal sex education within the school system, what it is like to talk about sexuality with parents and health professionals, and possible solutions for improving competency surrounding the delivery and uptake of sexuality information for youth, parents and health professionals. The second theme focuses on issues related to sexuality and self-image among the adolescents, specifically the issues of discovering one's sexuality, future goals related to marriage and family, navigating the world of dating and intimate relationships, as well as self-esteem and body image among these youth.

## *Theme #1 - Experiences with Sex Education and Talking about Sex*

### Formal Sex Education

All of the youth reported that they had received some form of sex education at school. This occurred mainly during elementary school, since half of the youth were exempt from high school physical education classes. They discussed how disability was never mentioned in any of their mainstream sex education classes, which left many of them trying to fill in the information gaps on their own, as Justin (Age 15) states, *"like I. . . if I learnt something in class in sex ed . . . then I'll go home on the computer and search up like . . . I try to learn more about it . . . and see if there are any topics of it for people with disabilities."* Lilly (Age 19) spoke about her frustration with the lack of information relating to sexuality and physical disability, "*nobody ever really discussed with me like how people in wheelchairs actually . . . um . . . achieve sexual pleasure.*" Some of the older adolescents who had been exposed to more liberal sexual education during their post-secondary courses found this experience to be a very positive and eye-opening one, as Lilly explained, *"it's really helped me realize that I'm entitled to . . . not only like a freedom in sexual expression, but a freedom in everything.*"

The participants were asked whether youth with physical disabilities should receive mainstream sex education or sex education programs specially tailored to their disability. There was a general consensus that mainstream education coupled with specialized, disability-specific information would be most beneficial. Many of the youth spoke about the importance of introducing the idea of disability and sexuality into the mainstream school system, as Elena (Age 20) described:

> *E: I think it can only be beneficial to have a quick session on disability and sex*
>
> *L: What if there was no one in the class that had a disability, do you think it could still be useful?*
>
> *E: I think it could still be useful, cause I think some people are afraid to go up to someone at a dance and dance with them cause they don't know . . . how to like interact with them in that way.*

The youth and parent participants explained that many of the current sex education programs taught in schools were focused primarily on anatomy and contraception and rarely covered the important issues like peer pressure, media influences, relationships and pleasure. Justin spoke about the need for these types of topics to be taught in school, *"I really think there needs to be more education on that instead of . . . just put a condom on and everything will be ok . . . cause that doesn't always work."* Patrick, the father of 19 year old Tyler and 21 year old Megan, both of whom have experienced challenges with social isolation, felt that specialized sex education programs might help to address the specific social and relationship challenges sometimes faced by youth with disabilities, *"maybe that's where you start . . . how do I get friends? . . . Before you start talking about wearing a condom."*

## **Discussing Sexuality with Parents and Peers**

All of the parents in this study indicated that they have tried to be open with their children about sexuality and felt that it was an important topic to be discussed within families. While most of the parents said they felt quite comfortable talking to their children about sexuality, they often described a disconnect between their own openness and their child's willingness to talk about the subject. Catherine, mother of 20 year old Grace explained, *"I've been open with her, she's not always been very open with me."* Tessa, mother of 18 year old Olivia, also discussed this imbalance between comfort levels, *"I think she feels less comfortable than we are . . . probably because we start talking about it too much right . . . cause she probably got the answer in the first two minutes and we talk about it for fifteen minutes."* While the parents described the challenges they sometimes face when discussing sexuality with their children, they all felt that being open and frank about this topic would benefit their youth in the long run by showing them that sex is an important issue in their lives and not something to be ashamed of or embarrassed about. Here Catherine discusses why she felt the need to talk to her daughter about sexuality regardless of Grace's response, or lack thereof, *"I mean I* *talked . . . she didn't talk . . . but she listened . . . so I thought, well she's not talking about it but she's definitely listening to me."*

For each parent, the importance that sexuality played in their children's lives depended greatly on the child's personality, disability and other challenges that the family was facing at the time. While some parents whose children were sexuality active spoke about the challenges of accessing sexual health services and birth control, other parents felt that discussing sexuality was not a main priority for them or their children. As Patrick said, *"in our experience in having two children with no friends . . . um no, there's not a whole lot of information about sexuality that we are [laughs] begging to find."* This quote is an example of a moment when I realized the issues that I thought would be important to the participants and the information that I had set out to find was not at all in line with the beliefs and perspectives of the person that I as interviewing. I came into this interview hoping to learn about Patrick's views on sexuality education and disability, and the types of sex education resources that needed to be developed. I ended up discovering that for Patrick, his most significant concern was not related to whether or not his children received adequate sex education, but rather it related to the fear that his children would never make a single friend.

Patrick later explained why sexuality was a topic that was rarely discussed with his children and how his beliefs about their future sexual relationships have impacted his view on the subject:

> *P: We try and be as open as we can . . . it's different for each of them, but it's . . . it's not a frequent topic of conversation because it's so sensitive*
>
> *L: Right, and because of . . . them being . . . sensitive about it?*

*P: Because . . . no . . .because of the isolation they both have socially . . . you know, why talk about something that's really . . . not gonna say it's not in the cards, but it's certainly not um . . . in the moment.*

Several of the parents described the discomfort that both health professionals and other parents often feel about discussing sexuality issues with these youth. They believed this discomfort was related to the taboo or stigma associated with sexuality and disability. *"I think that the whole issue around sexuality is a huge elephant in the room that's there. It exists, and even as parents you tend to not be totally open and frank and wanna talk about it"* (Patrick). The stigma that is often associated with disability and sexuality was brought up by the youth, parents and health professionals in this study and is described in further detail during chapter 5. It seems as though the disregard for people with disabilities as sexual citizens is deeply embedded in a broader societal discourse that sometimes views individuals who deviate from the culturally accepted norm in terms of appearance, behaviour or function as not deserving of the same treatment and acceptance as the rest of society.

While the youth's perspectives on talking to their friends about sexuality varied between the participants, there seemed to be an overarching theme related to the fact that sexuality was still seen as a difficult topic to discuss, particularly in relation to disability. Justin explained that he frequently discussed issues related to sexuality with his peers; however, I found it quite interesting that he only mentioned speaking to his friends about their sexual experiences, rather than his own. "*I actually talk to my friends about it all the time . . . and I talk to them about their girlfriends and what their experiences [were] and stuff.*" For Olivia, sexuality was a topic that was rarely discussed in a serious manner among her peers, most of whom also have some type of disability. *"I speak to a couple of them . . . like they're all teenagers right . . . so I'll say something and it's kind of sexual, but it's meant to be a joke . . . things like that, but we don't go into a full conversation about it.*" Lilly expressed her own reasons for not wanting to talk about sexuality with her peers, as well as the discomfort that she believes others feel about this topic. *"We'll never go . . . hey! how's your sex life? . . . because . . . I think I was afraid of it before and I think a lot of people . . . still are just really not comfortable with sharing it.*"

The health professionals also discussed the challenges facing their youth clients in terms of discussing sexuality issues among their peers. Here a social worker provides some examples of these challenges and why they believe adolescents with physical disabilities are unlikely to talk about sexuality with their able-bodied peers:

> *Because they do get their education from the hallways or from school but they . . . the young people I work with feel like they are very limited because it comes to a point where they aren't turning to their other peers saying well how do you get your Depends off [laughs] . . . or how do you pick your date up, how do you co-ordinate the transportation?*

## Discussing Sexuality with Health Professionals

The lack of communication between the youth and their health professionals with regard to sexuality and sexual health issues was a significant finding of this study. Almost all of the youth stated that sexuality had never been brought up in any of their medical appointments. Many of them had never been asked if they were sexually active or if they would like to go on birth control and were never offered any information about their future fertility or sexual function. A student in her second year of university, Elena stated that *"I've never had a doctor just say 'are you having sex?"* Many of the youth and parents felt that health professionals should play a greater role in providing sex education information and believe that it would be a very positive step towards validating the youth's ability to think about and engage in intimate relationships. *"Oh I think it would make a big impact on them [the youth] . . . I think if they [the health professionals] were saying it's quite possible or whatever then I'm sure they would probably. . . 'oh well the doctor said so it's probably ok,' you know"*(Marie, mother of Elena).

The focus group conducted with health professionals provided insight into some of the challenges these practitioners experience when addressing sexuality issues among their adolescent patients who have physical disabilities. A social worker describes one of the main barriers she faces when dealing with sexuality issues among these youth:

> *Parents are certainly a barrier . . . you know, that . . . you are aware that it's somebody's kid and that they have parents . . . it's interesting as a professional you have almost the same barrier as the teenagers themselves do right, I'm just aware that it's somebody's daughter, it's somebody's son and . . . this is pretty important stuff.*

Parents came up frequently as a barrier for discussing sexuality with youth. Not only did the health professionals fear potential negativity or backlash from some of the more conservative parents, they also felt that parents were an obstacle to delivering sex education to youth since many of them sit in on the appointments with their child. This makes it difficult and uncomfortable to openly discuss private issues related to sexuality.

An occupational therapist discussed why he felt gender was also a barrier to providing sexuality information to youth, *"there is an added stigma of being a male that works with children . . . definite added stigma and vulnerability there for sure."* He went on to talk about the discomfort some parents feel about males working alone with their children, possibly fearing the risk of sexual molestation. For this reason he was often hesitant to discuss sexuality with youth, fearing the negative consequences it could have on his reputation and even his job security. *"There's nothing necessarily stopping them from going home and saying 'hey guess what, so and so talked to me about sex today' . . . and that has all of the ramifications for my particular practice, my livelihood."*

In addition to parents, health professionals who work in schools often felt as though other teachers and school administrators also impeded the delivery of comprehensive sex education to students with disabilities. One occupational therapist described the discomfort many schools have with discussing positive and healthy sexual development, *"I think inappropriate sexuality, schools are very comfortable discussing that with you . . . regular sexuality, not very comfortable discussing with you."*

The idea of placing blame on euphemistic others for not delivering adequate sex education to youth with physical disabilities seemed to be a recurrent theme throughout the study; however, placing the blame on someone else for a large, complex problem is not unique or limited to this particular topic. I believe that the participants in this study were finding ways to diffuse the responsibility of sexuality education onto someone else because of the discomfort surrounding this issue that so many of the participants described. During this study, the health professionals often blamed the schools as well as the parents for being too overprotective or as being in denial of their adolescents' sexual capabilities. The parents tended to blame the health professionals for not initiating the conversation or bringing up sexuality issues with their young clients. The youth also placed the blame on the health professionals, since they believed it should be the responsibility of these "disability experts" for providing good quality sex education that was relevant and specific to the needs of young people living with physical limitations.

Although this blaming mentality was apparent throughout all of the interviews, there was also a consensus among the participants that the responsibility of providing sex education to adolescents with physical disabilities should be shared among several different groups, including parents, schools and health professionals, in order to ensure that these youth receive a well-balanced, comprehensive sex education experience.

## Ideas and Solutions

### For Youth

Youth, parents and health professionals all felt very strongly about the need to provide information to youth that helps to reassure them of their status as sexual beings. The participants felt it was important to inform these youth that regardless of their disability, they were all capable of expressing their sexuality and engaging in intimate relationships, as Lilly states:

> *I think it should be encouraged that people with disabilities have sex . . . and you know, [that] it's not just automatically assumed that cause . . . you know, they're not as able as other people, that they automatically don't have it . . . cause that's not true, that is so not true.*

Many of the youth felt that there was a lack of information available to people with physical disabilities, making this an area of sex education which needed a great deal of improvement, as Justin explained:

> *I do wish that there would be more um . . . information about sexuality for people with disabilities . . . I think there is a lot more information about sexuality for people who are not with disabilities . . . too much of it . . . I think it should be more balanced out.*

During our discussions about possible solutions to this problem, three main suggestions were given by the participants, which included the 'The Independence Program' (TIP), the Teen Clinic approach and an increase in online resources for youth; each of which is discussed in more detail below.

*TIP* has been in existence for over twenty-five years and is a three week program run through Holland-Bloorview Kids Rehab in Toronto. This program allows young adults with physical disabilities the opportunity to experience what it is like to live independently, by providing them with the chance to engage in tasks many of them have never attempted, such as cooking, doing laundry and navigating the city using public transit. Several of the participants in this study had either participated in TIP or knew someone who had and they spoke very positively about TIP's approach to sex education. Elena, who participated in this program last summer, explained how TIP used humour, interactive activities and real life examples to deliver relevant sex education to the youth within a safe and non-judgmental environment. Elena described what a positive and empowering experience this was for her and believes that this model should be adapted in other cities, so that many more youth with physical disabilities could learn about sexuality in a way that is encouraging and meaningful to them. Elena said, *"I really thought that you should discuss the most undiscussable topics,"* as she described how this program was able to tackle even the most taboo of issues in a comfortable and non-threatening manner.

*The Teen Clinic* was a model of health care that the CRC used to offer to adolescents with spina bifida but it was recently cancelled because the primary doctor of the clinic moved away. This specialized clinic was set up in a similar way to the regular spina bifida clinic except for one major difference- the parents were not allowed to come into the room during the appointment. A specialized physician who was very knowledgeable and comfortable with discussing sexuality issues was brought in from an adult rehabilitation hospital in order to facilitate the clinic. During these appointments the doctor asked the adolescents questions about their sexuality, sexual function, relationships and other "teen issues" in a very relaxed, private and non-judgmental manner. The Teen Clinic approach was initially brought up by the health professionals during the focus group as the ideal program to promote sex education between practitioners and their adolescent patients. When I mentioned this to the youth and parents they agreed that it would be a perfect program design due to the privacy and specialized information, and told me that they wished these types of clinics were available to them.

During the focus group, a nurse described the negative impact that cancelling the teen clinic has had on her patients and their access to sexual health information:

> *That clinic has recently stopped because the doctor had moved away and it's a big hole, I can see it now. Those issues are not being addressed as are all the*

> *other teen issues are not being addressed with that population in a regular multi-doctor clinic. So . . . um . . . definitely there needs to be a good forum for discussing these issues.*

All of the participants agreed that the teen clinic approach should return to the CRC, as it is one of the only opportunities many youth have to speak to their doctor about sensitive issues without a parent or caregiver being in the room with them. They also felt that these types of clinics should be held for youth with other disabilities, such as cerebral palsy and muscular dystrophy, instead of just limiting it to youth with spina bifida.

The need for *Online Sex Education Resources* was another common theme discussed among the youth participants, who described the internet as their main method of accessing sex information. The internet offers an ideal channel for providing sex education information for youth who have physical disabilities because it is accessible and barrier-free, contains large amounts of practical and relevant information and can generally be accessed in an anonymous way. Parents and health professionals discussed some of the downsides to using the internet for sex education, such as the questionable credibility of certain resources and the fear of predators on interactive or social networking sites. The participants felt there should be a safe and credible website geared towards youth with physical disabilities, which offers information about many issues including sexuality, relationships, peer and school issues, drugs, self-esteem and other topics that adolescents may find difficult to talk about. They said it would be beneficial to have a section where youth could post anonymous questions and then receive answers from qualified professionals, as well as a section where older adolescents and young adults could share their experiences with sexuality and dating. The parental and health professional participants believed that this type of peer support could help youth to feel like they are not alone, by seeing that others have faced many of the same experiences and challenges that they have.

### *For Parents*

One of the main suggestions parents gave about sex education for youth who have physical disabilities was the importance of talking about being a sexual person and having the ability to engage in dating and intimate relationships when the time is right, as Catherine explained:

> *You know that even though your child is in a wheelchair . . . you know it doesn't mean that they're not going to have . . . um . . . a sex life, and as a parent you should talk to them just to reassure them that they can have a sex life.*

Some of the parents felt that there were not enough resources available to them, that they were not being offered them at the CRC, or that the resources were available but they just did not know where to look. Many of the parents brought up the idea of having workshops and programs at the CRC or online, which could provide them with strategies and resources about how to talk to their child about sexuality, discuss the importance of sex education for youth with physical disabilities and help find solutions to the discomfort and challenges that many parents face when trying to address these issues with their children.

I asked the parents who they felt was responsible for providing sex education to youth with physical disabilities and their responses were fairly uniform. They all felt that this was a joint responsibility between the parents, schools and health professionals; however, most agreed that the majority of the responsibility lies within the family to provide information about morals, values and relationships. They felt that the school played a role in creating a strong basis for sexual knowledge and understanding by providing comprehensive information regarding anatomy, development, sexual behavior and contraception. They also believed that for these youth, who often have unique or complex physical needs, it was the responsibility of the health professional to provide specialized information about sexuality that related to people living with physical disabilities.

### ***For Health Professionals***

All of the health professionals felt that they had not received adequate training in the areas of sexuality and disability. Some had learnt more than others during their time in professional school, but this education was often geared towards the elderly or adults with spinal cord injuries. They explained that youth who had physical disabilities were rarely brought up during their training. The health professionals felt that sexuality issues should not only be addressed during professional training, such as through specialized seminars or during their practicum, they believed it was also important to offer continuing education for health professionals already working with youth who have disabilities. One of the health professionals suggested the use of e-learning and online training modules to get up to date information about the current best practices for sex education. An occupational therapist also suggested the addition of a sex education specialist to the rehabilitation team. *"I'm also a big fan of people as resources. It would be great to have a designated person or persons here that we know that that's a person to talk to about these kinds of issues."*

The health professionals also discussed the fact that parents were often the biggest barrier to providing sex education to their young clients. They felt that having more of an opportunity to interact with the youth without the parents being present, such as the Teen Clinic approach, would be highly beneficial. The focus group participants also believed that increased communication with the parents, especially in the school environment, about the types of sexuality issues that will be discussed with their children could help the health professionals feel more comfortable and confident about providing sex education information to their youth clients without the fear of misunderstanding or backlash from the parents.

The participants felt that health professionals should play a role in providing sex education to these youth, since they were deemed to be the ones who knew the most about the anatomical and physiological aspects of having a disability. This knowledge of the physical aspects of disability may be useful in providing relevant information about puberty, reproduction and sexual response; however, there may also be some potentially problematic outcomes related to the medicalization of sexuality if the responsibility of providing sex education fell solely under the domain of these health care providers.
By viewing sexuality and sexual health from a purely bio-medical standpoint, these health professionals may not necessarily take into account the complex interplay of social factors, such as ones' family, peers, school environment as well as the media's influence on an adolescents' view towards their own sexuality and desirability as an intimate partner. In order to ensure that youth with physical disabilities receive a comprehensive, well-rounded sex education experience within the health care setting, it may be beneficial for health practitioners to receive additional sex education training that frames sexuality

in a holistic way, emphasizing not only the anatomical and physiological aspects of sexuality, but also the social, cultural and environmental influences that play a role in the sexual development of adolescents with physical disabilities.

### *Theme Summary*

Health Canada (2003) states that sex education is an important component of promoting overall health and wellbeing and should be available to all Canadians, regardless of age, race, sexual orientation or level of ability. However, research shows that many youth with physical disabilities are often inadvertently excluded from these lessons, due to absence from school or being exempt from physical education classes (Berman et al., 1999). Some of the youth participants in this study explained that they had missed out on sex education at school, particularly during high school, where relevant lessons about sexual health and safety are taught in considerable detail. All of the participants believed that it was important for youth with physical disabilities to receive adequate sex education in school, as it provided them the opportunity to learn the same sexual health information as the rest of their able bodied peers. Besides gaining sexual knowledge, researchers have also described the important role that learning about sexuality plays in a young person's overall sense of identity and understanding of oneself, as Guest (2000) explains, "sex education is not simply a matter of imparting facts about biological sex, but the knowledge of sexuality as crucial for a child's personal development" (p.138).

During adolescence, youth learn a significant amount of information about sexuality by interacting with their peers (Bleakley et al., 2009). While this kind of informal sex education is common among able bodied youth, many of the youth participants in this study explained that sexuality was an issue that was rarely brought up within their social group, especially when the majority of their friends also had disabilities. Some of the youth believed that their able bodied peers felt embarrassed about discussing sexuality when they were around, making them feel as though they were perceived to be too naïve or innocent to hear these types of conversations. Researchers have found that youth with physical disabilities often lack many of the normative social experiences, such as hanging out with friends, attending school dances or going to sleepovers, that allow adolescents to learn about sexuality in an informal, culturally relevant and age appropriate manner (Moglia, 1986). This impairment in social development can negatively impact young people's sexuality and result in limited sexual knowledge, confusion about sexual identity and misunderstandings about the range of appropriate forms of sexual expression (Mona, Gardos, & Brown, 1994).

The findings in this study showed that it was rare for youth with physical disabilities to receive any form of sexuality information from their health care provider, a result that was also noted in a recent Dutch study by Wiegerink (2010). Health professionals can play an important role in providing specialized sex education to young people with physical disabilities, yet many of the participants felt that the practitioners working at the CRC were uncomfortable, unwilling or unprepared to discuss sexuality related issues with their adolescent clients. The participants felt that future health practitioners should receive specific training regarding sexuality and disability issues, as well as on-going professional development and support for current health professionals focused on how to deal with sexuality issues within a rehabilitation setting.

Although the challenge of educators and health professionals being inadequately trained to deal with sexuality issues among adolescents with physical disabilities was brought up by many of the participants, an issue that is often overlooked pertains to the types of resources and information we base our understanding of sexuality and sexual health from. Understanding these sources of sexual knowledge may provide insight into the barriers people living with physical disabilities often face when trying to access good quality information about their own sexuality and sexual function. The literature describes how traditional resources that have guided our knowledge of sexual function, arousal and behaviour, such as the Masters and Johnson model of sexual response, place a major emphasis on climax oriented, intercourse based sexual activity. Mitchell Tepper (2000), a prominent sex researcher who also has a physical disability, describes how the widespread acceptance of this type of information poses many challenges for people with physical disabilities because it excludes those who are unable to achieve orgasm or who may need to explore alternative forms of sexual expression due to physical limitations. Perhaps it is not only the training the health educators receive that is a problem, but also the type of information guiding their understanding of sexuality. Developing comprehensive, non-discriminatory resources and training guides for future health educators would help to validate the idea that sexuality occurs on a wide continuum and does not need to include heterosexual penetrative intercourse to the point of orgasm for both partners in order to constitute healthy, satisfying sexual activity.

The difference in how males and females receive and interpret sexuality information was not discussed in the findings as it was not mentioned by any of the participants. The fact that there were more females than males taking part in the study makes it difficult to formulate generalizations about sex education based on gender.

However, research shows that out of the already limited number of individuals with physical disabilities who receive professional counseling or information regarding their sexuality, women are only half as likely as men to receive these types of services (Donahue & Gebhard, 1995). This is particularly significant in relation to this study, which found that the female youth participants were quite uninformed about their own reproductive function and capabilities. All of the females in this study explained that they had never been asked by a health professional if they were sexually active, if they are in need of birth control or if they wanted to have children of their own one day. Perhaps this is why the girls felt very strongly against having their own biological children and believed that adoption would be the best choice for them, a finding that is discussed in Theme #2. It may be that the lack of knowledge about their own reproductive capabilities, coupled with the feeling that their health care providers have ignored or discounted their status as sexual beings, causes these girls to internalize the negative beliefs that society sometimes expresses with respect to women with physical disabilities having children of their own.

All of the participants expressed the need for more accessible, relevant and practical resources related to sexuality and relationship issues among adolescents with physical disabilities. A consensus was reached that sex education for this population requires the integration of mainstream formal sex education combined with specialized, disability-specific information, resources and professional advice. Possible modes of delivering effective sex education for youth living with physical disabilities might include youth empowerment programs based on the "TIP" model, specialized teen clinics and the development of online resources that provide adolescents with physical disabilities an accessible, anonymous and accurate forum for receiving information about sexuality, dating and other important "teen" issues.

### ***Theme #2: Sexuality and Self Image***

#### **Developing Sexuality**

Most of the youth participants did not share explicit details about their experiences with sexual exploration. They did, however, explain that for some of the more severely disabled youth who they knew, physical forms of self-exploration such as masturbation were a big challenge for them due to a lack of privacy, independence and issues with mobility. They believed that many of these youth never get the opportunity to masturbate, achieve orgasm or even begin to discover how their bodies feel and function sexually. Lilly, however, quite openly discussed the sexual desire she experiences and her hope of one day being in a sexual relationship:

> *LY: Although it [sexual activity] hasn't happened for me yet, you know I think about it a lot . . . [laughs]*
>
> *L: Do you think your body works the same way as everyone else's?*
>
> *LY: It does . . . I mean . . . I might not be as experienced with a whole lot of this sexual positions or whatever, but the whole you know . . . instinct . . . and the need for sex . . . it's in everyone . . . so you can't really deny them of that just because . . . their body works differently.*

Lilly stated that from a young age, she associated sexuality with something that was dirty or taboo, as a result of witnessing her mother's behaviour which she described as "loose". Here she explains how these negative views towards sexuality limited her sexual exploration during adolescence, "*I had trouble when I was young thinking that I wasn't normal so . . . so . . . if I wasn't normal and I tried all these sexual things, like that would just add to my . . . abnormality.*" While some of the youth who participated in the study already saw themselves as sexual beings who had experienced intimate relationships, others were not at this stage yet. Patrick described how he believes his children perceive their own sexuality:

> *L: Do you think your kids see themselves as sexual beings?*
>
> *P: No [no hesitation] . . . no, do they want to? Absolutely . . . but no, I don't think so.*

While Patrick never mentioned discussing it with his children directly, he did feel that sexuality should be a part of his children's lives. *"I guess the bottom line is that they deserve to be sexual, just like . . . every person does right."*

While several of the youth mentioned struggling with the idea of not finding a partner, only Lilly explicitly described her sexual frustration associated with this issue:

> *Honestly, when I . . . first started feeling the . . . the . . . sexual tension and frustration . . . I automatically thought you know . . . I should get an escort and just get it over with . . . but . . . I've discovered that, I'm not really that type of person that can just give it all away like that . . .it's something that I have to . . . you know, I have to find [for] myself.*

While the current literature on sexuality, disability and youth posits that sexual abuse and exploitation is a significant problem among this population (Moglia, 1986; Schor, 1987), it was not a prominent issue for many of the parents and youth who I interviewed. Only one parent brought up a specific instance of abuse, where his daughter was taken advantage of by another student at her school. Patrick described his fear of this type of abuse happening again. "*All she needs is the wrong guy at the wrong time and she'll be in . . . I can't imagine what would happen if she got pregnant . . . scares the hell out of me.*"

I asked the youth whether they had ever questioned their ability to have sex. All of them believed that they would like to be sexually active one day; however, for some it took until late adolescence to overcome the doubts they had about whether or not this was in fact achievable. As Elena explained:

> E: *I think for a long time I questioned even could I have sex? . . . [laughs ] was that possible?*
>
> *L: Did you ever ask that to anyone, or was it more . . . ?*
>
> *E: No . . . it was very . . . well my one friend asked me and then I was like I don't know. . . that kind of got me thinking*
>
> *L: Yah, and what has made you kind of realize that?*
>
> *E: Um . . . I guess, well I had an idea cause I thought well if sex is what everyone says it is . . . why can't I?*"

For some of the parents, the question was not so much of 'can my child ever have sex?' but rather 'will my child ever have sex?' At the end of Patrick's interview he began asking me very subtle questions about my view on prostitution for people with disabilities. After noticing his awkward yet eager tone, I picked up on the fact that perhaps he has wanted to discuss this issue for quite some time, so I began sharing with him my own opinion on the topic. I also informed him that certain European countries offer sex workers' services as part of their therapy regime for people with disabilities. It was during this time that Patrick began to open up to me and explain that the idea of hiring a professional or "therapeutic" prostitute for his son Tyler, who is not expected to survive more than a few more years, had indeed crossed his mind. He discussed the challenges that he faces when considering this as an option for his sexually and socially inexperienced son:

> *I think that would be a very . . . uncomfortable discussion to have . . . I think if it was available . . . generally [laughs] and somebody else looked after it . . . but you know as a father son or father daughter relationship. . . hey Tyler you want me to go find you a hooker . . . it's . . . it's a bit of a stretch, let's put it that way.*

A very interesting and unexpected finding in this study was that all of the female participants felt very strongly about not having their own biological children and instead wanted to pursue adoption. Each girl had a different reason for this decision, which ranged from the fear that pregnancy and birth would put herself and the baby's health at risk, to not being able to physically care for an infant and wanting to adopt an older child, or wanting to help children who are in need of a good home. Here Lilly explains her rationale for not wanting to have her own children:

> *You know when I thought that I was having kids . . . I discovered that it's not really the best path for me cause of my capabilities . . . and I really don't think a child should be left in the care of you know . . . trillions of workers every single day so that just . . . something I came to myself but you know, before when I thought that I was having kids, I remember my biggest concern was . . . am I*

> *going to spread whatever I have to my child and make. . . their life as difficult as mine is?*

While Justin was unsure about what he wanted in his future with regard to marriage and children, all of the female participants were quite certain that they wanted to get married and start a family at some point. Lilly talks about where she sees herself in the future, which seems to be strongly related to her desire for sexual exploration and satisfaction:

> *LY: Hopefully with a nice husband . . . hopefully*
>
> *L: Have you been planning your wedding?*
>
> *LY: Well I've dreamt about it . . . mostly the honeymoon to be honest . . . haha.*

## Dating

For most of the youth I spoke with, finding a dating partner was something that they often thought about and although some of them explained that dating was not their number one priority right now, others felt very strongly about the importance of finding a partner:

> *What I want the most right now is just to find somebody that makes me happy and understands me . . . and you know . . . is not freaked out that I know like . . . next to nothing about how to. . . kiss a guy . . . how to [giggles] have sex, but you know . . . before that, I want to make sure that I got all my ducks in a row . . . I'm in a stable . . . job . . . you know . . . got enough confidence to you know . . . prove myself, cause that's what it's been my whole life, proving myself.* (Lilly)

The youth discussed what it has been like to navigate the world of dating as an adolescent with a physical disability, which Justin described, "*it's . . . it's a bit different* *than when normal. . .when other people date because of my wheelchair and how girls see me.*" He then goes on to talk about some of the positive aspects of having a disability when it comes to dating:

> *Most girls are like . . . even though they know I'm in a wheelchair, even though they know I have a disability, they still like me, it's not . . . they're more actually. . . I've notice that they . . . some girls are . . . actually more interested in me because I'm in a wheelchair and that I'm like different.*

The youth had varying opinions about whether or not they would like to date someone with a disability. While all of the youth said that it was the personality of the partner that they cared about much more than the physical appearance, some were more open to the idea of dating someone with a disability compared to others. Lilly felt fairly indifferent about the matter, as she explained:

> *That really doesn't bother me, I. . . just like I said, I'm waiting for the right person . . . and it doesn't matter if that person can walk on their own two feet or walks with crutches or is in a wheelchair or whatever, it's whatever . . . clicks . . . that's all that matters.*

Elena on the other hand, was more aware of some of the challenges she could face by dating someone who had a disability similar to her own:

> *It would depend on what the disability is . . . I just had this thought, like if both of us are unable to like feed ourselves, that would not be a very easy relationship, cause if we need attendants to come out on our dates, that's kind of weird . . . so . . . I think a mild disability would be ok.*

The youth spoke very openly about their fear of not finding a partner because of their disability, as Elena explains:

> *I felt a lot like because I had a disability there would be no chance that I would ever have a boyfriend or anything, like any partners . . . so I think that was a big thing. I saw people going out, holding hands, kissing and I thought oh I'll never have that.*

Lilly talked about some of the negative experiences that she has faced in her life, which resulted in her lack of self-confidence about dating and her fear of never finding the right person:

> *It's just the experiences in my life . . . the rejection by guys . . . especially prom, it was like the pivotal moment when you're supposed to . . . grow up and . . . I don't know. . . it was right at that pivotal moment, where everything could be ok or . . . it could be really bad, and apparently . . . it just decided to be really bad.*

The youth often described themselves or other peers who have disabilities as becoming so obsessed with the idea of finding a partner that they begin to lose sight of who they really want to date or what they want out of a potential relationship. *" I think at one point it almost gets to the point where you are like so . . . almost desperate that you want someone that you're like . . . oh I'll take anyone*" (Elena). Elena also discussed the reason why she believes so many youth who have physical disabilities feel that they are never going to be in a relationship or do not see themselves as potential dating partners:

> *I think cause no one really talked about it to me . . . so then I thought . . . oh . . . well . . . it is kind of less likely to get into a relationship, especially when you are younger. . . if it's not even cool to be friends . . . with someone . . . dating them*

> *was out of the question . . . so like stuff like that, I think people don't talk about it . . . no one asks, hey you wanna date me or wanna go to the dance or that whole . . . like . . . stuff.*

### Self-Image

The youth participants demonstrated varied degrees of self-confidence and self-esteem during the interviews; from those who talked about feeling good about themselves, not caring what other people thought about them and having lots of friends to those who hated the way they looked, had no friends and often felt depressed and isolated. For some of the youth, their self-esteem improved as they got older and went on to post-secondary education. They explained that this is largely due to how accepting and open minded the people they now interact with are compared to their immature, image conscious high school peers. Elena discussed how her confidence has changed since this transition:

> *Really I think I just used to care when people would look at me and how they saw me, and now I'm kind of like well if you don't like it then don't look I think, that kind of thing. Cause I know who I am and I know what I can do.*

Several of the youth described the impact that the media has on their self-esteem and self-image. They felt that there was a lack of positive role models for young people who have disabilities and believed that images of successful, attractive people who use wheelchairs were largely absent from the media. Elena explained why she believes many adolescents with disabilities feel that they are not attractive or desirable when compared to those who are able bodied:

> *I think it [the media] impacts me more because you don't see any of the pretty girls being in wheelchairs right, so subconsciously it's kind of like . . . oh I'm in a wheelchair, I'm not pretty . . . kind of thing . . . that has changed . . . but I think that impacts a lot of people . . . because again I think because it's like you're just being told over and over again . . . like you're not ok to be disabled.* (Elena)

While body image was not a theme that I had originally planned on asking the youth about, it became apparent during their responses to questions about self-esteem, confidence and the media's portrayal of people with disabilities that this was a very significant issue in many of these adolescents' lives. Some of them told me that they were surprised I was asking questions about body image, since this issue rarely came up in discussion with their parents, teachers and health professionals. The lack of importance given to body image among youth with physical disabilities frustrated many of them, as Lilly explained:

> *A lot of people just assume . . . that people with disabilities already have the worst thing that they could possibly have so . . . what are they doing worrying about . . . other smaller issues . . . I don't know . . . it just seems like that.*

The youth's responses to questions like 'what is your favourite and least favourite part of your body?' were as varied as the adolescent's personality. Surprisingly, only a few mentioned something related to their disability as an insecurity they had with the way their body looked. When asked what part of their body they liked the most they responded with: "*Just my overall strength, how much strength I have, cause without strength you can't get around*" (Justin), *"I like my nose . . . everyone tells me I have a* *cute nose"* (Elena), *"um . . . my boobs . . . haha"* (Lilly), *" I like my muscles in my arms . . . it helps with . . . wheeling and playing sports"* (Olivia).

When I asked them about the part of their body they liked the least, they said: *"Just the part of puberty, that's the part I hate . . .especially acne . . . it's just, I don't feel comfortable how I look . . . I always try to . . . I always try to work out how to get rid of the acne as fast as possible, I want to get rid of it before I . . . before I turn into an adult"* (Justin), *"I would say my thighs . . . but I'm working on that"* (Elena), *"my stomach . . . I wish it was skinnier . . . but it's not"* (Lilly), *"well there's a couple parts I'm not . . . overly pleased with, and that's why I'm working out and trying to . . . like the belly and legs sort of"* (Olivia).

When the youth were asked what part of their body they would most like to change, they said, *"my spine for sure [laughs] . . . yah cause my spine is curved and I do get pains from it . . . and I do want it to get straight but they . . . the surgery that they have to do is not that good"* (Justin), *"I don't think I would change . . . like again, be more fit looking overall but . . . I would never be like 'oh I'm going to go get liposuction or plastic surgery'"* (Elena), *"Just my size . . . it would make me feel comfortable . . . it would make me feel confident . . .and you know, that's a huge problem with my esteem"* (Lilly), "*Probably my stomach*" (Olivia).

Many of the youth discussed their perspectives on attendant care and privacy, and how their experiences influenced the way they viewed their own sexuality and self-image. While some of the youth had only ever had their parents as caregivers, others had the experience of support workers and attendants helping them with personal care, such as toileting, changing and showering. Olivia discusses the awkward experience she faced with catheterization during middle school:

> *I can still remember you know, being in that washroom at school and my mom trying to train like 5 different EA's and I'm like . . . this is not what I want . . . not being in grade 6 and being . . . spread wide open.*

Although Olivia described this time as being fairly uncomfortable and unpleasant, she did not believe that her experience with attendant care had influenced the way she felt about her body or her sexuality in any way. Some of the youth found it more comfortable to have their parents as attendants, while others said they preferred the assistance of support workers. Some of the youth explained that having support workers was more conducive for exploring one's sexuality through masturbation, since they could ask the worker to help undress them or maneuver them in a certain position that would allow them to gain better access to their body but would be too embarrassing to ask their parents to do.

The youth participants expressed a range of feelings about having a disability and how this influenced their self-image and self-esteem. While some of them were very positive and accepting of their disability, others showed a large amount of resentment and frustration towards the challenges they have faced. The youth described the way their views towards having a disability or the way they defined their disability have changed over time:

> *When I was little I'd just say that I'm in a wheelchair . . . and that was how I defined it, now I'm like well . . . yes, I use a wheelchair . . . I'm not attached to it.*

> *When people say you're confined to a wheelchair . . . it's like no, I'm not, I'm not* (Elena).

Lilly described how she often felt self-conscious and ostracized because of her wheelchair, *"when you are in a sea of thousands and thousands of walking people at [name of school], you become very aware that you're the . . . girl attached to 300 lbs of metal."* While Justin initially talked about his optimism and acceptance of having spina bifida, he later opened up about the emotional pain he experiences when thinking about his disability:

> *I do hurt on the inside because I know I have spina bifida, I do wish that I could walk . . . but, some people don't understand . . . how I feel . . . that I want to walk, instead of being in a wheelchair."*

The issue of mortality and how it can affect one's sense of self came up frequently in my interview with Patrick, whose son Tyler has a fatal form of muscular dystrophy. As Patrick began to explain what his experience was like with the CRC and how the professionals there dealt with Tyler's prognosis, I began to see many parallels between the way health professionals discuss sexuality and mortality with youth who have disabilities. Patrick explained that similar to sexuality, mortality was an issue that few health professionals felt comfortable discussing and that they often tried to pawn the topic off onto someone else. Patrick believes that most health professionals working with young people who have disabilities have not been adequately trained to handle such delicate situations. Although sexuality and death are both realities of life, they seem to be issues which people often try to suppress or avoid. Here Patrick talks about his teenage son's increasing anxiety surrounding his own mortality:

> *He's always been a bit of worry wart, so when you throw him into . . . hey let's go down to [name of city] and start talking about how you want your life to end [small laugh] it's really not a fun topic.*

As Tyler gets older and his health continues to deteriorate, Patrick explained how the reality of this imminent mortality has begun to play heavily on his son's emotions:

> *I think top on his mind . . . right now is his mortality . . . because it's come up as something that he has to deal with . . . and I think he's started . . . it scares him to death . . . right . . . what's been said now is . . . you have to decide how you want to be dealt with . . .once you become ill enough to be hospitalized . . . with um . . . DNR [do not resuscitate] instructions and . . . whether or not you want to be intubated and what happens if your heart stops and things like that which . . .who wouldn't be scared to death . . .when you know that's something in your future.*

### *Theme Summary*

While developing one's sexuality is a crucial part of identity formation during adolescence, youth with physical disabilities often face many barriers that limit their psychosexual development during this time. Challenges such as a lack of privacy, discomfort about sexuality and issues related to mobility and physically accessing their own bodies were all mentioned by the participants as possible reasons why youth with physical disabilities may not have the opportunity to engage in the same degree of personal exploration as their able bodied peers.

The literature that examines how youth with physical disabilities see themselves as sexual beings seems to be congruent with the findings from this study, where many of the youth expressed feelings of uncertainty or ambivalence about their sexual and relationship capabilities. As Tepper (2001) states, "children with disabilities first learn that they are disabled before learning to see themselves as sexual people" (p.5), which can lead these youth to grow up seeing their disability as the definitive characteristic of their identity. For many of these adolescents, the major emphasis that their family, school and health care workers have placed on their disability often means that other areas of their development, such as sexuality, relationships and independence may be largely overlooked. This can make the understanding and acceptance of being a sexual person challenging for many young people with physical disabilities, especially when these oversights are coupled with the pervasive disability related stigma and myth of asexuality that is so apparent in society.

The responses that the youth participants gave in terms of what they believed sexuality was and what it meant in their lives provide us with some insight into the complexity that exists between our understandings of sex versus sexuality, and particularly how this distinction impacts on the development of sexual subjectivity among adolescents. The youth spoke about sexuality in very general terms referring mostly to sexual orientation; however, topics such as touch, intimacy, self-awareness and sexual pleasure were rarely brought up during the interviews. In fact, the youth tended to relate sexuality mostly to the biological or physiological aspects that we would generally associate with sex, such as puberty, reproduction and fertility, rather than the broader, socially constructed understanding of sexuality that has been discussed throughout this study. While pleasure and intimacy are often seen as fundamental aspects of a healthy, fulfilling sexual relationship, the discourse surrounding the importance of these issues for people living with disabilities is generally ignored or overlooked by researchers, educators and health care professionals (Berman et al., 1999, Tepper, 2000). Tepper (2000) explains that this "missing discourse of pleasure" (p.1) results from the fact that the majority of the sexuality related messages that people with disabilities receive are mainly focused on negativity, deviance, protection and the underlying myth of asexuality, rather than on the basic human emotions and needs related to positive sexuality and sexual development such as intimacy, pleasure, belonging, acceptance, self-awareness and autonomy. The fact that the youth in this study framed sexuality within the realm of biology and physiology rather than as a socially constructed entity that is intricately tied to a person's overall identity and sense of self may help to provide insight into how sexuality is constructed among adolescents with physical disabilities and in turn, how this construction impacts on the way in which these youth validate the importance, understanding and awareness of their own sexual pleasure, capabilities, entitlements and identity as sexual beings.

The literature that is currently available on the rates of sexual activity among youth with physical disabilities has shown results which differ quite dramatically from the anecdotal evidence obtained through this study. For example, the majority of youth in this study either explicitly stated that they had not engaged in any kind of sexual activity yet, or at least hinted at this notion, whereas Suris et al. (1996), Cheng & Udry (2002) and Choquet et al. (1997) all reported that adolescents with chronic disease and physical disabilities engaged in sexual activity at the same rate as their able bodied peers, and in some cases possibly even a higher rate. While these results could provide evidence to help dispel the myth of asexuality surrounding young people with disabilities, they may also be misleading or not necessarily applicable to adolescents with severe physical limitations due to the researchers' vague classification of disability. While it would be problematic to make sweeping statements about a population based on a qualitative study involving only four youth participants, it is still important to differentiate the population of youth being studied in this narrative inquiry versus those involved in the larger, quantitative studies mentioned above. Compared to the adolescent participants in this research project who all had moderate to severe disabilities requiring the use of a wheelchair, the aforementioned studies included a very wide range of physical disabilities and chronic conditions, including many youth who had asthma, diabetes or mild physical impairments. The majority of the youth participating in these studies did not use any form of mobility device, assistance with personal care or show any outwardly visible clues that they in fact had a disability. Due to these widespread differences in the types of disabilities, the extent of physical and social challenges and assistance required with daily tasks among these different groups of youth, the findings related to sexual activity and behaviour from Suris et al., Cheng & Udry and Choquet et al.'s studies may not necessarily ring true for groups of youth with severe physical limitations.

However, a finding from the literature that echoed the opinions of the youth in this study related to the link between challenges with dating and the lack of media exposure portraying people with disabilities as desirable intimate partners. Howland and Rintala (2001) explain that due to limited experiences with dating, adolescents with physical disabilities may rely on unrealistic and oversimplified images of romance and intimate relationships among able bodied people in the media, thus further distorting their understanding of realistic and appropriate dating behaviour. Being unable to find a dating partner was a significant fear for a number of the youth participants, who at some point during their adolescence felt that their disability made them unattractive or undesirable to potential partners. The youth explained that during high school it was difficult enough for their able bodied peers to just accept them as a friend, which led them to believe that the prospect of someone wanting to date them would be nearly impossible. Researchers have described the process of finding an accepting partner as being the biggest challenge many people with physical disabilities will face in their quest for sexual and emotional fulfillment. This is largely due to negative societal views towards people with physical disabilities as being undesirable or incapable of sexual activity. Shakespeare (2000) explains that the most challenging aspect of sexuality for many people with physical disabilities "is not how to do it, but who to do it with" (p.161). Fortunately, it seems that as the youth participants in this study have gotten older and been exposed to more people with disabilities who are in relationships, many of them have developed a more positive, optimistic outlook towards finding a partner in the future.

A significant finding from this study related to self-esteem and body image was that all of the youth participants expressed some degree of discomfort about the way their bodies looked, even though body image was rarely brought up in conversation with parents, teachers or health professionals. They believed that most people assumed the only things concerning these youth were issues related to their disability, which essentially dismissed the "normal" body related concerns typically experienced by most young people during adolescence. Interestingly, the parts of the youth's bodies which they felt the most insecure about were not related to their disability at all, rather they were self-conscious about the same areas that most able bodied youth worried about, such as the size of their stomach and thighs, or the status of their acne. Also, the severity of the youth's physical limitations did not seem to be linked with their confidence or level of body dissatisfaction, which contrasts Wolman et al.'s (1994) finding that adolescents with severe visible disabilities tended to have poorer body image and lower emotional well-being compared to youth with mild or "hidden" disabilities.

In two well-known studies focusing on sexuality among youth with physical disabilities, Cheng and Udry (2002) and Greydanus et al. (2001) found that issues related to low self-esteem, unsatisfactory body image, challenges with socializing and independence were common among this population and played a significant role in the level of knowledge, comfort and confidence these youth had regarding their own sexuality, sexual function and reproductive capabilities. The youth in this study displayed many of the same challenges that were found in the aforementioned studies; however, this study also found that the way in which the youth felt about having a disability, their self-esteem and how they identified themselves appeared to be constantly changing and evolving over time. They seemed to become more confident and accepting of their disability as they got older, particularly after leaving high school and moving onto post-secondary education, where they were able to make friends who were genuine, open-minded and accepted them exactly as they were.

# Chapter Five: Findings - Part 2

This chapter outlines the two secondary themes that emerged from the data. While they may not be directly related to sexuality, these themes do play a significant role in understanding the challenges many youth with physical disabilities face during adolescence. Theme #3 looks at the different kinds of relationships that exist in the lives of youth with physical disabilities namely with their peers, parents and health professionals. Fitting in and feeling accepted were important aspects of the youth's relationships with their peers, along with the youth's notions of what it means to look and feel "normal" compared to their peers who are able-bodied. This theme also explores youth-parent relationships and the impact that these have on the development of independence and autonomy among the youth, as well as the complex and sometimes strained relationship between adolescents with physical disabilities and their health care providers. Theme #4 pertains to the data collected on what the participants' thought about society's views towards disability, with a particular focus on some of the pervasive myths, negative misconceptions and stigmas that inform dominant ideas about sexuality among this population. This theme also explores the way in which these negative perceptions impact the adolescents' views towards their own identity, capabilities and self-worth.

## *Theme #3: Relationships*

### Relationships with Peers

Feeling accepted by one's peers is a crucial part of adolescence and the youth in this study all described how important being accepted and fitting in with their peers was in their lives, regardless of their age, gender or type of disability:

> *L: So what would you say is the most important or the most meaningful part of your life right now?*
>
> *J: Um . . . probably just fitting in with all of my friends and them accepting that I have a disability. Them just saying that hey, just because you have a disability . . . you're still a cool guy* (Justin).

The parents also described how important it was for youth with physical disabilities to feel a sense of acceptance and belonging among their peers. Here Catherine describes Grace's experience of feeling left out and ostracized once she reached middle elementary school (grades 4-6), when her "friends" decided they no longer wanted to have anything to do with her, *"the acceptance had gone and it was reflected in her attitude, that's sort of when the problems started."* Catherine also described the challenges Grace faced with being accepted in high school, particularly by her female peers. Through her experience with Grace, Catherine believed that during adolescence females with physical disabilities generally experience more challenges related to acceptance from their peers compared to males:

> *It's a challenge for any parent having . . . having a female adolescent, I think boys seem to sail through adolescence easier . . . I know Grace had a friend at this time, same age and same school . . .um he was disabled as well . . . he didn't*

> *need to use a wheelchair . . . but he didn't have the same problems, he was much more accepted . . . because boys don't look at things in the same way . . . so he never really had [the] problem with acceptance that Grace did . . . and she was well aware of the difference as well. The boys sort of accepted her . . . at this time we realized that . . . by the time she was about 15 . . .16, her only friends were boys.*

The discussions I had with the youth regarding their social lives revealed a variety of opinions about the topic and seemed to depend largely on their age and what stage of education they were in. The older youth who were attending post-secondary education described having lots of friends, going to parties and bars, and feeling an overall sense of satisfaction with their current social life. They explained that the people they interacted with now were much more open-minded, accepting and mature compared to the peers they knew in high school. The younger youth, or the youth who were not attending any kind of organized post-secondary program, seemed to have more negative views of their social life and often felt left out and somewhat isolated. Many of the younger adolescents described their social circle as consisting mainly of other youth with disabilities which, for some, was an asset because it made them feel accepted, while others saw this as something which only further segregated them from the rest of society.

Both the youth and parents spoke about the various challenges many adolescents who have physical disabilities face with making and keeping friends. These challenges ranged from issues of transportation and accessibility to isolation caused by absences from school, low self-esteem, overprotective parents and a lack of opportunities for socializing with peers. During early adolescence, many youth rely on school as their primary means of socializing, so when they miss a great deal of school due to an illness, surgery or other medical appointments, they can often feel left out and socially isolated. Justin described what he misses the most about school after being absent for over 6 weeks due to a recent surgery:

> *J: I kind of miss the arguments, the fights and stuff*
>
> *L: The drama [laughs]*
>
> *J: Yah the drama . . . typical teenage school drama [laughs] that's what I miss the most.*

Some of the youth brought up the issue of peers treating them as though they were dependent and helpless. They felt as though people either avoided them at school or tried to baby them, which made the youth feel as though their physical and social capabilities were being undermined:

> *J: I can usually tell if they are going to help me or over help me . . . I tell them that I know that you are trying to help, but this is a part that I can do by myself*
>
> *L: How does it make you feel when people try and do things for you that you can do on your own?*
>
> *J: I feel like I'm uh . . . actually more disabled then I actually am, I feel like they're taking a part that I can actually do away from me* (Justin).

While most of the youth said they had a fairly active social life, some of the parents I interviewed shared their heartbreaking stories of what it was like to have a child who has no meaningful social relationships, as Patrick explained, *"it kills him that he has no friends"*. These parents spoke about how difficult it was to see their children being constantly rejected by peers at school, never being invited to birthday parties and sleepovers, and eventually giving up and becoming introverted and reclusive. Patrick was particularly disheartened that his children had little to no social interaction and often put the blame on himself for the loneliness and isolation his children experienced:

> *I would obviously much prefer that they had some friends and had a social life, cause right now it's zero . . . I don't know . . . sometimes I blame myself, maybe we as parents are too protective, but . . . so it's hard to say how much is personality driven and how much is environment driven, for the position that they're in socially."*

A common theme that came up in the youth interviews was the idea of being "normal". I asked the youth what they thought about the word normal and although most of them said they believed that nobody was really "normal", they still seemed to have a desire to look, act and feel just like their able bodied peers. Some of the youth associated being normal with being able-bodied, which made them feel severely ostracized and misunderstood by their peers, as Lilly explained, *"no one really understood me, and nobody thought that I was normal."* When I asked Justin what he thought about the idea of being "normal" and having a disability, he responded by saying *"it still isn't the full normal, but for me it's the normal.* Catherine believed that this drive to feel accepted and be seen as a "normal" adolescent was the reason why her daughter began engaging in sexual activity. *"She badly wanted to be accepted into society and I think a boyfriend and going the sexual route was a way of being accepted . . . right . . . 'look at me I'm normal'."* (Catherine).

## Relationships with Parents and Health Professionals

During the youth and parental interviews, as well as the focus group with health professionals, parents and caregivers often came up as the main barrier to independence for youth who have physical disabilities. A number of reasons why parents may prevent their children from being independent were discussed, including parents being overprotective and fearful of their child getting hurt, sick, ridiculed or taken advantage of, as well as the co-dependency that sometimes forms between parents and children who have special needs. Often times the parent's entire identity is based around taking care of a child with a disability, so the idea of that child moving out and being independent can leave parents feeling lost, worthless and without a purpose in life. Marie experienced this loss of purpose and feeling like she did not know what to do with herself when her daughter Elena attended the TIP program in Toronto. Here she explains what she learnt from the experience, *"the kids have been ready for years . . . it's the parents that don't want to cut those apron strings."*

The issue of independence was significant among all of the participants, as it came up in every interview. The youth explained how important it was to feel a sense of autonomy in their lives, especially for those who had more severe disabilities and required assistance with everyday tasks. All of the youth expressed a desire to eventually move away from their parents and live on their own. Although many of these youth knew that they would still require considerable assistance from others, living independently was a way of proving that they were able to take care of themselves and did not have to rely entirely on their parents or caregivers for everything. Lilly discussed the sense of accomplishment she has experienced since moving out on her own, *"It's changed me because it helps me understand what I'm capable of."*

Some of the youth described how they were constantly trying to push the boundaries of their independence, in order to prove that they were actually capable of doing more than their parents believed they could, as Elena explained:

> *Yesterday I was home alone and I just decided that I would try to get from my chair to the couch on my own . . . and I did it, and I was so happy and then my mom came home and was freaking out, like what if you fell and hit your head, and I'm like that's why I did it when you weren't here, so you couldn't stop me [laughs].*

All of the participants felt that overprotecting a child who has a disability can limit his or her independence and can also have many detrimental effects on the child's self-esteem, sense of self-worth and future capabilities. *"There's a lot of kids out there that would be a lot further in independence if the parent would let them grow up like an able bodied person" (Marie).*

> *I know a lot of people who let their parents talk for them . . . and I think that's so like sad, cause . . . your parents don't know what you want, really and . . . I think it's a big lack of self-confidence I see in those people* (Elena).

Adolescence can be a time that many parents dread due to the supposed irrational outbursts, negative attitudes and rebellious behavior commonly associated with this time of life. A common theme throughout many of the parental interviews pertains to the relief they seemed to feel because of the fact that their adolescent did not or was not able to partake in any kind of normative "teenage" behavior, as Marie explained:

> *Because of . . . she doesn't have the freedom, she can't . . . . um . . . open the door and take off in the middle of the night . . . or um . . . not show up at home so I think . . . I like to think I had less worry of that.*

The youth were also aware that, for some of them, their disability prevented them from engaging in certain adolescent-type behaviour they may have taken part in had they been able-bodied:

> *I think when it comes to the rebellion thing . . . it's a lot harder to sneak out of the house if I need my mom to get me into my chair . . . and get me to the door, so [laughs] stuff like that"* (Elena).

Some of the youth described instances where they were given the opportunity to experiment with risky behaviours, such as trying marijuana or underage drinking, although none of them admitted to actually talking part in these activities. Despite their children being exposed to the same risky temptations as any other able bodied youth, many of the parents still seemed to be blinded by a false sense of security, believing that since their adolescent was unable to move around or do certain tasks independently, they would never get into any trouble. This belief is somewhat unfortunate as it can perpetuate the myth that people with disabilities are innocent, naïve and dependent on others.

Many of the youth expressed a significant amount of resentment and bitterness towards the medical profession, since those who had experienced severe complications at birth were often given extremely pessimistic prognoses for their future. Two of the youth shared what the doctors had told their parents soon after they were born:

> *The doctors said I would never talk, I wouldn't eat, I wouldn't live. They said 'oh she'll be a complete vegetable you should give up now' . . . and my mom was like . . .um . . . no . . . take that doctors* (Elena).

> *They told my parents I was going to be a brain dead vegetable and that I shouldn't even bother going into a regular school system* (Lilly).

Currently, both of these youth are highly successful students in the process of completing their post-secondary education. For many of the youth, it is society's doubt and pessimism about the capabilities of people living with a disability that has motivated them to keep achieving and succeeding far beyond the low expectations set forth by their doctors. *"Like every time I accomplish something I'm like take that science . . .you were wrong!"* (Elena).

### *Theme Summary*

The parent and youth participants discussed several challenges facing adolescents with physical disabilities in terms of making friends and feeling a sense of acceptance from their schoolmates. While some of the young people in this study had very active and fulfilling social lives, it is not uncommon for youth with physical disabilities to face challenges in terms of developing social relationships, due to long absences from school, not having the opportunity to integrate with able-bodied peers, having low self-esteem, lacking independence, facing rejection and being in a socially isolated environment (Blum, Resnick, & Nelson, 1991; Wiegerink, Roebroeck, Donkervoort, Stam, & Cohen-Kettenis, 2006). As a result of these challenges with socialization, adolescents with physical disabilities may be seen as subordinate, marginalized or met with ambivalence by their able bodied peers (Brunnberg et al., 2009).

Feeling accepted by their peers was one of the most important topics the youth brought up during their interviews, often linking this idea of fitting in with their friends with the concept of being perceived as “normal”. Skär (2003) explains that the way in which adolescents with physical disabilities view themselves is profoundly influenced by the way they believe others perceive them. This was evident among some of the youth participating in the current study, who explained that they felt better about themselves when they believed others saw them as being ‘normal’. Although the idea of normalcy came up in almost every youth interview, it seemed to be a confusing and ambivalent issue for many of these adolescents. When I first asked them about their feelings on the word ‘normal’, I noticed that many of the youth gave me a very politically correct answer, saying that no one is really normal and that we are all different. However, they later opened up to me about feeling like they were not normal because of their disability and expressed their desire to look and feel normal so that they could fit in with everybody else.

The desire to fit in and be viewed as “normal” by one’s peers may play a role in the significance youth with physical disabilities place on being in a sexual relationship. Brunnberg et al. (2009) explains that these adolescents may view sexual activity as an important aspect of fitting in with their peers, motivating some youth to engage in sexual relationships with multiple partners as a means of feeling accepted. This desire to fit in and feel ‘normal’ may help to explain the findings from Suris et al. (1996) and Choquet et al.’s (1997) studies about the higher than expected rate of sexual activity among youth with mild to moderate physical disabilities. Catherine, a parental participant, described this scenario happening to her daughter Grace, believing that the need to fit in and be seen as "normal" was precisely the reason why her daughter became involved in numerous sexual relationships during high school.

As mentioned in the findings section on youth-parent relationships, many of the parental participants felt a sense of safety and reassurance about their child entering adolescence, believing that because of their physical limitations, they were not going to experiment with any sort of rebellious or risky 'teenage' behaviour. The way these parents of youth with physical disabilities felt about their children entering adolescence contrasts Buchanan and Holmbeck's (1998) study, which looked at the general perception of adolescence from the point of view of parents who have able-bodied children. The parents in their study were found to hold many negative stereotypes and fears about their child entering the teenage years, perceiving this stage as a time of rebellion, peer pressure, defiance and risk-taking. During the narrative interviews, some of the youth discussed the fact that their parents' beliefs about them being unlikely to engage in rebellious adolescent behaviour were often warranted. For instance Elena, who requires assistance with all of her personal care, explained how difficult it would be for her to sneak out of the house when she needs her mom to help her get into her wheelchair and open the front door. The youth in this study who had more severe physical limitations tended to be viewed as less likely to engage in any kind of risky teenage behaviour compared to the youth who were more physically independent and mobile.

In the case of young people with severe physical limitations, parents may become overprotective and view their children as less capable then they actually are. This type of behaviour can limit an adolescent's ability to go through the normative stages of development that are necessary in order to become an independent, confident adult (Greydanus et al., 2002). Olkin (1999) found that when parents raise a child with severe physical and medical challenges, the child's medical care and daily needs are generally their top parenting priorities and they often ignore or avoid issues that are seemingly less immediate, such as the youth's emerging sexual development or need for independence. The health professionals in this study described similar experiences, as the following interview excerpt from a nurse explains the difficulty some parents have with letting go and encouraging their child to gain independence:

> *Some of the kids have had a really rough start and they've arrested [gone into cardiac arrest] . . . so these are parents that won't even let . . . the kids sleep in their own bed, they'll sleep with them in case they have a seizure in the night or . . . you know they're just paranoid, and for good reason . . . so it's really hard for them [to let go].*

The health professionals described the tension they sometimes encounter between themselves and parents who are unable or unwilling to take their advice about allowing the youth more freedom and independence; however, they did not bring up any of the challenges they faced in terms of the relationship they had with their adolescent clients. I found this interesting since the youth participants often shared their pessimistic views regarding the beliefs and expectations of their health care providers, especially among the adolescents with more severe physical limitations who expressed a deep-seated resentment and skepticism towards health professionals, particularly doctors. They often held negative views towards the medical profession as a result of incorrect and profoundly hurtful assumptions made during their early childhood about their future capabilities. A number of them also described the discomfort they now feel about telling their doctors personal information, particularly with regard to sexuality. As a result of the negative experiences these youth have had with their health professionals in the past in terms of feeling discredited and undermined, they may have a difficult time trusting their practitioners and opening up to them, often feeling fearful of being judged or patronized during the appointment. This demonstrates how resentment and distrust towards the medical community can pose significant barriers for youth with physical disabilities with respect to accessing specific information related to their own sexuality and reproductive capabilities.

### ***Theme #4: Societal Views Toward Disability***

The notion that people with physical disabilities are asexual is pervasive in our society and is often due to ignorance and misunderstandings about the intellectual, social and emotional capabilities of people living with physical limitations. Although the youth participants in this study believed that they were sexual beings capable of having fulfilling intimate relationships, they were all well aware of and particularly frustrated with the prevalence of this myth. From the youth's perspective, the myth of asexuality is clearly tied into the belief that people with disabilities cannot be sexual, *"I think people think people with disabilities don't have sexuality"*(Elena), or should not be sexual, *"I think that society naturally has a view that you know, if you're disabled then you're naturally discouraged from having sex*" (Lilly). When the youths were asked why they felt this myth was still so common, most said that the media was to blame because it was extremely rare to see a person with a disability being portrayed as a romantic or sexual partner in the popular media:

> *It's the media . . . you never . . . you never saw like . . . on soap operas you never saw a guy lift a girl in a wheelchair into bed . . .you never saw that . . . it should be normal for everyone, whether you sit on your ass for the rest of your life or you like boys, girls, it doesn't matter* (Lilly).

While none of the parent participants believed that their children were asexual, they did agree that sexuality and disability were not often thought of as complimentary ideas, as one mother explained, *"I think for a lot of them [other parents], it probably doesn't even cross their mind . . . I think had she [her daughter Grace] been more severely disabled, it might not have crossed my mind"* (Catherine). Both the youth and parent participants also brought up the issue of people with disabilities often being thought of as innocent, naïve and childlike. Here Elena discusses why she thinks people often talk down to youth who have disabilities and what she wishes would change:

> *I don't know if it's that people view us as innocent, like little kids almost* . . . well *people who don't know me, I wish they wouldn't come up to me and talk to me like I'm two years old . . . [laughs] cause that drives me insane.*

Once again, the media was seen as the main culprit in perpetuating this myth, *"then the media doesn't help [laughs], portrays us like these helpless individuals"* (Elena). Many of the parents understood how challenging it was for these youth to try and prove their capabilities to society when the misconception that they are completely dependent on others is so widespread. *"I don't think any of them want to be seen as helpless"* (Tessa). Another misconception that frustrated some of the youth was the belief that people with disabilities do not possess the same feelings and emotions as their able bodied peers. While some people with more severe disabilities may not be able to clearly express these emotions to others, the youth in this study described how much they wished people understood that young people with disabilities go through the same ups and downs of adolescence as everyone else, as Elena explained, *"I think people think I'm constantly like . . . always happy . . .never get upset, and the thing is I just hide it really well, and I mean I'm a human being."*

All of the participants believed that society generally holds very low expectations about what people with disabilities are capable of achieving, particularly in relation to their cognitive abilities. Both the youth and parents discussed how people often group cognitive and physical disabilities together, which means that individuals with physical disabilities are often thought of as having low intelligence and being unable to function in society:

> *Well I can already tell you that from a young age . . . I've always known that people expect people in wheelchairs to have low intelligence levels . . . and not really be smart enough to . . . you know, know what everybody else wants and know what they want . . . so there's been like a general sense of . . . pity* (Lilly).

Several participants described how people would often assume that if someone uses a wheelchair, they must also have a sensory or communication disorder. Catherine noted, *"people think disabled people can't hear, can't see, and they make comments to me that are very insulting to Grace, or because she's in a wheelchair they actually talk to me."* As a result of these widespread misconceptions and low expectations that society tends to hold towards people with disabilities, several of the youth discussed their struggle with constantly having to prove themselves to others, as Elena explained *"you have to push harder, even just to be average."* They also talked about how these low expectations can eventually lead to a self-fulfilling prophecy, *"I think it can bring somebody down a lot . . . it can change who they are completely and they start thinking 'oh, I can't do this' "* (Olivia).

While some of the participants believed that society was becoming more accepting of disability, almost everyone agreed that multiple levels of stigma surrounding people with disabilities were still apparent, including negative or misconstrued perceptions about the way they look, the way they act and their ability to function in society. The presence of these negative stigmas were especially upsetting for some of the youth, as Lilly explained:

> *It is really difficult when you have society shoving down your throat that there's something wrong with you and you know . . . no matter how many ramps or accessible places there are . . . you know that . . . being disabled is still something that's viewed as very weird.*

Several parents spoke about their frustration with the way society often disregard the basic needs of those living with a disability with regard to accessibility, housing, employment and relationships. *"I think they see them as a non-person in some ways"* (Tessa). Despite all of the challenges that many of the adolescents in this study deal with on a daily basis, the youth participants still expressed a great deal of optimism, pride and self-confidence, as Olivia responds to this question:

> L: *How does that make you feel, when we talk about pity and people feeling sorry for people with disabilities?*

> O: *I feel sorry for them . . . yup . . . haha . . . that's how I think of it, you feel sorry for me, well I feel sorry for you.*

### ***Theme Summary***

The issue of societal views towards disability was seen as a significant topic by all of the youth, parents and health professionals. While no one who took part in this study believed that people with physical disabilities were asexual, everyone was very aware that the misconceptions regarding sexuality among this population were still highly prevalent in society. These include the notion that people with disabilities are innocent, vulnerable, dependent and in need of protection, or the belief that people with physical limitations lack any form of sexual desire and are unable to engage in sexual activity (Boyle, 1994; Farrar, 1996). Many of the youth participants described how they had experienced these types of negative misconceptions first hand, such as being rejected by opposite sex peers, being seen as naïve and treated like a child, or by having their sexual health needs overlooked during medical appointments.

In discussing this research study with members of the able bodied community, I have noticed that many people are greatly misinformed about the sexual capabilities of people with physical disabilities. Even while speaking to educators, health professionals and members of my graduate program about my research topic, I often heard comments such as, "I've never even thought about that" and "but they can't actually have sex though . . . right?" These types of comments have lead me to understand how pervasive the myths and misunderstandings surrounding sexuality and disability are, not only among the general population, but also among highly educated academics who are involved in the field of health research. This unfortunate reality is a prime example of the need to develop disability-specific sex education resources not only for youth with physical disabilities, but also for the able bodied community in order to dispel some of these damaging and stigmatizing misconceptions.

The youth in this study often made connections between the challenges they face as adolescents with physical disabilities, such as finding a partner, fitting in with their peers, and being accepted as sexually capable individuals, with the low expectations and misconceptions about disability and asexuality which they believed to be present in society. These findings parallel the existing research which states that the myths and misconceptions regarding young people with physical disabilities being seen as asexual beings not only affects their opportunity to find accepting and willing dating partners, it can also cause them to internalize the negative societal stigma surrounding sexuality among people with disabilities (Berman et al., 1999; Milligan & Neufeldt, 2001). This internalization process can make it difficult for the youth to accept and embrace their sexuality and feel as though they are worthy of being in an intimate relationship. Milligan and Neufeldt (2001) describe this phenomenon in their study, which found that the myth of asexuality can act as a self-fulfilling prophecy for some people living with physical disabilities, causing them to avoid intimacy and suppress their innate sexual desires.

Although many of the participants believed that the treatment and acceptance of people living with disabilities had improved over time, they still felt that the general public held many negative beliefs and assumptions about this population. These negative views stem from the same low expectations and ignorance that leads society to believe that people with disabilities are asexual, have low levels of intelligence or other sensory impairments, are completely dependent on others, are unable to form meaningful relationships, and lack basic human desires such as love and intimacy (Farrar, 1996; Shakespeare, 2000). While many of the participants believed it would be very difficult to change society's views about disability, they felt as though having a strong support system from family, peers and the community allows young people with physical disabilities to overcome these negative attitudes and feel confident and proud of who they are.

# Chapter Six – Discussion and Conclusion

## Discussion

The primary aim of this study was to gain a greater understanding of what the experiences of learning about sexuality are like for adolescents living with a physical disability and, in turn, how these experiences influence the way they see themselves as sexual beings. While the youth all agreed that adolescents with physical disabilities could be sexually active and require the same sex education opportunities as the rest of able bodied society, they often expressed feelings and ideas that reflected a significant degree of ambivalence towards their own sexuality. Developing a sense of identity and understanding about sexuality is an important aspect of adolescence, yet the process of developing a sexual identity can be particularly difficult for many youth with physical disabilities due to the immense challenges they face with being accepted and respected as sexual citizens within society.

A second aim of this study was to explore the kinds of resources and services that exist and also need to be developed in order to improve sex education opportunities for youth living with physical disabilities. The findings from this study have shown that ensuring these adolescents receive relevant, useful information about their own sexuality is viewed as the responsibility of several different groups, including parents, health professionals, teachers, and the youth themselves. Each offers a unique area of expertise and plays a different, yet equally significant role in providing a well-rounded sexual education for adolescents with physical disabilities. In order to meet the needs of a variety of educators, it is crucial to develop individualized sex education training programs and resources that address the particular issues and communication barriers each of these groups face.

An issue that has major significance on how adolescents with physical disabilities feel about their sexuality, desirability as a dating partner, body image, confidence and self-esteem is the influence that the media has in the lives of these youth. The youth participants often discussed the negative impact they believe the media has on their self-confidence, explaining that it was generally not a direct comment or image that made them feel as though they did not measure up to their able-bodied peers, but rather the absence of positive images portraying people with disabilities as attractive or desirable that caused them to internalize these negative beliefs about themselves. The youth felt it would be beneficial to have confident, good-looking and successful individuals with physical disabilities portrayed in the popular media as a way to expose other youth with disabilities, as well as the rest of able-bodied society, to the idea that people whose bodies look or function differently from the culturally accepted norm could still be seen as desirable, attractive and someone to look up to.

Adolescents with physical disabilities are facing many of the same issues as able bodied teens, including a desire to fit in and be accepted by their peers. They are also dealing with unique challenges that are directly related to their disability, such as finding a balance between gaining more independence and still relying on others for assistance or constantly trying to prove their capabilities to a society that is often patronizing and doubtful of their abilities. Being viewed as naive, childlike and dependent makes it challenging for these youth to engage in independent self-discovery, particularly in relation to exploring their own sexuality and sexual identity. In order to research sexuality and sexual identity among these youth, we must first gain a more general understanding of the important, yet largely misunderstood areas of identity formation and self-awareness among adolescents with physical disabilities. The presence of these significant knowledge gaps warrant the need for more qualitative research to be conducted with this population, an issue that is discussed in greater detail later on in the chapter.

## Strengths of the Study

One of the main strengths of this study is that it examines the complex and largely misunderstood subject matter of sexuality and sex education among adolescents with physical disabilities. This field is often overlooked by health researchers, resulting in outdated literature, a lack of knowledge among health professionals, and the perpetuation of myths related to asexuality among this population. The parents, youth and health professionals who participated in this study all stated how pleased they were that this topic was finally being studied. They felt there was an immense need for more awareness and information about sexuality and physical disability, yet the resources and interest among researchers seemed to be lacking. The youth told me that they had been approached numerous times to participate in research studies and often turned down the offers because they did not feel as though the study topic was relevant to their lives. However, after mentioning what my study was about, many of the youth and parents showed a keen interest in participating because it was an issue that was significant to them, yet was rarely discussed in a professional or rehabilitation environment.

An additional strength of this study was the inclusion of participants from a diverse range of socioeconomic backgrounds, as well as different types of physical disabilities, including cerebral palsy, spina bifida, muscular dystrophy and other neurological disorders. The focus group also comprised of a diverse group of participants, as it included an equal number of male and female participants and involved a wide range of different professions, including a nurse, occupational therapist, teacher and social worker.

The multifaceted approach chosen for this research project can be seen as an additional strength of this study, since I utilized a number of qualitative data collection techniques including narrative interviews, focus groups and field notes in order to explore the largely misunderstood and often taboo topic of sexuality among adolescents with physical disabilities. By interviewing youth, parents and health professionals, I was able to capture a richer, more diverse understanding of the personal, societal and institutional interactions that inevitably occur when exploring such a complex, multilayered topic. Conducting in-depth narrative interviews with adolescents who have physical disabilities was particularly beneficial, as it offered these youth an opportunity to have their voices heard about topics which they had rarely been asked about and often felt ashamed or embarrassed to discuss. Due to the flexible, open-ended nature of narrative inquiry combined with the rapport building that occurred during the initial phases of recruitment, the youth expressed to me the comfort, reassurance and in some cases catharsis that they experienced during the interviews. I believe that the gratitude the participants expressed to me for conducting this type of study, along with the positivity and reassurance that the youth experienced from participating in the narrative interviews are some of the most poignant and significant strengths of this study.

After hearing first-hand about the numerous challenges that youth with physical disabilities must face in terms of poor self-esteem, the fear of not finding a partner, inadequate sex education and limited knowledge about their own reproductive capabilities, it became very evident to me how immense the need for better quality sex education and a stronger understanding of emergent sexuality among these adolescents really is. This study is both relevant and timely, and offers practical, tangible solutions for improving the availability, delivery and uptake of sex education information for adolescents living with physical disabilities. It also offers a candid, emotional gateway into the lives and stories of young people whose physical impairments and challenges often overpower their psychosocial needs, such as independence, feeling accepted by their peers, and partaking in healthy, intimate relationships.

## Limitations of the Study

The majority of the limitations in this study are related to the challenges faced during the youth recruitment process, which proved to be a much more difficult endeavor than originally anticipated. Some of these included a very limited pool of participants who fit the youth inclusion criteria, issues with my own transportation and accessibility to participants living in rural areas, the availability of the participants, discomfort surrounding the discussion of sexuality and poor communication between staff at the CRC and potential participants regarding the study. As a result, the age-range and gender diversity of the youth participants was somewhat limited. Ideally this study aimed to include five to six youth participants of equal genders; however, the study ended up including four youth participants, three females and one male. It would have been beneficial to have had an equal number of boys and girls participating in the study, since having only one male youth made it difficult to explore and draw conclusions about sexuality and disability issues based on gender. The issue of gender imbalance also applied to the parent participants, since only one out of the four parents I interviewed was male. However, this type of imbalance was anticipated because a large proportion of the parents who attend clinics with their children at the CRC are mothers.

Another limitation of this study was that it only included adolescents with physical disabilities who were fully capable of verbally expressing their opinion on sexuality and other issues explored in this study. For many youth who have additional developmental, cognitive or sensory impairments, issues of sexuality are rarely addressed, especially when adolescents are unable to have a verbal conversation. Also, due to the sensitive nature of this study, some of the youth who were approached to participate felt embarrassed, ashamed or uncomfortable talking about such personal issues. I believe this may have discouraged some of the shyer, more reserved youth from participating in the study, which may have limited the diversity of the information collected. However, by triangulating the data and incorporating parents' and health professionals' viewpoints into the project, I was able to collect very detailed information from a variety of perspectives that informed my understanding of the challenges related to low self-esteem, social isolation and sexual inexperience among these youth.

This study involved families who were already well-connected with the CRC and many other disability services within their community. This may have posed a limitation, since it was unlikely that I was able to learn about the experience of those who may be marginalized from medical and social support services. As a result, the findings of this study may not necessarily represent the experience of all youth living with physical disabilities. Fortunately, this narrative inquiry was not concerned with generalizability and instead focused on the uniqueness of the individuals' lived experiences. This type of information is required in order to generate essential base line data which can be used to create much needed resources and services, as well as provide a foundation for more research in the area of adolescent sexuality and physical disability to be conducted.

## Recommendations

There are several recommendations that came out of this study with respect to the development of resources and services aimed at improving sex education for adolescents living with physical disabilities. While some of these ideas came directly from the participants, others were formulated after identifying some of the shortcomings and knowledge gaps that are present in the resources and services currently available to these youth. The following recommendations are aimed at improving the effectiveness, delivery and uptake of sex education information for youth with physical disabilities, focusing on programs for youth, modifications to formal sex education and curriculum, increased resources for parents and improved training for health professionals.

### *Youth*

The three main recommendations for strategies aimed at improving sex education among youth with physical disabilities are the development of TIP style programs, a reinstatement of specialty teen clinics at pediatric rehabilitation centres and the development of safe and accessible online resources that give adolescents with physical disabilities the opportunity to anonymously obtain credible information related to sensitive yet important issues facing youth.

Several of the youth participants were aware of or had participated in "The Independence Program" (TIP) in Toronto, which is a three week residential program that teaches young adults with physical disabilities over the age of 18, the skills and knowledge needed to help them lead more independent lives. TIP spends an entire day focusing on sexuality and relationships, using frank yet humorous discussions and disability-specific information to address many issues related to sexuality and disability which are often not covered in conventional sex education classes, such as how to work with attendants, modified positioning and the use of sex toys and other assistive devices. The youth who participated in this program felt as though the comfortable, non-judgmental approach taken by TIP was the perfect model for providing "real life" sex education to youth with physical disabilities. It would be beneficial to expand TIP into other cities across Canada and create programs targeted at the 14-18 age group, in order to foster independence and provide effective sex education during these important adolescent years. Possible variations on this program targeted at younger adolescents could be the introduction of shorter week-long residential programs, or possibly day workshops. This modified type of programming would be beneficial for youth who have a greater difficulty being away from their family or who require more intensive medical assistance by still allowing them the opportunity to learn the necessary skills and information needed to live more independently, just in smaller, gentler stages compared to the traditional TIP program.

Both the parents and health professionals believed that the CRC should bring back the specialized teen clinics which were originally created for youth with spina bifida, but had recently been cancelled due to a lack of appropriate staff. The teen clinic approach has been recommended as a highly successful solution to the barriers many youth and health professionals face surrounding the ability to speak comfortably about sexuality issues in a health care setting. The teen clinic discourages parents from being present during the youth's appointment, allowing the health professional to freely ask questions about the adolescent's relationship and sexual history without the fear or discomfort of having a parent or guardian present. It would also be beneficial to expand the teen clinic to include a wide range of physical disabilities, instead of only being limited to youth with spina bifida.

A final recommendation for improving sex education resources and services for adolescents with physical disabilities is the development of an accessible website which would provide these youth with credible, relevant and disability specific information about sexuality, sexual health, dating, LGBT issues, self-esteem, depression, peer pressure and other "teen" issues that may be difficult to discuss. This website could model itself after scarleteen.com, a popular online sex education resource which uses health professionals, as well as specially selected youth mentors to continually monitor the site, answer youth's questions, provide advice and ensure that the material found on the website is factual, practical and non-discriminatory. Creating a website such as this would allow youth with physical disabilities a safe and anonymous outlet to ask personal questions, receive information about the topics and issues that are most important to them and read about other youth's experiences, in order to understand that they are not the only one dealing with the challenges of navigating adolescence as a person living with a physical disability.

### *Schools*

Before I began thinking about how my data could help inform sex education within the context of the school system, namely with respect to the current curricula available, I familiarized myself with the sex education curriculum that is offered to students in Ontario, spoke to sex educators and curriculum advisors, as well as reflected on my own experience as a volunteer sex educator in the high schools.

One possible way to improve sex education for youth with physical disabilities is to incorporate information about people with disabilities into the mainstream curriculum. This would not only help students who have disabilities feel as though they are accepted as sexual beings within the school environment, it would also help to enlighten the able bodied students that people living with disabilities are capable of engaging in sexual and intimate relationships. Discussing sexuality and disability issues with able bodied adolescents can also be an effective way of breaking down some of the negative stigmas and misconceptions that relate to this topic.

Another recommendation for improving the accessibility and relevancy of sex education in schools is by incorporating general changes to the mainstream curriculum which put a greater focus on sexuality as a continuum, meaning that there are a wide range of possibilities for experiencing and expressing one's sexuality. This could include explaining to students that engaging in heterosexual intercourse is not the only way one can be considered a sexual person, which might help to increase understanding and tolerance towards people with disabilities, as well as other individuals belonging to sexual minority groups. Talking about sexuality and disability can help bring awareness to the fact that people with physical disabilities have the same sexual urges, needs and responsibilities as the rest of society. It is also recommended that the sex education curriculum focus less on the anatomy and fertilization aspects of the course, as these are also taught in detail during science class. Instead the curriculum should place a greater emphasis on issues that are more immediately relevant to an adolescent at this time, such as relationships, communication, accessing and using birth control effectively, emotional and practical consequences of sex, how to know when you are ready, online safety, media and social influences, personal awareness and coercion, peer pressure and body image.

A final recommendation for schools to consider is to ensure that students with physical disabilities receive the same amount of comprehensive sex education as their able bodied peers. Adolescents with physical disabilities are often at risk of receiving inadequate sex education due to the fact that many of them are exempt from physical education class in high school or are frequently absent from school due to illness, surgery or specialist appointments. If these youth miss their regularly scheduled sex education classes, schools should provide them with alternate arrangements, such as placing them in a different sex education class, bringing in a public health nurse or other specially trained health professional, or offering printed and online resources to ensure that they are not lacking in any of the necessary knowledge or skills needed to make informed choices related to their sexual health and behavior.

### *Parents*

The parental participants in this study recommended that specialized parent workshops be provided at the CRC, which would offer advice and strategies about how to speak to children with disabilities about sex, encourage parents to discuss what it means to be sexual and reassure their children that they can find a partner, are able to have sex, and can one day become parents if they chose to do so. These workshops could take on many different forms, including lectures from experts in the field, informal group discussions, question and answer periods and role play activities. These types of group activities have been recommended by the parent participants because they believe that parents can benefit from hearing the stories and challenges of others, allowing them to feel as though they are not alone. This type of group setting also helps to emphasize the idea that youth with physical disabilities are sexual beings and require the same good quality, comprehensive sex education as any other able bodied youth.

Along with interactive group activities, parents should also have the opportunity to take home up to date, relevant information related to sexuality and physical disability, in order to help them address any questions or issues that may arise with their adolescent. This can be easily accomplished by creating brochures, pamphlets and information guides available for parents to anonymously access at rehabilitation centres and other disability services. A website similar to the one recommended for youth may be beneficial for parents as a means of asking anonymous questions, gaining expert advice and sharing experiences with other parents on the challenges they have faced while dealing with sexuality issues affecting their adolescent.

Finally, it may be beneficial for parents to have one on one time with their adolescents' health professional, in order to ask any questions about their teen's sexual capabilities which they may be embarrassed or uncomfortable asking when the adolescent is in the room. These interactions could occur directly before or after the child's scheduled appointment, as this would not require any additional travelling, time off work or other inconveniences that parents often mention as barriers for accessing sex education information for their children who have disabilities.

### *Health Professionals*

There are several recommendations for improving the knowledge, comfort and delivery of sexuality education among health professional working with youth who have physical disabilities. An issue that came up repeatedly during the focus group with health professionals was the lack of adequate training surrounding sexuality and physical disability issues available to current and future health professionals. The focus group participants recommended that lessons, workshops, case studies and practicum opportunities be offered to individuals currently training to become health professionals, particularly for those who will be working with young people who have disabilities. It is also important to provide continuing education and training for health professionals currently working in the field, in the form of online training modules, bringing guest speakers into the workplace and providing health professionals with resources that they can access if a question or issue arises that they need more information about. Sex education information and training for health professionals should focus on a number of areas including: the current best practices for delivering sex education, skills for increasing comfort and reducing embarrassment as well as information on protection from inappropriate behaviour allegations, an issue that many of the health professionals in this study were particularly concerned about when discussing sexuality issues with their young clients.

It is also recommended that health professionals try to incorporate sex education into their regular clinical practice, by finding ways to link common issues facing youth with physical disabilities with lessons on sexuality and sexual health. For example, people with spina bifida often have latex allergies, so while discussing the health risks of this type of allergy, the health practitioner could also bring up the use of non-latex condoms. This would help to validate the youths' position as sexual beings while providing information with which to protect themselves in a sexual relationship.

## Implications for Future Research

The knowledge gained from this study in terms of the significant impact that issues such as sexuality, sex education, reproductive choices, dating, acceptance, independence, body image and self-esteem have on adolescents with physical disabilities, present a need for further exploration into the lives of these youth. Areas of future research might include dating practices among youth with physical disabilities, sexual exploration and masturbation, reproductive choice and capabilities, disability and body image and the possible origins and solutions to disability related stigma and the myth of asexuality.

Issues that frequently came up during this study were the challenges, fears and uncertainties related to adolescents with physical disabilities starting to form relationships and explore the world of dating. Dating is a very important and complex aspect of sexual and identity development during adolescence, yet very little is known about these types of relationships among young people living with physical disabilities (Howland & Rintala, 2001). What is known is that these adolescents face a particularly difficult time with dating during high school, due to the stigma by association that often faces future dating partners of these youth, and thus limiting their pool of potential mates (Goldstein & Johnson, 1997). Exploring dating practices among young people with physical disabilities would make for an interesting and complex area of study for future research, since this in-depth issue encompasses a wide variety of other topics including relationships, self-esteem, sexuality, self-confidence and societal values.

Sexual exploration and masturbation are topics that came up several times throughout the study but were rarely discussed in detail, assumingly due to the immense discomfort many of the participants, both with and without disabilities, felt about this issue. As a result of the widespread societal taboo surrounding masturbation and other forms of sexual exploration, research on this topic is extremely limited, particularly among youth with disabilities. Since discovering one's body and sexual function can be a particular challenge for those requiring assistance with mobility and personal care, conducting research in this area would be highly beneficial for people living with physical disabilities. Studies could look at challenges with privacy, the use of sex toys and other assistive devices, sexual fantasies, attendant issues, adapted techniques, positioning and other areas which could help people with physical disabilities discover more effective ways of exploring their sexuality and improve the satisfaction of their sexual experiences.

The topics which came up in almost every interview included body image, reproductive choices, the myth of asexuality and disability-related stigma, all of which were clearly significant in the youth's lives; however, they also seem to be issues that were not well-researched and largely misunderstood by the general population.

All of the youth spoke about the challenges they faced with body image, yet they felt this was an issue which few able bodied people realized was significant in their lives. The youth felt that most people believed adolescents with physical disabilities were only worried about issues related to their disability and were not affected by the general challenges faced by all adolescents, a misconception the youth participants strongly objected to. These findings warrant the need for more research focusing on how these youth feel about their bodies, the barriers and challenges they face in reaching their ideal body size, how their experience with body image and acceptance differs from able bodied youth, and what kind of impact the media has on body image among youth with physical disabilities.

An issue where all of the female youth participants seemed to share very similar opinions on was the decision of whether or not they wanted to have biological children. All of the girls had made the decision that they did not want to have biological children and said they would instead like to pursue adoption. There was a common thread throughout many of the interviews which related to the dominant discourse that people with disabilities are discouraged from being in relationships and having a family. Since the topic of reproduction and parenthood was rarely discussed with the youth by their health professionals, many of the female youth in particular were largely unaware about their reproductive capabilities and often internalized the societal belief that they are unable to or discouraged from having a family of their own. This is a particularly important area for future research, since little is known about the reproductive knowledge and choices among adolescents with physical disabilities.

The myth of asexuality and disability-related stigma were issues that all of the participants brought up during the study. Everyone felt that this myth, along with other negative stigma surrounding disability, were highly prevalent in our culture; however, many of the participants were also skeptical about the possibility that these issues could ever be completely absent from society. Conducting research which focuses on why disability-related stigma and the myth of asexuality are still so prevalent, as well as exploring effective methods for breaking down these negative societal misconceptions would be a highly positive step towards people with physical disabilities being treated as desirable, capable and equal members of society.

## Conclusion

The main findings from this study relate to the original aim of the research project, which was to explore the experience of learning about sexuality for adolescents with physical disabilities, and in turn, how this experience influences the way they view themselves as sexual beings. A secondary aim of the research project looked at the resources that should be made available in order to improve the availability, relevancy and uptake of sex education information for youth with physical disabilities and their families.

Firstly, it was found that adolescents with physical disabilities require a combination of comprehensive sex education from school, specialized information from health professionals and informal sex education from family and peers in order to gain the knowledge and skills needed to understand their own sexual capabilities and make informed decisions about their sexual health and intimate relationships. However, they rarely receive disability-specific sexuality information, particularly from their health professionals, leading to possible uncertainties and insecurities related to the youth's sexual and reproductive capabilities.

Secondly, in this study it was noted that body image and self-esteem play a significant role in the lives of youth with physical disabilities and how they see themselves as sexual beings and potential dating partners. Unfortunately, these issues are generally not discussed with the youth and often overlooked by the able-bodied community, who may not realize that these adolescents face the same insecurities and challenges as their peers who do not have disabilities, especially in terms of their desire to feel attractive, desirable and measure up to the cultural ideals of beauty and body image set forth by the media.

Thirdly, it was established that among youth with physical disabilities, fitting in and being accepted by their peers was one of the most important aspects of their lives during high school. In this study, the desire to fit in with their peers tended to become less of an issue as the youth moved on to post-secondary education and became more confident and accepting of who they were and less concerned with how other people viewed them .

Lastly, this study found that the majority of the challenges and barriers these youth faced in terms of accessing sexual health information, finding an intimate partner, feeling accepted, developing confidence and understanding their own sexual identity were largely the result of the widespread myth of asexuality and other negative stigma surrounding the perceptions and expectations society has towards people living with physical disabilities.

Along with collecting data that are directly related to my original research questions, the information gathered as well as the research process itself afforded me the opportunity to reflect upon the issues of adolescence and sexuality more generally.

It is evident that some of the fundamental aspects of adolescence, such as forming an identity, gaining independence and feeling accepted are universal features among this population, regardless of their social status or physical capabilities. The stereotypical representation of adolescence as a time of rebellion, defiance and angst-ridden mood swings is often exaggerated in the media and in our social imagination. In reality, most adolescents and their families come through this stage of development relatively easily and unscathed (Holmbeck, 1996). However, there seems to be a different stereotype operating among parents of youth with physical disabilities, who often believe that their children are somehow protected against the "devious" adolescent behaviour that so many parents of able bodied teens nervously anticipate during this time (Buchanan & Holmbeck, 1998; Suris et al., 1996). This may be due to the widespread societal misconception that people with disabilities are thought to be innocent, naïve and childlike. This study found that many of the youth participants had experimented with, or at least been offered the chance to experiment with risky behaviours such as drinking alcohol or smoking marijuana, which demonstrate that all adolescents have the potential to display some degree of the "typical" behaviour associated with being a teenager, regardless of how innocent their parents believe them to be.

This study also contributes to our understanding of sexuality in several ways, including the differentiation between sex and sexuality, what it means to be a sexual citizen, and the way in which societal myths and misconceptions can affect a person's sexual identity and overall sense of self. An important finding from this study relates to the way in which these youth viewed sexuality as something related more to the biological and physical components of sex than to the broader social and interpersonal aspects of sexuality. This was evident in the fact that when the youth were asked about sexuality, the areas of reproduction, intercourse and fertility were discussed several times throughout the interviews, yet the topics of pleasure, touch and intimacy were hardly ever brought up. Another significant observation from this study relates to the fact that the majority of the youth spoke about sexuality in a way that was very separate from their own lives, as if they could not relate to this idea on a personal level and discussed sexuality mostly in terms of general definitions and clichés. While this may be due to specifics about the youth, such as their disability or a lack of sexual experience to draw from, these findings do provide meaningful insight into the larger, general realm of adolescent sexuality, by exploring how one begins to understand, discover and develop ownership over their own sexuality and sexuality identity. The findings from this study also allow us to expand the notion of what it means to be a sexual citizen within society by providing data to support the idea that everybody is a sexual being and deserves to be treated as one, regardless of their physical limitations. This belief was expressed by every participant numerous times throughout the study, which helps to emphasize the importance of sexuality as a fundamental aspect of being human, rather than the traditional notion that commonly associates sexuality with attractiveness, desirability and stereotypical gender roles. Throughout the study the participants also discussed the pervasive myth related to people with disabilities being viewed as asexual and how destructive this can be towards the sexual identity and self-esteem of this population. Addressing the myth of asexuality will not only help to decrease the negative stereotypes surrounding sexuality and disability, it can also bring awareness to other minority groups that are often affected by this myth, such as the elderly, stroke and cancer survivors, those suffering from chronic disease, and people living with mental illness.

There are many practical and applied outcomes relating to the information generated in this study, including program and resource development aimed at improving sexuality and disability training for parents, educators and allied health professionals. These include guidebooks, workshops and support services on how to discuss sexuality with children and youth who have physical limitations, along with interactive web-based programs that are relevant, informative and geared towards the needs of these young people. Lastly, this information could be used to help guide future policy recommendations within the education and public health sectors in order to ensure that sexual health information and services are accessible and widely available to all citizens, regardless of age, location or level of ability.

While society has begun to adopt more accepting, ability-based perspectives of individuals living with disabilities over the years, little has changed in relation to people's attitudes towards sexuality and disability since the 1960's, when Goffman (1963) first wrote about the idea of a negative perception or stigma towards those who looked, behaved or functioned differently from the majority of the population. Goffman's theory employs a particular framing of the term "normal" which is used to refer to those who do not embody the undesirable or deviant attributes he associated with "the other" (Shuttleworth & Kasnitz, 2004). According to this theory, individuals with physical disabilities were seen as abnormal, causing this group to be stigmatized and marginalized from the rest of society. From the findings in the current research study, it is evident that youth with physical disabilities still feel as though they are perceived to be abnormal, which is reflected in the widespread desire to be "normal" so they can fit in and be accepted by their able bodied peers. It is also evident that the different types of stigma Goffman described almost fifty years ago are still very apparent today, with the participants in this study describing the prevalence of several types of stigma operating simultaneously. The participants discussed the stigma that people with physical disabilities face because their bodies physically do not look or function the way that able-bodied society believes they should, which Goffman described as "abominations of the body". The participants also discussed the stigma associated with people who have disabilities engaging in sexual relationships, an aspect of Goffman's second type of stigma known as "blemishes of individual character." As is the case with many stereotyped or misunderstood groups in society, the stigma that is attached to a certain aspect or type of disability can often be placed on the entire population, also known as "tribal stigma" "that equally contaminates all members of a family (or group)" (Goffman, 1963, p.4). The youth participants described this situation numerous times throughout the interviews, expressing the frustration and anger they felt when people assumed that because they used a wheelchair they also had low intelligence, could not see or hear, and were completely dependent on others.

These multiple forms of stigma related to sexuality issues among people with disabilities can be attributed to the prominent societal misconceptions that assume this population to be asexual, naïve, dependent and incapable of intelligent thought. These negative views and low expectations are expressed to youth with physical disabilities through adults communicating with them in a childish or patronizing manner, through the absence of discussion about body image, dating and sexuality, as well as through the general discomfort and awkwardness that is often expressed by educators and health professionals when they are faced with questions related to sexuality among this population. The prevalence of these negative stigmas creates educational, as well as social barriers for youth with physical disabilities to easily and comfortably access information regarding topics that are already deemed to be taboo, even for able bodied youth, such as sexual function, exploration, masturbation, sexual identity, understanding desire and sexual expression.

The title of this thesis refers to the metaphor of the ‘elephant in the room’, which has been used in popular culture to describe an issue that people choose to disregard or overlook, even though it is as obvious and difficult to ignore as a massive elephant standing in the middle of a room. Patrick, the father of two children with severe physical limitations, used this metaphor in his interview to describe the discomfort and awkwardness parents, educators and health professionals often feel towards acknowledging the sexual needs of youth who have physical disabilities. This discomfort became very apparent to me during my recruitment process when I went into speak to a mother of two teenaged sons, both of whom had muscular dystrophy. As I explained what the study was about to her and her sons, she pointed to one of them and said “well he’s not interested in talking about any of that stuff” and then pointed to her other son and said “he tries to ask me questions about it, but I don’t answer them, I just don’t know what to say.”

Developing and conducting this study has extended my understanding of several issues including sexuality, being a teenager, living with a disability, dating, acceptance, self-esteem, perseverance and the way in which society truly thinks about and treats people who are different. From speaking to people with disabilities during the development of my study to meeting with the youth participants and hearing about their lives, their struggles, their crushes, their angst, their goals and their hopes for the future, I have not only come out of this research experience with a much richer, more intimate understanding of the topic of sexuality among youth with physical disabilities, I have also come to realize that I have much more work to do in this area. Participating in this study has also taught me to appreciate the complexity or "messiness" of the research process, since it was the uncertainties, digressions and surprises inherent within qualitative research that yielded some of the most poignant and meaningful findings from this study. My passion for this topic has deepened tremendously as a result of participating in this study and even though I have already gained a great deal of useful, meaningful knowledge, the more I speak to people within the disability community and understand how immense the need for more acceptance and acknowledgement of people with disabilities as equal, capable sexual beings really is, I know that this thesis is only the beginning of the work that must continue to be done in this area.

In order to ensure that youth with physical disabilities are viewed as sexual beings and entitled to the same sexual health education and services as the rest of the able bodied population, strategies must first be developed in order to break down the widespread social stigmas that currently dominate approaches and ideologies relating to sexuality and disability among this population. This begins by creating and sharing relevant and meaningful information, such as the knowledge gained from this study, with the community both academic and public. Enlightening others about the experience of sexuality and sex education for adolescents with physical disabilities not only helps to open up lines of communication regarding sensitive topics such as sexual exploration, self-esteem, inclusion, the importance of intimacy and the need for independence, it also legitimizes the very true but often ignored fact that people with disabilities are sexual citizens and should be treated as such.

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# Appendix A: University of Western Ontario Ethics Approval

**Western**

**Office of Research Ethics**

The University of Western Ontario
Room 4180 Support Services Building, London, ON, Canada N6A 5C1
Telephone: (519) 661-3036 Fax: (519) 850-2466 Email: ethics@uwo.ca
Website: www.uwo.ca/research/ethics

## Use of Human Subjects - Ethics Approval Notice

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**Principal Investigator:** Dr. T. Orchard
**Review Number:** 17186S
**Review Level:** Full Board
**Review Date:** July 09, 2010
**Approved Local # of Participants:** 19
**Protocol Title:** Understanding Sexuality among Adolescents with Physical Disabilities: A Narrative Inquiry
**Department and Institution:** Health Education, University of Western Ontario
**Sponsor:** OGS / CIHR
**Ethics Approval Date:** August 17, 2010
**Expiry Date:** July 31, 2011
**Documents Reviewed and Approved:** UWO Protocol, Letter of Information and Consent (Narrative Interview), Letter of Information and Consent (Focus Group), Information Letter (families). Ad.

**Documents Received for Information:**

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This is to notify you that The University of Western Ontario Research Ethics Board for Non-Medical Research Involving Human Subjects (NMREB) which is organized and operates according to the Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans and the applicable laws and regulations of Ontario has granted approval to the above named research study on the approval date noted above.

This approval shall remain valid until the expiry date noted above assuming timely and acceptable responses to the NMREB's periodic requests for surveillance and monitoring information. If you require an updated approval notice prior to that time you must request it using the UWO Updated Approval Request Form.

During the course of the research, no deviations from, or changes to, the study or consent form may be initiated without prior written approval from the NMREB except when necessary to eliminate immediate hazards to the subject or when the change(s) involve only logistical or administrative aspects of the study (e.g. change of monitor, telephone number). Expedited review of minor change(s) in ongoing studies will be considered. Subjects must receive a copy of the signed information/consent documentation.

Investigators must promptly also report to the NMREB:

a) changes increasing the risk to the participant(s) and/or affecting significantly the conduct of the study;
b) all adverse and unexpected experiences or events that are both serious and unexpected;
c) new information that may adversely affect the safety of the subjects or the conduct of the study.

If these changes/adverse events require a change to the information/consent documentation, and/or recruitment advertisement, the newly revised information/consent documentation, and/or advertisement, must be submitted to this office for approval.

Members of the NMREB who are named as investigators in research studies, or declare a conflict of interest, do not participate in discussion related to, nor vote on, such studies when they are presented to the NMREB.

Chair of NMREB: Dr. Riley Hinson
FDA Ref. #: IRB 00000941

| **Ethics Officer to Contact for Further Information** | | | |
|---|---|---|---|
| ☑ Grace Kelly<br>(grace.kelly@uwo.ca) | ☐ Janice Sutherland<br>(jsutherl@uwo.ca) | ☐ Elizabeth Wambolt<br>(ewambolt@uwo.ca) | ☐ Denise Grafton<br>(dgrafton@uwo.ca) |

*This is an official document. Please retain the original in your files.*

cc: ORE File

## Appendix B: Children's Rehabilitation Centre Ethics Approval

15 June 2010

Ms. Lauri East
MSc Candidate
The University of Western Ontario
Health and Rehabilitation Sciences, Child and Youth Field
Elborn College
1201 Western Road, Room 2539
London, Ontario, N6H 1H1

Dear Ms. East,

As you know, on 14 June 2010, Research Advisory Committee (RAC) reviewed and approved your above-named project. Congratulations! The Committee felt that the project investigates an important topic for clients with disabilities and their families. **Once the Research Program has received a copy of an ethics approval letter for your study from the University of Western Ontario, you may conta and begin recruitment of study participants.**

The Committee has provided some feedback for your consideration as you conduct your project.

There are two other qualitative studies that will be getting underway at at about the same time as your study. The Committee requests that you inquire if clients are already participating in another qualitative study prior to their acceptance to be involved in your study. It is not a requirement that they only participate in one study at a time, but the Committee feels that it is important to let clients know that, should they choose to be involved in two qualitative studies simultaneously, they could perhaps find this somewhat onerous.

The Committee felt it was unclear in the proposal whether the study was primarily about exploring youths' perceptions about their sexuality or about how effectively they received information about sexuality. It was thought that your objectives should be clarified. The Committee also thought that the second aim of the study (i.e., to identify the types of resources and services that are needed to help develop sexuality education and knowledge) might be too great an expectation, given the study's sample size and diversity.

The Committee thought that involving 5 to 6 adolescents from at least 4 diagnostic groups would not allow any generalizations to be made as a result of this study. Members also questioned including both youth with progressive (e.g., Muscular Dystrophy, Spinal Muscular Atrophy) and non-progressive (e.g., Spina Bifida, Cerebral Palsy) conditions. It was suggested that you might want to focus on either non-progressive or progressive conditions to obtain relevant information for that specific group. For example, some of the genetic diseases have fertility issues and some have transmission concerns that may alter ideas about sexuality. It was also suggested that asking a question about whether their specific disease makes a difference as to how they think about sexuality, might help bring out themes.

RAC members also recommended using 21 years as the cut off age for the youth completing interviews. There are 21 year olds seen at The Committee also felt that parents might prefer to participate in individual interviews rather than focus groups, especially when discussing sexuality. Members suggested offering the two options and comparing the themes that emerge in each, to make sure you have the widest range of themes.

Members of the RAC also would like to point out that if the study eventually includes teachers, you would need to seek approval for your study from the relevant Boards of Education. Finally, the Committee recommended that you speak with I about the possibility of a social worker consulting with any participant who may become distressed by the study interview.

The Committee extends their best wishes for a successful project!

Yours sincerely,

Researcher, Research Program
Chair, Research Advisory Committee

Cc: . Director, Privacy Officer
Director, (
Physiotherapist, Clinic

## Appendix C:

# Letter of Information and Consent for Participation in Narrative Interviews

**TITLE OF THE RESEARCH STUDY:** ***Understanding Sexuality among Adolescents with Physical Disabilities***

**Researcher:** Lauri East, MSc (candidate), Health and Rehabilitation Sciences – Child and Youth Health, University of Western Ontario

**Supervisor PI:** Treena Orchard, PhD, Assistant Professor, School of Health Studies, University of Western Ontario

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The pronouns "you" and "your" in this letter should be read as referring to the participant and not the parent and/or guardian who is signing the consent form for the participant.

**ABOUT THE PROJECT:** This study aims to explore how adolescents with physical disabilities learn about sexuality and how this experience influences the way they see themselves as sexual beings. We are also interested in looking at what types of resources and services should be developed in order to improve sexuality education for these youth. Narrative interviews, which are open ended interviews that aim to understand a person's life story and how they make sense of the world, will be conducted with adolescents living with a physical disability, along with two focus groups, one involving parents/guardians of youth who have a physical disability and the other involving teachers, physicians and allied health professionals who are involved in the delivery of sexuality education.

**PURPOSE OF THE NARRATIVE INTERVIEWS:** Narrative interviews will be conducted in order to gain an in-depth understanding of what learning about sexuality is like from the point of view of an adolescent living with a physical disability. These interviews will allow you an opportunity to share your thoughts, feelings and opinions about a variety of topics related to adolescence and sexuality.

**PARTICIPANTS:** Adolescents between the ages of 14-19 who have a physical disability that requires the use of a wheelchair, and who do not have any major cognitive or speech impairments, are invited to participate.

**WHAT WILL HAPPEN?**

If you agree to participate, your involvement in this study will consist of 2 narrative interviews. Each interview will last approximately 1 hour.

**First Interview:** You will be asked some open ended questions about yourself. These will include questions about being an adolescent, how you have learnt about sexuality, what that experience has been like for you and what kinds of sex education information and resources you think should be made available.

**Second Interview:** You will be shown a transcript of the first interview and asked if you want to remove or change anything. Then, you will be asked more open ended questions about some of the topics that came up in the first interview.

The interviews will be conducted in a private space either at the CRC, a local community centre, or at your home, depending on what you feel most comfortable with. The interviews will take place during a mutually agreed upon day and time, not during school hours.

**POTENTIAL RISKS AND BENEFITS TO PARTICPANTS AND/OR SOCIETY:** Discussing sexuality is a topic that may not be comfortable for some participants. You may choose not to answer any questions that they do not feel comfortable with. Adolescents with physical disabilities are a group who may be at a higher risk for issues such as sexual abuse and social isolation. These are issues that could arise during the course of the study which may cause emotional and psychological distress. The name and contact information of a CRC social worker will be provided to all the adolescent participants, if you feel the need to speak to someone about the topics discussed during the interviews. You will not benefit directly from participating in this study. By participating in this study you may help us understand some of the issues and challenges related to learning about sexuality for youth who have a physical disability. This information can be used to develop resources and services aimed at improving the access, delivery and uptake of sexuality education for this population.

**CONFIDENTIALITY:** The members of this research team are committed to ensuring that any information you provide during this study will be kept confidential. The narrative interviews will be audio taped for transcription purposes. Any identifying markers about you will be removed from the transcript. Your research records will be stored in a locked cabinet in a secure office in Elborn College at The University of Western Ontario and will be kept for 7 years and then destroyed. Only the investigator and supervisor of this study will have access to your information. Should the results of this study be published, neither your name nor any other identifying information will be used. Parents/Guardians will not receive any information on your child's individual results from this study. By law, any disclosure of abuse by a minor during the interview process must be reported to the appropriate authorities.

**PARTICIPATION AND WITHDRAWL:** Your participation in this study is voluntary. You may refuse to participate, refuse to answer any questions or withdraw from the study at any time with no effect on your future care or involvement with the CRC.

You will be receiving a $15 Chapters gift card to thank you for your participation. If needed, transportation costs, to a maximum of $10 per visit will also be covered.

**QUESTIONS :** If you are interested in participating or have any questions or concerns about this study, please feel free to contact Lauri East at (xxx) xxx-xxxx or Treena Orchard at (xxx) xxx-xxxx. For questions related to the CRC you may contact

If you have any questions about your rights as a research participant or the conduct of this study you may contact the Office of Research Ethics, University of Western Ontario email ethics@uwo.ca.

You do not waive any legal rights by signing this consent form.

Thank you for taking the time to read this, this letter is yours to keep for future reference.

## CONSENT AND SIGNATURES – Narrative Interviews

**Title of Study:** ***Understanding Sexuality among Adolescents with Physical Disabilities: A Narrative Inquiry***

**Researcher:** Lauri East, MSc (candidate), Health and Rehabilitation Sciences: Child and Youth Health, University of Western Ontario

**Supervisor PI:** Treena Orchard, PhD. Assistant Professor, School of Health Studies, University of Western Ontario

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I have read the Letter of Information, have had the nature of the study explained to me and I agree to participate. All questions have been answered to my satisfaction.

Name of Youth Participant (Please Print)

Name of Parent/Guardian (Please Print)

Signature of Parent/Guardian

Date (dd/mm/yyyy)

Name of person obtaining consent

Signature of person obtaining consent

Date (dd/mm/yyyy)

Appendix D:

# Letter of Information and Consent for Participation in Focus Groups

**TITLE OF THE RESEARCH STUDY:** ***Understanding Sexuality among Adolescents with Physical Disabilities***

**Researcher:** Lauri East, MSc (candidate), Health and Rehabilitation Science – Child and Youth Health, University of Western Ontario

**Supervisor PI:** Treena Orchard, PhD, Assistant Professor, School of Health Studies, University of Western Ontario

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**ABOUT THE PROJECT:** This study aims to explore how adolescents with physical disabilities learn about sexuality and how this experience influences the way they see themselves as sexual beings. We are also interested in looking at what types of resources and services should be developed in order to improve sexuality education for these youth. Narrative interviews will be conducted with adolescents living with a physical disability, along with two focus groups, one involving parents/guardians of youth who have a physical disability and the other involving teachers, physicians and allied health professionals who are involved in the delivery of sexuality education.

**PURPOSE OF THE FOCUS GROUPS:** Focus groups will be held in order to give you the opportunity to share your thoughts, opinions and ideas about the types of services and resources that should be made available in order to improve sexuality education for adolescents with physical disabilities. Information from the focus groups will help us gain a deeper understanding of the types of resources and services that are needed in order to overcome some of the challenges faced by sexuality educators.

**PARTICIPANTS:** For the focus groups we are looking for:

a) Parents/guardians of youth age 10-21 who have a physical disability

b) Professionals who work with adolescents who have physical disabilities and are involved in the delivery of sexuality education, including teachers, nurses, physicians, occupational therapists, physiotherapists, recreational therapists and social workers.

**WHAT WILL HAPPEN?**

If you agree to participate, your involvement in this study will consist of 1 focus group, made up of 4-6 other participants. The focus group will last approximately 90 minutes and will be audio taped for transcription purposes. During the focus group you will have the opportunity to share your thoughts on a variety of questions related to sexuality education among adolescents with physical disabilities.

The focus group for parents will be held either in the evening or on the weekend, while the focus group for professionals will be held during working hours with approval from your director or services leader at the CRC.

Complimentary refreshments will be provided during the focus groups. If needed, transportation/parking costs to a maximum of $10 will also be covered for all visitors to the CRC.

**POTENTIAL RISKS AND BENEFITS TO PARTICPANTS AND/OR SOCIETY:** Discussing sexuality is a topic that may not be comfortable for some participants. You may choose not to answer any questions that they do not feel comfortable with. The name and contact information of a CRC social worker will be provided to all the parent/guardian participants, if you feel the need to speak to someone about the topics discussed during the focus groups or if you feel any emotional or psychological distress as a result of participating in this study. For the professional participants, you will be able to contact the CRC employee assistance program (EAP) for any additional support you may need. You will not benefit directly from participating in this study. By participating in this study you may help us understand some of the issues and challenges related to learning about sexuality for youth who have physical disability. This information can be used to develop resources and services aimed at improving the access, delivery and uptake of sexuality education for this population.

**CONFIDENTIALITY:** The members of this research team are committed to ensuring that any information you provide during this study will be kept confidential. The focus groups will be audio taped for transcription purposes. Any identifying markers about you will be removed from the transcript. Your research records will be stored in a locked cabinet in a secure office in Elborn College at The University of Western Ontario and will be kept for 7 years and then destroyed. Only the investigator and supervisor of this study will have access to your information. Should the results of this study be published, neither your name nor any other identifying information will be used. You will not receive any information on your child/client's individual results from this study.

Focus group members are asked to keep everything they hear confidential and not to discuss it outside of the meeting. However, it cannot be guaranteed that group members will maintain confidentiality.

**PARTICIPATION AND WITHDRAWL:** Your participation in this study is voluntary. You may refuse to participate, refuse to answer any questions or withdraw from the study at any time with no effect on your child's future care or your involvement with the CRC.

**QUESTIONS :** If you have any questions or concerns about this study, please feel free to contact Lauri East at (xxx) xxx-xxxx, or Treena Orchard at (xxx) xxx-xxxx or email. For questions related to CRC you may contact

If you have any questions about your rights as a research participant or the conduct of this study you may contact the Office of Research Ethics, University of Western Ontario, email ethics@uwo.ca.

You do not waive any legal rights by signing this consent form.

Thank you for taking the time to read this, this letter is yours to keep for future reference.

## CONSENT AND SIGNATURES – Focus Groups

**Title of Study:** ***Understanding Sexuality among Adolescents with Physical Disabilities: A Narrative Inquiry***

**Researcher:** Lauri East, MSc (candidate), Health and Rehabilitation Science – Child and Youth Health, University of Western Ontario

**Supervisor PI:** Treena Orchard, PhD, Assistant Professor, School of Health Studies, University of Western Ontario

---

I have read the Letter of Information, have had the nature of the study explained to me and I agree to participate. All questions have been answered to my satisfaction.

______________________________
Name of Participant (Please Print)

______________________________ ______________________________
Signature of Participant Date (dd/mm/yyyy)

______________________________
Name of person obtaining consent

______________________________ ______________________________
Signature of person obtaining consent Date (dd/mm/yyyy)

Appendix E: Information Letter for Families

# Understanding Sexuality among Adolescents with Physical Disabilities

## INFORMATION FOR FAMILIES

### *What is this study about and how will it be useful?*

This study will explore how adolescents with physical disabilities learn about sexuality and how this experience influences the way they see themselves as sexual beings. We are also interested in understanding what the experience of delivering sexuality education is like for parents/guardians, educators and heath care professionals and what types of resources are needed in order to make this process easier and more effective.

Exploring the experiences and challenges surrounding the delivery and uptake of sexuality information will allow us to gain a better understanding of the types of resources and services that are currently available and what still needs to be developed. Creating effective and relevant resources will help to increase sexual knowledge and competency and improve communication about sexuality issues between adolescents living with a physical disability and the significant adults on their lives.

### *Who are we are inviting to participate?*

- Adolescents between the ages of 14-19, who have a physical disability that requires the use of a wheelchair and who do not have any major cognitive or speech difficulties
- Parents/guardians of youth (age 10-21) who have a physical disability (same criteria as above)

### *What are we asking you to do if you chose to participate?*

ADOLESCENTS: You will be asked to participate in **two** individual narrative interviews with the study investigator which will last approximately **60 minutes each** either at the CRC, a local community centre or at your home, depending on what you prefer. During the interviews you will be asked several open ended questions about yourself, being an adolescent, dating, and what your experience of learning about sexuality has been like from family, friends and school.

PARENTS/GUARDIANS: You will be asked to participate in **one** focus group at the CRC with 4-6 other parents/guardians which will last approximately **90 minutes.** During the focus groups, questions will be asked regarding your experience talking to your child about sexuality, some of the challenges you face and what information and resources would you like to see available.

Both the interviews and focus groups will audio recorded for transcription purposes

### *Will you benefit from this study?*

There is no direct benefit to you as a result of this study. We will however, give you a copy of the study results in the mail if you chose. Your thoughts and ideas are very valuable to us and we hope that the knowledge gained from this study will be used to develop resources and services aimed at improving sexuality education and knowledge among adolescent with physical disabilities.

### *Who are the researchers?*

LAURI EAST - Investigator, MSc (Candidate) Health and Rehabilitation Science – Child and Youth Health, *University of Western Ontario*

TREENA ORCHARD – Supervisor, PhD. Assistant Professor, School of Health Studies, *University of Western Ontario*

### *What if I have more questions?*

If you would like any more information about the study, or are interested in participating please feel free to contact **Lauri East** at (xxx) xxx-xxxx

For questions related to the CRC, please contact

Appendix F: Focus Group Poster

*You are invited to attend a focus group on . . .*

# Understanding Sexuality among Adolescents with Physical Disabilities

We are looking for teachers, physicians, nurses, occupational therapists, recreational therapists, physiotherapists and social workers to share their thoughts on sexuality issues and education among adolescents living with a physical disability.

**If you agree to participate in this study:**

You will take part in 1 focus group with up to 6 other educators and health professionals, which will last approximately 90 minutes.

Focus groups will take place at the CRC– Date and Time TBA

***Complimentary refreshments will be provided***

## CONTACT INFORMATION

For more information about this research project, or if you have any questions or concerns, please feel free to contact the study investigator:

**Lauri East, MSc (Candidate)** Health and Rehabilitation Science – Child and Youth Health, *University of Western Ontario* (xxx) xxx-xxxx

For questions related to the CRC, please contact

**R.S.V.P** - To confirm your attendance please contact **Lauri East** at xxx-xxxx

# Appendix G: Interview Guide

## ***Narrative Interviews - Adolescents***

1. Can you tell me a little bit about yourself?

2. How would others describe you?

3. How do you choose to identify yourself? (*ex. Have a disability, disabled, in a wheelchair, uses a wheelchair, differently abled, not disabled)*

    3a. Has this identification changed over time

    3b. Does anyone else in your family have a disability, if so what is that like for you?

4. How would you describe what it's like to be an adolescent with (*cerebral palsy, spina bifida, muscular dystrophy)?*

5. What are the some of the biggest challenges you are facing right now?

6. What do you wish people knew about you?

7. What has your experience with dating been like?

8. What does sexuality mean to you? How important is it?

9. How have you learnt about sexuality?
(Or) can you tell be a little bit more about what is has been like to learn about sexuality from . . .

    9a. Did you learn sex education in school?
        If so, what was that experience like for you?

    9b. Do your parents/guardians talk to you about dating/sexuality?
        If so, what has that been like for you?

    9c. What is your relationship like with your peers?
        Do you talk about sexuality/dating?

        How is it different talking to your friends who have a disability compared to your able bodied peers?

    9d. Has your doctor/OT/PT ever discussed sexuality with you?
        If so, what kinds of things did they talk about

10. How do you think sexuality and disability is viewed in our culture?

11. How is disability portrayed in the media?

 11a. What have you learnt about sexuality from the media/internet?

12. What kinds of things (related to sex education, dating etc.) would you like more information about?

13. What kinds of information/resources/services should be available to adolescents who have a disability, how should they be delivered (*ex. web based, books, brochures, meetings etc.)?*

14. Is there anything else that you would like to add in?

## ***Focus Group – Parents***

1. What is it like talking about sexuality/dating with your child?

2. What are some of the fears/challenges you face when discussing these issues?

3. Are there issues that you would like to discuss but haven't - why?

4. Are there issues that you don't want to discuss - why?

5. What type of guidance/help/support have you received in dealing with sexuality issues with your children?

6. What kinds of sexuality education resources would you like to see available?

7. What has it been like coming to terms with your child becoming sexually mature?

8. What are the biggest challenges you face as the parent of an adolescent with a physical disability?

9. In your opinion, what are the biggest challenges facing adolescents with physical disabilities?

10. What is it like talking to your sons compared with your daughters?

 10a. What is it like talking to your children who have a disability about sexuality compared to your able bodied children/what do you think might be different?

11. How do you think sexuality and disability is viewed in our culture?

12. Is there anything else anyone would like to add?

## ***Focus Group – Educators/Health Care Professionals***

1. Who would like to share some of their experiences of talking about sexuality issues/sex education with adolescents who have physical disabilities?

2. What are some of the barriers/challenges you have faced?

3. Do you feel comfortable talking about sexuality with your clients/patients/students?
    3a. How could you become more comfortable?

    3b. Is there a difference speaking to male versus female clients/patients/students, if yes, how so?

4. Did you learn about sexuality and disability in your training?
    4a. If so, how was it delivered, what kinds of things were/weren't discussed?

5. What kinds of resources/services should be available to help sexuality educators?
    5a. What type of specific information/issues would be the most beneficial?
    5b. How should it be delivered?

6. How do you think sexuality and disability is viewed in our culture?

7. In your opinion, what are some of the biggest challenges facing adolescents with physical disabilities?

8. Is there anything else anyone would like to add?

# Appendix H: List of Themes

1) <u>**Sex Education**</u>

   a) **Talking about Sexuality with Health Professionals**
      1a-i) Challenges and discomforts
      1a-ii) Sex education resources
      1a-iii) Sexuality/sex education training

   b) **Talking about Sexuality with Parents**
      1b-i) Children talking to their parents about sex
      1b-ii) Parents talking to their children about sex
      1b – iii) Challenges and discomforts
      1b-iv) Sex education resources/finding information
      1b –v) Parent's views about their child's sexuality

   c) **Talking about Sexuality with Peers**
      1c-i) Types of topic discussed
      1c-ii) Talking to friends with and without disabilities
      1c-iii) Not wanting to talk to peers about sex

   d) **Formal Sex Education at School**
      1d-i) Learning about sex at college/university

   e) **Sex Education on the Media/Online**
      1e-i) Where to find information on the internet

   f) **Discomfort and Challenges**

   g) **Sexual Knowledge – General**
      1g-i) Where you received most of your sexual information from

   h) **Sexuality Education and Disability**
      1h-i) Who should be responsible for providing sex education
      1h-ii) Inappropriate sexual behaviour
      1h-iii) Importance of sex education

2) <u>**Sexuality/Dating**</u>

   a) **Finding a partner**
      2a-i) What you are looking for in a dating partner
      2a-ii) Fear of not finding a partner

**b) Desire to Date**
  2b-i) Importance of dating
  2b-ii) Online dating
  2b-iii) Dating partners helping with personal care
  2b-iv) Offering dating advice to others
  2b-v) Prom

**c) Discovering Sexuality**
  2c-i) Being Sexual
  2c-ii) Ability to have sex
  2c-iv) Exploring sexuality/masturbation
  2c-v) Sexual frustration
  2c-vi) Being a virgin
  2c-vii) Puberty
  2c-viii) Prostitution

**d) Opportunity and People's Attitudes**

**e) Dating others with and without Disabilities**
  2e-i) Societal views on dating someone with a disability
  2e-ii) Personal views
  2e –iii) Preferences on dating someone with or without a disability

**f) Challenges for Dating and Sex**
  2f-i) Attendant/personal care issues
  2f-ii) Accessibility and transportation issues

**g) Abuse and Sexual Violence**

**h) Family and Religious Values**

**i) General Sexuality**
  2i –i) What sexuality means to you
  2i-ii) The importance of sexuality

3) <u>**Solutions for Sex Education**</u>

3-i) What should be done with this research upon completion
3-ii) The importance of this research
3-iii) Being part of the study

**a) Programs for Youth**
  3a-i) TIP
  3a-ii) Specialized teen clinics
  3a-iii) Group settings

b) **Reducing Discomfort**

c) **Specific Information for Youth**

d) **Resources for Parents**

e) **Resources for Health Professionals**

f) **Sex Education in Schools**
3f-i) Integration versus special programs
3f-ii) Mainstream sex education

g) **Online Resources**
3g-i) Using the internet for sex education
3g-ii) Online resources for health professionals
3g-iii) Online resources for youth and parents

4) **General Adolescence and Challenges**

a) **Future Goals and Ambitions**
4a-i) Having a family
4a-ii) Adoption
4a-iii) Not wanting to have biological children
4a – iv) future academic and career goals
4a –v) Where you see yourself in 10 years
4a-vi) Parents view of their children's future

b) **Rebellion and Mental Health Issues**
4b-i) Depression
4b-ii) Stereotypical adolescent behaviour
4b-iii) Promiscuity
4b-iv) Parents and adolescent rebellion

c) **Accessibility and Transportation**
4c-i) Accessibility and sexual health
4c-ii) Accessibility/transportation and socializing

d) **Government, Policy and Funding**
4d-i) Employment
4d-ii) Finances

e) **Media/Societal Perception of Disability (General)**

f) **Living with a Disability**

4g-i) Disability terminology
4g-ii) Causes of disability
4g-iii) Family members and disability
4g-iv) having the ability to communicate
4g-v) How it feels to have a disability
4g-vi) Comparing disabilities
4g-vii) Choosing whether or not to have a disability

g) **Issues at School**

h) **Medical Procedures, Treatment and Surgeries**

i) **Mortality**
4i-i) Discussing mortality
4i-ii) Sexuality and mortality

j) **Technology**
4j-i) Technology and socializing

5) **Expectations**

a) **Positive Expectations - Abilities and Achievements**

b) **Assuming and Labeling**
5b-i) How people with disabilities "should" act)

c) **Misconceptions about Disability**
5c-i) Asking questions about disabilities
5c-ii) Interacting with people who have disabilities
5c-iii) What you wish people know about having a disability
5c-iv) Solutions

d) **Low Expectations & Patronizing**
5d-i) Societal expectations of disability
5d-ii) Over-helping

e) **Talking down & Infantilizing**
5e-i) Being seen as naïve/innocent

f) **Expectations from Health Professionals**
5f-i) Expectations at birth/early childhood
5f-ii) Proving them wrong

g) **Grouping Disabilities**

5g-i) Understanding cognitive versus physical disability

**h) Having low expectations for oneself**

**i) Expectations from Family and Peers**

**j) Societal expectations of people with Disabilities**

6) <u>Independence</u>

**a) Desire for Independence**
6a-i) Living on your own

**b) Challenges for Independence**

**c) Family and Independence**
6a-i) Sibling issues

**d) Health Professionals and Independence**
6d-i) Going against HP's advice

**e) Parents inhibiting Independence**
6e-i) Consequences of over-protecting

**f) Attendant Issues**

**g) Standing up for Oneself**

**h) Transitioning into Adulthood**

7) <u>Stigma</u>

**a) Fear and Discomfort with Disability**

**b) Children's Reaction to Disability**

**c) Derogatory Comments and Negativity**
7c-i) Religious beliefs

**d) Myth of Asexuality**

- **e) Stigma surrounding Disability**

- **f) Misconceptions about Disability and Dating/Sex/Relationships**

- **g) Stigma and Negativity surrounding Sexuality – General**
  - 7g-i) Negative outcomes of sex

- **h) Media and Disability**
  - 7h-i) Sexuality and Disability in the media

- **i) Pity**

**8) <u>Peers & Acceptance</u>**

- **a) Being "Normal"**
  - 8a-i) What is "normal"

- **b) Transition - High school/Post-Secondary**

- **c) Peer Issues**
  - 8c-i) What your social life is like

- **d) Being Accepted/Having Friends**

- **e) Confidence**
  - 8e-i) Being confident
  - 8e-ii) Lacking confidence

- **f) Fitting In**
  - 8f-i) Being treated like everyone else
  - 8f-ii) Peer pressure

- **g) Feeling Different**
  - 8g-i) Social isolation
  - 8g-ii) Feeling left out

- **h) Visibility of Disability**

- **i) Friends with and without Disabilities**
  - 8i-i) Having friends with disabilities
  - 8i-ii) Negativity towards friends with disabilities

- **j) Mentorship**

**k) Challenges for Socialization**

8k-i) Sleepovers
8k-ii) Accessibility

9) **Self-Image & Identity**

**a) General Self Image and Self Esteem**
9a-i) How you see yourself
9a-ii) Meaningful aspects of your life
9a-iii) How others describe you
9a-iv) What you wish people knew about you
9a-v) Self-esteem

**b) Negative Self Image**

**c) Body Image – Positive**
9c-i) Favourite part of your body

**d) Body Image – General**
9d-i) Body image and disability
9d-ii) Buying clothes

**e) Body Image – Negative**
9e-i) Least favourite part of your body
9e-ii) Aspect of your body you would like to change
9e-iii) Eating disorders

**f) Privacy and Personal Care**
9f-i) Using catheters
9f-ii) Needing help with personal care
9f-iii) Discomfort and privacy issue
9f-iv) Personal care and gender

**g) Physical Activity and Recreation**
9g-i) Playing sports
9g-ii) Being physically active

**h) Self-Efficacy**

**i) Body Image and Media**