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SEXUAL HEALTH AND ADOLESCENTS WITH DISABILITIES: UNDERSTANDING THE EXPERIENCES AND ROLES OF NURSES IN A HOSPITAL SETTING

BY

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Abstract

Research shows that across a variety of settings, nurses demonstrate a lack of attention to the impact of illness or disability on sexual health. Individuals with disabilities often exhibit lower sexual knowledge, and are at a higher risk of being sexually abused. Unlike their 'able-bodied' peers, the sexual health of youth with disabilities may be overlooked, in part due to preconceived ideas about this population. Nurses enter into a therapeutic relationship with patients and families, and are in an ideal position to promote sexual health with patients and families. This project focused on sexual health care, provided by nurses, to adolescents with physical and/or developmental disabilities, with attention to the institutional and social discourses that shape these interactions. A critical ethnography was employed, supported by a theoretical framework based on the works of Foucault, Goffman, and Shildrick. Interviews were conducted with nurses and social workers. The study involved the collection of mute evidence and an observation of the institutional setting. Results show that nurses were supported and encouraged to address sexual health with youth and families, however they did so within a clinical milieu imbued with opposition – from structural issues, to the presence of larger social misconceptions such as beliefs of the asexuality of people with disabilities. The major findings of this project are that: (1) nurses occupy, and strive to maintain the role of caring agent in their relationships with patients and families; (2) that despite institutional support for the integration of sexual health care, remnants of the total institution remain which undermine the larger agenda to promote sexual health, and finally (3) in order to both maintain therapeutic relationships with patients and address sexual health care, sexual health is often medicalized. These findings point to the importance of continuing to modify the clinical milieu to support nurses in their endeavours to address sexual health. In addition, it raises an important need for further research to be conducted on the impact of repeated experiences in health care on perceptions of sexuality held by youth with disabilities.

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Chapter One – Statement of the Problem

In the context of disability[1], sexuality and sexual health is not always seen as a given human right. Adolescents and young adults regularly engage in the exploration of their sexuality, while the structured lives of some individuals with disabilities may prevent or minimize similar exploration. As a registered nurse who has worked with youth with physical and developmental disabilities and their families it is evident to me that addressing sexual health remains a difficult and, at times, taboo topic for nursing staff, patients, and parents – both in general and specific to the context of adolescents with disabilities. In general, there is reluctance within nursing practice to address issues of sexual health[2].

Shell (2007) notes: "nurses rarely have difficulty talking about bowel habits, the most unpleasant side effects of treatment, or impending death, but they often stop short of discussing topics of a sexual nature" (p. 686). This reticent attitude is echoed in the findings of studies that investigate how, and if, nurses integrate sexual health care into their general practice and the challenges they face in doing so (Higgins, Barker & Begley, 2006; Jolley, 2001; Magnan, Reynolds & Galvin, 2005).

While these studies demonstrate an overall lack of attention to sexual health care, they also reflect that nurses acknowledge sexual health and sexuality as an important component of being human. Clearly, nurses are in a position to include sexual health care

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[1] The term disability, as it used in this paper, reflects the definition of disability employed by the World Health Organization. Disability is seen as the complex phenomenon that results from the interaction between an individual's body and society in which they live (World Health Organization, 2010). This definition speaks not only to the impact of an impairment in one's body structure or function, but also to the social, political, and economic nature of disability.

[2] The definition of sexual health, utilized for this project, extends beyond the promotion of safe sexual practices. It encompasses the promotion of a number of sexual rights, including: the right to sexual freedom; sexual pleasure; sexual health care; sexual autonomy; emotional sexual expression; sexual equity; comprehensive sexual health education; and the right to make free and responsible reproductive choices (Pan American Health Organization, World Health Organization & World Association of Sexology, 2000).

into their current practice, regardless of an individual's ability or age. Through the work undertaken for my dissertation I endeavoured to uncover, and raise awareness, of the complex social interactions that affect and frame nursing work in relation to sexual health, sexuality, and disability.

This dissertation documents the work and findings of this project, and is divided into seven parts. Chapter 1 provides an overview of the research problem and research objectives and questions. Chapter 2 presents a review of the literature, chapter 3 describes the theoretical framework that supported the research project, and chapter 4 presents the methodological aspects of the project. Chapter 5 puts forth my analysis of the information collected, and chapter 6 offers a detailed discussion of these results within the context of the theoretical framework and the existing literature. The last section concludes this dissertation and puts forth some suggestions on next steps.

1.1 - Research Problem

Adolescence is well documented as a time of sexual development. This period in an individual's life, from the rapid physical sexual development that occurs in early adolescence, to the interest in and establishment of relationships during mid to late adolescence, typically corresponds with increased independence from one's family (Brown & Brown, 2006; Fonseca & Greydanus, 2007). Despite these facts, the sexual health and sexuality of adolescents with physical and developmental disabilities are often interpreted as problematic (Anderson & Kitchin, 2000; Crawford & Ostrove, 2003; McConkey & Ryan, 2001; Tepper, 2000). With respect to nursing, sexual health tends to be an area that is overlooked or poorly addressed in many areas of practice (Magnan & Reynolds, 2006). This may result in patients not having opportunities to ask pertinent questions about how their health status will impact their sexual health, and could be detrimental in the overall health of the patient. One area where this is a concern is in the adolescent population, specifically those with disabilities.

Typically, youth in the adolescent phase, engage in a wide spectrum of activities to explore and express their sexuality, from outings with friends, to wearing makeup and holding hands, to the most intimate of sexual acts. Most 'able-bodied' adolescents receive formal sexual health education in school and health care settings, and become autonomous decision makers with regard to sexual health and their bodies. Recent statistics report that by age 14 or 15, 13% of adolescents in Canada have had sexual intercourse (Garriguet, 2005), and that by 19 years of age, 65% of youth report having had sexual intercourse (Rotermann, 2005).

The statistics for youth with disabilities are not quite the same. To understand the differences, it is helpful to consider the range of disabilities on a spectrum. Individuals with mild to moderate physical disabilities would be at one end of the spectrum, and those with severe physical and/or developmental disabilities at the opposite end, with the understanding that any individual could move along this spectrum given a change in their health status. Youth with mild to moderate physical disabilities demonstrate similar rates of sexual activity to their non-disabled peers (Cheng & Udry, 2002; Suris, Resnick, Cassuto & Bloom, 1996; Vansteenwegen, Jans & Revell, 2003). In contrast, youth further along the spectrum, with developmental disabilities and low cognitive abilities, have fewer sexual experiences (from adolescence to adulthood) than their non-disabled peers (Cheng & Udry, 2005; McCabe, 1999; Szollos & McCabe, 1995).

Sexual activity and the expression of sexuality often coincide with adolescents reaching a state of heightened independence and fraternization within peer groups. Adolescents with physical and/or developmental disabilities often experience lower levels of social interaction with peers, as compared to adolescents without disabilities.

Increased isolation from social networks may be attributed to the highly managed and, at times, highly dependent lives of this population (Cheng & Udry, 2002; Shepperdson, 1995; Stevens et al., 1996; Wiegerink, Roebroeck, Donkervoort, Stam & Cohen-Kettenis, 2006). Social isolation, coupled with a restrictive view towards the sexual rights of individuals with disabilities in general, may inadvertently affect their health status, particularly as it relates to sexual health. Social stereotypes, such as the belief that people with disabilities are asexual, can be very damaging to the conception of the individual with a disability. As a result, these stereotypes can also have an impact on the nature and accessibility of health care services available to this population. The seemingly problematic nature of the sexuality of people with disabilities, coupled with social stereotypes, and the lack of clearly defined nursing roles around this topic has the potential to negatively impact the overall health of adolescents with physical and/or developmental disabilities.

As health care professionals, nurses have an obligation to provide safe, competent, and complete care to all patients, including sexual health care. A working definition of sexual health has been proposed by the World Health Organization (WHO) (2006). Although not officially endorsed by the WHO, this definition supports a broad understanding of sexual health, one that is inclusive of an individual's physical, social, mental, and emotional well being as they relate to sexuality. Sexuality encompasses "sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy, and reproduction" (World Health Organization, 2006). Sexual health care in the context of nursing then should aim to promote sexual health and sexuality. This could be accomplished through sexual health education, goal setting and planning related to increased independence, and providing the tools and knowledge to facilitate the formation of healthy relationships. Through such practices, nurses may provide individuals, families, and caregivers, with the power to identify potentially dangerous situations, facilitate independence and dignity in personal care, and actively acknowledge and respect an individual's sexual rights (i.e. body integrity, respecting decisions etc.). Providing such tools and knowledge is just as crucial for adolescents with disabilities as it is to provide these resources to individuals across the lifespan regardless of ability.

The responses and actions of nurses, relating to sexuality, are a reflection of broader societal views and beliefs (Guthrie, 1999). The general social stereotypes and stigma attached to the embodiment of individuals with disabilities, and the sexual expression of individuals with disabilities, may explain why nurses have difficulty placing sexual health as a priority in the lives of individuals with disabilities. This research project aimed to address dominant ideologies and discourses (social, professional, and institutional) that affect the role of the nurse and nursing actions as they relate to the government of sexual health of adolescents with physical and developmental disabilities.

Regardless, of the type or severity of their disability, youth and adults with physical and/or developmental disabilities appear to be a vulnerable group. Overall, individuals with disabilities tend to demonstrate more negative attitudes towards sexuality and have lower sexual self esteem than those without a disability (Hellemans, Colson, Verbraeken, Vermeiren & Deboutte, 2007; Taleporos & McCabe, 2003; Vansteenwegen et al., 2003); and are also at a greater risk for being the victim of sexual abuse (Cheng & Udry, 2002, 2005; Murphy & Young, 2005, Suris et al., 1996). Complicating matters more is the fact that children with disabilities, such as Spina Bifida and Cerebral Palsy, may experience the early onset of puberty, known as precocious puberty. Siddiqi, Van Dyke, Donohoue and McBrien (1999) found that children with neuro-developmental disabilities (including cerebral palsy, developmental disabilities, and hydrocephalus) were twenty times more likely to experience early pubertal changes than their peers. This would mean that families and youth have a shorter time frame to prepare for natural changes that occur with puberty.

The statistics presented above indicate a need for sexual health care, including the support of, and advocacy for, youth with disabilities and their families. This information also directly contests commonly held misconceptions about individuals with disabilities, for instance that individuals with disabilities are asexual or that their sexuality is problematic. Despite the fact that sexuality and sexual health are assumed a natural component of human life, they have often been ignored or problematized in the context of disability. Given the focus of Western society on sex and sexuality, it is difficult to imagine that the sexual rights of an entire segment of the population have been, and continue to be, ignored, devalued, and denied. Sexual rights, such as exploring one's sexuality, engaging in intimate relations, and parenthood, are typically seen as rites of passage; however, for many individuals with disabilities they are not given the same attention or may not be considered viable options. This may occur for a variety of reasons; there are a number of myths and misconceptions that surround the sexuality of individuals with disabilities.

The misconceptions and misguided social attitudes that may affect the understanding of the sexual health of individuals with disabilities include the perception that their sexuality is a threat to society. This was emphasized through the eugenics movement of the late 18th and early 19th century (Park & Radford, 1998). In this time period, the reproduction of individuals with developmental disabilities was considered a threat to society, as it was assumed that these individuals had 'defective' genes that would result in offspring that would degrade society (i.e. criminals, burdens to society). The threat of sexuality continues to surface today. Adults with disabilities, capable of full sexual functioning, may be unjustly seen as disgusting and fear inducing (Picard, 2007).

The medical establishment is not immune to misguided attitudes towards the sexuality of individuals with disabilities. The discourse of protection has often been used to justify the continued sterilization of women and girls with developmental disabilities. For example, in 1994, a United States Supreme Court Justice denied an appeal to ban the sterilization of Cindy Wasiek, a 'severely retarded' 26 year old woman whose mother and family wanted to have her sterilized to protect her ("A Justice refuses", 1994). In 2006, the so-called "Ashley Treatment" made headlines in both medical and mainstream media. Gunther and Diekema (2006) detailed the "Ashley Treatment" in the *Archives of Adolescent and Pediatric Medicine*, which was performed on a 6 ½ year old patient who had severe developmental and physical disabilities. The complete treatment included a hysterectomy, removal of the breast buds, and the administration of high doses of estrogen to arrest the maturation of growth plates, which would result in a permanent shorter stature. The hysterectomy and the removal of the patient's breast buds, was rationalized by the physicians, and the patient's caregivers, by concluding that the hysterectomy would eliminate the possibility of future uterine and cervical cancers, and that the removal of the breast buds would prevent the development of breast cancer and the development of "large breasts could 'sexualize' Ashley towards her caregiver, especially when they are touched while she is being moved or handled" which would be eliminated by removing her breast buds ("The Ashley Treatment," 2007). These procedures, justified as informed medical treatments in the best interest of the patient, are defended and validated under the narratives of caring, therapy, and protection.

The Ashley treatment also illuminates how subjectivity and embodiment become central in discussions relating to health care. Discussions of sexuality and sexual health often position the physical body, an individual's embodiment, and subjectivity at the centre of attention. Nursing work, in general, often involves situations in which a patient's physical body is at the centre of interactions between the nurse and his or her patient. The embodiment of an individual is often linked to perceptions, of self and others, about the subjectivity of the individual. Mansfield (2000) suggests that the perception of self (our subjectivity) is inevitably connected to the people, culture, and ideas that surround the individual.

In relation to nursing work, the nurses' interpretation and assumptions about a patient may be mediated by the patient's embodiment. As identified by Mansfield (2000), it is through social interactions that individuals come to understand themselves and others. Sometimes, the embodiment of an individual, or the actions of an individual (including nurses), threaten the perceived subjectivity of an individual, and therefore threaten assumptions about what that person is or should be. In relation to sexual health and individuals with disabilities, embodiment and subjectivity of the patient may play an important role in how nurses interpret their responsibilities and roles and ultimately the actions they take.

Nurses engage in therapeutic relationships with patients and families, with the aim of providing holistic care, as such they are in an ideal position to assess and promote sexual health and sexuality, and to integrate therapeutic interventions when planning care (Katz, 2003). In the context of youth with disabilities this may require nurses to occupy a difficult position, one which negotiates the provision of sexual health care within the complex network of social and personal interactions that affect and frame nurses' work in relation to sexuality and disability. In order to gain an understanding of how this could be achieved, it is necessary to explore the experiences and roles that nurses have occupied with relation to the sexual health care of adolescents with disabilities. The resulting knowledge could facilitate nurses in the provision of sexual health care to adolescents with disabilities; including the knowledge and the tools to form healthy relationships, and to become sexually competent adults, who can engage in both safe and pleasurable sexual experiences.

1.2 - Research Objectives and Research Questions

The purpose of this project is not to examine how nurses feel about and interpret the sexual behaviours of youth with disabilities, but to examine how they contribute to either challenging the status quo or enforcing it, through their actions in a given context. Guided by the work of Michel Foucault on biopower (1978) and governmentality (1991), and the work of philosopher Margrit Shildrick on embodiment (1997; 2002), and the imperfect body (2002), and the work of Goffman on stigma (1963) and total institutions (1961), this project had the following three objectives:

1) To understand the experiences of nurses in relation to the sexuality and sexual health of adolescents with disabilities in a hospital setting
2) To identify existing or potential roles for nurses in relation to these adolescents' sexual health
3) To understand what affects nursing actions and/or inaction in relation to the sexual health care of adolescents with disabilities.

Research that addresses the roles of nurses and the positions that they navigate regarding issues of sexual health in relation to youth with disabilities is undoubtedly important. I propose that the findings of this project will not only contribute to an understanding of nurses' experiences dealing with sexual health issues in the context of disability, but will also tackle the psychological processes (e.g. abjection and moral distress) that nurses encounter during such interactions. In addition, through this project I hope to address how nurses understand the influence of prevailing social, professional and institutional ideologies, personal psychological processes (i.e. feelings of abjection), and the impact that patients and families have on nursing interventions, and beliefs related to the provision of sexual health care to youth with disabilities.

In order to achieve the objectives listed above the project was guided by four specific research questions (and sub questions):

1) What are the experiences of nurses regarding the sexuality and sexual health of adolescents with disabilities?
    a) How do nurses engage in and/or avoid discussions of sexual health (through space/actions/words)?

2) What influences nurses to address or avoid sexual health care issues?
    a) Do nurses feel that a patient's embodiment (corporeality) affects their approach to sexual health issues?
    b) How do nurses perceive the involvement and roles of patients, parents, and other health care professionals with regard to sexuality/sexual health?
    c) How do allied health care professionals perceive the involvement and roles of nurses with regard to sexuality/sexual health?

3) What influence do larger social discourses, psychological processes (e.g. abjection), ethics (including moral distress), institutional norms (e.g. policy and education), and the roles of other health care providers have on nursing actions?

4) What roles do nurses envision for themselves in relation to the sexual health needs of youth with disabilities?

Government, in a Foucauldian sense, is a key theoretical concept driving this research, and as a result through this project I will examine specific norms that have been established, how these norms have come to be, how knowledge and techniques are used to govern, who and what is being governed and how it is conceived, and address why specific behaviours or rights are being governed and both the intended and unintended consequences of this government of practices. There is a need to explore both the social and political government of people with disabilities in order to expose the physical and social barriers that people with disabilities encounter when accessing and utilizing health care services and in their efforts to maintain healthy lifestyles.

Chapter Two – Review of the Literature

Using the research objectives that directed the study, the literature review was conducted to provide background information and identify the current knowledge base in areas related to sexual health, nursing, and individuals with physical and/or developmental disabilities. In addition, the influence of the literature on the medical and social conceptions of the disabled individual as a subject, and the social conception of the disabled subject as portrayed through mass media will be highlighted.

The literature review has been divided into three major sections. The first section focuses on sexual health in the context of disability, including historical perspectives on sexuality and sexual expression, and a discussion of the current literature that addresses sexual behaviours and sexual knowledge of individuals with disabilities, including adolescents. The second section examines the available literature on nursing practices and beliefs in relation to the provision of sexual health care to individuals with disabilities. The third, and final, section explores the concept of the individual with a disability as a socially constructed subject.

The search strategies that were utilized to locate the appropriate literature for this review included database searches, the use of the internet to locate relevant and reliable 'grey' literature, and reference tracking of collected works for additional leads. The databases that were explored include: CINAHL, Medline, PsychInfo, Dissertations and Theses (Proquest), America: History and Life, and Sociological Abstracts. Because this literature review was not limited to a specific disability, a variety of search strings were used to recover articles related to this population, including: developmental disability, intellectual disability, physical disability, learning disability, and the use of specific disabilities (e.g. Autism Spectrum Disorder, Cerebral Palsy, Spina Bifida). These search strings were then combined with keywords such as: adolescence, attitude to disability, nursing, nursing practice, sexual abuse, sexual development, sexual health, sexual knowledge, and sexuality. Certain restrictions were also utilized during the literature search, these included limiting the review to articles which were of the English language, and had been published in peer reviewed journals.

2.1 - Sexual Health and Individuals with Disabilities

There is a growing recognition within the general literature that individuals of all ages with disabilities are in fact sexual beings, interested in relationships and sexual experiences, regardless of either developmental disability (McCabe, 1999; Siebelink, de Jong, Taal & Roelvink, 2006) or physical disability (Cheng & Udry, 2002; Suris et al., 1996; Vansteenwegen et al., 2003). However, the broader perspective that frames many publications, focused on sexual health and individuals with disabilities, is the management of natural life events such as menstruation or sexual intercourse. Approaching the subject matter from this perspective suggests that these events are in some way problematic and that they need to be controlled or governed in some way. Nowhere is this more apparent than in a historical analysis of the control of sexual behaviours and expression in those with disabilities. While this is a part of our collective history, it does not remain in the past, rather some of the ideas and attitudes that emerge from history continue to permeate and affect ideas about people with physical and developmental disabilities.

2.1.1 - Sexual Health and Disability: A Historical Perspective

Sir Francis Galton first used the term eugenics in 1883, to describe a social movement aimed at the improvement of the human race through interventions targeted on human hereditary processes. The eugenics movement was based upon the position that society was suffering from racial denigration, that unfit and defective individuals were the cause of the downfall of society. Thus, the criminal activity and socially offensive behaviour of these individuals needed to be controlled (Carey, 1998). Crime was frequently linked to individuals deemed 'mentally defective', and eugenicists believed that crime rates would decrease if the mentally defective were prevented from bearing children. Early discussions within the eugenic movement focused on the benefits of both sterilization and segregation of individuals to achieve the aforementioned goals (Grekul, Krahn & Odynak, 2004). In an effort to eradicate the undesirable elements in society efforts were taken to limit reproduction among those deemed 'unfit', and strategies used to achieve this included institutionalization, sterilization, and public education (Grekul et al., 2004). The literature that covers these topics provides historical examples that demonstrate the outward control and violation of the human rights of individuals with disabilities.

Forced sterilization was implemented in various parts of North America in the late nineteenth century. In 1907 the state of Indiana legislated forced sterilization; by 1920 sixteen other states in the United States of America had similar legislation (Park & Radford, 1998). By 1960, over 60,000 'mentally retarded' residents of state run facilities in the United States had been sterilized, justified by the imperatives established by the eugenic movement (Reilly, 1991). In Canada, Alberta and British Columbia were the only two provinces that passed official sterilization legislation (Grekul et al., 2004). Alberta passed a Sexual Sterilization Act in 1928, which also saw the formation of the Alberta Eugenics Board. The board was responsible for reviewing and approving submitted requests for forced sterilization, and between 1929 and 1969 they approved the sterilization of 2102 individuals (948 women, 1154 men) described as mentally defective and 370 individuals (114 women, 256 men) classified as psychotic (Park & Radford, 1998). Reasons for sterilization, provided by the Alberta Eugenics Board, included behavioural difficulties, abnormal sexual behaviour, criminal tendencies, as a precondition for release, and parental request (Park & Radford, 1998). The ideas and beliefs enforced and represented by the eugenics movement continued to influence state and medical decisions until the early 1970s (Park & Radford, 1998).

The forced sterilization of individuals with developmental disabilities reveals the social concept of the developmentally disabled subject as abnormal, criminal, and difficult. Such a perception of individuals with developmental disabilities persists today, especially regarding sexuality. In addition, these historical examples demonstrate how people with developmental disabilities were seen as individuals whose rights can be violated for the sake of the public good. While forced sterilization was conducted in the early to mid twentieth century and supported with a view that it was in the best interest of the public good, sadly, forced sterilization continues to this day, only with a different set of justifications.

2.1.2 - The Current State: Forced Sterilization in the 21st Century

The practice of forced sterilization demonstrates the violation of a sexual right – the right to sexual autonomy and safety of the sexual body (Pan American Health Organization, World Health Organization & World Association of Sexology, 2000). In addition to the violation of bodily integrity, forced sterilization also directly impedes the individual's right to have control over one's body. Sterilization continues to this day, and remains a prominent example of the continued governance of sexual conduct of individuals with disabilities. The cases of Cindy Wasiek and Ashley, introduced earlier, demonstrate the ongoing sterilization of individuals with disabilities justified through social and medical discourse as acts of caring and protection, similar to the justifications provided for the sterilization and institutionalization of individuals during and after the eugenics movement.

Brady (2001) reviewed the court materials, dating from 1992-1999, that were associated with cases of caregivers seeking the sterilization of women with developmental disabilities in Australian family court. She found, in some of the cases, caregivers presented sterilization as a procedure that would result in the improved community integration of the individual, because caregivers would no longer need to be worried that the women in question would become pregnant. This type of argument echoes that found by Stansfield, Holland, and Clare (2007) in their review of sterilisation cases brought forth in England and Wales between 1988 and 1999. They found that the majority of requests were made for individuals with developmental or intellectual disabilities and that the reasons put forth by those seeking the sterilisations (most often parents) were focused on the prevention of pregnancy and alleviating the discomfort of menstruation. Interestingly the authors here point to the fact that sterilisation was not being conducted to promote a healthy sexual relationship for the individual, but rather out of "fear of the unexpected" (Stansfield et al., 2007, p. 577) and to relieve the concerns of future pregnancies.

As can be seen in this argument the focus on the prevention and not on the creation of positive healthy relationships demonstrates little concern for the sexual activity of individuals with disabilities; and the focus on preventing procreation evokes some of the fundamental ideas of the eugenics movement. In these instances, women with disabilities are perceived as unfit or incapable of being parents and sexual partners, and their potential child is regarded as a social or personal burden. These examples illustrate the continued influence of the eugenics movement and the way in which it has permeated medical, social, and legal discourse. A separate study, conducted in Australia, examined sterilization and the use of drug to suppress sex drives in young males with developmental disabilities (Carlson, Taylor & Wilson, 2000). The study found that decisions regarding the sexuality of young men with developmental disabilities was largely defined by the possibility of sexual deviance and that interventions were driven by the need to control sexual expression by way of medication, surgery, or exclusion. Although neither Brady (2001) nor Carlson et al. (2000) use terminology associated with government (in a Foucauldian sense) the researchers seem to view sterilization from a critical standpoint. There is much discussion in these papers regarding the creation, control, and legitimization of the procedures sought and performed within social and medical discourses.

Clearly, historical actions continue to influence assumptions and beliefs about individuals with disabilities, this is demonstrated by continued attention to the control of sexuality and sexual expression among these individuals, and the overall lack of attention to the sexual needs and positive sexual expression of people with disabilities (McCabe, 1999). In providing a historical perspective on sexuality and individuals with disabilities, the lack of attention to the sexuality of individuals with disabilities must also be understood in the context of the institution.

2.1.3 - Institutions and Individuals with Disabilities

Another historic relationship between health and individuals with disabilities is the role of the institution. Ontario's first institution, the Huronia Regional Centre (originally named the Orillia Asylum for Idiots) opened in1876. By the mid 1970s, in Ontario, there were nineteen residential facilities in operation, housing people with developmental disabilities (including youth with cerebral palsy). At their peak these facilities collectively housed over 6,000 residents (Ministry of Community and Social Services, 2006).

In both the United States and Canada, a shift in thinking occurred around the late 1950s and into the early 1960s. It was at this time that attention was drawn to deplorable living conditions within many institutions and families and advocacy groups campaigned for the development of more robust community based services, so that individuals could live in their home communities, or in their own homes (Community Living Ontario, 2006; Davis, Fox-Grage & Gehshan, 2000). This was coupled with growing awareness of the concepts of normalization and self-determination (Molony & Taplin, 1988; Wehmeyer, 1988).

Advocacy groups in Canada (e.g. Community Living, People First of Canada), as well as groups around the world (e.g. European Coalition for Community Living) continue to campaign for the closure of these types of facilities as well as for appropriate living arrangements for people with disabilities, promoting self-determination and the rights of an individual to choose where and how they live. Over the past fifty years the focus of individuals, families, policy makers, and governments has shifted from the provision of care within institutions, to systems that are based on community programming, the establishment of community supports, and the meaningful inclusion of individuals with disabilities.

In Ontario, the last three remaining residential facilities were closed in March 2009 which marks a formal commitment to the development of a system fully dependent on community based services, the key objectives of which are full citizenship and complete community inclusion (Ministry of Community and Social Services, 2006). This process, of deinstitutionalization and the development of community based services, highlights the importance of examining interactions between health care providers and individuals with disabilities that take place within a health care institution. Any point of contact with health care professionals, specifically nurses, should aim to address the health of the whole person, and this includes addressing sexual health. The provision of health care to individuals with disabilities has been raised as a concern that demands attention especially with the shift to community based systems (Davis et al., 2000; Fisher, Haagen, & Orkin, 2005; Kozma & Mason, 2003; Parsons, 2003).

The process of deinstitutionalization has moved individuals from environments where designated knowledgeable individuals provided attention to specific health needs

(Kozma & Mason, 2003) to the community where practitioners must develop a new knowledge base in order to provide competent comprehensive care to this growing population. Unlike the attention given to the provision of inclusive education and housing, it has been suggested that community based alternatives for health services have been neglected (Fisher, Haagen, & Orkin, 2005). This need is echoed by the findings of public consultations conducted by the Ontario Ministry of Community and Social Services in 2006. The concerns of parents, caregivers, and individuals with developmental disabilities were brought to the forefront, which highlighted the need for more qualified professionals to be available to meet the needs of individuals with developmental disabilities, especially in remote areas of Ontario (Parsons, 2006).

Deinstitutionalization is not a new concept. Before the shift to community based services occurred, the care of individuals with disabilities was characterized by institutionalization. This period highlights how the denial of sexual expression was used to control those with disabilities and emphasizes an ongoing need to attend to issues of sexual health within a community context. Dotson, Stinson, and Christian (2003) drew attention to the impact of institutionalization on women with developmental disabilities and the resulting denial associated with existence as sexual beings and occupiers of the roles of women and mothers. What cannot be forgotten is that the relocation of housing and services to the community does not eliminate the need for attention to ongoing health and socialization requirements for individuals with disabilities. In fact, living in group home settings may result in a host of new issues – such as lack of privacy, multiple care providers (perhaps unregulated), and ongoing issues of socialization and meaningful inclusion and participation in society. Rowe (2007) points out that staff members in residential settings may take responsibility for the sexuality of their patients out of fear of pregnancy, abuse, or that knowledge of sexual activity within a group home would become public. Therefore the need to address these concerns supersedes the encouragement of patients to take responsibility for their own sexuality and associated behaviours. Rowe (2007) proposes that a potential solution to this issue is the creation of sexuality policies for residential facilities –providing a balance between protecting patients from abusive behaviours and supporting individual sexual rights and freedom. In addition, the institution of policies also provides overall guidance for regulation rather than guidance based on staff attitudes towards sexuality and sexual expression.

Much of the available literature regarding sexuality and individuals with disabilities has focused on the perceptions of caregivers (i.e. parents, health care providers, unregulated health care providers) in relation to sexual behaviours and sexuality, the management of sexual behaviours and physical changes associated with maturation, sexual education, and the treatment of deviant behaviours. While much attention is given to the management of problematic behaviours, there is also research that explores the natural growth and development, and the sexual experiences and knowledge of adolescents and adults with disabilities.

2.1.4 - Sexual Experience and Sexual Knowledge of Individuals with Disabilities

The experience and knowledge of individuals with a physical disability or developmental disability varies between the groups, and also varies according to the severity of the disability. Research conducted with adolescents has shown that adolescents with or without a mild to moderate physical disability demonstrate similar rates of sexual activity (Cheng & Udry, 2002; Suris et al., 1996; Vansteenwegen et al., 2003). In a Swedish study involving youth with moderate disabilities (including hearing, visual, motor and learning disabilities) Brunnberg, Boström, and Berglund (2009) compared the age of first sexual contact between boys and girls ages 15 and 16 to those without a disability. They found that regardless of age or gender, individuals with one or more disabilities reported a higher rate of first sexual intercourse than those with no disability. Cardenas, Topolski, White, McLaughlin, and Walker (2008) researched the sexual experiences of adolescents and young adults with Spina Bifida and found that dependent on gender and the presence of hydrocephalus, between 44% and 68% of the sample population had been sexually active. The study also showed that adolescents and young adults with hydrocephalus were less likely to have dated (Cardenas et al., 2009). Verhoef et al. (2005) also focused on adolescents and young adults with Spina Bifida and found that overall, participants with hydrocephalus demonstrated lower levels of sexual activity (including masturbation), but that the majority of individuals expressed an interest for sexual contact (from 59% - 96%). Wiegelink et al. (2008) studied the sexual relationships of youth with Cerebral Palsy in the Netherlands and found that 73% of the participants had experience with dating, but overall participants demonstrated lower levels of sexual experience (from masturbation to kissing to intercourse) than their non-disabled peers. These studies demonstrate the range of sexual experience that is displayed by youth with disabilities, highlighting the differences between mild to moderate disabilities and more involved disabilities with a cognitive component. There is also evidence suggesting that individuals with physical disabilities have a greater risk of contracting a sexually transmitted infection (STI), or being a victim of sexual abuse (Cheng & Udry, 2002; Suris et al., 1996). This demonstrates that regardless of level of sexual experience youth and adults with disabilities remain a vulnerable population in regards to the risks associated with sexual activity.

Overall, regardless of the type of disability, individuals with either physical or developmental disabilities tend to demonstrate more negative attitudes towards sexuality and have lower sexual self esteem than those without a disability (Hellemans et al., 2007; Taleporos & McCabe, 2003; Vansteenwegen et al., 2003), and are at a greater risk for sexual abuse (Cheng & Udry, 2002, 2005; Murphy & Young, 2005, Suris et al., 1996). For example, Moin, Duvdevany and Mazor (2009) conducted a study in Israel with women with and without physical disabilities and found that women with a physical disability displayed significantly lower rates of sexual self esteem as well as sexual satisfaction than those without a disability. These lower rates were attributed to the stigma of asexuality attached to women with disabilities and increased social isolation resulting from a lack of opportunities for social interaction.

The literature suggests that individuals with either developmental and/or physical disabilities are less knowledgeable about sexual topics than non-disabled individuals (Cheng & Udry, 2002; McCabe, 1999; Milligan & Neufeldt, 2001; Szollos & McCabe, 1995). Szollos and McCabe (1995) examined the sexual knowledge of people with mild developmental disabilities and found that both male and female participants showed the greatest knowledge in body part identification. Further, women demonstrated high knowledge scores in menstruation and dating and intimacy, and low knowledge scores in sexual interaction and sexually transmitted diseases, while males showed highest knowledge scores in dating and intimacy and masturbation and lower knowledge scores in regards to sexually transmitted diseases and menstruation. Overall the study found that the sexual knowledge of individuals with developmental disabilities was often only partial or rife with inaccuracies and misconceptions (Szollos & McCabe, 1995). For example, some of those involved in the study reported that "sexual intercourse is intended to hurt the female, that women can give birth without being pregnant, that masturbation causes harm, that men have periods" (Szollos & McCabe, 1995, p. 216). Lesseliers and Van Hove (2002) conducted a study in Belgium that involved interviewing adults with "mental retardation" about their personal interpretations of relationships and sexuality, including levels of sexual knowledge. Most participants were unable to name sexual organs (using proper terminology or slang) and had little to no knowledge of reproduction. Despite this lack of knowledge some participants were actively engaged in sexual experiences. The participants in Swango-Wilson's (2009) study, who had a developmental or cognitive disability, expressed a desire for sexual health education that focused on relationship knowledge (i.e. how do you know it is safe to be friends with certain people) as well as general sexual knowledge (i.e. how do you prevent diseases). Cardenas et al. (2008) worked with adolescents and youth with Spina Bifida and found that almost all participants reported having received sexual health education through the school setting. A study from the Netherlands, conducted with youth with Cerebral Palsy, showed that while nearly all the participants had received sexual health education, only 14% of those with Cerebral Palsy received education specific to their diagnosis (Wiegerink et al., 2008). Overall, participants in this study felt that the information they received was sufficient (Wiegerink et al., 2008). Lastly, Verhoef et al. (2005) found that almost all the participants in their study (youth with Spina Bifida) received sexual health education in some form, mostly in a formal school setting, but that this education rarely included information specific to individuals with Spina Bifida.

Berman et al. (1999) interviewed adolescents with physical disabilities in relation to learning about sexual health and found that 55% of those questioned, between the ages of 12 and 15, had not attended school based sexual education classes, because many of these classes occurred in physical education classes that students were excluded from. Many of the adolescents interviewed, felt that the health classes were directed towards the ambulatory population and did not address the needs of those with physical disabilities. A national study of adult women with physical disabilities conducted by Nosek, Howland, Rintala, Young and Chanpong (2001) discovered that 41% of those questioned believed they did not receive adequate information about how their disability would affect sexual activity, or their ability to sustain a pregnancy. Sexual activity and a lack of sexual health knowledge, especially knowledge specific to an individual's disability, may create dangerous situations. This combination could result in individuals being victimized or entering into situations without the knowledge or tools to engage in safe sexual experiences. This speaks to the need for comprehensive sexual health education.

Ailey, Marks, Crisp and Hahn (2003) outline the philosophical approaches that have been taken towards sexual health education and individuals with disabilities. These philosophies range from early thoughts that education for individuals with developmental disabilities should focus on the elimination of sexual expression, to the control of sexual expression in relation to time and place, and a more recent understanding that sexuality and sexual satisfaction are a component to human life and should be accessible to everyone (Ailey et al., 2003). Currently, in Ontario, the approach to sexual health education seems to align with the final philosophy. In Ontario, sexual health education typically occurs in formal school settings as an aspect of sexual health education, and is included in the Health and Physical elementary curriculum (grades 1 – 8), and in the secondary curriculum (grades 9-10). Most of the content falls within the healthy living strand. Objectives for learning progress throughout the grade levels. For example, in the elementary curriculum a student in grade one may be taught basic body part identification (Ontario Ministry of Education, 2010). As the student progresses to grade six the learning objectives are focused on more relevant material for the age group including describing the emotional and interpersonal impacts of puberty, and in grade eight objectives include the identification and explanation of factors that influence engaging in sexual activity (Ontario Ministry of Education, 2010). The student in secondary school engages in higher level skills including the use of decision-making and assertiveness skills that promote healthy sexuality and the identification of community supports that are related to sexuality and sexual health (Ontario Ministry of Education, 1999). Clearly the information and delivery of information should be tailored to the age group as well as be sensitive to the specific learning needs of students. In relation to youth with disabilities the importance of this information is essential, and the Ontario curriculum includes an appreciation for the need to adapt information to a student's learning level, and recognizes the limited social learning that may occur:

> "Some students with intellectual and physical disabilities may be at greater risk of exploitation and abuse. These students may also have had fewer formal and informal opportunities to participate in sexual health education. Teachers need to ensure that these students' privacy and dignity are protected, and that the resources used are appropriate to their physical, intellectual, and emotional development. Different kinds of accommodations and approaches will be required for different students, but it is important to ensure that all students have access to information and support regarding their sexual health." (Ontario Ministry of Education, 2010, p. 51)

The recognition of the importance of delivering sexual health education to all students (regardless of ability), as well as the recognition that students with disabilities may encounter fewer informal learning opportunities represents a positive step towards comprehensive sexual health education for all youth.

Sexual health education does not always take place in the confines of a classroom or in discussions with parents and caregivers, often adolescents turn to social networks or health care providers to supplement their sexual health knowledge. Gougeon (2009) supports the idea that sexual health education also takes place outside of formal educational settings and refers to this as the "ignored curriculum" (p.284). The ignored curriculum is one taught among peer networks, during lunch or in the hallway, and includes not only advice from peers, but also informal advice from a trusted adult. However, friends, trusted family members, and healthcare providers may be less accessible for individuals with disabilities, especially those with developmental disabilities (Ager & Littler, 1998). While the knowledge gained in informal learning situations may not always be accurate, it does provide a sense of reality to youth - balancing the messages of hypersexuality proffered by the media with the messages heard through structured classroom experience (Gougeon, 2009). However, the ignored curriculum is typically unavailable to youth with intellectual disabilities (Gougeon, 2009). This may be due to increased surveillance and involvement of caregivers (Shepperdson 1995, Cambridge, Carnaby & McCarthy, 2003, Szollos & McCabe 1995) which result in highly structured social experiences and supervised settings which challenge the development of social networks. Parents of youth with physical disabilities, interviewed in one study expressed a number of concerns that focused on the social development of their children. These concerns included the ability of children to develop friendships and social lives, especially in adolescence, and the risk of social isolation due to a lack of peer interaction outside of the school environment (Antle, Mills, Steele, Kalnins, & Rossen, 2008). These concerns, as expressed by parents address the ability of youth to learn from peer to peer interactions, an issue at the core of the ignored curriculum. Another challenge that some students may face are their experiences with either segregated classrooms, or integrated classrooms with an assigned educational assistant. Both options may limit contact with non-disabled peers. While Gougeon (2009) focuses on youth with intellectual disabilities, the same could be said of youth with moderate to severe physical disabilities especially in relation to increased levels of supervision and assistance which mediates time spent with peers and the development of the social networks where the ignored curriculum is enacted.

Gougeon (2009) suggests adopting a critical pedagogy approach to sex education, emphasizing the importance of sexual health while remaining sensitive to the lived experience of the participants. Within this approach the learning environment is inclusive and includes all students regardless of ability or gender (Gougeon, 2009). The teaching environment also utilizes a comprehensive approach to sexuality education seeing it as a cross-disciplinary event. For instance, language arts classes may attend to the media portrayal of sex, while a science class may cover the physiology of reproductive systems (Gougeon, 2009). This integrated approach to sexual health, that weaves sexuality into the larger curriculum, and removes the topic from the isolated box of physical and health education may help to prevent the exclusion of students with intellectual disabilities, and arguably physical disabilities as well. The critical pedagogical approach requires that those involved in teaching be aware of the lived experience of the individuals and the relevance of specific material to individuals. For example, a discussion on public versus private behaviours may have less relevance to a youth with a disability who requires constant supervision and assistance with private matters (i.e. bathing/toileting etc). By questioning the relevancy of material and being sensitive to individual lived experiences, educators may uncover that a discussion about private versus public behaviours would facilitate skills building for students around issues of negotiating care with care aids. A critical pedagogical approach emphasizes the importance of peer to peer teaching as an aspect of comprehensive sexuality education. Peer to peer education helps to ensure the relevancy of subject matter and integrates what Gougeon (2009) refers to as the ignored curriculum directly into the classroom setting.

While the provision of information is important, so too is ensuring the comprehension of this information. For instance, O'Callaghan and Murphy (2007) surveyed a group of adults with developmental disabilities attending residential and community services in England regarding sexual relationships and the law. Over half of the individuals surveyed either thought that they were not allowed to have sex intercourse, or were not sure if they were legally allowed to do so. It is not enough to simply provide information, it is equally important to ensure that patients understand the material covered, are provided with any necessary assistance to improve this understanding, and that the material is adapted to their specific situation.

Another factor to consider is the reluctance of some caregivers to sexual health education for individuals with disabilities. Antle et al. (2008) conducted research at a Canadian facility with parents of children with physical disabilities to examine how parents participated in health promotion activities and education with their children. On the topic of sexuality some parents expressed high levels of comfort with while others were fearful of embarking on such a discussion with their children. Parents also expressed a variety of opinions on who should provide sexual health information. Some parents identified information as primarily coming from family and friends, while others showed a reliance on the school system and even television (Antle et al., 2008). Isler, Beytut, Tas, and Conk (2009) interviewed parents of children with intellectual disabilities, focusing on the perceptions parents had about the sexuality of their child. The study, conducted in Turkey, found that 32.5% of parents interviewed had not spoken with their child about sexuality and that 55% believed sexual education should take place in the school setting. This is consistent with Berman et al. (1999) who found that parents often felt that it was difficult to speak with their children, with intellectual disabilities, about sexual health issues. These findings support the suggestion that families and family members need the emotional, social, and physical support of community members and community agencies in order to be able to participate in sexuality education with their children (Harader, Fullwood, & Hawthorne, 2009)

The reluctance to discuss sexual health may be rooted in the fear that providing sexual health education will stimulate an interest in sexual activity (Smith, Wheeler, Pilecki & Parker, 1995). Shepperdson (1995) found that as individuals with Down's Syndrome moved from adolescence to adulthood, the number of caregivers that had previously considered sex education as unimportant rose from 13% to 60%. One possible reason for this dramatic increase could be that of the individuals in the study, many led highly supervised lives; 44% were not left alone at home as young adults for more than 15 minutes. This may have resulted in the perception of caregivers of these individuals having a low 'risk' of unknown relationships. The study also noted that when sex education did occur it was more likely to take the form of warnings against inappropriate touching by oneself or others, as caregivers felt that further education may have led to experimentation (Shepperdson, 1995).

The implications of both inadequate or absent sexual health education are important to understand. Murphy and Young (2005) suggest that adolescents with disabilities may engage in sexual experiences without adequate information or skills to "keep them healthy, safe, and satisfied" (p. 641). The inclusion of satisfaction here speaks to a message that includes, but also moves beyond only, safety and prevention. The provision of clear, accurate, and customized information available to youth with disabilities may be complicated by the provision of information with strong moral judgments. As well, youth with developmental disabilities may experience difficulty interpreting the factual information presented in sexual education classes without assistance (Smith et al., 1995). And, youth with physical disabilities may feel that the information being presented is not useful to them or not tailored to their specific needs (Berman et al., 1999). It is important to ensure that individuals with disabilities are receiving not only positive messages about their bodies and their sexuality but also receive comprehensive information about sexual health promotion in order to support healthy, safe and enjoyable sexual experiences.

Avoiding sexual health education, or the presentation of only abstinence-based information, does not decrease the age of first intercourse within youth in the general population (McKay, 2000). In outlining the objectives of sexual health education for youth with developmental disabilities the American Academy of Pediatrics (1996) stated that sexual health education should discuss pleasure and affection in addition to the appropriate expression of physical affection and "...expressing clear expectations that their behaviour conforms with family and societal standards for privacy and personal modesty" (p. 276). While the Academy acknowledges the value of sexual health education for this population, it seems to do so with a caveat. This caveat echoes the disconnect between what researchers identify as important components of sexual health education and what may actually be provided to this population. While the provision of well-rounded sexual health education for youth with developmental disabilities is advocated, the literature continues to suggest that individuals with developmental disabilities are consistently ill-informed and come to hold negative self-attitudes towards sexual conduct. Promoting sexual health and sexual health education for adolescents with disabilities can be especially difficult when caregivers are navigating seemingly difficult or problematic situations.

2.1.5 - Managing the Problem

The expression of sexuality among people without disabilities are frequently presented through the media as "normal" everyday occurrences, and certainly usually accepted as such by society. However, these same acts carried out between people with disabilities may be viewed in a more deviant light. Sexual behaviours, such as masturbation, may elicit a negative response from parents and health care providers and thus come to be described as a problematic behaviour (Dotson et al., 2003). The categorization of such behaviour as problematic reflects a need to control the behaviour either because it is inappropriate given the context, or because it disturbs the parents or caregivers and those around them. This need to control sexual activity in conjunction with the belief of disabled persons as asexual has resulted in a view of the disabled population as unacceptable "...candidates for reproduction or even capable of sex for pleasure" (Tepper, 2000, page 285). Sexual behaviours that occur 'normally' among individuals without disabilities may be interpreted as deviant behaviour in certain situations. For example, living accommodations designed to provide increased supervision transform the nature of an individual's living arrangements, shifting socially acceptable private behaviour into unacceptable public behaviour (Smith et al., 1995). These living accommodations could range from in-home care provided by parents to group living facilities for young adults with physical disabilities.

Masturbation is a common example of a private behaviour which may become a public behaviour. As children or teenagers, most individuals learn that masturbation is considered a private activity and most individuals are given opportunities to express themselves in private. However, individuals with disabilities may not be granted these same opportunities. For example, the construction and organization of social and physical spaces in environments designed for individuals with developmental disabilities often blends community space and private space (Cambridge et al., 2003), areas that are normally private, such as showers, bathrooms, and bedrooms, become supervised or shared areas (i.e. assistance required in washrooms, or shared bedrooms). The same could be said of environments of care for youth with physical disabilities, especially those that require assistance for personal care. While the physical structure of living environments may not be seen as a controlling measure of sexual conduct, not providing space for sexual exploration sends the same messages as negative comments about sexual conduct – that it is not appropriate or acceptable for people with disabilities.

Where masturbation serves as an example of the impact of supervision on sexual conduct, menstruation is an example of a normal process of maturation that can be interpreted as problematic within adolescents and adults with disabilities. A study conducted at the gynecology clinic at Sick Kids, in Toronto, Ontario, revealed that 48% of visits to the clinic involved children who were pre-menarche, whose parents had concerns about the future management of menstruation and were requesting the suppression of menstruation (Dizon, Allen & Ornstein, 2005). Management of menstruation in this pre-emptive manner, not only prevents pregnancy and avoid menstruation but also inadvertently restricts individual behaviours and social roles. Menstruation remains a social taboo for disabled women, and with menarche comes a new interpretation of the female with a disability. No longer is she a child or girl, but a young woman transitioning to adulthood with the ability to bear children, and express oneself sexually (Brady, 2001).

In her review of applications to the Australian Family Court, between 1992 and 1999 requesting sterilizations for women with developmental disabilities, Brady (2001) noted that many of these applications were based on the subjects' inability to perform adequate self care. This revealed that the management of menstruation may have more to do with the opinions and needs of caregivers, and less to do with the individual's self-care ability. Neither the fear of transition to womanhood or caregiver opinions form legitimate medical problems on which to base an application for sterilization, but rather demonstrate broader social issues and social values (Brady, 2001).

The classification of sexuality or sexual conduct as problematic extends far beyond masturbation and menstruation. Another example of the problems that arise when private discussions enter the public forum is related to the provision of consent for sexual activity. Christian, Stinson, and Dotson (2001) surveyed agency staff working with adult women with developmental disabilities and found that over two thirds of the staff expressed that an individuals' ability to consent to sexual relations should determine a patients' involvement in sexual relationships. It is interesting to note that the private act of consent has been made public by the caregiver.

Sexual expression may be interpreted as deviant because of the location in which it occurs (McConkey & Ryan, 2001); the activities or preferences in entails; or because it falls outside of established social norms. However, since the concept of deviant behaviour is a social construct, any behaviour that falls outside established cultural norms may be considered deviant. Therefore, an individual with a disability who expresses a sexual interest could be considered deviant, and historically individuals with disabilities were considered as asexual, incapable of sexual activity or predatory.

Unfortunately, most of the participants in studies related to sexual conduct and people with disabilities are caregivers, parents or health care providers (i.e. Christian, et al., 2001; Shepperdson, 1995; Van Bourgondien, Reichle, Palmer, 1997). The involvement and voices of individuals with disabilities in research tend to be less noticeable or simply absent. This exclusion has the potential to provide an inaccurate picture of the level of understanding or engagement in sexual activities, as was demonstrated by Szollos and McCabe (1995). Also, the perceptions of unacceptable, problematic, or deviant behaviours come to be seen from only the perspective of the caregiver or society. The influence of space on the creation of problematic behaviours has been outlined, as well as the involvement of caregivers in intimate body care (i.e. personal care). Despite the priority that seems to be given to caregivers and health care professionals within research focused on the sexual conduct of individuals with disabilities, the perspectives of these individuals can influence attitudes on sexual health. Therefore, it is important to understand the impact of caregiver attitudes on the sexual health of youth with disabilities, especially given their level of involvement in the lives.

2.1.6 - *The Influence of Caregiver Attitudes on Sexual Health*

The information available about sexuality and caregivers in the context of disability is focused largely on the developmentally disabled population. Messages communicated through the attitudes and actions of caregivers (i.e. parents, health care professionals, unregulated health care workers, and educators) about the sexual health and conduct of people with disabilities, either positive or negative, affect how one interprets their own sexuality and associated behaviours (Szollos & McCabe, 1995). Negative messages given by caregivers may lead individuals to believe that they are not worthy nor allowed to embrace their sexuality or to develop sexually intimate relationships. Curra (2000) writes, "people who are developing their sexual identities confront a great deal of ambiguity and confusion" (p. 39); imagine compounding this confusion and ambiguity with negative messages around natural human needs and drives.

While caregiver's may feel they understand their patient's sexual lives, this may not always reflect what is actually occurring or how their patients actually feel. As a part of a larger study, Szollos and McCabe (1995) surveyed caregivers of people with mild developmental disabilities living in community settings, regarding their perceived knowledge of patient sexual knowledge and experiences. The study found that caregivers consistently overestimated both the sexual knowledge and the sexual experiences of their patients. Although attention is given to the sexual conduct of people with developmental disabilities, the literature suggests that in practice the support of sexual conduct (i.e. forming and maintaining relationships) is far from adequate.

Certainly, one could argue that the presence of sexuality and sexual experiences depicted in the media, the growth of the porn industry, and the inclusion of sexual health education in school curriculums, signifies a growing acceptance of sexuality and sexual conduct in everyday life. However, this acceptance has come with a price; it has defined who may or may not partake in and discuss matters of sexuality, sexual health and sexual behaviour. Discussions of sexual expression and sexual health that involve people with intellectual disabilities are often avoided in fear that these conversations will spark arousal or provoke interest in sexual experiences (Shepperdson, 1995). This anxiety, around sexual interest, seems to stem from the caregiver, and is based on the potential for sexual intimacy. Perhaps this anxiety also stems from a fear of awaking the deviant, that is, the person with a disability as a sexual being.

Yool, Langdon and Garner (2003) found that institutional staff working with adults with intellectual disabilities in a medium-secure setting had liberal views towards masturbation as an appropriate expression of sexuality and the privacy required. However, staff members were less liberal towards the decision-making process related to homosexual relationships and sexual intercourse, as sexual activity was strictly prohibited between patients. Although these attitudes may have been reflective of the institutional context and policies, it is interesting to note that private/individual sexual conduct was well tolerated, while conduct that has historical roots of being deviant (homosexuality) was less tolerated. It suggests that what is not seen or heard is acceptable but that which is made public is not. In a similar vein, Shepperdson (1995) found that caregivers demonstrated permissiveness towards sexual behaviours of their teenagers that could be described as "controlled sexual experience at its most sanitized" (Shepperdson, 1995, p.339). These examples speak to the fact that behaviours that digress from social norms are less acceptable in a group where asexuality is the perceived norm.

Despite the fact that youth with mild to moderate physical disabilities engage in sexual activity, or the fact that youth and adults with disabilities are more likely to contract a STI, the provision of sexual health care and education and the behaviours of this population continues to be a source of anxiety for many caregivers. In addition, the sexual activities of this population and the provision of sexual health care are both highly influenced by a number of factors. These influences include controlling the negative consequences of sexual exploration and sexual activities (i.e. sexually transmitted infections, unplanned pregnancies, social stigma, legal consequences), the creation of problematic behaviours through space, and the role of caregivers in the lives of individuals with disabilities. However, the construction of the individual with a disability as a subject, in general, also influences the interpretation of the sexuality of youth with disabilities.

2.2 - Nursing and Sexual Health Care

Nurses have a pivotal role to play not only in the promotion of sexual health amongst people with disabilities, but also in challenging prevailing attitudes about sex and sexuality in regards to this population (Earle, 2001; Phillips & Phillips, 2006; Wheeler, 2001). In this section of the literature review I address two key areas. The first area is nursing practice and sexual health care, and includes an examination of common attitudes and behaviours of nurses. The second section is focused on nursing and sexual health care in the context of disability. If the overall goal of nursing practice is to provide holistic care to the whole person then it is essential to include sexual health care within nursing work. In order to do so, the larger discourses that affect the provision of this aspect of care must be uncovered. And in doing so, nurses may be able to move beyond simple discussions of attitudes and behaviours and acknowledge the involvement in larger social discourses in the construction of their actions or inaction, especially as it relates to youth with disabilities.

2.2.1 - Nursing Practice and Sexual Health Care

Nursing involves a number of intimate practices including: dressing, bathing, wound care and catheterizations. Often nurses encounter patients and families at very vulnerable moments in their lives, and this contributes to the intimate nature of care. This intimacy, combined with the impact of illness or disability can render sexuality a constant presence in nursing practice (Odney, 2009). Nursing theorist Hildegard Peplau (1997) was more than aware of the unique role nurses have in relation to the physical care provided to patients. Peplau discusses the nature of nursing work and the fact that nurses have:

> "privileged access to the naked body of patients. This aspect of interpersonal communication taps into the needs of patients for respect and dignity and conversely the need to avoid felt shame, embarrassment, and humiliation. Therefore nurses need to grasp the dimensions of these important interpersonal constructs" (p. 164).

Certainly, not all patient encounters will evoke the same emotions that Peplau speaks of, however, it is important to note that the same emotions of shame, embarrassment and humiliation may be evoked in patients or nurses during conversations around sexual health. This unique position that nurses occupy, in terms of access to vulnerable moments, the intimacy of care, and the therapeutic relationships that are the cornerstone of a nurse-patient relationship position nurses to take up the conversation of sexual health with patients. Given the therapeutic relationship that nurses enter into with patients, they are in an ideal position to assess sexuality and integrate therapeutic interventions when planning patient care (Katz, 2003). The awareness of the role of nurses in providing sexual health care, coupled with the acknowledgement of the importance of sexual health to patients, has resulted in the endorsement of such care by national nursing associations. As early as 1974 the American Nurses Association recognized the importance of including sexual health as a component of nursing practice (Dattilo & Brewer, 2005). In 1992, the Canadian Nurses Association (CNA) issued "The Role of the Nurse in Reproductive and Sexual Health". This position statement outlined nursing roles in relation to the sexual health of patients and is no longer supported by the CNA; it has since been superseded by "The Role of the Nurse in Reproductive and Genetic Technologies" (2002). The original position statement, presented here for historical purposes, outlined that nurses have a role in the provision of sexual health care, specifically in advocating for informed decision making around reproductive and sexual health matters and practices.

The Canadian Nurses Association (2010) outlines fundamental competencies for nurses; sexual health is addressed under three competencies of Health and Wellness, including promoting healthy lifestyle practices (including sexual health), addressing actual and potential risk factors of health, as well as existing or potential risks for abuse. However, competency and endorsements of the importance of sexual health do not provide nurses or nursing students with concrete goals focused on the integration of sexual health into daily practice or education. Sexual health and sexuality are both components of the human experience; as a result it is the responsibility of nurses to provide sexual health care as a component of nursing practice, regardless of ability or age.

The Royal College of Nurses (2009) in the United Kingdom has developed a comprehensive framework of competencies for nurses and midwives focused on nursing care related to sexual and reproductive health. The framework was developed to assist nurses (of all levels of expertise and experience) in the integration of sexual and reproductive health into practice. The guideline outlines specific tools to support professional development and to assist professionals in the identification of gaps in knowledge that can point to ongoing educational development. The dimensions of care that are addressed in the guideline include assessment, examination and specimen collection, the interpretation and provision of findings, the provision of treatment and therapies, and lastly health promotion. Within each dimension specific competencies are included for each level of practitioner. For example, under health promotion there is a competency focused on the integration of skills-building interventions into routine sexual and reproductive health care (Royal College of Nurses, 2009). For a competent nurse performance criteria include encouraging patient assertiveness and responsibility for sexual health, and engaging the patient in skills-building such as negotiation. The guideline presents practice based competencies that the nurse can then translate into their specific clinical milieu and tailor to their specific patient population.

Despite efforts to outline the importance of sexual health as a component of nursing care in general (Ekland & McBride, 1997; Guthrie, 1999; Higgins et al., 2006; Shell, 2007), studies continue to show that nurses are consistently hesitant to integrate sexual health into their practice (Jolley 2001; Lewis & Bor, 1994; Magnan et al., 2005; Treacy & Randle, 2004). Research conducted with regards to nurses' behaviours in general clinical settings is important to examine, in light of the subject at hand, as it provides an overview of current practices and challenges to practice experienced by nurses.

Magnan et al. (2005) surveyed nurses in a large metropolitan hospital, 85.8% of those surveyed indicated they understood how diseases and treatments could affect patient sexuality. However, only 51.7% of those surveyed expressed confidence in their ability to address sexual concerns with their patients. Southard and Keller (2009) focused on the need for sexuality assessments in cancer patients and found that only 17% of patients surveyed had been asked about sexuality concerns by their nurse (either during treatment or follow-up). In addition 42% of participants cited that discussing their sexual health concerns with their nurse was important. The reluctance to provide sexual health care and the absence of sexual health care in general areas of practice have been documented elsewhere, including a literature review by Gamel, Davis and Hengeveld (1993). The review explored the literature to determine if sexual health was a component of nursing care, and the researchers found that while nurses identified sexual health as an important aspect of patient health, the majority of nurses did not include this component of care in their nursing practice.

Guthrie (1999) interviewed 10 staff nurses in an acute surgical ward in regards to addressing sexuality with patients without identified disabilities. The perspectives shared by Guthrie's participants are an example of the hesitant nature nurses have in providing sexual health care to patients. The nurses felt it was the patient who should initiate discussions about sexual health and that patients did not want to talk about sexuality with nurses (Guthrie, 1999). Nurses need to take a proactive approach and identify the importance of sexual health when interacting with patients and establish an inclusive environment to discuss this topic within. Patients with a physical or cognitive disability face physical and social barriers when accessing sexual health services that the non-disabled population access easily. These services include, but are not limited to; sexual health clinics, health care providers who understand the impact of the disability on sexual activity and reproduction, and social situations. Nurses must take advantage of all patient interactions, and not assume that sexual health will be addressed by another professional. Nurses who are not confident in their abilities to perform sexual health assessments, combined with an avoidance of sexual health in the practice setting devalues the importance of sexual health to patients, and affects the beliefs and values of new and novice nurses. When time is not dedicated to making space for sexual health within the clinical setting it directly impacts student perspectives regarding the importance of this skill as well as limits their ability to see their future colleagues engaging in sexual health care (Dattilo & Brewer, 2005).

The acknowledgement of nursing's collective reluctance to address sexual health matters has triggered other researchers to identify factors that influence nurses to avoid or engage in discussions regarding sexual health with their patients. When Dattilo and

Brewer (2005) interviewed senior nursing students about the inclusion of sexual health assessments in their practice, the students cited a lack of inclusion based on a number of reasons including: personal discomfort with the topic, lack of educational preparation, and that similar practice was mirrored by their colleagues. The students also reported that while they valued sexual assessment, they felt that they did not have an appropriate comfort level or enough expertise to practice this skill. Treacy and Randle (2004) evaluated student nurses and their understanding of sexuality in children, focusing on children with special needs. Students perceived that the nurses did not consider addressing sexuality as part of their role (Treacy & Randle, 2004). Finally, the student participants identified the need for more education in sexual health, with one student stating "I don't like talking about it because I don't understand it" (p. 22).

Magnan and Reynolds (2006) interviewed nurses across five different areas of specialization and found that regardless of the clinical setting the same barrier to addressing sexuality with patients was the same; nurses did not believe that patients expected them to ask about their sexual health concerns. Many nurses in this study also expressed that sexuality should not be raised unless the patient makes the initiative to discuss this with the nurse.

One tool that has been presented as a means to address sexual health in the clinical milieu is the PLISSIT (Permission, Limited Information, Specific Suggestions, Intensive Therapy) model. Originally introduced by Annon (1976), the PLISSIT model has since been utilized by nurses as a tool to assist in the initiation of discussions related to sexuality. The use of the PLISSIT (Annon, 1976) model has been examined in nursing care to explore sexual health care among variety of patient populations including patients with stomas (Ayaz, 2009), gynecological cancer patients (Stilos, Doyle & Daines, 2008), patients with both developmental disabilities and Alzheimer's (Klepping, 2008), chronic illness (Taylor & Davis, 2007), and end of life care (Stausmire, 2004). Ayaz and Kubilay (2008) conducted a study in Turkey that focused on the effectiveness of utilizing the PLISSIT model in solving the sexual problems of individuals with a stoma. Issues that face patients with a stoma may include odour and leakage as well as more psychological issues such as altered body image and embarrassment. Overall the study demonstrated effectiveness in dealing with sexuality issues for this patient population when the PLISSIT model was implemented, especially in terms of giving specific suggestions (Ayaz & Kubilay, 2008). The PLISSIT model has also been tested with couples post radical prostatectomy for prostate cancer (Monturo, Rogers, Coleman, Robinson, & Pickett, 2001). Monturo et al. (2001) worked with advanced practice nurses and developed an eight week protocol that was implemented immediately post surgery with patients and partners; the protocol was structured around the PLISSIT model. The nurses involved cited that utilizing the model assisted in building their self-awareness as well as the knowledge and skills required to address sexual health issues. Nurses also commented that the development of a trusting relationship, that respected the pace and the readiness of the couple, was essential in addressing sexual health issues (Monturo et al., 2001).

The PLISSIT model consists of four distinct phases. The first phase, Permission, involves the creation of an environment within which individuals and family members feel free to express questions about sexual health, or sexuality without fear of judgment by professionals. Providing permission to discuss sexual health legitimizes it as a valid and acceptable aspect of health care (Odney, 2009), as well as a valued topic. Introducing sexuality legitimizes it as a valid acceptable aspect of health care (Odney, 2009). Raising the topic of sexual health and creating an environment that fosters these discussions also communicates to patients and families the value of sexual health as an aspect of human identity. The second phase, Limited Information, involves the provision of information to patients that is relevant and directly related to the questions and concerns expressed, and nursing work at this level is focused on increasing patient and family knowledge (Ayaz, 2009). Specific Suggestions is phase three and focuses less on knowledge development and more on skills building and offering specific suggestions aimed at the issue being discussed. This phase may require the involvement of or referral to additional professionals. Lastly, the Intensive Therapy phase reflects the limits of an individual practitioner's abilities and knowledge base and involves referral to a specialist.

The original PLISSIT model has been extended recently by Taylor and Davis (2007) to the Ex-PLISSIT model, the essential difference being that in the Ex-PLISSIT model, permission has been made essential to each phase of the model. Taylor and Davis (2007) suggest that permission giving can normalize sexuality as a valid topic of conversation, and that even though permission has been given once, it may also be required in subsequent conversations with patients to emphasize and encourage questions and self-reflection. Taylor and Davis also highlight the need to promote ongoing learning through review, reflection, and the challenging of assumptions.

If nurses, in general, do not feel prepared or able to address sexuality in general, this may contribute to the lack of information provided to youth with disabilities, especially when prevailing stereotypes about this population are taken into consideration. The reluctance of nurses, and nursing students, to discuss sexual health in general practice may be rooted in the fact that the profession has not always taken a positive approach towards sexual health and sexuality (Aylott, 1999). However, nurses are in a unique position; they encounter patients at their most vulnerable moments, and in other situations nurses have prolonged contact and relationships with patients, which would allow nurses to address more private topics, such as sexual health and sexuality. Nurses may have more consistent contact with patients and families than other professionals and have the responsibility to address the needs of the whole person and to integrate sexuality as a component of a holistic nursing care (Dattilo & Brewer, 2005; Treacy & Randle, 2004; Webb, 1987). As such, nurses are well positioned to help their patients by being leaders in changing attitudes and meeting the needs of marginalized populations, specifically youth with physical and/or developmental disabilities.

2.2.2 - Nursing, Sexual Health Care, and Individuals with Disabilities

A small body of literature exists in relation to the general population, sexual health, and nursing, however, there is limited information focused on sexual health care provided by nurses in the context of disability (Carr & Purdue, 1988; Dormire, Becker & Lin, 2006; Earle, 2001; Lehmann, 2005; Treacy & Randle, 2004; Tse & Opie, 1986;). This despite the fact that attention to sexuality and disability is gaining attention in more literature aimed at general health practitioners (see Berman et al., 1999; Di Giulio, 2003; Dotson et al., 2003; McCabe, 1999; Murphy & Young, 2005; Szollos & McCabe, 1995). The hesitation of nurses to engage in sexual health care, described above, may be even more pronounced when nurses are caring for adolescents with physical and/or developmental disabilities. Professional failure to address the sexual health of individuals with disabilities can result in negative impacts on both the psychological and physical well-being of adolescents and adults with developmental disabilities (Milligan & Neufeldt, 2001).

Odney (2009) suggests that integrating sexual health care into general nursing practice may result in stigma, which affects what may be considered acceptable practice. Stigmatizing behaviours may include those practices which blur ethical, personal and professional boundaries, as may occur in the case of facilitated sex. Building on the broad range of interventions and skills that nurses may employ when addressing sexuality and sexual health in clinical situations, Earle (2001) developed a continuum of care that explores the role of the nurse in facilitating sexual needs of patients with disabilities. The continuum presented includes the provision of information and services, supporting patient privacy, encouraging and enabling social interaction as well as assisting with or arranging for sexual surrogacy. Earle (2001) suggests that acceptance of such a continuum will assist nurses in empowering their patients (through information provision) as well as providing an opportunity for nurses to engage in a wider social justice project that challenges the dominant stereotypes that circulate in regards to disability and sexuality.

Pursuing the idea of nursing care and the sexual rights of individuals with disabilities, Treacy and Randle (2004) interviewed nursing students at the Masters level in regards to their attitudes towards the sexuality of pediatric patients with "special needs". These students identified that these patients had the right to express their sexuality and engage in sexual behaviours. However, both the students and their preceptors described they felt that the children did not want to discuss or express their sexuality. As a result, sexual health was not included as a component of care. Ignoring the sexual health needs of youth with disabilities is a method of governing behaviour. Ignoring these needs suggests that sexual health is either not a concern, or simply is not applicable for this population. It implies that individuals with disabilities should not be engaged in sexual conduct, and although ignoring this issue does not overtly communicate a negative message, avoiding the topic also does not communicate any positive messages about sexuality and sexual conduct.

While sexual health education may be valued as an important aspect of general education, educators encounter barriers to enacting this in practice and these barriers are similar to those that may be encountered by nurses and health care professionals working with youth with disabilities around issues of sexual health. Sexuality may be interpreted as a risk in relation to adolescents and young adults with disabilities especially if they have sexual desires and needs but lack the access to additional information, services and inclusive environments (Tice & Hall, 2008). Parents may be another barrier to conducting sexual health education with patients and students. Swango-Wilson (2009) conducted a study to uncover the expectations for a sexual health education program for individuals with developmental or cognitive disabilities, capturing the perspectives of individuals with developmental/cognitive disabilities, parents, professionals, and health care professionals in regular contact with these individuals. A common theme that was presented in the parent cohort was denial (Swango-Wilson, 2009). Professionals in this same study were concerned with the safety and legal ramifications of sexual health education, especially around protecting individuals from potential abuse (Swango-Wilson, 2009). Despite an awareness of the importance of sexual education, the theme of fear emerged from the parent interviews, especially around the implications of sexual education and potential activity (Swango-Wilson, 2009). Some parents, similar to those of non-disabled youth, may have conservative views about education and sexual health (Tice & Hall, 2008), and may feel it is more appropriate to teach topics of this nature within the family home. However, research has shown that this is not occurring (Cheng & Udry, 2002).

Typically when sexual health is addressed, with the general population, it is in regards to safe sex. Sexual health education should also address the development of healthy relationships, masturbation, and other forms of sexual pleasure, and advocating for independence and privacy in self care, especially when addressing sexual health in the context of disability. Smith et al. (1995) discussed the role of the nurse practitioner working with adolescents with developmental disabilities as it relates to sex education. The authors suggest that sexual health education should include assessing the social-sexual development of the youth (i.e. basic body care, gender awareness, sexual expression, social awareness and relationships), factors that may place the patient at risk for exploitation and victimization, and examine available resources to support their patients in all aspects of their lives. Smith et al. (1995) also identified the need to discuss birth control options and provide information around the prevention of STIs.

While content is important, those that deliver the content should also be considered. Ailey et al. (2003) stress the involvement of both parents and youth in sexual health education. Parents require support in understanding normal developmental processes and may require encouragement to raise sexual health topics with their children (especially at a young age). For example, from ages 0-3 education with caregivers may involve teaching them that a child's curiosity about their genitals is an aspect of normal development. As well caregivers should be supported and assisted in providing education to children with a focus on public and private body parts, body part identification, and stranger safety (Ailey et al., 2003). While parental involvement in health care may decline as children age and prepare for the transition to adult services, Ailey et al. (2003) continue to integrate caregivers into the learning process by sharing family and cultural values with their child while supporting them to define their own values around sexual health.

Addressing sexual health issues with patients challenges existing "cultural perceptions that people with cognitive disabilities are perpetual children allow parents to influence or control all aspects of their adult lives" (Block, 2000, p.247). The nurse working with the parents of a youth with a disability who is developing a sexual self, must remember that parents will also need support as they watch their child move into adulthood and that the parents' fears and anxieties must be listened to and explored (Aylott, 1999). This is a well supported position, as can be demonstrated in relation to the requests of parents for assistance with menstruation and masturbation. If the day-to-day caregivers of patients with complex health needs are not supported then the work done within the context of the nurse-patient relationship may be unravelled after the support of the nurse is withdrawn.

Nurses as advocates need to challenge the prevailing attitudes that affect and marginalize the sexuality of people with disabilities (Wheeler, 2001). Political advocacy involves the nurse working towards facilitating access to healthcare services for all members of society (Kubsch, Sternard, Hovarter & Matzke, 2004). This may be demonstrated by the nurse in a number of ways, including lobbying for services. In regards to sexual health and people with disabilities, this may involve supporting inclusive sexual education classes in schools and community programs for adults with disabilities. On a broader level it may involve the nurse working with various community agencies to create and subsequently raise awareness of sexual health services aimed at people with disabilities (Aylott, 1999). Advocating for an increased awareness of the existence of sexuality in people with disabilities is aiming education at society in general, what Milligan and Neufeldt (2001) describe as the "other half of the problem" (pp. 101). If nurses remain silent and dismissive of sexual health topics in the context of disability, then there will be little reason for society to question or change currently held beliefs and attitudes. While the inclusion of sexual health care is a component of a holistic approach to nursing practice, there are clear barriers engaging in this type of care. These barriers include personal discomfort, lack of education, and difficulty identifying if youth want to discuss sexual health. Another factor that may silently be creating a barrier to providing sexual health care is the concept of the subject with a disability. This subjectivity, which may include the individual as asexual or as incapable of sexual activity, may be enforced through the avoidance of sexual health care for youth with disabilities or simply through the movement of private experiences into the public realm.

2.3 - The Social and Medical Concept of the Disabled Subject

Clearly issues of sexuality are as equally important to individuals with disabilities as they are to those without disabilities. Youth with disabilities have the same interest and curiosities as those without disabilities (American Academy of Pediatrics, 1996). Although sexual interests and maturation is a normal part of growing up, teenagers with disabilities have difficulty acquiring information and social skills related to sexual development (Smith et al., 1995). Given the obvious gap between what is encouraged (i.e. comprehensive sexual health education) and what is occurring (i.e. lack of sexual knowledge), there needs to be an examination of how the conception of the disabled subject may influence nursing practice.

Individuals with disabilities have been cast into roles and defined ideas that have the potential to limit and distort their views and the views of others regarding sexual conduct and sexual feelings (Karellou, 2003; Milligan & Neufeldt, 2001). In part this may be a result of myths and misconceptions about people with disabilities, who often are viewed as either asexual or childlike (Di Giulio, 2003; Szollos & McCabe, 1995) or as sexually aggressive and out of control (Szollos & McCabe, 1995). The two categories that will be explored here are disabled subjects created as asexual/childlike and the disabled subject as deviant.

2.3.1 - The Asexual/Childlike Subject

Historically it was thought that people with disabilities were not capable of love, nor were they interested in forming long term relationships, marriages, or becoming parents (Karellou, 2003). This is unusual in a society where the sexual self is considered crucial to the development of self identity. However, as Earle (2001) points out, the topic of sexuality remains taboo, especially in the context of disability. The media contributes to the idea that sexual activity belongs to a select group of individuals, as it is most often presented as "...a privilege of the white, heterosexual, young, single, and non-disabled" (Tepper, 2000, p. 258). Jordan and Dunlap (2001) term the lack of representation of others "the media vacuum"; popular magazines, television shows and movies fail to include people with disabilities leading typical adult lives, and never are they represented as consumers, which communicates a devalued position for such people in Western culture. Gougeon (2009) notes that in mainstream movies individuals with disabilities are often portrayed as two-dimensional characters, disability first and the person second; sexuality is rarely if at all included in the character. Additionally Gougeon (2009) adds an interesting point that characters with intellectual disabilities are often "compared with children replete with an innocence towards intimacy and sex" (p. 281) thereby allowing the viewer to remain within an established comfort zone. This point is not only applicable in the educational setting, and often emerges from medical opinions, for instance, the assignment of cognitive ability levels, such as "a mental age of 6 years old". This diagnosis or label confers a permanent 'child-like' portrayal of the subject, despite their actual biological age and associated drives.

The media vacuum contributes to the portrayal of sexual activity as exclusive to the non-disabled population and perpetuates the belief that people with disabilities are asexual. Milligan and Neufeldt (2001) suggest two sources for the stereotype of people with disabilities as asexual. First that people with physical disabilities have, or are presumed to have a sexual dysfunction and as a result their sexual needs are thought of as absent or in need of control. Second, that the individuals with developmental disabilities lack the capacity to engage in sexual relationships due to impaired social judgment, despite the fact that their sexual functioning may remain intact (Milligan & Neufeldt, 2001). The medical community can also be held responsible for this stereotype especially as it relates to the diagnosis of sexual disorders. Tepper (2000) points out that the DSM-IV states that orgasmic disorders must be distinguished from dysfunctions that result from a 'general condition' (i.e. disability). This could influence practitioners to expect some type of sexual disorder in people with disabilities. In addition, the focus on 'sexual relationships' and organ function negates the importance of sexual expression that comes without physical intercourse, such as touching, holding, kissing and the formation of healthy relationships.

Another problematic subjectivity that people with disabilities are forced to occupy, closely related to asexuality, is that of the perpetual child. People with disabilities tend to be infantilized by society (Di Giulo, 2003). Some individuals may require assistance with self care. This makes the personal care (i.e. dressing, toileting) of youth a more public occurrence – doors may be left open and caregivers become involved in what many consider private actions. As pointed out earlier, discussions about private matters, such as masturbation and menstruation, become public topics (Watson, Venema, Molloy & Reich, 2002). This transforms typical maturation events, such as erections, menstruation, and wet dreams, into public events which subsequently may be problematized because the individual continues to be viewed as a child.

The transition from adolescence to adulthood thus becomes challenging. This shift signifies a transition from the innocent child in need of protection, to the adult who can make decisions and be recognized as a sexual being. However, caregivers and society are uncomfortable with this transition in individuals with disabilities and demonstrate resistance (Smith et al., 1995). People with disabilities who live in the family home are "often denied the right to pass from childhood to adulthood. This is because so many parents continue to regard them as children" (Wheeler, 2001, p. 924). Szollos and McCabe (1995) found that many of the individuals with developmental disabilities in their study required support and supervision which made it challenging "to break away from caregiver dependence, to experiment with sexual relationships, and to experience the social reality of being an adolescent, or an adult, in the community" (Szollos & McCabe, 1995, p. 218). Negotiating personal care needs could be included as another aspect of sexual health care, as it does involve themes such as bodily integrity, privacy, and negotiating private aspects of care with caregivers, who may be strangers. These themes are common conversations that parents have with children, however in adolescents with disabilities, privacy and access to the body, may not be considered in the same light, due to the nature of care.

While childhood is a time of sexual innocence, adulthood is seen as a time when there is no longer a need to protect this innocence (Jordan & Dunlap, 2001). Therefore, if an individual remained in a perpetual childlike state, that individual would be in need of protection from sexual exploitation. Often discussions of sexual conduct and sexual health education are partially justified by the need to protect this population from exploitation and abuse. Smith et al. (1995) notes that sexual health education can facilitate sexual development for disabled people; as well, sex education can assist in protecting this vulnerable population. The American Academy of Pediatrics (1996) addresses the importance of satisfying relationships for youth with developmental disabilities, but quickly balances this with the need to protect children from exploitation and teach youth socially appropriate behaviours as to prevent them from becoming sexual offenders or victims of sexual offence. The Academy also states that the "best protection from abuse is effective education of the children about sex and their right to assert themselves in refusing sexual advances" (American Academy of Pediatrics, 1996, p. 275). Clearly, keeping an infantilized view of the individual with a disability prevents such education from happening. Increasing the knowledge base of youth with disabilities not only prepares them to refuse unwanted sexual advances, but also affords them with the tools to negotiate safe and satisfying relationships, and communicates a belief in their abilities as an individual.

The perception of individuals with disabilities as incompetent increases their risk of control by professionals, family members, caregivers, and the larger society (Olney & Kuper, 1998). An excellent example of perceived incompetence surfaces when the ability of an individual with a developmental disability to consent to sexual relations is questioned. Within Canada, the age of consent, as established by the Criminal Code of Canada is 16 years of age for most people, however there are 'close in age' and 'peer group' exceptions to this (Department of Justice Canada, 2010). Consent is a major issue related to the sexual conduct of people with disabilities (Kennedy & Niederbuhl, 2001; McCabe, 1999; Treacy & Randle, 2004). Kennedy and Niederbuhl (2001) examined criteria for sexual consent for people with developmental disabilities by surveying psychologists, claiming that the creation of objective assessment procedures for consent would lead to "enhancement and protection of sexual rights and the promotion of safety skills of people with mental retardation" (Kennedy & Niederbuhl, 2001, p. 510). The American Academy of Pediatrics (1996) declared that a physician may deem an adolescent competent to make decisions about sexual matters as well as stating that an individual is entitled to privacy in regards to their decisions. The need for a mediator in determining consent is an ongoing debate. Spiecker and Steutel (2002) proposed that sexual interaction between people with intellectual disabilities requires moral and paternalistic supervision to ensure that valid mutual consent is given and that the experience is not exploitative. Both of these views imply that caregivers and health care providers have the right to govern the sexual conduct of others, and to direct sexual experiences, and emphasizes the childlike view of individuals with disabilities, in need of parental guidance at all junctures. The concern is that permitting paternalistic and moral supervision of sexual behaviours provides an external party with the power to condone certain behaviours as acceptable behaviours, while other behaviours as unacceptable (i.e. heterosexual versus homosexual or bisexual relationships). In addition, this external party would also have the ability to limit the kind of behaviours that someone may consent to, thereby restricting behaviours that the caregiver may be uncomfortable with (i.e. anal sex).

The conception of youth, and adults, with disabilities as asexual and childlike clearly influences how sexual health can or is approached. What has been demonstrated here is that from negotiating personal care to intimate sexual acts the view of the disabled individual as childlike or asexual clearly affects the way in which these topics are approached. When private matters and behaviours are transformed into public affairs, due to an asexual or childlike view of the individual with a disability, it reinforces this subjectivity. The individual with a disability may be seen as abnormal, and therefore behaviours that are outside of established social norms may be seen as deviant.

2.3.2 - The Deviant Subject

The increased supervision and lack of privacy that individuals with disabilities may encounter are cited in the literature as explanations for low levels of sexual experience amongst individuals with disabilities. Szollos and McCabe (1995) noted that the lifestyle of the individuals with developmental disabilities involved in their study resembled that of children, and although the participants had their own rooms, their actions were closely monitored by caregivers. Like watching children, caregivers have a watchful eye over these individuals to ensure that no harm comes to them and to see that troublesome situations are avoided. This supervision decreases the likelihood of spontaneity of sexual exploration; and as pointed to earlier the lack of privacy results in private activities becoming public, which then may result in these behaviours being labelled as deviant or socially unacceptable (Hingsburger & Tough, 2002; Smith et al., 1995).

Society has viewed the sexual behaviour of individuals with disabilities as unnatural, undesirable, and dangerous (Anderson & Kitchin, 2000; Tepper, 2000). This conception of individuals with disabilities as deviant continues to influence the attitudes towards the sexuality of people with disabilities (Di Giulio, 2003). This is evidenced by fears that deinstitutionalization and the movement of individuals from facilities into the community would result in an influx of sexual offences committed by people with intellectual disability (Szollos & McCabe, 1995). The representation of women with developmental disabilities as a social threat and that of men with developmental disabilities as sexual predators is a common stereotype (Block, 2000). These stereotypes may be rooted in the eugenics movement that linked developmental disability and "feeble-mindedness" to crime and criminal activities. However, the actual incidence of sexual offense behaviours demonstrated by individuals with developmental disabilities is not clear (Ward, Trigler & Pfeiffer, 2001). Waxman (2000) argues that stereotypes such as these influence societal beliefs around the need for controlling the sexual expression of individuals with developmental disabilities.

Another deviant stereotype that contributes to how society views the disabled is that women with developmental disabilities have been perceived as sexually uncontrollable (Olney & Kuper, 1998). Luiselli, Sherak, Dunn and Pace (2005) performed a retrospective study relying on the memory of 'professional' staff at a neurorehabilitation institute located in Massachusetts, United States of America, for children and adolescents with acquired brain injuries (ABI). The study was conducted to determine what types of sexual behaviours children/adolescents with ABI exhibited and the clinical needs that these behaviours would require. The authors discovered that some residents required sexual education that was based on information about physical changes, gender specific issues, and awareness of one's own body and personal boundaries of self and others. In addition the report that children and adolescents were engaging in sex talk, soliciting sex, and making sexual advances led the authors to conclude that it was clear that some students would require additional training.

The idea that individuals with developmental disabilities require additional sexual health education supports the theory of counterfeit deviance that has been offered as a defence for individuals with developmental disability who commit sexual offences (Hingsburger, Griffiths & Quinsey, 1991). Counterfeit deviance suggests that sexual offences are precipitated by the individual's lack of sexual knowledge, poor social skills coupled with limited opportunities to establish sexual relationships and not inappropriate sexuality (Lindsay, 2005).

Conceptions of the disabled subject did not suddenly develop, rather they are the result of a number of historical and social events that have led to the evolution of stereotypes, and the privilege placed on sexual behaviour as belonging to those without disabilities. The view of individuals with developmental disabilities as perpetual children or as deviant beings results in caregivers and health care professionals perceiving that these individuals are in need of constant protection from sexual exploitation and allows for justifications to be made around the need for governance of sexual behaviours. It is apparent that care professionals have an influential position in terms of educating both youth and caregivers about sexuality and sexual health.

2.4 - Chapter Summary

There is a general acknowledgement in the literature reviewed that individuals with disabilities are not only sexual beings, but also have the right to sexual health information and sexual experiences. While some may become sexually active, they do so with a lack of information, while others struggle to understand how the information should be interpreted or could be altered to accommodate their specific disability. However the focus of much of the literature remains on deviant and inappropriate behaviours, the management of behaviours and bodily functions.

In regards to nursing, the literature identifies sexual health as a topic area that is not well integrated into practice, and continues to focus on nursing attitudes towards addressing sexuality in general and specifically with individuals with disabilities. Sadly, what is largely absent from the literature is the 'treatment' of sexual conduct as normal and with the exception of literature based on sexual health education there are few articles that address supporting individuals in forming and maintaining relationships. In addition, research studies appear to rely heavily on parents and caregivers as the primary and frequently the only source of information. What remains is a disconnect within the literature – a proclamation that individuals with disabilities are sexual beings and have sexual rights and a focus on the deviant, challenging and inappropriate behaviours of this population. All health care providers, working with individuals with disabilities, need to be aware of the destructive impact that negative attitudes regarding sex can have on health and wellbeing of these individuals (Di Giulo, 2003).

Chapter Three – Theoretical Framework

"Getting mad is no longer enough. We must learn how to act in the world in ways that allow us to expose the inner workings of an invisible empire…"
(Denzin & Lincoln, 2005, p. 187)

This chapter will review the major theoretical underpinnings that are used in this research project. They have been broken into three sections: critical theory, imperfection and rejection, and deviance. The first section will explore critical theory and situate the ideas of Michel Foucault within post-structuralism. The discussions on imperfection and rejection will focus on the work of Margrit Shildrick (2002) on the imperfect body, stigma (Goffman, 1963), rejected bodies (Wendell, 1996), and abjection (Kristeva, 1982). Lastly, the section on deviance (Curra, 2000) brings the sections together in a discussion of normalization, otherness, difference, and the creation of deviant acts.

The nursing profession is constantly evolving, and as such, it is important that nurses and researchers continue to question nursing systems and routines as they relate to practice, theory, and research, especially those that reflect the status quo. Continued questioning and challenging of the status quo is essential if new understandings and ways of being are to be created. The theoretical perspective supporting my research project is founded on the work of poststructuralist philosophers. This foundation provides a framework to examine nurses' current ways of being, beliefs, and assumptions in relation to sexual health and youth with disabilities and perhaps permit a new perspective to be generated.

This theoretical framework, specifically the philosophical perspective of critical theory, provides a broad context for examining how adolescents with disabilities, and the nurses who care for them, are constructed as individuals and how their actions are situated within various discourses. The theory provides a lens through which the role of nurses in supporting and addressing the sexual health of youth with disabilities can be examined. The framework provides the language and tools needed to explain the research problem, analyze the data, and support the discussion of the findings. The use of a poststructuralist framework for this project provides the ontological and epistemological foundations for the research. The use of critical theory, as the philosophical stance for this project, is reflected in the overall methodology (critical ethnography), the methods of data collection (interviews, observation, and the examination of mute evidence), and data analysis (critical discourse analysis).

3.1 - Philosophical Stance: Critical Theory

While this project could have been approached and conducted from different theoretical paradigms, the use of critical theory supports the research objectives of this project as I strive to examine the underlying power structures that govern the actions of nurses in relation to the provision of sexual health care to youth with disabilities. Sexual health (an extension of sexual rights) in the context of disability has largely been addressed from a biomedical viewpoint and examined with a clinical focus. By providing an alternative to this traditional perspective, critical theory supports questions focused on the interpretation of the culture of nurses and brings into question the power relations that may be uncovered through research. The focus on power relations and dominating ideologies provides a new perspective through which nursing work can be interpreted. Critical theory also challenges commonly held beliefs, ways of being, and assumptions in order to interpret interactions and experiences in new and different ways. On a broader level, this research will demonstrate the worth of a critical approach to the examination of nursing practice. In doing so, it will be revealed that critical theory revisits what is taken for granted and accepted without question within nursing practice, theory, and research.

A paradigm, put simply, is a worldview that contains beliefs about the nature of reality or the world (ontology), encompasses the relationships of the inquirer to what can be known (epistemology), and identifies how knowledge can come to be known (methodology) (Guba & Lincoln, 1998). The paradigm that a researcher is situated in, influences how the world is seen, and affects how and what questions are asked, therefore it is important to acknowledge the ontological, epistemological, and methodological assumptions of critical theory as these obviously influenced how I conducted my research.

The ontological position of critical theory is that reality is both virtual and historical, specific to time and place, and therefore shaped by a number of factors including; society, gender values, culture, and politics (Guba & Lincoln, 2005). Over time this once dynamic reality comes to represent a true and accepted representation of the period – however contested this interpretation may be. For instance, the facts presented in history books are normally accepted unquestionably as the true interpretation of a period of time. However, one must ask: who wrote this truth and how have the dominant powers in the world constructed this version of the truth?

According to Guba and Lincoln (1998), critical theory encompasses a number of paradigms including: poststructuralism, postmodernism, feminism, neo-Marxism, and postcolonialism. The common assumption underlying critical theory is that inquiry, and the knowledge it generates, are value-mediated, subject to the values of the inquirer, the setting, the participants, and the larger sociological framework. Guba and Lincoln (1998) describe knowledge as a production of transactions between people. If knowledge is subjective and transactional then what is 'found' during research will be dependent on the individuals and social interactions that the researcher has exposure to.

As a result of the ontological and epistemological positions of critical theory put forth by Guba and Lincoln (1998), the process of research itself (methodology) is both dialogic and dialectical. The dialogue between the researcher and the subjects of inquiry becomes a process of intellectual investigation. This methodology reflects the need for critical theory to address and uncover the assumed truth of 'reality', to "transform ignorance and misapprehensions … into more informed consciousness" (Guba & Lincoln, 1998, p. 206). In my own work, this process of uncovering assumptions about reality will involve transforming the misapprehensions that have led those with disabilities to be characterized as asexual or the sexual expression of these youth as somehow problematic.

The methodological assumptions of critical theory frame the purpose of inquiry as critiquing the previously unquestioned and taken-for-granted structures. In some cases this may lead to a focus on restitution and emancipation for the participants or society that is at the aim of inquiry (Guba & Lincoln, 1998). This purpose differs from that of post-positivist inquiry, which aims to explain and predict; or that of research rooted in constructivism which would work to understand and reconstruct. With a focus on exposing opposing forces, emancipation, and restitution, the researcher conducting research supported by critical theory is not an innocent bystander quietly recording their surroundings. Rather the researcher becomes transformed into a subject, an advocate or activist, and is charged with the duty of uncovering the status quo, discovering previously unnoticed power relations, and questioning the way in which the subject or self is created.

The perspective used for this project is that of postmodernism, specifically poststructuralism. Postmodernism has expanded philosophical and cultural movements in Western thought since the 1960s, and resulted from the rejection of the previously heralded movement of modernism (Mansfield, 2000). Postmodernism rejected the grand narratives that were proposed under modernism, was sceptical of authority in general, and saw language as being central to subjectivity and culture (Mansfield, 2000). Within postmodernism there are two broad categories – poststructuralism and postcolonialism.

Poststructuralists such as Foucault, Derrida, Lyotard, and Kristeva focused on the relationships between concepts or meaning (also called the signified) and their material forms (also called the signifier), the relationship between the signified and the signifier are considered to be both unpredictable and unstable (Mansfield, 2000). In addition, meaning, truth and identity are all considered as concepts that are incomplete and contradictory (Mansfield, 2000). While postcolonialist work (including that of Said) focuses on the relationship between power and knowledge in non-Western nations. One of the key figures of the poststructuralist movement, French philosopher Michel Foucault, spent much time focusing on power/knowledge, the construction of truth for a given moment and the development of subjects.

3.2 - Michel Foucault

The work of Foucault is essential for this research project because there is a need to understand how the subject, the adolescent with a disability, is conceived. The major concepts of a Foucauldian approach are power/knowledge, discourse, and the subject. These concepts are all intimately linked and are dependent on each other for their existence and continuance. The fourth major concept that emerges from Foucault's work is that of governmentality which will be addressed later.

3.2.1 - Power/Knowledge

Power and knowledge are inseparable concepts for Foucault because power requires the generation of 'truths' in order to justify both the actions and outcomes of power (McHoul & Grace, 1993). For instance, during the eugenics movement, truth was generated via scientific studies showing that criminality was linked to feeblemindedness, and helped justify the sterilization of those deemed feebleminded. Foucault's concept of power breaks from the traditional historic type of power, power as a constraining force, exerted by a sovereign.

Sovereign power was characterized, in part, by the right held by the sovereign to make decisions about life and death (Foucault, 1978). During the classical age a transformation began; power came to be less about the judicial authority of the sovereign to spare life and sanction death; power began to extend beyond life itself, essentially it became "a right of seizure: of things, time, bodies, and ultimately life itself" (Foucault, 1978, p. 136). Ultimately power was exercised in order to protect and maintain the sovereign, not the subjects. This shift in power occurred as the deductive aspect of power became only one element among many others (Foucault, 1978). The focus was no longer on destruction and forcible submission of subjects; now the focus was positioned on the organization and growth of forces, and the control and monitoring that this requires. The power over death, was transfused into a power "that exerts a positive influence on life ...to administer, optimize, and multiply it, subjecting it to precise controls and comprehensive regulations" (Foucault, 1978, p. 137). Power was no longer a right exercised by the sovereign to protect their own life, but rather it was exercised for and by the subjects in order to ensure the existence of the whole. The conversion from power over life to a power focused on organizing life itself – biopower. The population was no longer interpreted as one that simply needed to be controlled; rather, they were seen as a resource that could be tended to, cultivated, and transformed in response to the needs of the state. This new view of the population required a new conception of power in order to regulate the masses.

Foucault introduced the idea of biopower in *Discipline and Punish* and extended his ideas in *An Introduction: Volume 1. The History of Sexuality.* Biopower, the power over life, emerged during the Classical period, out of the disciplines (in the form of army, schools, and barracks), the emergence of perceived social problems (such as public health, birthrates and housing), and the discovery of the body as a target for power. The focus on individual bodies and their discipline, aimed to optimize the function and usefulness of the population as a whole.

The appearance of biopower replaced the power of death, the symbol of sovereign power throughout the Classical period, with a "calculated management of life" (Foucault, 1978, p. 140). The outcome of a society based on technologies of power over life, according to Foucault, is that which uses anatomo-politics and biopolitics to develop and institute norms around which the population can be governed. Both forms of power developed throughout the 18th and 19th century, with anatomo-politics developing first and biopolitics arising later, finally these two poles merged in the 19th century to form biopower (Foucault, 1978).

3.2.2 - Anatomo-politics

The concept of anatomo-politics is especially important in relation to the nursing profession. Perron, Fluet and Holmes (2005) examined biopower (including anatomo-politics) in relation to nursing. In their work Perron et al. (2005), highlighted that interventions that result from anatomo-politics, including the management and categorization of docile bodies, ultimately function to identify individuals and groups that fail to conform to general social expectations. In their examination of biopower and nursing, Perron et al. (2005) situate nurses within a position of power that is conferred by their expertise; however nurses are also agents of the state and enact this role through knowledge and their conferred responsibilities to a larger social mandate. As such nurses come to occupy positions that enact the strategies of anatomo-politics.

Anatomo-politics are policies of coercion that act directly upon the body to manipulate not only its behaviours but its gestures and relations to others, it describes how one can control another's body, "not only so that they may do what one wishes, but so that they may operate as one wishes, with the techniques, the speed, and the efficiency that one determines" (Foucault, 1977, p. 138). The overall intent of anatomo-politics is the creation and training of docile bodies. Foucault (1977) argues that the creation of docile bodies involves the art of distribution, the control of activity, the organization of geneses, and the composition of forces.

The art of distribution is the allocation of individuals in space. The creation of dedicated spaces, separate, enclosed, and different from others, such as asylums, manufacturing spaces, hospitals, or barracks is required to create a docile body (Foucault, 1977). Within these enclosures each individual must be partitioned, or assigned a specific place. Partitioning functions to help supervise the movements, communications, and conduct of individuals and in turn to asses and judge. The distribution of individuals and work also occurs according to functional site, space that is organized around common characteristics. For instance, in hospitals there are spaces designated for lab work and research work and those designated for patient work. Lastly, the distribution of individuals also occurs by rank, which "individualizes bodies by a location that does not give them a fixed position, but distributes them and circulates them in a network of relations" (Foucault, 1977, p. 146). Rank may involve spatial assignment (i.e. to specific ranks within the military or hospital staff), but may also be accomplished by hierarchical assignment, based on one's knowledge or skills. Ranking individuals allows for both the supervision of the specific individual and for the supervision of the work of everyone (Foucault, 1977). Separating individuals not only communicates information about the subject, but also creates space within the institution and outlines what the space is used for and by whom.

Distributing individuals to specific locations is not the only tool used in the creation of docile bodies, the observation and supervision of these individuals is also crucial. The control of activity requires that activities are broken up and re-arranged into a timetable which both orders and asserts control over behaviours and actions. The timetable originated in monasteries and was based on the establishment of rhythm and the repetition of cycles. The usefulness of the timetable has extended to organizations such as schools and hospitals. Within the cycles of a timetable the temporal elaboration of the act becomes important - it is not enough to have time designated to a specific action, such as marching the troops, the act must also be broken down into specific elements within this time period (Foucault, 1977). This elaboration combines the body, and the gesture, with the body-object articulation. Attention to the body and the gesture focuses on the efficiency and speed of task performance (exhaustive use), while attention to body-object articulation defines the relation of the body to object that it manipulates. For Foucault (1977) body-object articulation is a disciplinary power of synthesis, which draws together the body and the object. The art of distribution and the control of activity establish set guidelines for behaviours, outlining who is allowed to occupy space, and how tasks conducted within those spaces is to be accomplished, this necessitates discipline based on the efficient use of time and space, a way to capitalize on time.

The third component Foucault outlines for the creation of docile bodies is the organization of geneses. Capitalizing the time of individuals involves that the organization of time, bodies, and abilities in a way that is susceptible to use and control. In order to examine this, Foucault focused on the structure of activities as parallel and successive events. The organization of time and bodies in this way ensures that specific groups do not mix but rather occur in different spaces simultaneously; activities are successive in that they begin and end at specified times. The schedule is constructed in accordance with a larger plan, which ensures that modules build on each other in increasing complexity, allowing for the examination and advancement of individual and collective abilities. Structuring activity in such a way also creates an opportunity for subjects to evaluate their own abilities against the abilities of others, in a given space and time.

The fourth and final discipline Foucault outlines for the creation of docile bodies is the *composition of forces.* This composition results in an efficient machine; for example, consider the movement of battalions in the army. While each battalion is composed of individuals, all the members must function in relation to one another, moving together to arrive in a final configuration. The result of the composition of forces is a single productive force whose effect as a whole is superior to that of the effect of its individual parts (Foucault, 1977). It is a force that requires the calculated management and effort of each individual member.

Anatomo-politics functions not only to create docile bodies, that function at the will of another in terms of efficiency, speed, and use of techniques, but also functions to train these bodies, so that they may act in accordance with social norms and learn to govern their own actions. Training the body requires that the body is attended to as both an object and instrument, which is accomplished through hierarchical observation, normalizing judgment, and examination (Foucault, 1977). These disciplinary actions ensure that the subject is aware of their position, actions, as well as the positions and actions of others in a given environment.

Hierarchical observation coerces subjects through direct supervision or the suggestion of supervision; this requires specific architectural components and the role of the supervisor. One method to achieve this supervision is through the creation of observatories as an architectural feature of hospitals, prisons or asylums. The observatory transfers the focus of observation from the outside world to observation of the world within, making those within a space visible (Foucault, 1977). The development of the panopticon by Bentham in the 1700s, utilized in prisons, is a prime example of hierarchical observation. The panopticon, originally a tower with windows, allowed for the observation of individuals in their cells and was meant to induce "a state of conscious and permanent visibility that assures the automatic functioning of power" (Foucault, 1977, p. 201). Another feature of the panopticon is a corridor radiating from a central location (i.e. the guard tower). This aspect of the panopticon allows the observer (located centrally) to see everything and everyone, but also keeps the observer from the sight of others. This presence, or presumed presence, leads the individuals being supervised to believe that are potentially subject to observation at any given time, resulting in their conformity to the norms and rules of the institution. The principle of the panopticon is something that continues to be seen, even in modern healthcare environments; consider the placement of nursing stations in relation to patient rooms and the increased visibility that this provides, of both professionals and patients. The opportunities for surveillance are reliant on "... individuals, its functioning is that of a network of relations from top to bottom...and laterally" (Foucault, 1977, p. 176). Surveillance and increased visibility exposes the behaviours of individuals not only to a higher power but also to each other. This allows for penalties and corrections to be administered by the subjects and by higher powers.

While hierarchical observation creates visibility for all of those within a given space, normalizing judgment functions as a system of micro-penalties. These punishments are essentially corrective measures that relate to the control of deviations related to time, activity, behaviour, speech, the body, or sexuality (Foucault, 1977). Punishments seek to reduce gaps between the individuals in the collective norm, and may be structured around gratification-punishment, forbidding advancement based on deviations, and the authorization of advancement based on adherence to behaviours of the norm. Normalizing judgement then is constantly at work, as subjects can measure their own actions according to the norm and govern their own bodies and actions to match those of the norm. This approach to punishment enforces norms and separates individuals based on achievements and abilities. The division between normal/deviant becomes even more apparent when the third disciplinary measure of training bodies, examination, is employed.

Subjecting bodies to examination combines the techniques of hierarchical observation and normalizing judgment. Examining and analyzing individuals differentiates them and gives visibility to their behaviours and actions in relation to others. Constant examination assures the hold of power over individuals, when a subject is constantly observed, or constantly threatened to be observed, it "maintains the individual in his subjection" (Foucault, 1977, p. 187). Foucault raises an interesting point in relation to examination – that the individual becomes defined by a network of writing and documents that are aimed at identifying, describing, and analyzing both individual and collective behaviours and actions. This is especially relevant to the field of health care as information about patients is largely communicated through assessments, evaluations, and documentation.

The creation of docile bodies and the training of these bodies, while presented as separate entities clearly work in tandem with each other to achieve the overall purpose of *anatomo-politics; the formation and manipulation of individual behaviours.* However, biopower, of which anatomo-politics is only one component, is focused on the management of life itself, at the level of the population. While the governance of the individual is an important aspect of this, to ensure that he or she functions efficiently and in accordance with norms, the management of the larger group must also be considered.

3.2.3 - Biopolitics

Anatomo-politics was one component that contributed to the development of biopower. The second component, biopolitics, formed later than anatomo-politics and was focused on the management and regulation of entire groups or populations. The concerns of biopolitics are birth and mortality rates, life expectancy and the conditions that affect these variables, such as health status or education. Biopolitics functions at the population level and does not involve the same individual observation as anatomo-politics. Rather, power is exerted through interventions and regulatory controls. Biopolitics uses larger narratives, such as public health, safety, and protection to manage specific populations. The combination of these two opposite poles – a discipline of the body and the regulation of the collective made possible the power over life itself, through the emergence of biopower (Foucault, 1978),

3.2.4 - Discourse

Biopower cannot function without discourses, as it is within these discourses that knowledge is generated. This knowledge subsequently supports and rationalizes behaviours that compose the accepted societal norm. The concept of discourse typically conjures visions of texts and linguistics – and an analysis of the written or spoken word. However, Foucault envisioned discourse to be broader and more encompassing than the written word. For Foucault, discourse includes discursive practices in the form of scholarly disciplines and disciplinary institutions (McHoul & Grace, 1993). Scholarly disciplines include fields such as nursing, education, science, and psychiatry, whereas disciplinary institutions include prisons, hospitals, and schools. Both scholarly disciplines and disciplinary institutions create bodies of knowledge, procedures and rules that are used in discursive practices and in doing so legitimate and propagate this knowledge. In addition to the generation of discrete bodies of knowledge, scholarly disciplines create various forms of social control which adds to Foucault's conception of discourse (McHoul & Grace, 1993). For example, the scholarly discipline of psychiatry has worked to differentiate abnormal and normal behaviours, and in doing so has justified the social control and medical management of those deemed ‘abnormal. A detailed example of the function of biopower and the interplay of its components is put forth by Foucault in a discussion of sex and sexuality.

In *An Introduction: Volume 1. The History of Sexuality* Foucault specifically describes biopower in relation to sex and sexuality and depicts how sexual conduct moved into political and public discourse. In the 18th century, with the decline of sovereign power, government came to view the general population as both an economic and political problem (Foucault, 1978). Population “as wealth, population as manpower or labour capacity, population balanced between its own growth and the resources it commanded” (Foucault, 1978, p. 25), became the concern of government. As the wealth and power of the government was contingent on the health and stamina of the population as well as the resources it required. As a result, sexual conduct of the population emerged in public and political discourse, resulting in the generation of knowledge, disciplines, sanctions, and interventions.

Sanctions and interventions are made possible through the use of both anatomo-politics and biopolitics. The use of anatomo-politics, allowed for spaces to be constructed in a specific way, Foucault (1978) uses the construction and distribution of dormitories as an example – single sex, with or without screens and partitions. In this example the use of anatomo-politics serves to order and control the space, which allows for the increased surveillance of the individual. In an environment such as this, the individual begins to self-govern their practices in order to conform to the goals of control and monitoring. On a larger scale sanctions can be enforced through biopolitics, interventions are targeted at specific groups and the entire social body. Modern day examples of this include advertising campaigns for birth control, or vaccines, and political debates about homosexual marriage. These interventions are legitimized and made even more public through regimes of practice made possible by various discourses; medical and social discourses combine to produce and reinforce truths around the negative impact of smoking and drinking during pregnancy, thereby legitimizing the processes put in place to prevent this from occurring.

Sanctions and discourses around sexual conduct continue today, Coleman (2002) notes that by the end of the 20th century, monumental changes in Western society had occurred in relation to sexual conduct. Birth control on school agendas, masturbation as a natural/healthy occurrence, homosexuality being unclassified as a psychiatric disorder, and the growth of the pornography industry all indicate that sex and sexuality, have become more open public items. However, one cannot help but wonder if these new social norms along with the production of knowledge and truths – by the discourses of public health, nursing, medicine – only increased the attention to, and acceptance of, specific forms of sex and sexuality. If so, then did this attention also identify specific populations for whom these behaviours were deemed acceptable? In regards to youth with disabilities subjectivity often creates them as dependent and asexual – stereotypes that persist into adulthood. And as a result of this, individuals with disabilities are an example of a 'subject' for which sex and sexuality is not an appropriate behaviour.

3.2.5 - Subjectivity

Foucault was interested in the way in which subjects were created through both power relations and discourse. Rejecting prior conceptions of the individual/subject that held that the subject existed first and power was exerted afterwards in the form of oppressive political and social powers, Foucault saw the subject as both the creation of power and as a vehicle for power (Mansfield, 2000). Power comes before the subject and allows for its creation. For example, to be disabled requires that the individual fit into a pre-designed mould, something that is in opposition to what, in Western culture, fits the definition of able-bodied. Such definition exemplifies the interconnectedness of the concepts – discourse creates the subjectivity of the disabled and by participating in the diagnostics, classifications, funding formulas created and required by society and government the individual with disabilities acts within this framework.

As is demonstrated above, Foucault interprets subjectivity as being created through the relationships between power and subordination; the 'individual' is an effect of power and their characteristics are considered as having been designed for, not created by, the individual (Mansfield, 2000). Separating the subject from others, physically and mentally, allows the individual and their actions to be measured against various norms and standards, which in turn result in the identification of behaviours and the creation of subjects that can easily be slotted into categories that are ranked by acceptability (Mansfield, 2000). The concept of subjectivity is closely linked to that of biopower. For example, consideration must be given to the health of the population as a whole and also to the health of individual subjects. This is especially important when the state is dependent on the availability of a healthy, skilled, and docile population. As such, the health of the individual is, in part, a result of sexual conduct, and in order to maximize the health of the population, specific individuals may be subjected to the regulation of their sexual health (the premise of eugenics). Governmentality and the government of conduct is a way to accomplish this.

Government has been defined simply as the "conduct of conduct" (Foucault, as cited by Dean, 1999, p. 15). Government is focused on the guidance of human behaviour, and endeavours to transform who individuals are and how they behave (Dean, 1999). In regards to sexual expression and sexual health of youth with disabilities, the exercise of government may be concerned with how youth with disabilities are punished or rewarded when engaging in sexual expression (i.e. displaying affection, masturbating). As well the government of behaviour may present itself in the way the interactions of youth with disabilities are structured or experienced in order to promote asexuality or normalize heterosexuality.

Government is not carried out by the state in isolation; rather it occurs within institutions and on the individual level through self-governance. Self-governance can be thought of as the adjustment of behaviours or actions in order to satisfy accepted norms and rules and truths.

> The punishment or stigmatization of so-called ‘unnatural’ actions and identities is everywhere apparent in our society, and function to reaffirm or naturalize that which is held to be ‘normal’. And we are all both agents and effects of disciplinary regimes. (Sullivan, 2003, p. 84)

This quote reflects the power of stigmas, those attributes that differentiate someone from others in a specific category in a less desirable way, thereby reducing the individual from ‘normal’ to ‘tainted (Goffman, 1963). Sullivan’s quote can also be applied to the involvement of nurses in the care of adolescents with disabilities. As a respected professional body, nurses have the power to enforce punishment, stigmas, or instead to challenge them.

The work of Foucault provides a comprehensive base on which the actions of individuals and groups can be understood and interpreted. From the spatial organization of institutions to the establishment and propagation of the norm, Foucault’s work provides a theoretical understanding of how and why subjects become active participants in maintaining the status quo.

3.3 - Rejection and Imperfection

The collective need to normalize the population as well as individuals is clarified through the work of Foucault. But what happens to those that fall outside the norm? Historically, individuals and groups who fall outside of what is considered ‘normal’ or ‘acceptable’ have been excluded from society both structurally (i.e. institutions) and socially. Such exclusion serves to separate the 'imperfect' individual from the general population. Imperfection may be determined by actions that fail to meet social norms, or by bodies and ideas that disturb the status quo. In the context of disability, this may involve the rejection of individuals as suitable sexual partners or the abjection of activities or bodily functions that are both familiar and yet somehow constructed as dirty. To complement the work of Foucault this section will detail the concepts of abjection, purity and the rejection of the imperfect body, social and spatial exclusion, and the total institution and stigma, to provide a broader understanding of the implications of the imperfect subject.

3.3.1 - Abjection

Abjection has been described as "that which does not respect borders, positions, rules. The in-between, the ambiguous, the composite" (Kristeva, 1982, p.4). Abjection then is the unconscious reaction to a compromise of our subjective border, the expulsion of what is interpreted as "other" (McAfee, 2004), it is the exclusion or refusal of something that is both familiar and yet seemingly impure or volatile. Abjection is closely related to the concepts of self and the other. Subjectivity, the sense of self, as described by Foucault, has been presented above. However, in order to fully understand abjection, it is necessary to explore the notion of self as presented by Julia Kristeva, who is situated within the psychoanalytic tradition. Similarly to Foucault, Kristeva saw *'le sujet en procès'* (the subject in process or on trial) as a construction, not as a pre-existing entity; the subject is constantly changing as a result of interactions with others and the effect of this feedback on the orientation of the self – feedback that affects our self-construction and the actions chosen in the future (McAfee, 2004). For Kristeva this process begins in the infantile stage – when the infant begins to "expel from itself what it finds unpalatable" (McAfee, 2004, p. 35) and continues throughout life as it interacts with those around it.

Like Foucault, Kristeva sees the subject and their world as two inseparable dependent concepts – each continuously defining and restructuring each other.

Kristeva (1982) views subjectivity as what is contained within the imaginary borders drawn around the body (much like the chalk outline of a body). However, this imaginary line is constantly compromised by the natural functions of the body, urine, vomit, menstrual blood, ejaculation; the self is constantly flawed, tainted, and as a result unstable. This border of the self is not clean or permanent; it requires continuous work because of the natural flow of these bodily fluids that disturb the borders of selfhood.

Abjection then is an unconscious reaction to the compromise of our subjective border, the expulsion of what is interpreted as "other" (McAfee, 2004), it is the exclusion or refusal of something that is both familiar and yet seemingly impure or volatile. Bodily fluids alone are not the only stimulus for abjection; the abject includes "what disturbs identity, system, order. What does not respect borders, positions, rules. The in-between, the ambiguous, the composite" (Kristeva, 1982, p.4). Kristeva presents extreme examples to make her point – cadavers, excrement, spoiled milk, the blood and pus of a wound – all represent objects and experiences which are familiar yet at the same time tainted and impure. The process of abjection also involves a reconstitution of the subjective border, in relation to the repulsion of spoiled milk Kristeva (1982) states: "but since the food is not an "other" for "me," ...I expel myself, I spit myself out, I abject myself within the same motion through which "I" claim to establish myself" (p. 3). The abject does just this; it signifies what is other, while establishing the subject. Those things that do not respect rules or boundaries that are ambiguous are often times also very familiar and enticing. Death and the sight of the cadaver, is an example Kristeva utilizes to describe this. Death in its most permanent form, the cadaver, is a memory of our own mortality. The cadaver compromises the stability of our own subjectivity; it is a familiar person, yet that person is vacant, hollow, and filled with liquids not their own, cold. The familiar individual, as a cadaver, is violated and impure.

Abjection includes what physically crosses the boundary of the self, as well as the experiences and ideas that unsettle the individual, which cross boundaries and challenge an accepted notion of truth. This is often an unexplained or overlooked area of nursing practice. Nurses' reactions to specific behaviours (such as sexual practices) are often neglected in research and practice (Holmes, Perron & O'Bryne, 2006). For example, the anus is "a site of disgust and abjection par excellence" (Holmes et al., 2006, p. 307) that can be used to explore the reactions of disgust and danger. To many the anus is singly associated with defecation and therefore dirt and excrement, while to others it is an erogenous zone. With the relegation of the anus, in Western culture, to solely an orifice through which one defecates, any connection to sexual pleasure or arousal may result in negative feelings (Holmes et al., 2006). In regards to unprotected anal sex between men, Holmes et al. (2006) state that facing and accepting this behaviour would "allow the Other to symbolically penetrate the Self. This would admit the potential penetration of a contaminated (polluted) entity into the boundaries of the Self" (p. 310). The abject in this case, crosses a thought boundary versus a physical boundary.

Abjection becomes the refusal or disposal of something both impure and familiar at once, the expulsion of something that is a part of oneself. For example, the reaction to the sexual conduct of the disabled subject may provide an example of abjection. Sexual intimacy, while familiar, may violate accepted truths – that the individual with a disability is asexual, or in need of protection. Imagine a nurse working with a woman with a developmental disability who is seeking information about safe sexual practices for anal sex. The nurse in this situation may be faced with abjection on two levels: first, that an individual with developmental disabilities is engaging in sexual activities and second, these activities may be considered deviant.

Nursing discourse promotes behaviours and lifestyles that create and enable the ideal healthy body. However, the construction of the nursing profession makes accommodations for the care of individuals who may be seen as polluted or unclean challenging, as the nurse remains a subject who usually is forbidden to express disgust (Holmes et al., 2006).

3.3.2 - The Other

In the past, moral issues in the context of health care have been examined from a perspective that places the practitioner at the centre of the examination. Such a focus helps to ensure that the practitioner is reflecting on, and practicing in accordance with, existing professional codes of conduct (Shildrick, 1997). In doing so, the practitioner keeps their practice within binary categories of good/bad, health/disease, normal/abnormal, and moral/immoral the definitions of which are influenced by various discourses. This historical approach to moral issues positions the patient as a passive receiver of service, rather than, a self determining moral agent within the situation. Shildrick interprets moral agency as the "sense in which an individual can be said to be in control of and responsible for choices made and acted on within the moral sphere" (Shildrick, 1997, p. 6), thereby positioning all parties in a situation as moral agents, not only practitioner. These are important concepts to sexual health and disability, as it repositions the power from the practitioner and divides it amongst all parties involved.

An additional concept that Shildrick addresses in her work is that of embodiment and the "imperfect body". Shildrick favours a view of subjectivity that demands attention to the physical manifestation of the body (embodiment/corporeality); this approach draws attention to the implications of the "imperfect" body. Using the concepts of the monster and vulnerability, Shildrick (2002) explores the permeability of boundaries and binaries that Western society has used to establish the normal/abnormal divide. Representations of the monster, conjoined twins, and cyborgs, reveal bodies that blur the distinction between normal/abnormal bodies. Furthermore, these bodies represent a vision of 'the other', an 'other' who violates the ideal autonomous, closed self of Western ideals (Shildrick, 2002).

The corporeality of the 'other' has implications in the modern world, those that fall outside of the social understanding of 'normal' or 'acceptable' have historically been excluded from society both structurally (i.e. institutions) and socially. In relation to disability this social and structural segregation is intimately linked with the total institution (Goffman, 1961), and the stigmas that are attached to specific subjects and their actions. Exclusionary practices, attitudes and policies serve to separate 'abnormal' individuals from the general population. Such exclusions have served multiple purposes; to separate the perceived 'imperfect' individual from the general population for custody and caring, as was evidenced by the institutionalization of individuals with disabilities. Alternatively, this separation has been used to rehabilitate or assimilate 'the other', for instance residential schools for aboriginal youth.

3.3.3 - Impurity and Rejection

Douglas (1966) discusses the concept of dirt and people's reactions to dirt; she states; "our pollution behaviour is the reaction which condemns any object or idea likely to confuse or contradict cherished classifications" (p. 45). For example, finding underwear in the kitchen and frying pans in the bedroom would contradict where these objects are normally found. Douglas notes that the items themselves are not necessarily dirty, but their placement outside of the classification system marks them as dirty. However, in a system of total classification, there will be anomalies. An anomaly could be the ill-placed frying pan or an individual with a physical, mental, or social difference.

Douglas (1966) identifies that there are several ways anomalies are dealt with. They can be ignored, they can be recognized and then condemned, or they may force the creation of a new conception of reality in which the anomaly has a place. The last option, of creating a new reality, while ideal, is rife with complications. It is not impossible for an individual to revise their own scheme of classifications to make room for an anomaly; however, the influence of culture, community and society normally affect the scheme (Douglas, 1966). The influence of this larger system establishes the organization for classification schemes, which makes reorganization of the entire system challenging. Douglas suggests there are five ways for approaching and dealing with anomalies within a culture: the creation and utilization of an interpretation of the anomaly, physical control, avoidance, labelling the anomaly as dangerous, and the use of rituals.

Historically physical control, avoidance, and labelling of the anomaly, exemplify the typical means that medical and social discourses have engaged in to 'manage' individuals with disabilities exhibiting sexual interest and behaviours. Because of the construction of the disabled subject as childlike, the category within which they "fit" is that of the asexual innocent. When individuals break out of this system of classification by acting on natural impulses and drives, they demonstrate pollution behaviours. Instances of physical control (sterilization), avoidance (exclusion and segregation), and labelling as deviant (the attention to defining deviant behaviours in this population), have all been used to adjust the classification system around this pollution behaviour.

While systems of classification outline where objects or people belong, there are events that challenge these systems. One valuable experience is the social model of disability. The social model shifts the focus of disability from a medical issue to a political and social issue (Oliver, 1998). Wendell (1996) addresses the rejected body and notes that disability has, in part, been created by physical structures and social organization, which has resulted in a failure to provide an adequate amount and type of support required for individuals to fully participate in society. The role of health care professionals, including nurses, in the process of othering and stigmatization cannot be underestimated. Farrell and Corrin (2001) discuss medical treatments offered to children born with congenital abnormalities. While some treatments aim to reduce associated health complications, others focus on concealment, such as plastic surgery options offered to eliminate the facial 'deformities' associated with Down Syndrome. The implication this type of treatment communicates is that difference of this nature cannot be tolerated, and is *repairable* (Farrell & Corrin, 2001).

The concepts of impurity and rejection are closely related to abjection, in part, because what is considered abject contributes to what is impure and how the rejection of the impure are managed. Another aspect of impurity and rejection is that of stigma, because stigma, like abjection, may result in rejection or exclusion.

Goffman (1963) describes stigma as an attribute that differentiates someone from others in a specific category in a less desirable way and thereby reduces that individual from normal to tainted. Like the meaning of the term itself, stigmas are also not static. Historically a stigma was the marking of the flesh of an individual to signify that they were tainted (Curra, 2000). The term stigma originates from Greek terminology to refer to a mark made with a pointed tool (Pearsall, 2002), and has been connected to a tattoo mark used to brand individuals to display their connections to a specific temple; the same use of the tattoo could later signify that an individual was a slave or a criminal (Whitehead, Mason, Carlisle & Watkins, 2001). But in our current context, the description of stigma provided by Goffman seems most applicable. The attribute need not be physical; it may result from a discrepancy between a perceived norm and reality that causes the problem (Curra, 2000).

The development of stigmas may reflect the aftermath of dramatic events in which societies re-prioritize what is seen as important and engage in the reform of categories that function to rationalize stigma and social exclusion (Whitehead, Carlisle, Watkins & Mason, 2001). In relation to sexuality and disability, the eugenics movement serves as an example of the rationalization of stigma and social exclusion. The desire for a healthy population, one absent of crime and 'feeblemindedness' provided the ground for new terminology to emerge and redefined the values that drove habitation programs for individuals with mental health issues and developmental disabilities. Individuals with developmental disabilities were seen as threats to the gene pool, and as presented earlier, the sterilization and segregation of these individuals was supported throughout North America. The discourse of the movement functioned to rationalize the stigma around sexuality and disability as well as the actions that were felt to be necessary – institutionalization and/or sterilization. As this example demonstrates, stigma is not a concept that functions independently, but rather is closely linked to other processes that aim to marginalize and exclude (Whitehead, Carlisle et al., 2001).

Society establishes means of categorizing persons and attributes normal/acceptable behaviour to the category. One of the norms that categorize youth with cognitive disabilities is the belief that they are asexual, which classifies sexual expression by these individuals as unnatural or deviant. Since stigmas are based in societal definitions, it makes sense that stigmas are culturally and temporally defined – the definitions and thereby implications of stigmas, even within the same society, can change over time (Mason et al., 2001). In addition to being temporally and culturally specific, stigmas may vary within a culture, deeming some sets of behaviours appropriate for a group of individuals and unacceptable for another.

Mason et al. (2001) implicate health care providers as contributors to the stigmatization and exclusion of the same individuals that they claim to help. They characterize the health care system as dependent on conformity, a position which cannot accommodate individual medical philosophies or advocate for individual choice and control related to treatment on/of the body. Care providers expect individuals with disabilities to be asexual and therefore frequently find it difficult to identify sexuality as a component of care. Health care settings and associated processes legitimate perceptions of difference because of the medical model framework that established different treatments, procedures and types of care based on an individual's diagnosis (Whitehead, Mason et al., 2001). However, when in a health care setting, the affect caused by stigma may be significantly reduced, as it is an appropriate space for the individual to exist in. It has been noted that outside of this context, say on the street or in the supermarket, stigma may result in the disgust or fear of others, and may lead to avoidance of the individual (Whitehead, Mason et al., 2001). A good example of this behaviour would be the prolonged glances that are given towards individuals who have physical features that may not be considered 'normal', such as the facial features typical of individuals with Down Syndrome.

The stigmatization of individuals with disabilities and the labelling of conditions is a double edged sword, as being assigned a label or category can allow one to have access to specific services. However, the categories on which labels are rigidly based can have detrimental effects on the individual, as was recently demonstrated in the United Kingdom with the removal of support services from an individual with Asperger's Syndrome because his IQ was deemed to be too high to be eligible for services (BBC News, June

2007). Stigma, the construction of the subject, and discourse can lead to physical exclusion and psychological exclusion not only from services, but also from social processes and so called 'communal' spaces.

3.3.4 - Total Institutions and Stigma

In his work on asylums, Goffman (1961) describes the idea of total institutions as enclosed places where specific categories of individuals work and live an administered life, for a period of time. The institutionalized care settings that youth with disabilities encounter, (i.e. rehabilitation facilities, hospitals, schools) can all be considered total institutions. Goffman suggests a total institution exists to care for persons that are seen as incapable of doing so. Within total institutions there is a control of the dissemination of information and a definite difference in the hierarchy between staff and residents, and a deterioration of the barriers between routines of sleep, play, and work. While Goffman may not have agreed with the idea of a hospital or group home as a total institution, because of a lack of absolute barriers, using Foucault's notion of disciplinary mechanisms, it can be seen how places, such as hospitals, are total institutions.

Foucault (1977) regarded the processes of discipline as mechanisms that create individuals as objects and as "instruments of its exercise" (p. 170). Within healthcare settings disciplinary mechanisms function to physically and mentally segregate patients from the staff, the external world, and regular daily routines. In addition, these mechanisms create the patient as a docile body, a compliant subject, by subjecting them to normalizing judgment, hierarchical observation, and examination. As such, it is possible to envision the hospital environment as a total institution, especially given the set of characteristics that Goffman provides.

Goffman (1961) presents four characteristics as representative of the total institution. First, events of life that normally occur in different areas or environments, within the total institution, take place in the same location, under the direction of an authority figure. For instance, in the world outside, the patient may have the ability to wake when he or she chooses and move about freely to eat breakfast in the kitchen, and bath in a private washroom. Within the total institution of the hospital these activities occur within the same setting, usually the patient room. The second and third characteristics describe regular daily life in the institution as driven by a schedule imposed by a higher authority with activities being performed in the company of others (Goffman, 1961). This routinization is common to the world of the hospital. For example the daily life of a nurse is organized around repeated secular events, the object of which is the patient (Chambliss, 1996). Events, especially in hospitals, are fixed to a schedule; medications are administered at specific times, vital signs are expected to be finished for morning rounds, and meals are eaten at certain times. Lastly, the activities conducted within a total institution are performed to fulfill the overall goals of the institution; in the case of rehabilitation facilities, the goal may be to improve or maintain health and promote healing. The activities of the total institution must then reflect these goals, and activities sanctioned by the hospital may take precedence over the desires of the patient. In many ways the patient becomes the object of work.

The social lives of people with disabilities may become more circumscribed than the lives of those without disabilities because of the increased care needs posed by their conditions (Zajicek-Farber, 1998). The social isolation this creates may be fostered by communities and caregivers. A good example of this is the resistance to group homes being established in communities and neighbourhoods, a phenomenon often referred to as NIMBYism (Not in my backyard). A case study investigating the establishment of group homes in Montreal, Canada, examined community opposition against the establishment of a home focused on mental health, one supporting individuals with intellectual disabilities and a third which provided transition housing for those recently released from prison (Piat, 2000). In all three cases the majority of those in opposition to the establishment of the group homes based their arguments on the fact that the residents of these homes would never successfully integrate into community life. This is an example of the way in which the lives of individuals branded as different lead lives that are established and governed by others, where the right to do something as simple as choose where to live is overseen or influenced by the larger community. This can lead to exclusionary practices which dictate not only where someone lives, but also the manner in which life is lived.

Sibley (1995) discusses exclusionary practice as those that are less noticed, thereby concealing the ways in which control is exercised. As raised by Foucault in his description of the art of distribution, the structuring of social space communicates who belongs in a given space and who does not belong. Contributing to the structuring of social space is the urge to separate the other, to "expel the abject" (Sibley, 1995, p.8). Kitchin (1998) discusses how spatial segregation, through institutions and inaccessible public space, contributes to the exclusion of people with disabilities in society, which in turn propagates social misconceptions.

Social structures function to 'safeguard' members of a community and outline specific boundaries and margins (Whitehead, Mason et al., 2001). These structures are not always physical in nature; they include values, norms and standards that create a specific social identity. Values include what is considered to be good and important by a society, such as sexual rights. Norms are the informal rules that govern behaviours, for example, typically voyeurism is seen as a violation of sexual and social norms. Standards are expectations that relate to a person's behaviour in a specific situation (Whitehead, Mason et al., 2001). Those who conform to these values, norms, and expectations will be rewarded, while those who act outside of them run the risk of being identified as different and branded as deviants.

3.4 - Deviance in Difference

This section will explore the construction of deviant behaviour, specifically sexual behaviour in those populations considered 'different' or 'dangerous' to the so-called normal population. Deviance, like stigma, is temporal – specific to a time, place, and society – and is a social relationship (Curra, 2000; Whitehead, Carlisle et al., 2001). As such, no single behaviour or feature will be considered deviant across time and place, just like no single stigma would hold the same meaning across different times, places, and societies. Culture is based on the understandings that are created and shared by people in a specific time and place, then transmitted to future generations (Curra, 2000). This type of socialization is evident in nursing and in the 'inheritance' of professional practices and beliefs. For the sake of stability, a culture, presents a uniform impression as to values, norms, and standards, and in doing so communicates to those within the culture appropriate ways to act, feel, and think. Those who fail to meet these norms and standards risk condemnation and persecution (Curra, 2000). Deviance then, is a social construction; "people acting together create social deviance by what they believe, feel, say, and do" (Curra, 2000, p. 1).

Deviance is a binary and in order to classify something as deviant there must already be a category that signifies 'normality'. As outlined by Douglas (1966) social patterns can be disturbed when an anomaly presents itself. When differences are recognized they may develop into value-based social constructions that encourage the development of prejudiced views and actions (Whitehead, Mason et al., 2001). For individuals with disabilities, these value-based constructions are everywhere, from the presence of sterilization procedures in the 19th century to modern day 'work programs' that prepare individuals to fulfill the supposed ideal vision of a contributing member of society. Another example is the diagnosis of psychiatric disorders, some diagnoses are assigned to patients on the bases of infractions of moral and ethical codes, which result in a 'treatment' that removes the 'offender' from the larger social context (Mercer & Simmonds, 2001). This removal returns peace to the disturbed outer world and, through treatment, attempts to instate a moral and ethical code within the individual. However, the individual is marked as deviant, and it is these symbols and representations that come to communicate difference to the community.

Symbols exist and are perpetuated because the group, as a whole, agrees with them, because as they learn these symbols the individual begins to understand how they and others are defined (Curra, 2000). Echoing the work of Foucault, Curra acknowledges that through the perspectives of others we come to see ourselves and develop a sense of what and who we are. Developing the sense of self, is closely linked to Foucault's notion of self-governance, the way that someone acts or appears in a given situation, and whether this represents 'normal' or 'deviant' behaviour. In relation to the sexual expression of individuals with disabilities, the construction of the subject as asexual, coupled with negative messages regarding sexuality, may be internalized by the individual and affect their definition of self and how they, or those around them, govern their behaviour.

3.5 - Chapter Summary

Foucault's work on power, discourse, and subjectivity combined with an understanding of abjection, rejection and exclusion and how these create and enforce deviance, are foundational to this research. The work of theorists such as Foucault, Goffman, Kristeva, and Shildrick affirm that the use of a critical approach – one that uncovers the taken for granted regimes of practice – is essential in order to reveal how nurses either perpetuate given stereotypes or participate in resistant measures that challenge preconceived notions about sexual health and disability.

Chapter Four – Methodology

A distinction is made in this chapter between methodology and methods. Methodology refers to the approach that structures the research and how it is conducted, whereas methods are the tools used to gather information. All methodologies have a theoretical or philosophical underpinning, this outlines the purpose and role of the researcher, what types of questions are asked, and structures how the research is conducted. Both the methodology and the methods used must reflect the qualitative paradigm and the epistemology of the researcher. In the case of this research, the qualitative paradigm is that of critical theory as described by Guba and Lincoln (1994), and the epistemology has been identified as postmodern, specifically poststructural. This chapter contains a discussion of ethnography, with a specific focus on critical ethnography, which was used for the study. Differences between classical and critical ethnography will be identified and critiques of critical ethnography will be addressed. This will be followed by a description of the methods that were utilized to collect data and the processes of data analysis employed.

4.1 - Research Design - Ethnography

The word ethnography conjures images of privileged, white researchers spending long periods of time in remote villages, where studying or observing inhabitants who, presumably, had yet to be sullied by Western influence. In the late 1800s and early 1900s this would have been an adequate description of the ethnographic researcher. Cultural anthropologists such as Franz Boas, George Bird Grinnell, and Margaret Mead all spent extended periods in the field working among different cultures in locations ranging from British Columbia to American Samoa. At this time, cultural anthropologists were using ethnography in an attempt to study small societies or cultures (Savage, 2000), before these communities were exposed to the influence of Western culture (Savage, 2006). In the 1920s, ethnography was adopted by sociologists for use in urban areas. Ethnographies published by sociologists in this time period shifted the focus from remote communities to those at home and in urban settings (Savage, 2000). While small societies and specific cultures were still the main point of interest, these societies were now segments of the Western population. These ethnographies tended to focus on marginalized communities, as exemplified by Whyte's (1955) *Street Corner Society* which focused on life in the "Italian slums". Perhaps most well known are those ethnographies published by students associated with the Chicago School. Early ethnographies from the Chicago school were published under the guidance of Robert E. Park and Ernest W. Burgess, and included works such as Donovan's *The Saleslady* and Cressey's *The Taxi-Dance Hall* (Deegan, 2001).

Ethnographies of the 1960s were influenced by attention to everyday work and emergent meanings. Ethnographic writing in the early 1960s focused on professional socialization, the experience of patients, and the relationships between doctors and patients. Later writings focused on social constructionism and work practices (Bloor, 2001). Examples include *Boys in White: Student Culture in Medical School* (Becker, Greer, Hughes & Strauss, 1961) and *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates* (Goffman, 1961).

In the late 1960s and 1970s ethnography continued to develop, social scientists began rejecting the grand theories offered by previous generations and began to be influenced by the writings of critical theorists (Anderson, 1989). The combination of these events led to the development of critical ethnography. More recent adventures in ethnography have focused on gaining multiple perspectives of many individuals – to gather a range of voices – some perspectives may be more prominent, while others may be marginalized (Savage, 2006).

Nursing has utilized ethnography, in various forms, to explore the lives of those that are marginalized. Kinavey (2006) used ethnography to explore self-understanding in adolescents with Spina Bifida and the influence of larger cultural discourses on the development of self. Renaud (2007) employed critical ethnography to describe the experiences of lesbians with the health care system during pre-pregnancy, pregnancy, and birth within the context of larger oppressive structures (i.e. family and politics). In her PhD dissertation, Martin (2004) used critical ethnography to explore family and staff responses to the sexual behaviour of individuals with dementia in long term care settings. All three of these research projects utilized ethnography to explore and understand the processes and experiences of marginalized populations. Savage (2006) notes that ethnography is particularly useful for health research, to situate what is seen in the field within the larger context; to see the links "between everyday action or interaction and wider cultural formations" (p. 385). The ethnographies conducted by the researchers described above situate the everyday in the context of wider discourses that are at play in individuals lives.

4.1.1 - Classical versus Critical Ethnography

The exploration of culture is central to ethnography. Culture has been identified as the basic element that drives ethnographic research (LeCompte, 2002). Initially culture was interpreted as a set of norms that was acceptable for a defined group of people, or a society, with culture changing only subtly between generations (LeCompte, 2002). The understanding of culture has shifted, with the help of individuals like Bourdieu and Goffman. Culture is seen now as both an inheritance as well as a set of choices and reconstructions (Foley, 2002; Savage, 2006). Just as the definitions of culture have evolved over the years, the goals and methods of conducting ethnography have also evolved.

Ethnography has been implemented by diverse disciplines, such as nursing, medicine, sociology, anthropology, and education, and has taken on new forms, expanding on the original ideas and methods of classical ethnography. Grbich (1999) identifies three main forms of ethnography; classical, critical, and postmodern/post-structural ethnography. Regardless of the form, ethnography aims to describe or explain a phenomenon or to develop a theory rather than to test a hypothesis (Hammersley & Atkinson, 1995).

The goals, researcher position and perspectives on researcher bias, and ideologies of classical and critical ethnography can be better understood if the theoretical underpinnings of each are made explicit. To begin with, classical ethnography stems from structural functionalism or interaction and is classically linked to colonialism (Grbich, 1999). The purpose of classical ethnography is to provide a description of a true insider's perspective (Thomas, 1993). While classical ethnography seeks to describe and interpret culture or cultural phenomenon, critical ethnography attempts to uncover the hidden or unnoticeable structures of power and oppression and researchers "seek to unmask structures of power and control" (Bransford, 2006, p. 178), thereby explicating a specific political agenda.

This is in contrast to Hammersley and Atkinson's (1995) opinion that ethnographic research should not serve political purposes but have the sole purpose of generating knowledge. Critical ethnography is rooted in theories that examine power relations, and there is an assumption that society and the subjects within a society or group are not fully conscious of the existence and function of power hierarchies (Grbich, 1999). These power structures create, legitimate and promote the continuance of specific worldviews that are accepted and assumed by those functioning within them; this subsequently creates inequalities and hegemonic practices. Critical ethnographers have historically utilized Marxist theory and the perspectives of Habermas to address power relations (Grbich, 1999) and now include the perspectives of postmodern/poststructuralist theorists such as Michel Foucault, whose work provides the theoretical underpinnings for my research.

The political nature of critical ethnography is reflected in its supporting assumptions; that the status quo and assumed meanings, available in a culture or society, should be challenged rather than accepted uncritically as in classical ethnography (Thomas, 1993). If the researcher assumes the status quo and accepts that the meanings provided within a specific milieu are indeed the "truth" then he or she will not look for alternate meanings or question how these meanings and truths have come to be created and accepted. Clearly the assumptions that provide the foundation for critical ethnography are not value free; rather there is a set agenda to uncover unacknowledged ideas and beliefs.

Post-positivists and, I would argue, naturalists such as Hammersley and Atkinson idealize neutral and value free research. Critical ethnography takes a different approach, and presents new complications for researchers, especially around issues of rigour. The development of naturalism occurred in response to critiques that qualitative research would not meet the requirements of what was considered ‘rigorous’ research as outlined by positivism (Hammersley & Atkinson, 1995). Naturalists believe that the social world needs to be studied in a “natural state” without disruption from the researcher, with the goal of describing “what happens in the setting, how the people involved see their own actions and those of others, and the contexts in which the action takes place” (Hammersley & Atkinson, 1995, p. 6).

The departure of critical ethnography from the goals of classical ethnography requires a new perspective on researcher bias and position. With the goal of uncovering hidden power structures and making these visible, the researcher must recognize their biases and accept that she will not only influence the research setting but that the research setting will also influence the researcher (Thomas, 1993). This explicitly political agenda is problematic for many, especially those who feel that research should not have specific political goals, but rather focus solely on the development of knowledge. However critical theorists would ask if any knowledge is developed in a neutral manner? All 'science' is driven by specific theories of knowledge (epistemologies) and thoughts about what is available to be known (ontology).

Ethnography in general, including critical ethnography, has been accused of failing to consider the broader context (e.g. political, economic) and social transformations that occur within the research setting (Hammersley, 2006; Wexler, 1987). Wexler, in examining schools and the educational system, points out that schools are no longer the only place of education and therefore cannot be the primary place of educational research. The very same can be said of nursing, as nursing and health care does not occur in hospitals alone. The broader discourses at play must be acknowledged and their effects on the research setting determined. Ethnographic research needs to demonstrate increased awareness of the external discourses that interact with the research setting and how these discourses produce and are produced by the broader contexts.

Critical ethnography is employed in this study, since it aligns with both the paradigm of critical theory and its epistemology that findings and knowledge are value-mediated (Guba & Lincoln, 1998). Ethnography obtains and displays the understandings and meanings of a culture (Grbich, 1999), while critical ethnography goes one step further to unveil hidden power structures, situate cultural understandings in a broader context, and to challenge prevailing assumptions pronounced by a society, institution, culture or a group of individuals. The chosen methodology was selected as it was directly relevant to the research objectives and questions. Critical ethnography provides a framework to explore the experiences and roles of nurses in relation to sexuality and sexual health within the specific setting of the hospital. This setting is complete with its own unique culture, a culture that must be understood within the given context in order to understand the experiences of nurses. In addition, critical ethnography also imparts the need to understand this culture within the broader discourses and examine the power structures that create and maintain the context. In this case of this research project, critical ethnography was ideal, as it emphasizes an examination of the influence of external discourses and the hidden power structures. This knowledge is necessary in understanding who is really involved in the sexual health care of adolescents with disabilities.

Historically, as demonstrated in previous chapters, individuals with disabilities have been unquestioningly constructed as subjects that are asexual and childlike. When the disabled subject engages in behaviours that fall outside of expected norms these behaviours become socially defined as problematic or deviant. Such assumptions, how they continue to be activated in healthcare settings, either overtly through staff behaviour or covertly through policy and procedures, must be examined and challenged. In addition, I have situated myself and by extension this study, within the paradigm of critical theory, as such my research employs methods that are dialogic and dialectical, so that I can openly investigate and challenge accepted structures, activities, and regimes of practice.

4.2 - The Setting

A setting, the specific context in which the phenomena may be studied, may contain several cases that allow the subject matter to be seen from a specific angle (Hammersley & Atkinson, 1995). Case selection in my research involved selecting observations and interviews that represented a variety of temporal periods, contexts, and people (Hammersley & Atkinson, 1995). The location for this research project was an urban health care facility that provides rehabilitation and complex continuing care for children and adolescents with a variety of disabilities, including neurodevelopmental and musculoskeletal conditions, in both inpatient and outpatient settings. This setting was selected, as it is one of the largest facilities of its kind in Canada. Only the outpatient setting was used for this research project, as the nurses in this setting are focused on health maintenance and health promotion, rather than addressing the acute medical needs of patients.

Access to the setting required the approval of both the University of Ottawa ethics review board (see Appendix A) and the review board at the research facility. Once the ethical requirements of both review boards were met, I approached the managers of the target programs, to discuss the research project and plan the most effective way to introduce potential participants to the project. Announcements were then disseminated through a neutral party via email to potential participants inviting them to information sessions. These methods allowed for a formal introduction to the staff and created an interested body of potential participants. The general observation of the setting, interviews, and examination of the mute evidence (i.e. mission and vision statements, job descriptions, informational material available to staff/patients/families online and in print) all combined to provide a wealth of information which required detailed analysis.

4.3 - Methods of Data Collection

The collection of data was guided by the research objectives: to understand the experiences of nurses in relation to the sexual health of youth with disabilities, to identify existing or potential roles for nurses in relation to these adolescents' sexual health, and to understand what affects nursing actions and/or inaction in relation to the sexual health care of youth with disabilities. The course of data collection within a critical ethnography examines the beliefs and attitudes of those at the heart of the inquiry, as well as the context within which the research is situated and underlying systems of organization, customs, rituals, and actions (Grbich, 1999). As a result of the variety of data that can be included and my research objectives, I conducted interviews with staff members, had staff members complete a demographic questionnaire, conducted an observation of the setting (using an observational grid), examined mute evidences (i.e. educational materials, policies and procedures), and kept both field notes and a reflexive journal. It is important to remember that the collection of data during ethnographic research does not follow a prescribed pattern; rather it evolves in response to what the researcher is experiencing in the field (Savage, 2006). I will now review the various methods utilized during my study.

4.3.1 - Interviews

Interviews serve a dual purpose: to gain information about events, practices, personal beliefs and interpreted meanings, and to reveal the "perspectives and discursive practices of those who produced them" (Hammersley & Atkinson, 1995, p. 156). Interviews can occur in formal settings, such as a private room as an arranged interview, or can be informal interviews, perhaps at the nurses' station during shift change or over coffee. The context in which interviews occur are likely to affect what is said and how subject matter is discussed (Hammersley & Atkinson, 1995). A number of concerns have been raised by qualitative researchers with regard to the traditional structured interview. Two specific concerns about the traditional interview are the nature of the interview relationship, and the product this interview generates. A power dynamic exists between the interviewer and interviewee, and the result of the interview is a social product – generated within the context of this power dynamic (Fontana, 2002). This situation requires that the interviewer be reflexive and aware of his/her position and influence within the interview space; the need for reflexive versus standardized interviews must be stressed within ethnography (Hammersley & Atkinson, 1995; Thomas, 1993). Fontana (2002) examines the impact of postmodernism on the interview process. Postmodernists consider the interview as a result of the situation and context. Fontana describes the interview as a "collaborative construction between two active parties" (p. 166). This implies a few necessary observations on the traditional research, which in years gone by has involved a structured hierarchical exercise to extract information from research subjects, with little alteration in questions between interviewees and an expectation that the researcher asks the question while the interviewee provides the answers. Viewed as social productions, interviews must be conducted with both parties playing an active role. This requires intent active listening on both parts, and in relation to the researcher, active listening may stimulate new questions or the need for clarification of the perceived meanings of activities by the interviewee, rather than accepting an assumed meaning. Context plays an influential role in determining how researchers perform research and interpret the collected data. In addition, the impact of the researcher in the research setting, as well as within the context of an interview must be considered.

The standard structured interview usually involves set questions, whereas the postmodern interview emphasizes listening rather than 'interviewing' (Grbich, 1999). The interviews I conducted were open-ended semi-structured interviews; they addressed key topic areas and promoted a natural conversational flow (see Appendix F). Hammersley and Atkinson (1995) refer to this as reflexive interviewing, following-up and asking questions based on the responses of the participant rather than jumping to the next established question. Thomas (1993) speaks to the danger of questions that are written in stone, identifying that they become a necessity for the researcher and limit their ability to pursue new questions during the interview based on the information that is raised by the participant.

Interviews enhanced my understanding of the meanings and actions of nurses in relation to sexual health and youth with disabilities, provided ideas for observations and future interviews, and brought attention to mute evidence that had not previously been identified (i.e. resources used by the health care team in the clinic environment). To reflect the team approach to patient care that is taken in this particular establishment, social workers and physicians were also invited to participate in this research project. There was a relatively small pool of nurses to draw from, so the inclusion of other health care professionals assisted in obtaining a comprehensive description of the clinic environment and clarified the various roles within the clinic. Interviews were conducted with a total of 10 participants. One participant withdrew from the study due to an inaudible interview recording and difficulty re-scheduling the interview. The final participant count included eight nurses and one social worker; this provided a general representation of the nursing staff working within the setting and provided some diverse perspectives on my research objectives. To supplement the information gathered from participants, key informants (i.e. program managers) were also interviewed. The information gained from these interviews supplied data about the institutional structure and position (such as mission and vision statements). As well, these interactions helped to clarify the perceived role of nursing work within the institution and highlighted current institutional priorities. This variety in participants and informants reflects the goal of postmodern interviewing to seek various perspectives and contexts (Grbich, 1999).

Recruitment was accomplished using purposeful and convenient sampling, achieved by sending out invitations to staff that invited them to attend a presentation about the research project (see Appendix G). All formal interviews were recorded and transcribed by the researcher for data analysis. In order to maintain anonymity and confidentiality, all transcripts were coded with a number rather than the name of the individual, and all identifying information (i.e. names) was removed. Recruitment and interviews with new participants continued until the material obtained during interviews no longer yielded new information. This is referred to as data saturation, the point at which no new themes or categories of data are being introduced. Data collection continued until it was believed that saturation had been reached; no new themes or essences were emerging from the participants (Speziale & Carpenter, 2007). After seven interviews the data that was being shared by participants started to repeat, and it is felt that data saturation was reached. Interviews and data analysis are part of an iterative process in qualitative research. This is because the collection and analysis of data occur simultaneously (Crabtree & Miller, 1999). As a result, the collection and analysis of data from one interview may change the nature of questions or avenues of exploration within the next interview and the data analysis itself may be altered by what is explored within an interview.

4.3.2 - Observation

Observing activities within the health care setting provided an alternate angle in investigating the research objectives, and complemented the information I gained from interviews and mute evidences. Specifically observation informed my understanding of the environment that nurses worked within and the context of their culture. Observation focused on specific aspects of the institution, including policies and procedures, and the movement of actors within the facility. Grbich (1999) describes two categories of observation: descriptive and focused. Descriptive observation is a broad examination of the entire setting (Grbich, 1999), for example documenting the physical architecture of the setting, the flow of work, identifying how spaces are utilized and for what purposes, what spaces are restricted to specific groups and who has access to space. Focused observation takes place as the research progresses and particular areas of interest have been identified (Grbich, 1999). For instance, as new mute evidences were discovered focused observation allowed me to explore how and if resources were utilized in clinic areas.

This supports the view of Hammersley and Atkinson (1995) who address the importance of using both observational and interview data; as each can illuminate and direct the other (the iterative process). Particularly, observation provided opportunities to investigate how topics raised within the context of the interview were reflected within documented policy, facility visions, and the structure of the clinic environment. Within ethnographic research it is important to be aware of contradictory situations and to make note of those observations that do not seem to 'fit' with the whole picture of what is going on, rather than simply dismissing these observations as isolated unimportant events (Thomas, 1993). Observations also reflected my engagement in a reflexive process. Particularly the interaction between observation and the interview process provided an opportunity to explore assumptions that I had held about the environment or specific events.

Observation, both focused and descriptive, was recorded using an observation grid based on one developed by Henri Peretz (2004) (see Appendix H). Peretz, a French sociologist, focused on participant observation, but the grid utilized in this study was adapted from his work on the research setting, and was utilized to understand the interaction between participants and the research environment. Understanding the work environment of nurses and how space is used by professionals and patients is essential to achieving the research objectives. In order to ensure patient privacy and to meet the ethical requirements established for this study; interactions between staff and patients were not purposefully observed and if interactions were witnessed, they were not recorded or utilized for study purposes.

4.3.3 - Mute Evidence

Hammersley and Atkinson (1995) point to the power of documentation in a literate society, specifically within healthcare; the production of recorded information is fundamental to the operation of these organizations. Many documents produced within the health care setting serve as a method of communication between professionals. Documentation in hospitals guides conduct (policies), specifies how specific practices are to be completed (procedures), suggests how records about patients are kept (provider notes), and may serve as educational tools (pamphlets, information displays). What is seen as essential paperwork, acts as "a primary resource for members of the organization in getting through their everyday work" (Hammersley & Atkinson, 1995). Mute evidences cannot be interpreted as independent entities, rather they should be considered and treated as social products, because records are used within the context of the institution and require an understanding of "shared cultural assumptions. Records construct a 'documentary reality' that, by virtue of its very documentation, is often granted a sort of privilege" (Hammersley & Atkinson, 1995, p. 173). Just as interviews and observations take place within a specific social context so do mute evidences occupy a space within a social milieu, and this cannot be neglected when reviewing and analyzing mute evidences. For the purposes of my study a number of different types of mute evidence were examined. These included, but were not limited to, blank progress notes, educational materials, policies and procedures, and documentation related to institutional positioning. Blank nursing progress notes were examined to gain an understanding of the guide that nurses use to conduct assessments in the clinical encounter. Educational materials used in the clinical were reviewed to investigate what types of information patients, families, and nurses had access to and to follow up on how they were utilized. Policies and procedures, such as nursing job descriptions, provided information about the expected roles and responsibilities of nurses in the institution. Lastly, institutional positioning documents such as the mission and vision statements were examined to understand how the overall priorities of the institution affected nursing work.

4.3.4 - Field Notes, Research Memos, and the Reflexive Journal

Field notes, research memos and the use of a reflexive journal comprise three different forms of data collection. In fact they each serve a very unique purpose during fieldwork. Hammersley and Atkinson (1995) distinguish the three types of records as follows: field notes contain data gained from observation, research memos capture analytic ideas that arise during data collection, and a reflexive journal provides a space for reflexive thought. It is important to appreciate the differences between these three records so as not to confuse what has actually been observed with the interpretation of the researcher. With such a clear difference between these methods, field notes and research memos written in the same location were clearly marked as one or the other and the reflexive journal was kept in a separate location. The separate locations for these items provided a distinct separation between analytic ideas and reflexive thoughts, this avoided any confusion about an entry being reflexive or a memo.

Recording field notes is an essential practice for those conducting ethnography, as these written accounts explore specific events, spaces, and people (Emerson, Fretz & Shaw, 2001; Hammersley & Atkinson, 1995). Field notes contain a description of an action or sequence of events and provide a description of observed social processes and the contexts in which they occurred (Hammersley & Atkinson, 1995). Field notes were written as shortly after observation as possible, in order to achieve a high degree of quality. Notes were also made during observations and interviews, depending on the appropriateness of making notes in the environment or situation, for instance if it was distracting to those around me. When writing field notes, Hammersley and Atkinson

(1995) recommend that verbal speech be represented as close to verbatim as possible, as the actual words used may be part of a situated vocabulary that provides information about how members of a culture or group perceive the world. In addition non-verbal behaviour, and silence, should also be represented; sometimes what is not said is as important as what is said.

In order to achieve reliable record keeping in my field notes, I clearly marked summaries of conversations and observations as separate from direct quotations. Whenever possible, I included notes reflecting nonverbal language as well. In addition, my field notes indicated other factors observed, such as who was present, where and when the observation took place, and what occurred.

As mentioned above, research memos are a tool for the researcher to record analytic ideas. In actuality, research memos provided information for the first step of data analysis (Hammersley & Atkinson, 1995). In this study, research memos were used to record my insights and ideas in relation to the data being collected, my memos also explored possible categories to be used during data analysis. While research memos captured evolving analytic ideas, my reflexive journal was used to explore my own reactions to observations or events witnessed in the field (i.e. discomfort, shock, disgust, and anxiety), as well as realizations that relate to my political and theoretical views. Hammersley and Atkinson (1995), note the importance of capturing the personal and subjective perspectives of the researcher because they will influence what the researcher decides is worth giving attention to, what is glossed over, and what is seen as normal or problematic. Both research memos and entries in the reflexive journal were written as needed as well as at the end of a period of field work. These notes and journal entries have been integrated into the data analysis as general information.

4.4 - Data Analysis

Data analysis is the process through which the researcher makes sense of the collected data. This study used both Norman Fairclough's (2003) approach to critical discourse analysis and data analysis as proposed by Hammersley and Atkinson (1995). Discourse represents a "particular way of talking about and understanding the world" (Phillips & Jørgensen, 2002, p. 1), and discourse analysis involves analyzing patterns that language appears to follow in different domains of life. For instance the types of language that are used by professionals and patients in a medical ward of a hospital do not follow the same patterns of language used by these same individuals in a grocery store. Discourse, as per Foucault, includes not only the spoken or written word, but also discursive practices as practiced within scholarly and institutional disciplines, the bodies of knowledge that are generated, and the truths and rules that are produced and reproduced (McHoul & Grace, 1993). This conception of discourse reflects the recognition of discourse analysis that the way individuals and groups speak are not neutral, rather the forms of speech communicate how the world, identities, and social relations are shaped and how these views may be changed.

4.4.1 - Discourse Analysis

Phillips and Jørgensen (2002) outline a number of premises on which all discourse analysis is based: it examines knowledge that is commonly taken-for-granted, that knowledge is specific to time and place, and that links exist between social processes and knowledge, as well as knowledge and social action. These premises fit well with the epistemology of critical theory, that assumed meanings should be challenged. The premise of discourse analysis also reflects the view of Foucault that discourse, power, and the subject shape and create the opportunities for the other to exist. Norman Fairclough's (2003) approach to critical discourse analysis involves examining how discourse is implicated in the construction of the social world as it is perceived and acknowledges that discourse is but one aspect of social practice.

Fairclough presents a three dimensional model of discourse analysis (Fig. 4.1), in the centre of which is the text (the written or spoken word, and visual representations), surrounded by discursive practices (the production and consumption of the text), and encircled once more by social practices (the broader context in which the text and discursive practices are situated) (Phillips & Jørgensen, 2002).

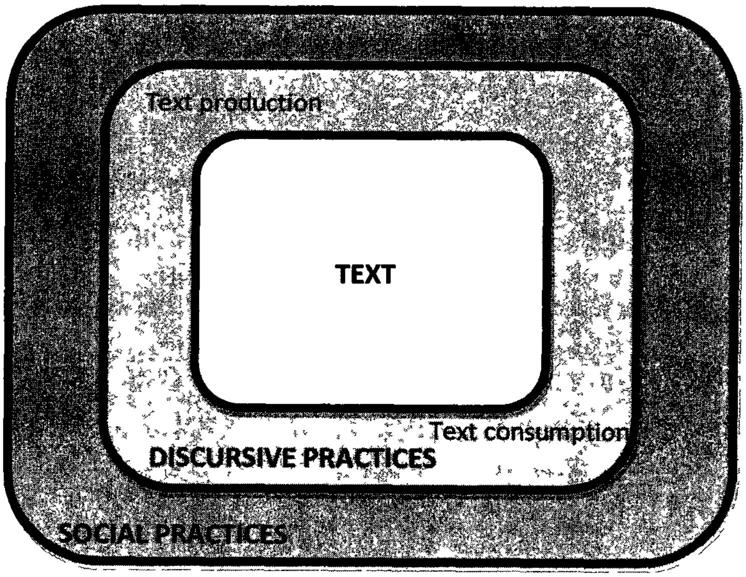

Figure 4.1 – Fairclough's model of critical discourse analysis (Phillips & Jørgensen, 2002)

Analyzing the written or spoken word requires an examination of the linguistic characteristics of the text in order to determine how discourse becomes activated in the text; this provides and structures a specific interpretation (Phillips & Jørgensen, 2002). Analysis may involve examining how identities are formed in the text by the use of grammar and wording. For instance, the language used by nurses communicates a specific view of a situation. The next dimension of Fairclough's model is to the study of the discursive practices in which the text is located, examining how the text is produced and consumed (Phillips & Jørgensen, 2002). This requires questioning the circumstances that prompted the creation or consumption of the text, how the text is utilized, and what the consumer of the text must know in order to consume the text the way the producer intended. The final dimension is that of social practices. The researcher considers the broader social practices and discursive practices that the text is a part of (e.g. nursing, medicine, education, hospital institutions etc.).

The goal of discourse analysis is to determine the relationship between discursive practice and the order of discourse and to identify the non-discursive elements of social and cultural relations and structures (i.e. economical and political) (Phillips & Jørgensen, 2002). In regards to my research this involved identifying the situations that produced a given text (for instance an interview, or policy development), how documents are used either in practice or by patients and families, and how this relates to, or is representative of, broader social understandings or contexts.

4.4.2 - Coding and the Development of Analytic Categories

In addition to critical discourse analysis the methods of data analysis as proposed by Hammersley and Atkinson (1995) were also utilized. According to Hammersley and Atkinson data analysis is not a single phase, but an ongoing process of coding, developing analytic categories relevant to the data, assigning data to these categories, and exploring the concepts that appear central to the analysis. Data analysis is usually focused on describing and understanding the deeper meanings that have emerged during fieldwork (Savage, 2006). This process required analyzing the data collected, creating categories and relations between these categories, developing an overall description, and then relating this to the broader social framework.

During the initial phase of data collection, research memos provided some preliminary data analysis, this type of preliminary analysis helped to generate initial categories. The use of the ideas that emerged from my research memos provided a starting point for coding and categorizing data; as analysis continued and new categories emerged, data was reorganized appropriately. Coding is a part of analyzing data and is not a substitute for data analysis; it links raw data to theoretical concepts (Coffey & Atkinson, 1996). Coding data brought fragments of seemingly unrelated information together to create categories that have common elements and relate to the overall theme or topic (Coffey & Atkinson, 1996). As interview transcripts, observations, and mute evidences were coded, the data was assigned to categories. Hammersley and Atkinson (1995) note that some researchers make multiple copies of data in order to include portions of a single source in different categories and then analytic comments can be written directly onto the categorized data.

During the initial phases of analysis, data was coded, and guided by the developing categories, which were then developed into specific concepts and the meaning of, and relation to, other concepts was explored. While some studies may progress to developing and testing theories, this study produced a critical discussion of the way of life in the setting to "shake our assumptions about the parameters of human life or challenge our stereotypes" (Hammersley & Atkinson, 1995, p. 207).

4.5 - Ethical Considerations

As with all types of research, critical ethnography has ethical concerns that are ingrained in the process. This is partially because of the inclusion of human subjects, and partially because research inherently involves power relationships between participants and the researcher. In order to achieve the goals of ethnography – the provision of a true account of a social phenomenon and the production of knowledge (Hammersley & Atkinson, 1995), research must include considerations that attend to the ways in which research is pursued. In addition to obtaining ethical approval for the project, a number of points were considered in terms of ethics including: informed consent, privacy, preventing harm, and avoiding the exploitation of participants.

The research conducted in this project was in no way covert. Hammersley and Atkinson (1995) discuss that informed consent involves the provision of full information to participants, in order to avoid deception. In this project, participants were provided with a full account of the purposes and goals of the research project through recruitment presentations. These points were reiterated during the process of obtaining written informed consent (see Appendix B) from participants, prior to completing the demographic questionnaire (see Appendices C and D) and beginning the research interviews.

Participants were aware that transcripts would eventually be used for the publication of this dissertation as well as other publications and presentations. As such anonymity and confidentiality concerns related to privacy, and had to be considered throughout the research process. Anonymity was ensured in a number of ways including ensuring that the participants and the setting were not easily identifiable, removing all identifiable features of individuals (i.e. names, titles, and descriptions) from transcripts, and using pseudonyms for programs and initiatives within the research facility. Measures to ensure confidentiality included not sharing information gained with other participants or management, and providing a secure location for the interviews to take place. The identification of individuals or places following the publication of results may result in harm to the participants. It is important that researchers protect participants from potential sources of harm throughout the research process.

Maintaining confidentiality and anonymity were not the only ethical concerns that had to be attended to within this project. Hammersley and Atkinson (1995) point out that at the very least, research may cause anxiety within participants. In addition, participants may have concerns or fears that they are being judged and that their practice is being compared to the practice of others. Given the sensitive nature of sexual health, participants were constantly reminded throughout the interview process of their right to conclude or pause the interview. Contact information for the College of Nurses of Ontario, along with the phone number of a separate support line were readily available should participants raise concerns of a personal nature or those related to nursing practice around sexual health.

Another ethical consideration that will be addressed is the potential of exploiting research participants. Hammersley and Atkinson (1995) point out that often participants supply the researcher with information and receive nothing or little in return. This is representative of the power inequity within research. In order to minimize the exploitation of participants in this project, the researcher presented a collaborative opportunity to the participants – to review and add to or delete sections of their transcripts. Participants were supplied with their transcript soon after their interviews. Each transcript was hand delivered and was accompanied by a letter (see Appendix E). Participants appreciated the opportunity to review their transcripts, and their descriptions of situations, and also volunteered additional information that clarified the areas that they felt were not properly explained in the interview. In order to engage in a reciprocal process with participants, the findings of this project will be shared with participants. In addition to sharing the results of this project, this presentation will also be an opportunity to elicit ideas and suggestions for next steps, with the participants themselves.

4.6 - Validity in the Research Process

The criteria that are used to evaluate the validity of research, also commonly referred to as rigour, assist in demonstrating the legitimacy of a research process. Rigour is the means by which researchers highlight the integrity of their work (Tobin & Begley, 2004). In their discussion of trustworthiness, Lincoln and Guba (1985) identify associated criteria of trustworthiness as credibility, transferability, dependability, and confirmability as means to establish validity in qualitative research (Lincoln & Guba, 1985). This section addresses how credibility and transferability were utilized as a means to establish the validity of this research project.

Credibility addresses the establishment of confidence in the 'truth' of research findings. This aspect of trustworthiness questions if descriptions and findings generated through the research process and presented by the researcher are truthful (Lincoln & Guba, 1985). Lincoln and Guba (1985) suggest that credibility can be strengthened by employing a variety of techniques including prolonged engagement. Prolonged engagement ensures that the researcher invests a sufficient time within the "culture" and provides the opportunity for the researcher to build trust, learn about the 'culture', and test for misinformation (Lincoln & Guba, 1985). Within this project, prolonged engagement was achieved by spending a sufficient amount of time within the facility before and during the research. On average, the time spent in the facility equalled 2-3 days per week for approximately 4 months. The researcher spent time getting to know the facility and the participants, and in doing so established a general understanding of the various activities that occur within the facility. In addition to interviews with participants, the researcher connected with key participants to create a broader understanding of the facility.

Transferability differs from establishing external validity in the post-positivist tradition. Within qualitative research, transferability is specific to the time and context where the research and analysis was conducted. Lincoln and Guba (1985) suggest that providing a thick description of research allows for external parties to decide if a transfer should even be contemplated. To meet this measure of validity and trustworthiness, efforts were taken with this project to provide a description of research that would facilitate others in evaluating how the findings of this project would be applicable in different situations.

Rigour and validity have been categorized by Guba and Lincoln (2005) as criteria the "goodness" of the outcomes of a research project. Tobin and Begley (2004) identify that establishing goodness in a research project is not a linear process, and especially not something that can only be applied during the collection of data. In combination with the above mentioned criteria for validity this research project also employed a third method – that of the reflexive journal. Building on the naturalistic and post-positivistic roots of reflexivity, French sociologist Pierre Bourdieu describes reflexivity as an echo, "the image sent back to a knowing subject by other knowing subjects equipped with analytical tools which may have been provided to them by this knowing subject" (Bourdieu, 2004, p. 4). He proposes that reflexivity can serve to strengthen scientific knowledge, but that the researcher must not involve solely in narcissistic reflexivity, which involves looking only at the researcher's own experiences.

Ethnographic writers, including Hammersley and Atkinson (1995), have long imparted the importance of reflexivity in ethnographic research. Reflexivity, the awareness of the influence of the setting and associated values and interests on the researcher, dismisses previously held notions that social research takes place in a vacuum like setting, free from the influence of the wider context (Hammersley & Atkinson, 1995). The use of reflexivity in critical ethnographic research has been cited as useful for researchers especially in efforts to prevent the "critical framework from becoming the container into which the data are poured" (Anderson, 1989, p. 254). Reflexivity is not simply the self-reflection of the researcher; it functions to address relations of power, and "operates on the basis of dialectic between the researcher, the research process, and its product" (Jordan & Yeomans, 1995, p. 394). Reflexivity provides the researcher with a forum to express his/her thoughts and to revisit events or images that shocked or disturbed the researcher. As a researcher, I utilized reflexivity to re-conceptualize events and ideas that initially seemed out of place, or that I was disturbed by. The use of reflexivity allowed me, as a researcher, to transfer these emotions, reactions, and discoveries into an understanding of how the culture of nursing functions within this specific institution. For example, the omission of sexual health on nursing assessment forms was something that was initially odd – but through interviews, and an exploration of this, in combination with a growing understanding of how the system functioned, it contributed to an understanding of the nursing culture related to sexual health.

Looking beyond simple self reflection, reflexivity can be thought of as an examination of the socio-historical location of the researcher and the researched. In this way reflexivity represents the interests and values are engraved by the location of research and the researcher, thereby clarifying what shapes the researcher's perspective, and therefore, the research (Hammersley & Atkinson, 1995). Bourdieu (2004), points out that the affects of social and historical determinisms must be guarded against within research, and that narcissistic reflexivity alone cannot serve this function. In order to identify and protect against these affects, Bourdieu identifies the need for researchers in the social sciences to apply objectivating techniques to their own practice through the use of reflexivity. This, he suggests, is accomplished through an examination of the researcher's scientific *habitus.* The concept of *habitus* is used by Bourdieu to describe the reality of social life that is often left unquestioned, for example the religious, cultural and historical components (Rhynas, 2005). It is through this "objectivation" of the subject of objectivation (the researcher), that Bourdieu feels historical and social determinisms can be guarded against within research. This objectivation occurs on three levels: the position within the overall social space, the position in terms of the field s/he finds themselves within, and third, attention to the position held within the "scholastic universe" (Bourdieu, 2004, p. 94). To accomplish these goals of reflexivity the reflexive journal was used to situate my habitus as well as to expand and attend to my theoretical stance and to situate the research within the current and historic literature.

Chapter Five – Results

Discourses, as defined by Foucault, are clearly defined realms of social knowledge that enable or constrain the actions of groups and/or individuals; these actions may be verbal, written, or enacted through behaviours (McHoul & Grace, 1993). The themes that emerged during the process of data analysis represent the larger discourses that inform and shape, not only nursing work, but the way that both nurses and youth are seen within and outside of the institution. The data analysis provided a rich description of the institution, the actors within the institution and the relationships between them.

The data analysis began as a collection of field notes, interview transcripts and mute evidences. While examining the various pieces of data, codes and categories slowly emerged and the relationships between broader categories became clearer. Ultimately this process resulted in the creation of four central themes which will be explored in this chapter. The four themes that are outlined here are:

1. Institutional Space
2. Professional Interactions
3. Engaging with Sexuality
4. Nursing Experience

Figure 5.1 depicts the relationships between the themes and the discourses discussed within each theme. Each theme represents the data that was collected using the data collection methods outlined in chapter 4 (collection of mute evidence, interviews, and observation). Within an individual theme, various discourses are presented that express how the theme contributes to an understanding of nursing work focused on sexual health and adolescents with disabilities. The themes and their components identify how internal and external discourses shape the existence and work of the institution, the actors, and ultimately frame their relationships. Following a presentation of the four themes, a brief synopsis of the data is presented.

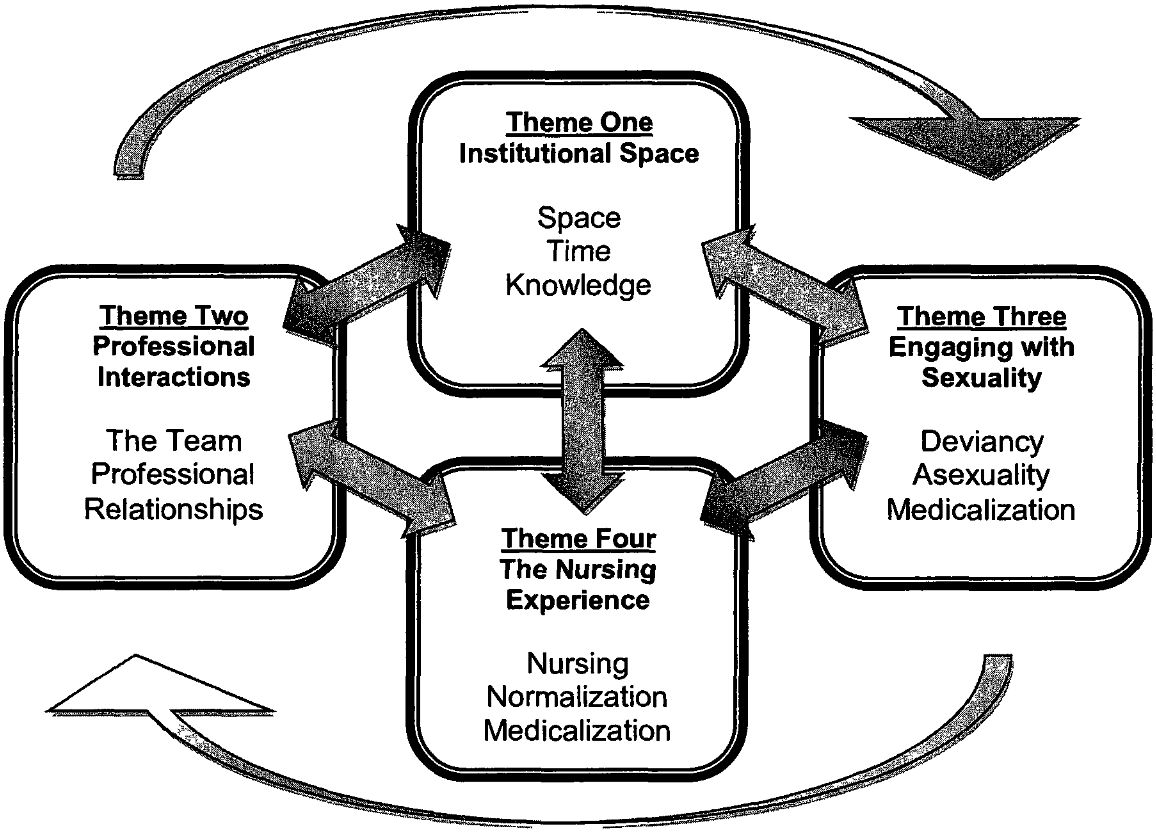

Figure 5.1 – Relationships between themes and discourses

5.1 - Theme One: Institutional Space

In order to situate nurses, nursing work, and patients in the context of the institution it is essential to examine where nurses work and interact with patients. This requires not only an observation of the setting but also an examination of how institutional priorities are interpreted, communicated, and enacted in practice. In reviewing my transcripts and field notes, I found the discourses of space and time (as described below) to be very influential in participants' descriptions of their work. The discourses presented here include the discourse of space, the discourse of time and the discourse of knowledge. Combined, these discourses illustrate the institution itself, the discursive practices that influence the deployment and uptake of institutional priorities. Exploring these discourses provides an opportunity to understand how actors (i.e. nurses, patients, health care providers) within the institution function, and how these discourses affect nursing work focused on youth with disabilities and sexual health. Initially it was challenging to locate the other discourses discussed within this theme. However, the essence of the theme of institutional space is not only the physical space, but also the knowledge and practices that those within the institution engage in.

5.1.1 - Discourse of Space

Space has both physical and institutional elements. Spaces influence how nurses can, and do, engage in their work. The use of specific spaces also communicates the types of work and values given high priority by the institution. Within the discourse of space, the physical architecture of an environment is equally as important as the element of institutional mindset, that is, an institution's vision, values and mission. Physical space is most evident in architectural design, which specifies who has access to areas, and how these physical spaces are used or are expected to be used. Institutional space reflects how the institution communicates priorities, agendas, and values – it is the organizational structure and the overall mindset of the institution. Physical and institutional space often overlap, inform, and structure each other. In my analysis they are both represented as the discourse of space. This theme has been broken into two discrete categories: physical space and institutional space.

5.1.1.1 - Physical Space

The research was conducted at a pediatric rehabilitation facility in southern Ontario, Canada. The facility has been in existence for over 100 years and throughout its lifespan has changed both locations and names. Despite these changes, the primary patient population of the institution has remained the same: children and youth (ages 0 -

18) with disabilities, and their families. The most common diagnoses seen within the facility include: Acquired Brain Injury, Cerebral Palsy, epilepsy, Muscular Dystrophy, Spina Bifida, and a variety of developmental disabilities (i.e. Autism). Four years ago an amalgamation took place that moved all programs, sites, and services, including research and administration, together into one brand new institution.

Situated in an urban area, the new facility offers programs and services to patients and their families, as well as some programs that are open to the larger community. The clinical services include: three in-patient units, a number of out-patient clinics (ambulatory clinics), physical and occupational therapy, a prosthetic and seating clinic, and a dental clinic. In addition, located onsite are a number of community resources including, but not limited to, a library, life skills programming for youth with disabilities, a nursery school, and an aquatic program. The facility also has a school (a program aimed at Kindergarten to grade one) and an extensive schooling program for patients of all ages working with the rehabilitation program.

The physical architecture of the building delineates public, shared, and private spaces. Public spaces are those areas accessible to, and utilized by, everyone in the facility, these public spaces include areas such as waiting rooms. Shared space, are those that are designed for staff and patient interaction (such as the clinic environment in general, and clinic rooms to be more specific). Private spaces are those rooms that professionals and staff have almost exclusive access to and use of, such as the anterooms.

Public space includes the lobby, the cafeteria, the library, stairwells, elevators, hallways and waiting areas. While public spaces often remain public, shared and private spaces frequently intersect. For instance, the in-patient units are comprised of both shared and private spaces. These units include 75 beds across 3 units and occupy an entire floor of the facility, which are easily accessible by elevator. Each in-patient unit has patient rooms, which are shared spaces where patient care takes place. Private spaces are areas such as the medication room or the nursing stations. The in-patient units focus on complex continuing care, acquired brain injury, and orthopedic/developmental rehabilitation. The units are staffed by a variety of professionals including: child life workers, occupational therapists, physical therapists, physicians, registered practical nurses, registered nurses, respiratory therapists, and social workers.

Another example of the intersection between shared and private spaces are the out-patient clinics (the focus of this project). The clinics are mostly located on one floor of the building, situated in a central location, easily accessible by elevators and stairs. The floor where the out-patients clinics are located also accommodates the dental clinic and x-ray department, nursery school, private therapy rooms and staff offices. The principal access to the clinical area is by way of the main elevators. Once on the first floor or upon exiting the main elevators on the clinic floor, the out-patient clinics are accessed through two separate, but centrally located, registration areas. One area is dedicated to out-patient appointments and clinics, and the second registration area is used by the dental clinic. Typically patients and families exit the elevators, register with the appropriate registration desk and proceed to the waiting space. Spacious, open, waiting areas are available for patients and families. These public spaces offer information boards, pamphlets, magazines, and video games and toys for the patients to use while they are waiting. Depending on the nature of the appointment, the staff at the registration desk will notify either the clinic or professional that the patient and family are scheduled to see. The patient and family would then be asked to wait in the waiting areas where a clinic representative, therapist, or social worker would escort them to the appropriate clinic room, therapy area, or private office. On one side of the main registration area is a long hallway that accommodates a number of rooms and therapy gyms. These spaces are typically used by occupational and physical therapists (and patients), but are available to all staff and allocated through a signup sheet located outside each room. On the other side of the main registration area is an entrance to staff offices. Also on this side is one of the waiting spaces, which looks into the clinic area through a large glass wall. It is through a door in this wall that patients and families enter the clinic environment.

Beyond the glass wall, the clinic space has a number of shared and private areas. First, there is a reception area for staff to congregate and organize the flow of the clinic. Then, a room for cleaning toys and supplies, a supply room, a large private anteroom, 11 clinic rooms, a room designated for height and weight measurements, and a large wheelchair accessible washroom. The anteroom is clearly a private space (for staff), utilized by nurses, physicians and clinic staff to discuss patients, review charts and carry out their charting. There are also three "overflow" anterooms for busy clinic days, one of which can also be used as a clinic room (it has an examination table and desk, but no lift system). The anterooms are 'private' spaces reserved for the clinic staff, whereas, the clinic rooms are shared space, where patients, families, and clinic staff interact. Each room has a door, examination table, and a lift system to facilitate patient transfers from wheelchairs to the examination table. Many of the clinic rooms have large windows overlooking a treed ravine, which is in keeping with the open feel of the entire facility.

The registration area and the waiting rooms are very public spaces, whereas the clinic space is a regulated environment that combines shared and private spaces. Staff have access to all types of the space, private or shared, within the clinic: the anterooms, supply closets, and clinic rooms. Patients and families are invited into the clinic environment and can only occupy shared spaces, such as the height/weight area, the hallways, and individual clinic rooms. The hallways do become areas of shared space because occasionally they are used for clinic purposes (testing patients on steps or examining their gait down the hall). One participant commented on the difference in shared spaces between the new facility and the old facility:

> It is a lot better than it ever was. In that, they are private rooms now. And in the old building they eventually got private rooms, well sort of. Because there were some that just had curtains ...and that's where they put the urologist. (J2)

In this comment, the participant describes the difference and implications of having private and shared spaces. When reflecting on the previous building, the participant recognizes the privacy provided by having closed doors on individual clinic rooms, and specifically the implications this had for various clinics that were being conducted. In this case, the urologist, in particular, was previously seeing patients and families behind a thin curtain that would not have provided much privacy for the patient in the shared space of a clinic room. Also, the urologist would discuss intimate details about bladder functioning, catheterizations, and bladder care regimes – all of which involve discussing genitalia, in a shared space.

There were a number of new features prominent in the new building, in comparison to the previous structure. The new facility boasted an increased amount of natural light, larger hallways, and more spacious public spaces. In addition, the clinic rooms were all individual rooms that provided more privacy than the previous layout, in which some clinic rooms were only separated by curtains and others were located directly off the anteroom. The new clinic environment was more patient-friendly – lifts were available in almost every clinic room, the rooms are bright, and there is a convenient wheelchair accessible washroom available. This, along with the improved privacy, conveyed a greater respect for patients and their families. Interestingly, this new modern, bright, and spacious environment does not automatically communicate that it is a hospital environment and clearly delineates public, shared, and private spaces.

The assignment of clinic rooms was communicated through a weekly schedule, which was created by the managers of the programs. The clinic schedule identified the date, start and finish times of the clinic, the name of the clinic, the physician or fellow conducting the clinic, the registered nurse or clinic assistant (not all clinics have nurses associated), fellows/residents or medical students attending the clinic, room assignments and anteroom assignments. At any given time there were at minimum two clinics running, and some days five clinics ran simultaneously. Although the clinic has 11 rooms (dedicated to clinics in progress), participants that were interviewed expressed that physical space can be at a premium. Physical space was spoken of in limiting ways; for instance, participants spoke about the need to address issues with patients and families that were either raised in public spaces, or that needed to be conducted in privacy:

> One thing there is no room. All the clinic rooms are taken, so there is no place to go. (J1)
>
> Our clinic is really, really, rushed. It can also be tough to find private physical space due to many clinics using a small space – these aren't waiting room questions. (A3)

The clinic space is busy, and a quick glance at the schedule indicates that one clinic may have a physician, clinic assistant and perhaps a fellow or resident assigned to it. In reality however, some clinics also include an occupational therapist, physical therapist, and a social worker, in addition to the nurse and any nursing students that may be in a clinical placement. While the schedule in place seeks to ensure that the clinical area is well utilized, in reality, the fast-paced environment may not provide enough time to have prolonged and in-depth conversations with patients and families. Participants expressed that on some occasions there was not enough private space in the clinic environment, especially when questions were raised by patients and families outside of clinic time. Clearly, physical space within the clinical environment was limited, and posed issues for providing privacy when topics arose that required extra time and space.

Whereas the clinic space is generally a collection of private and shared spaces, the space where nurses retreat to after clinics could generally be considered a private space, reserved for professionals and staff. This office space is described in order to fully portray the environment that nurses work within and how the environment affects nurses' exchanges with patients. The majority of offices belonging to out-patient clinical staff (i.e. administration support, nurses, occupational therapists, physicians) run the length of the building. They are separated from the clinic areas and therapy rooms by walls. Staff offices can be accessed via a few entrances across from the therapy gyms and private rooms and there is also an entrance through the clinic itself. Within the space designated for offices, are a number of individual offices occupied by managers, psychologists, physicians, and social workers. These offices line the exterior side of the floor, while the interior of the space contains a series of open concept cubicle offices. These offices are occupied by administrative staff, nurses and therapists. Depending on the size of the cubicle, cubicles accommodate anywhere from three to eight individuals, depending on the setup. Sometimes multiple professions share the same cubicle space. Each cubicle has one main access door and walls (approximately 6 feet high, then open to the ceiling above) that divide the cubicles or pods and delineate hallways. Each individual has a private workstation, within the cubicle. These workstations are partitioned from each other by small dividers. The cubicle environment provides an illusion of privacy, but it is not conducive for meetings with patients, as individual workstations are not fully enclosed. Nurses were acutely aware of the difference between their private workspace and the workspace of other professionals:

> Our social worker is able to bring people into their office and have a private area to have those conversations ... we could choose to find a therapy room away from the clinic area, but in terms of time constraints and space, it is really hard to find. (A2)

Initially, when the facility was first being populated with staff, some nurses had occupied the perimeter offices and shared them with other nurses. These rooms even had sinks installed, so that nurses could easily wash their hands after patient care. However, all the nurses now occupy the cubicles and there are no private offices available to them.

The discourse of physical space, as it relates to providing care and ensuring patient privacy was frequently raised as an issue by participants. Space was identified as a constraining force on nursing work. I directly observed how the physical space structured the work of nurses, in both positive and negative ways. For example, the new clinical space was an improvement on the old space. There was an increase in the number of clinic rooms and the new clinical space offered more privacy for patients and families. In addition, the there were new features in the clinical area that impacted nursing work including a centrally stocked supply room, lift systems in all clinic rooms, and larger anteroom for consulting with other team members.

5.1.1.2 - Institutional Space

Physical space contributes to the structure and organization of nursing work with patients. Nursing work also takes place within an institutional space. This space is the mindset of the facility and is communicated through mandates and priorities, mission and vision statements. The facility is focused on the provision of services to a pediatric population. The mission statement that guides the institution addresses the need to provide programs, services, and clinical care to those who require rehabilitation, and have complex care needs. The aim of these is to assist and facilitate patients in living life to the fullest extent possible. The mission statement also outlines the institution's desire to remain an outstanding educational facility that not only provides exceptional clinical care, but also remains at the forefront of research. The overall vision that inspires the facility is emphasized in the mission statement as: "A world of possibility" (Name of Hospital, 2009b). The core values that guide the organization are stated as caring, patient/family centered care, excellence, innovation, partnership, and respect.

From an organizational perspective, the delivery of services is divided into three separate programs: in-patient, out-patient, and community services. Each program has a senior director and a physician director (to both the in-patient and out-patient programs). The in-patient program encompasses all three in-patient units as well as professional services (i.e. professional practice, education, intake and discharge, infection control). The out-patient program is further divided into four separate teams, each responsible for different clinics and each with its own manager. The out-patient program covers the majority of outpatient services as well as satellite clinics. The third program delivers community services such as writing aids, life skills programming and aquatics.

In addition to the mission and values of the facility, there was one specific institutional priority often raised by participants during the interviews, which I will refer to as the “Prepared to Grow Up” program. Participants described the program as a new initiative within the centre. There was a strong presence of this priority on institution’s website and in the clinic area. The program is based on a series of checklists and age-appropriate timetables, for use with patients age 7 and up, intended to help patients and families engage in skills and experiences helping prepare patients to become confident adults. The program aims to prepare patients and families for the requirements of life as an adult, and the transfer to adult care settings and clinics. Evidence of the “Prepared to Grow Up” program was observed throughout the physical spaces of the institution. Each clinic room in the out-patient clinic has a large poster which detailed the timetable for the “Prepared to Grow Up” program.

Initially the program did not seem overly significant. However, as the interviews and observation progressed I understood how institutional space was used to highlight the program as a priority. The program represents not only the communication of institutional priorities in terms of the vision of the facility, but it also reflects the institution's use of physical space to highlight a priority issue to patients, families, and health care providers. The attention to the program and the emphasis placed on transitioning was noted by participants:

> We are just starting to do transition now, to talk about transitioning and growing up ready. And I think, along with that, there will be more attention to things like sexuality. (A2)
>
> We have the program ["Prepared to Grow Up"], so that's good. It's a good introduction for the age group. "Oh, you have to watch for this" So, it brings it [sexual health] up. (J1)

The institutional focus on transition services and preparing for adulthood emphasizes this aspect of care as an institutional priority; it also creates an opportunity for participants to address sexual health.

As demonstrated, physical and institutional space contribute to the organization of nursing work. Overall, the physical spaces that both nurses and families occupy and utilize facilitate and restrict the types, length, and nature of the conversations that can be had. In addition, the institution makes use of physical space to communicate priorities to patients and families that necessitate in-depth conversations, without acknowledging the lack of physical structures to support these discussions.

5.1.2 - Discourse of Time

The notion of time consistently emerged throughout the data analysis. Time was specifically referred to in three ways. First, the actual time spent with patients, second, the perception of needing more time in the day, and lastly the length of time that a nurse had worked with a specific clinic. The ways that participants spoke about time indicated that it was perceived as an organizing force affecting the way participants were able to interact with patients and thus the way nurses prioritized their work.

The amount of time participants spent with patients and families in the clinic environment depended on the specific clinic. The length of (appointment) time also differed between professions. Social workers openly stated that they had more time to spend with patients and/or families (anywhere from 30minutes to one hour) and could schedule private office visits with patients. Therapists also saw patients outside of clinic time for private therapy sessions in the therapy rooms or therapy gyms. Nurses, on the other hand, said that they had anywhere from 15 minutes to 45 minutes with the patient and family and only saw patients or family outside of clinic time for special reasons such as wound care or medication trials. Regardless of how much time nurses spent with patients in the clinic, nurse participants frequently returned to the notion of time as a factor that they felt limited their interactions, especially as it related to sexual health:

> Time. The time we spend with them ... I maybe spend 10-15 minutes them [client/family]. (J3)
>
> Time is of the essence. I only have so much time. And if they [the family] are lucky enough to get a parking space, they come in and they are on time, I do their height and weight, I find out what the current issues are, I address those, and I do the program ["Prepared to Grow Up"] very quickly. (J4)
>
> I have the advantage, I can take more time, I can potentially have more than 1 appointment, and take an hour and half to have a discussion about life and a lot of issues. (S1)
>
> It [sexual health] doesn't come up often enough...I think there are many reasons, time may be one. (A2)

Nurses were not the only individuals that were concerned about the affect of time on their work. Other professionals were also acutely aware of the time that nurses could spend with patients, and where this time came from:

> I think that is all based on time, they just don't have a heck of a lot of time to do as much as they want, but I know that they are taking some time to do that education and giving of information to families. And I think sometimes, they take more time than they have in their day. (S1)

These excerpts all demonstrate how the discourse of time affects nursing work. A perceived lack of time would affect the ability of a nurse, family, and patient to raise a variety of concerns or issue, including sexual health. In addition, the excerpts reveal the influence of time on the integration of institutional priorities (such as the "Prepared to Grow Up" program). Issues of time highlight the constraints that nurses work within – between attempting to meet the needs of patients and families, meeting institutional priorities, and the constraints within which these needs must be met.

Nurse participants also asserted that discussing sexuality and sexual health required more time than was available. Not only the actual time in the clinic setting, but the time required to develop the kind of relationship with patients and families that would allow for discussions around sexual health:

> It's not that they only don't have actual physical time to ask those questions. But the whole concept of having a discussion on sexuality usually takes more time, and there's a comfort level when you are asking that type of question. Especially when you ... having a conversation with the youth about it, you kind of need more of relationships to ask the good questions, to get the answers... Truthful, in-depth, about how life is really going, not just oh yah "it's fine". And that takes time and relationships. And I don't think that the system is designed to allow for that. (S1)
>
> I find that it's not really fair to start it [sexual health conversations] if you don't have enough time, and you don't see them that often, because they're here every 6 months or so, it's difficult that way. Unless, they brought it up and approached it, said something to me. And then I would find out, I would investigate it further, further the contact by phone. But for the little visit that we have...[trails off]. (J1)

Time spent with patients, as represented in these passages, was seen as something that limited the ability of the nurse to develop rapport with patients and families. The availability of time directly impacts the development of a relationship between the patient, family, and nurse. When the time is available to develop a relationship with patients and families, nurses feel that they had access to more intimate knowledge and a comfort level that facilitated the discussion of more sensitive topics.

Nurse participants reported that time shaped the content of clinical visits. During the limited length of a clinic appointment, the time allotted to nurses was dominated by 'priority issues'. The prioritization of issues will be addressed later in my discussion on the discourse of medicalization. However, the time available in some clinic appointments creates the environment for the patient/nurse interaction and a lack of time means that only specific priorities are met.

> I think that lack of time is a hindrance for everybody; that's not new. An hour sounds like a long time, but when you spend 45minutes talking about bowel and bladder, that doesn't leave you a lot of time. Or wounds, wounds definitely take a lot of time, if you have to stop and do something for them. Wound care can be very time consuming. (J5)

In this passage, wound care and bowel/bladder care represent pressing priority issues. Within the current health care context, time is always at a premium. Nurses felt that they had enough time with patients (during a clinic visit) to cover the important issues, and accomplish the high priority tasks, but lack of time hindered their ability to address non-priority issues and some institutional priorities, such as "Prepared to Grow Up".

5.1.3 - Discourse of Knowledge

The discourse of knowledge includes the access and utilization of information by nurses, professionals, patients, and families. Within any institution, knowledge is created and a flow of resources is established. This section details the data that emerged regarding the flow of resources and knowledge within the facility. Specifically, I discuss who has the knowledge, what knowledge is used and how this knowledge is utilized.

Because of the institutional commitment to engaging patients in "a world of possibility", there are multiple programs run at the facility accessible to patients and families. The clinic team, including nurses, can connect patients and families with these resources through direct referral or by providing information to families. The library is centrally located on the main floor and makes resources available to patients, families, and staff. I observed large display cases near the entrance of the library, filled with modified winter sports equipment for children and adolescents and a video running that demonstrated the use of some of the displayed equipment. Within the library, located near the main entrance, is a bank of computers and desks built to accommodate wheelchairs. The collections of the library include a large periodical section, full of various magazines and journals specific to disability, both for families and staff, and a number of book stacks. The library is also home to a number of staff including: a resource person for activities, an individual focused on connecting families to appropriate resource in the community and facility, and two librarians.

Patients and families have access to knowledge within the facility, including a vast library, a number of accessible computers in public areas (i.e. the lobby, library), and resources (such as pamphlets about internal and external programs) available in clinic areas and other public spaces. There are also a number of information boards and stands around the facility in central public locations, such as the clinic waiting areas and the main lobby. I observed that the stands were well stocked with a variety of pamphlets and information regarding programs run within the facility as well as external programs and resources. There are also bulletin boards near the out-patient clinical area and one on the research floor. On these boards I saw notices for upcoming events (such as a youth committee meeting), as well as recruitment posters for research studies being conducted at the facility. On the research floor, the bulletin boards also had information about participant recruitment as well as recent publications from facility researchers. Patients, family, and staff, all have access to this general public knowledge – such as programs, articles, magazines, pamphlets, all located in public places. The facility also maintains a current website that captures internal activities, and could be used as a source of information about the institution as well as information specifically for parents, youth, and children. All of the web sections have links to both facility resources and external websites.

Some of these examples of mute evidence (i.e. pamphlets and resources) addressed issues around sexual health, although in these cases the material would need to be reviewed, or sometimes located, in order to realize this. There were a few books in the library stacks, and more prominently there were a few pamphlets for external services, that, when investigated, offered support around sexual health. On an internal level, there were advertisements for youth groups and transition discussion groups.

Staff, including nurses, have access to all of the same general knowledge as families and patients, but also have access to additional information and *institutional knowledge.* This information may be accessed through individual computers in their private spaces (i.e. offices and clinic anterooms). Institutional knowledge is the knowledge created by the institution, such as policies and procedures, staff news, and knowledge of the system (i.e. external referrals etc.). This type of knowledge is available through the facilities' intranet (for staff only), and also through the network of resources that participants had access to (i.e. other professionals, connections to other facilities etc.). Access to institutional knowledge was something that participants depended on, especially in terms of answering or finding answers to questions posed by families and patients.

In addition to the plethora of public information available to patients and families, participants also made note of public and institutional knowledge that they used within the clinic setting:

> The team [Life Team] provides support...They have a youth coordinator. I think she helps a lot, because she is a youth living with a disability. And I think she provides that special/unique perspective... a variety of programs, they run groups, they run summer camps...and they run the independence program. (A2)

> Some of the other nurses and I definitely talk about it [sexual health], I know quite often she [an individual from the resource centre] will send out flyers about sessions that are going on... the social workers run some parent groups about different topics. And I'm sure we have families that go. ... I know that the flyers are out in the waiting room. And I do tend to peruse the topics, and if the family brings something up it triggers my memory to say "oh there was a session on that, check downstairs"... I know somebody else had talked about this sexability site [a website] ... they have ideas and discussions about sexuality and disability. And I know there are things going on in the community. (A3)

These participants identify the utilization of both institutional knowledge and public knowledge. Interestingly, the passages also allude to the fact that sometimes the nurse needs to reinforce the availability of resources, or connect patients and families to sources of public knowledge. The first passage points to a special form of institutional knowledge – the presence of a youth coordinator with a disability who provides a specific type of knowledge or support to patients and families. The youth coordinator is an invaluable resource, especially in terms of sharing real life experiences with patients, although perhaps not necessarily related to sexual health.

Some participants spoke generally about the availability of public knowledge, including programs and services that addressed transitioning youth, growing up independently, and healthy sexuality. Other participants spoke about the need for public and institutional knowledge that was aimed at specific populations:

> I don't believe in just throwing a brochure at everything. But there is not, as far as I know, a really good resource; not overly scientific, but not overly simplified, but somewhere in the middle. Resources, not for little kids, but for helping families try to. We'll talk to the girls about it as well, but some of them aren't ready to hear it when we see them, but we just try to prepare the families to say "you know, these girls can start going through puberty early". There's not a lot of good material for families to take away with them to use at home when they are ready for it. .... I think even just there is a lot of information I've found on sort of in the family planning side of things for adults with spinal cord injuries, but specific to Spina Bifida it's a different ball game, it's not exactly the same. And the information that I have been able to find, that is useful, is more geared to spinal cord injuries. (A3)

When questioned about what types of information would be useful for nurses, patients, and families, this particular participant identified that resources about the logistics of reproduction (i.e. conception and pregnancy) would be helpful, especially information that was specific to the level of the lesion. The need for knowledge about sexual health specific to populations, such as youth with Spina Bifida, is apparent. As this participant relates, general knowledge for specific populations is needed not only for patients and families, but also for the health professionals working with them. Another participant noted the lack of general knowledge in the form of resources that related specifically to sexuality and sexual health for use in the clinic environment:

> I have things, like general things about sleep, food guides, but not about sexuality. No, no, no. (J1)

There was a clear pattern that emerged in my discussions with participants around the availability of general knowledge. Some participants seemed to be aware of a greater number of resources related to sexual health. These participants also felt better equipped to discuss sexual health with patients and families when it came up in clinical discussions. Some of these resources seemed to be clinic specific, which suggests that institutional knowledge does not always flow freely between programs. One participant discussed a brochure that had been developed years ago by one of the teams:

> Several of us ... on the ... team ... got together and put this together. And we refer to it often, even though it is an older resource and it doesn't have the most recent logo. But it is a very good tool "Let's Talk about Sexuality", and dealing with some of the really common generic things, in very basic terms [referring to brochure] knowledge is power, your own space for privacy, you are beautiful the way you are, showing initiative, being open to diversity...It had been on the internet ... but given that it hasn't been updated, I'm not sure where it's at right now. We walk around with it in our supply, and I am still handing it out. There is a discussion about a few myths and realities in the pamphlet, and you know even a broad definition of sexuality and the influences that are there. And we emphasize the role of parents, parents as teachers. (J2)

Only a few participants had seen or used this resource, despite the fact that it had a very general approach to sexuality and disability and was not diagnosis specific. In discussing what had happened to this useful resources the participant noted:

> This is the sort of thing that could be updated on a regular or yearly basis. But you need an organization that puts it on the map as a useful activity. Because these web, book, and people resources need to be checked and new one's added. (J2)

This represents an interesting paradox between the availability of knowledge and institutional discursive practices that establish priorities around independence, transitioning and preparing for adulthood. Despite an institutional priority on preparing families and patients for adulthood, an existing resource had fallen through the cracks. This was especially interesting given the fact that almost all of the participants talked about the need for general knowledge about sexual health for patients and families.

Given that the participants worked across different clinics, there were differences in the needs of the populations they serviced (youth with Cerebral Palsy, Muscular Dystrophies, and Spina Bifida), but the general need for information was apparent. Nurses acknowledged many of the same resources that were available and spoke about the different ways that information was sourced for patients and families. The work of nurses to access information for patients is an example of institutional knowledge – finding the answers to questions posed by patients/families by utilizing established connections and relationships, such as those with other health care professionals. There were a number of channels identified by participants to help find this type of information, including both facility and community connections.

It is interesting to consider how participants spoke of the dissemination and sharing of knowledge, especially with attention to who had the knowledge necessary to answer specific questions. A few participants noted that there are occasions when they do not have the information to answer specific questions. In these cases they noted that they could depend on other members of the team to meet with patients and families, or they could be referred to other sources and clinics.

> I know that there is the transitioning clinic. But nothing that I am using right now, because they aren't coming to me for information, they are coming to the team. (J3)

This excerpt points to the fact that "the team" provides access to specific and institutional knowledge, and that the specialty of one team member complements that of the other. There were varying levels of formal and informal education on sexual health among the participants. Only three participants had any specific formal education or training in sexual health with a focus on disabilities. Other formal learning experiences included attendance at sexual health based conferences. However, many of the remaining participants expressed gaining sexual health knowledge, specific to their population, through experience within the clinic environment (informal education). Another participant spoke about accessing external services, which requires institutional knowledge:

> They can go to genetics, and we would definitely refer them to genetics because ultimately we don't hold the responsibility or the knowledge base because this is a new population of people. Of course, we let them talk and we talk to them about it. (A1)

Institutional knowledge also includes the knowledge and ability of participants to connect their patients with the appropriate resources. The knowledge held by nurses, including experiential knowledge and the knowledge of resources (including access to networks of people/clinics), is essential to nursing practice. This knowledge, supported participants when addressing the topic of sexual health. The discourse of knowledge and the discursive practices it entails involve the dissemination of knowledge and affect how knowledge (both general and institutional) is utilized by nurses and patients. Awareness of the availability and flow of knowledge and information are essential to understanding the context of the institution.

The discourses of time, space, knowledge and nursing work collectively create a specific clinical experience for patients, families, and health care professionals. These discourses inform, structure, and limit each other. For instance, institutional space, in the form of priorities brings specific topics to the clinic that should be highlighted, and thus informs nursing work. The discourse of time influences how nurses work since it structures their time with patients. Of course, these discourses alone do not fully explore how nurses engage patients in topics around sexual health, nor how nurses encounter, confront, and negotiate sexual health within the clinic environment. There are broader social discourses reflected in the data that frame the nurse participants' specific experiences. These social discourses structure the opportunities that nurses have to address sexual health, and present barriers to the full integration of sexual health care into the clinic experience.

5.2 - Theme Two: Professional Interactions

When I started the process of coding interview transcripts and field notes, categories surfaced that reflected interactions between the family, patient, and health care professionals. Many participants spoke about the interactions they had with parents and patients and the importance of forming and maintaining trusting relationships. Nursing interactions with patients and families are always conducted in a given context. It is within this environment that discursive practices emerge, practices which determine how individuals with disabilities and nurses engage in health care focused on sexual health. The theme of *professional interactions* captures several discourses that influence nurses and their position within the organization. Accordingly, this section covers the discourse of the team and the discourse of professional relationships and reveals how nurses approach and navigate interactions with patients and families.

5.2.1 - Discourse of the Team

After my first few days in the facility the importance of practices of the team (i.e. nurses, physicians, health care providers, social workers, patient, family), collectively referred to here as the discourse of the team, became apparent. The inter-professional communication and support that resulted as being a member of a team was created and maintained through discursive practices within the clinic. Some nurses recognized that the length of time they had spent working with a particular clinic affected their ability to participate in team discussions. As this participant explains she is new to a clinic:

> totally brand new, so I'm still learning. But my input, I know just from the team, would be considered just as important as anybody else's. If, I were to have any at any point, which I will. Eventually. Eventually I will for sure [participant laughs]. (J3)

Later the same participant, while talking about resources for patients, commented that patients and families do not come directly to the nurse for information, but rather they come to the entire team to have their needs met. Participants often viewed the entire team as the providers of care and acknowledged the team as a resource for themselves as well as for patients and families. As such, being able to rely on team members created time for nurses to develop knowledge relevant to their patient population. Nurses' accessed 'team resources' to meet the needs of the patient, while remaining conscious of time as well as their own development as a member of the larger team. The opportunity for team discussions regarding patients and the flow of institutional and public knowledge across the group was essential to the functioning of the team. On a practical level these discussions and knowledge sharing reflected discursive practices of the team. Some participants noted:

> There is nothing that we hide from each other about these kids. It's a completely open book, and we tell the parents that. (A1)
>
> If the client says something, any person on the team would either be willing to discuss it or say "is it okay if I get someone to talk to you about it." (J5)

The interprofessional environment was a resource in itself and individuals collaborated with each other to strengthen the care that was provided to patients and families.

The individual strengths of nurses were recognized by members of the larger team, both in terms of their professional knowledge or because of the ability of the nurses to connect with specific patients. A few participants spoke of the 'sex, drugs, and rock n roll talk' that they were sometimes asked to have with patients, as these adolescents moved into a new phase of their lives. This reflected the value placed on the nurse as a member of the team, despite the fact that the physician and/or social worker could also address these issues. One participant spoke of this type of interaction with the team, in reference to the patients schedule while in clinic:

> They [the client] will have a schedule, or one of the other team members will come to me and say "I need you to see little Bobby today". Often time our pediatrician will say "you need to have the 'sex drugs and rock n roll talk', or they need to have 'a girl to girl chat' ... So sometimes we'll get flagged specifically about that [sexual health] type of stuff, or it's an add-on. But kids are scheduled on their yearly visit to see the nurse. So I'll sit down and discuss how things are going. (A3)

Time with the nurse was an important component of a patient's visit to the clinic. Even in situations where there was minimal nurse-patient interaction, nurses still felt as though they were, or would become in time, valued members of the team. The perception of being a valued asset to the team contributed to the nurses' perceived ability, and responsibility, to address issues of sexual health in the clinic environment.

The nursing aspect of the professional team, and the work that nurses conduct directly impacted how their time was spent. In some situations, nurses were required to spend additional time with patients to address specific issues (i.e. wound care, sexual health, referrals to external agencies). In other situations, nurses described the challenge that the team nature of the clinic environment posed for discussing issues of sexual health, especially in trying to speak with older patients independently:

> Sometimes, when I say "would you like me to ask your parents to leave"? Sometimes it puts the child or the teenager in a situation, where they feel they need to still have their parents present. And they just don't want to talk about it ... And I think culturally too. To ask about sexual health in certain cultures, and I'm not sure if I should be generalizing, but in certain cultures if you ask the parents to leave, it's not 'normal' to them, to have them leave. Because it's a "doctors visit", it doesn't seem to be normal. Perhaps there is a better way to manage this, but I try to remain sensitive to everyone's wishes. (A2)

In this example, the family viewed the appointment as less of an interprofessional appointment and more as a medical visit, specifically a physician's visit. Because of this perception, nurses were sometimes limited in their ability to negotiate time with patients.

In addition to being a member of the interprofessional clinic staff, nurse participants mentioned that out-patient nurses, across clinics, also formed a team, one of nursing professionals that were sources of public and institutional knowledge, especially around sexual health. Nurses also collaborated and shared knowledge in biweekly meetings, which were open to all of the out-patient nurses. This was a forum designed to address specific clinic issues, as well as, institutional and program based initiatives. In addition, this institutionally supported space allowed for and encouraged collaboration between the out-patient nurses, as one participant noted – the biweekly meetings would be an opportunity to discuss how sexual health care could be integrated into clinics by nurses.

The discourse of the team operated at two levels - the level of the interdisciplinary team, and second, at the level of the out-patient nurses as a unique team of professionals. Both levels involved collaboration with others (for proper functioning of the team), and the flow and transfer of general and institutional knowledge.

5.2.2 - *Discourse of Professional Relationships*

The discourse of professional relationships, involves the maintenance of professional relationships between health care providers, specifically nurses, and their patients and families. Many instances were raised by participants that exemplified the "difficult waters" that nurses must navigate in order to provide sexual health care. The issues discussed included how to balance raising difficult health topics, such as sexual health, while maintaining an open communicative professional relationship with patients and families. Participants reflected on the challenges of balancing the complex medical conditions of a patient with situations that might threaten the therapeutic relationship with the family and patient. Despite the fact that sexual health is an aspect of holistic patient care, participants cited it as a topic that could jeopardize the nurse/patient/family relationship.

One particular aspect of maintaining professional relationships raised was the need be sensitive to the culture and ethnicities of patients and families. Participants acknowledged the need to respect the culture and heritage of a patient and family, while attending to the unique needs of the individual patient. The unique perspectives of various team members (nurses, patients, families, and health care providers) are all influenced by broader contexts. Nurses were acutely aware of the diverse cultural and ethnic backgrounds of patients and the impact that this would have on views around sexual health:

> We develop a real relationship with them [the patients], and I know that they feel comfortable talking to us... I would say that in the last couple of years, we are getting very good at seeing them [patients] by themselves, so that we can talk to them. Because, a lot of them are from ethnic backgrounds in which girls would never be expected to have sex, outside of marriage, and you want to make sure that if they decide to, that they have the knowledge in place that makes it okay for them. (A1)

This same participant commented on the difficulty of ensuring that patients have the appropriate information available to them and the need to maintain a therapeutic relationship with the family. Specifically this participant reflected on the possibility of a patient's health declining outside of the clinic, and parents being hesitant to contact the nurse:

> We also have to keep a good rapport with their parents, we don't want them not to come back to clinic because we brought up something, that they don't want brought up, you know it's a real catch 22 ... because you don't want their respiratory health to fail, because the family didn't call you, because you brought up something completely contrary to what their beliefs are, and that's a big risk. (A1)

Balancing the needs of the patient, the duties of a nurse (to provide holistic care), and the desires of a family, was viewed as a challenge for the out-patient nurses. In order to meet the needs of the patients and families, nurses had to learn how to assess family values and interact with the family and patient as a whole, in order to ensure that the relationship with parents was maintained:

> We have people who don't even want their kids to know their diagnosis .... But when you are getting those kinds of messages from parents, you really learn to walk a rope, related to everything, including sex ... And with those people, then I would probably have the parents in the room [with the patient]. And we do it [have the discussion about sexual health] very gently, "you are growing up now, you might get married some day." Because you would always use the word marriage, in [some] cultures, because you know that outside of marriage it [sexual activity] is unacceptable. So you use the euphemisms, but get the word across that you may have sexual relationships at some point in your life. (A1)

These passages exemplified the influence of the discourse of professional relationships on the work of nurses. Nurses acknowledged that they are not simply working in solitude with youth who have complex medical conditions. Taking the institutional values to heart, nurses recognized that utilizing a family-centred approach requires recognizing the unique perspectives, cultures, ethnic backgrounds, and religions of families in relation to the clinic experience. This places nurses in a unique situation. Nurses involve parents and caregivers in discussions about sexual health, whereas non-disabled youth typically are not exposed to this level of parent/provider interaction. Parents and other primary caregivers of youth with disabilities may have an increased level of control over what their child can do or have access to, in comparison to caregivers and parents of non-disabled youth. Parents of teens with disabilities may have significantly more power over their children, whereas youth without disabilities tend to gain more independence at this stage, and engage in sexual exploration and socialization with peers.

Nurses approached their work with patients and families in a way that maintained the individuality of the patient, while also attending to the needs and desires of the family. When this balance could not be met, the nurse expressed concerns that they may place the patient at risk. The risk could be an inability to provide information provided to the patient or a loss of the family's trust in the team. Nurses' awareness of the needs of the family and their attendance to these needs shows how the institutional value of family-centred care affected and structured professional interactions.

Another aspect of the discourse of professional relationships was the attention to understanding the culture of a family in order to build a trusting therapeutic relationship with the family. Trust and relationship building were key elements that emerged as discursive practices of the discourse of professional relationships. For example, one nurse spoke about the cultural influence on family sleeping arrangements

> You know, there are some families where everybody sleeps together. And the children can be really old, and they [the family]are all still sleeping in the same bed, and that's natural to their culture, where it might be quite taboo to our culture here [in Canada]. But you know, we really like to think that babes, have to learn to sleep on their own, but other cultures don't think that way. And sometimes people won't tell us the truth. I know they're lying, but I can't make them tell me the truth. I know that they're all sleeping in the same bed, but they won't totally admit that. Or, they know that their culture is a little different than ours, and it takes a while for them to trust and tell us the truth about these things. (J4)

In this passage the nurse, through experience, has come to understand the influence of cultural understanding on his/her relationship with a family. The nurse recognized that if she/he were too quick to judge the situation that it might be damaging to the long term nurse-patient-family relationship. In addition, this excerpt emphasized the importance of a trusting relationship for nurses, as an essential element of their work. Another participant also acknowledged the importance of developing a relationship with patients and that in developing this relationship, access to sensitive topics may be created:

> I think it very much depends on the nurse, and on the child, and the relationship that we all have. We all enter into the life of the family at different points, at different vulnerable points, and sometimes another team member, be that a social worker, or a physician, knows the family in a different way and the family may not want to open up to a new person on a team ... those [individuals] that have been here a little bit longer, may have a little more background and history with the family. And it might be easier to broach sensitive subjects. (J2)

In addition to being sensitive and attentive to the diverse cultural needs of individual patients and families, this participant discussed the need to cultivate and maintain trusting relationships with families. The same participant noted the importance of understanding the context of the patient and family to be able to capitalize on teachable moments that may present themselves in practice:

> At any moment in time, be it with the nurse when they are talking about some other things, or doing a dressing change, or looking at a tissue trauma. It's the readiness that you have to capitalize on, that teachable-moment, and not so much who it is, but be ready to seize that moment with the client, and give them what they can benefit from. (J2)

The readiness of the family or patient involves understanding where the patient is in terms of their ability to learn about a given topic. This requires the nurse, or any other team member, to be sensitive to and aware of the readiness of both the patient and their family in order to utilize the right moments to address sensitive topics.

The discourse of professional relationships, and the discursive practices that emerged such as trust, cultural sensitivity, and relationship building, were influential in shaping what nurses are able to accomplish within the clinic environment. Also these practices mediated how nurses were able to attend to patient needs around sexual health.

Many participants spoke about the fact that the longer they knew an individual or family, or the more time they had spent with patients, the more open the patients and families tended to become. In this instance the discourse of time, identified in theme one (institutional space), contributed to the development of the trusting relationship. This demonstrates how multiple discourses can be at work in one situation. The discourse of time shapes the nature of relationships that nurses can form with patients and families. For instance, one participant spoke about an experience with a patient, who had been coming to see the nurse twice a month for almost a year. The patient required nursing care for a wound, the nurse explained that:

> One of the boys that I've probably had the most in-depth conversation with. His actual question was about the volume of ejaculate, he wanted to know if he could still have children, because he only got a small amount. And he was very embarrassed about it. But I had an ongoing relationship with him ...I wouldn't say that everyone would be that comfortable. (A3)

The participant connected the fact that his/her long professional relationship with the patient created an environment where the patient was able to be very honest with the nurse. The participant went on to explain that over the course of the relationship, the patient even opened up about the cause of the wound.

> Even over the course of seeing him for his foot he eventually said, well I wasn't wearing my AFOs [Ankle Foot Orthoses] and this is how it [the pressure sore] started, and we didn't persecute him for saying that, we just dealt with the outcome and got on with it. (A3)

In this example the length of time spent becoming familiar with a patient directly impacted the relationship between the nurse and patient, the patient felt they could be open and honest with the nurse. Maintaining therapeutic relationships requires that nurses develop and maintain the trust of their families and patients. Nurses' awareness of sensitive issues and their ability to maintain relationships are examples of discursive practices that result from a discourse of professional relationships. Relationships are formed and maintained with patients and families, in order to gain trust, and over time nurses also become more familiar with families. This familiarity provides nurses the privilege to raise issues around sensitive subjects, such as sexual health.

Just as the example above displayed the positive effects of time on relationships, the lack of familiarity with patients, was evident during the interviews. Lack of rapport with patients and families was cited by participants as one possible reason why patients and nurses may not be comfortable speaking about sexual health issues. For example:

> I just started; I'm only 1 day a week with the team. So I don't get time with them, I don't have the rapport that ...[nurse A] or ...[nurse B] has. I know they've talked about issues with girlfriends and stuff, but I don't seem to have the connection yet with the families, because I haven't been here long enough. (J1)

This participant identified how their new status in the clinic affected his/her ability to connect with families in the same manner as other nurses who had been working with the clinic for a longer period of time. Developing relationships that result in open conversations and mutual trust was seen as something that took time. As such, the discourse of professional relationships was intimately linked to the discourse of time, as time was a key structural component to the clinic visits and the development of professional relationships.

The theme of *professional interactions* includes those interactions between individual team members, within the out-patient nurses (as a team) and those between nurses and the patients and families that they work with in clinical practice. Relationships within a team contribute to the flow of information and provide support for nurses within their current roles, and for nurses that move into new roles and clinics. Relationships between nurses, patients and families affect how and when nurses are able to address sensitive subjects, such as sexual health. The perspective that the individuals within these relationships (team, nurse, patient, family) bring to the clinical encounter are all situated within a broader context. This context includes the institutional space, but is also influenced by larger social discourses that frame our understanding and comprehension of individuals, groups, and exchanges within the clinical environment and society as a whole.

5.3 - Theme Three: Engaging with Sexuality

Participants spoke about sexuality and sexual health, in relation to youth with disabilities, in a way that revealed the influence of wider social discourses on nursing work. The discourses discussed within this theme include deviancy, asexuality, and medicalization. These discourses affect nursing work on a clinical level, and inform the subjectivity of patients and nurses within the clinical setting. As such, specific discursive practices around sexual health promotion are generated. These practices are engaged in by professionals, families, and patients either overtly or inadvertently. The discourses and associated practices discussed within this theme affect not only the identities of the patient population, but they also impact the way professionals, care providers, and society in general, interprets sexual health and youth with disabilities.

5.3.1 - *Discourse of Deviancy*

Deviancy involves behaviours that fall outside of social norms, or that do not live up to social standards. As presented in the literature review, the sexuality of individuals with disabilities may be interpreted as deviant. Participants never presented their personal perceptions of the sexuality of youth with disabilities as deviant. However, they shared stories in which discourse of deviancy played a key role. For instance, one nurse shared an experience she had years ago while working with older clientele (over 18 years of age) in an in-patient unit:

> This one boy, he always got an erection when he was due for his catheter … this was a boy who accessed prostitutes, not on the [facility] property, so that was okay. But it got to a point, that he was very good about it [the catheterization], he'd joke about it, and say "oh well, I knew you were coming". And I'd say okay, we'll let's get this [procedure] done and over with then. But you know, some people, some nurses, would have said "I'll come back later", you know… The older boys had full mental capabilities, so if they wanted them [prostitutes/escorts] they looked for them – my concern, as a nurse, was his safety – physical and disease issues. (J1)

This passage demonstrated deviancy in two ways and explored the way perceived deviancy was diffused by the nurse. First, accessing prostitutes and the performance of sexual acts in exchange for money are often interpreted as deviant acts. The nurse immediately diffused this situation by noting that the acts took place off institutional property, and that the patient had full intellectual capabilities and was able to independently organize such encounters. The nurse also diffused the situation by noting that as a nurse, his/her role would be to attend to any physical safety or disease issues that may result from patient decisions; his/her manner of dealing with the patient represents a very medicalized approach. Secondly, deviancy was also raised in the description of the patient having an erection. The nurse detailed two very different reactions to this erection. In the first reaction, the nurse asserted that he/she would contextualize the erection and negotiate the nursing work that was required, while maintaining a therapeutic relationship with the patient. The nurse also described the way other health care professionals may have had the opposite reaction; the participant noted that other nurses may avoid the situation and the patient, suggesting that some professionals may feel uncomfortable in the situation, as they may see the erection as inappropriate, regardless of the context.

Another way that the discourse of deviancy became known was through stories participants shared in relation to the reactions of parents to “typical” age-appropriate adolescent behaviour. When adolescents displayed the urge to be like everyone else, to explore their sexuality and participate in seemingly ‘innocent’ acts – such as putting on makeup – they were interpreted by parents as engaging in something deviant:

> But it [sexuality] is just growing up and you can see, from the floor, that some girls, they are sort of cognitively there; they want to become like everyone else, to wear a little eye shadow. But the parents, no no, don’t want that, don’t want them to do that [put makeup on] they could be taken advantage of or whatever if they come across like they’re a sexual being.

> With a disability, it's like they're asking for trouble or something. (J1)

This passage presented the way discourses affect an individual's beliefs, actions, and reactions. As the participant noted, a family may feel that behaviours such as putting on makeup may result in unwanted sexual advances or situations, so rather a family may simply prohibit this from happening. Deviancy, in this example, focused on the behaviours of the family as a result of the actions of a patient. Innocent acts became deviant because of what they could unintentionally result in.

Another participant provided an interpretation of sexual expression as deviant with regard to a child with a developmental disability. Here, the particular patient was attending a community program at the facility:

> I think what happens is that when he gets very stimulated, he starts to rub himself ...So she called the parents. The parents came into observe the situation, and they tried to divert him, to redirect, and who knows maybe he had a urinary tract infection. I don't know. But the bottom line is that the teacher misinterpreted the whole thing and called child protection ... it all really stemmed from, the teacher not understanding what he [the child] was doing, and why he was doing it ... I think the teacher was just abhorred that he [the child] was doing that. And I think that because the parent wasn't as abhorred. The teacher just thought, and she made an assumption, that maybe he [the child] just readily did this, maybe because there was some abuse that had happened to him. (J4)

This account can be examined with two major discourses in mind: first, the idea of deviancy, where the act the child was committing is seen as abnormal; and second, the discourse of the asexual subject as it relates to individuals with disabilities, where the child is seen as an individual devoid of sexuality. These two discourses combine and structure the activity of masturbating as deviant in this context, especially because the child could not be successfully re-directed. Deviancy in this case is the result of a behaviour being interpreted as a sexual act. The participant, like those before, contextualized this behaviour, given the patient diagnosis. This is interesting, because the participants in these situations demonstrate an ability to understand the entire circumstance – the behaviour as a behaviour unto itself, the space where this behaviour occurs, and then in combination – as to why some individuals may find a given action inappropriate, for instance – overstimulation, and a possible urinary tract infection. The participant was able to comprehend the larger discourse at work by identifying an action, the context, and the disconnect that some individuals may see between the two.

Through the example provided above, the role that discourses play in the work of nurses becomes clear. Participants may be influenced by discourses, knowingly or unknowingly, but in some situations they are able to identify a broader discourse that is at work in their clinical environments. The examples presented here suggest that participants understand that deviant acts are often misunderstood behaviours, but they also found that they struggled to explain these behaviours to other individuals. This does not apply only to the discourse of deviancy, it is also apparent in the discourse of asexuality, especially in the struggle between recognizing that sexuality is a component of being human, while it often is dismissed or left unaddressed with their patients.

5.3.2 - Discourse of Asexuality

When sexuality and the sexual expression of a group are considered "deviant," it may stem from the fact that those individuals have not been afforded the same human rights as others. People with disabilities may be considered asexual, depending on their age and the nature of their disability, much like the general population considers children to be asexual. This can be extremely problematic, especially as nurses aim to employ holistic care.

In some cases sexuality and sexual health is simply seen as not applicable or not a priority for a given individual.

> I think the general population sees people with any type of disability as being "non-sexual. (J1)

> It [sexual health] doesn't come up often enough. ... I think there are many reasons, time may be one. I think also because it's a pediatric setting and parents, and we are just starting to do transition now, to talk about transitioning and growing up ... And I think along with that there will be more attention to things like sexuality. (A2)

> I would say, with the older population, it is really, really, important. Typically teenagers don't want to talk to their parents about it at all. And, typically I think that when we look at children with disabilities we might make assumptions that are wrong...Such as, maybe they're not having sexual awareness. That they're not masturbating. (J4)
> Some parents, actually I find ...are more interested in folic acid for their other kids, and don't really acknowledge their child with a disability is a sexual being, and that it would ever become an issue for them ... It's difficult to see parents and even other people, both professional and "lay", not acknowledge that aspect of our kids. It's like they don't recognize them as whole beings. (A3)

These passages reflected the struggle experienced by nurses to communicate the wholeness of their patients to others and the nurses' desire to attend to all aspects of their patient's care. In particular, the reference to folic acid is particularly poignant. Folic acid is typically required in greater volume to prevent neural tube defects if there is a history of this within the family. The parents in this passage seem to overlook the fact that their chid with Spina Bifida could potentially have children, but show concern regarding this for their other children. There is a similar undertone to these passages, as those discussed within the discourse of deviancy. These excerpts detail how patients may be seen as asexual beings, while some nurses are able to see the patient as a whole being inclusive of sexuality. These participants acknowledged that others, including professionals, the general public, or families, may not see the patient in this way.

Participants also spoke about asexuality from the patient perspective, drawing on experiences and interactions with patients in various contexts:

> We used to run a ... sports and skills camp here during March Break, and one interesting comment from a little girl, who actually had a spinal cord injury. Very, very, very, bright, we had a coach for the camp, who had a spinal cord injury himself, and was a paraplegic. He was married, and I was commenting to this girl about his wife, and she said "Oh, he's married?" And I said "Yah, he's married, he's a really cool guy" and she

> said "Oh, well could I get married?" and I think she was in grade 6 at the time, and she had no idea that she could get married or have a family ... It's one thing that's kind of stuck in my mind ... she was a super bright girl, and she thought that she would be an Aunt... And later on in the week she said: "I kinda have a crush on one of the other boys in camp" she didn't use crush, she used another silly word. So that was kind of neat, she had never thought about it, it was interesting, surprising, that she never did. (A3)

This passage demonstrated how the patient was affected by the idea of asexuality and how the nurse worked to dispel this. Participants often discussed how they took on a role which challenged the status quo and dispelled myths around asexuality.

Other participants spoke of the challenge they faced when parents did not want to acknowledge that their children would develop sexuality. Often times this was raised around the issues of menstruation:

> For this one girl, there is nothing really on my sheet [assessment form] about menstruation and stuff. And we just sort of got talking, and I kept going back. I said "do you have a gynecologist" cause Mom was sort of No no ... Mom jumped into the conversation quickly. Maybe that would mean that her "little girl" was in fact a woman. (J1)
>
> I think that we could do better with younger kids, in preparing them for puberty. Especially girls, for going through precocious puberty, I don't think we do such a great job at being able to support. You know the reality is, supporting the families helping their young girls go through that. And often we have a seven year old girl that starts her period, and maybe hasn't even learned about puberty, it's a tough thing, for our families to cope with. (A3)

Participants spoke about the need to address sexuality with parents and patients in order to help them with normal transitions through life. As these examples show, sometimes despite their best efforts, the family may not be ready to address issues, even though they need to be addressed in that moment. These passages also hinted at another aspect of asexuality, that of children in general. In the context of precocious puberty, very young girls can be going through life events that are connected to an older group (e.g. menstruation). These changes bring with them a significant amount of symbolism, of becoming a woman and of becoming a sexual being, which directly challenge the notion of both the child and the individual with a disability as asexual

Another aspect of the discourse of asexuality that came up in interviews was the need for more specific education targeted at youth with disabilities around sexual health. One participant noted how youth may require new or specialized information about sexual health:

> There are myths out there, about asexuality, that people with disabilities are sexual. And I think that it's even harder for people that have cognitive disabilities – that they are sexual, or how can they be sexual? It's so difficult a topic, and people don't even go there. (S1)
>
> I think at school they get a certain amount of education [sexual health], but I don't think it's not specific to living with disabilities ... I guess in general, if they've been identified as, and they identify themselves as, someone with a disability, I think that they may have a lot of questions. And they may feel that they may be different than their schoolmates, because they are different in other ways. They may be thinking, well they are bringing up sexual health in school, but they may identify feeling different, because of a disability. (A2)

These excerpts expose how aware participants were to the perspectives and beliefs of other individuals: a direct effect of the discourse of asexuality. In addition, they noted that their patients might internalize the beliefs of others and as a result, may feel that they are different. Or, like the little girl in the earlier example, patients may not even realize that having a sexuality is even a possibility. Recognizing that patients may require additional information, or that the patient may feel excluded from sexual health, indicates that participants are aware of the ways in which this discourse functions outside the walls of the institution. The participants quoted here recognized a need for more attention to education.

The discourse of asexuality was not a factor in how participants saw their patients. In fact, all the participants interviewed had an understanding that their clients had sexual health needs, and that these needs may or may not be addressed in the clinic setting.

Some participants even acknowledged that despite their knowledge that patients are sexual beings, they did not integrate sexual health care into clinic practice. Asexuality was seen as a challenge to overcome, especially with regard to the way others saw adolescents with disabilities and the way patients interpreted their own sexuality. Much like the discourse of deviancy, the discourse of asexuality was an external discourse that nurses felt the need to challenge and disrupt through their work.

5.3.3 - Discourse of Medicalization

The medical model has influenced health care and nursing work for decades. It is a specific way of interpreting the body and the disease process specifically as "problematic." The influence of the medical model may also infiltrate the way specific topics are approached by patients, staff, and families, and may result in seeing the body and interactions with the body from a very physical and biological perspective. The medical model is a powerful influence on nursing work, nurses' approach to patients and the types of interventions undertaken with patients. Nursing work, as identified through the job description, was intended to be holistic in nature, and participants frequently referred to the holistic type of care that they intended to practice. However, as the interviews progressed the dominance of the medical model in the clinical setting became evident.

The discourse of medicalization was often apparent when nurses spoke about 'priority' issues in regards to patients or the effect of not attending to priority issues. Often these issues were of a medical nature:

> The population is almost all children, adolescents, and young adults who have neuromuscular disorders, and shortened life expectancy of varying degrees. Almost all are very compromised, and if they don't have a shortened life expectancy, they could get pneumonia, or something that would make them ill enough, that they would die. (A1)

> Quite honestly it [sexual health] is not something that I think of up front, because we are dealing with such bigger issues. Are they going to get a

> cold this winter? How will they manage their secretions? We only have so much time, we have a lot of time, in a typical clinic visit I would have an hour to an hour and half, and I could go back in at the end if I needed to. But if I was going back in at the end it's related to how I could teach them something else... chest stuff, so we can get them coughing properly, those kinds of things, that are so much more a part of their ongoing life, and their priorities. (A1)
>
> For a kid who has a lot of issues going on, I can tell you that this [sexual health] is probably some of the first stuff that goes. And we are focusing on bladder and bowel, skin stuff, because that's the bare minimum that we have to do. So definitely, I would say relationships and that sort of stuff falls by the wayside. If we know coming in that they've had major bowel blow outs every day for the last three weeks, then that's the priority. (A3)

The participant(s) above clearly outlined the types of issues that structure the nursing care provided. In a limited space of time, the nurse must attend to matters that, quite literally, are of a life and death nature. The priority medical issues dominate the time with the patient and leave little room to address 'extra' items, such as sexual health.

When sexual health was addressed by participants as an aspect of care they provided, it often was framed in relation to a patient's medical needs. This particular participant stated that they often accessed sexual health from a medical perspective:

> Our main focus is on bladder, bowel, and skin stuff. And we do comprehensive assessments and care and monitoring which includes everything from schooling, general health and well being, immunizations, diet, neurosurg concerns. With the diet, we tend to talk about folic acid and family planning and we may get into it [sexual health] that way. (A3)

This particular participant used discussions about diet and nutrition to access the topic of sexual health, for instance through a discussion of folic acid for youth with Spina Bifida. On occasion participants mentioned that the best approach to raising sensitive topics with patients and families was through a medical perspective. This may be because of the beliefs raised within theme two, professional interactions, as broaching sensitive topics from a medical perspective is in keeping with some families view of the purpose of a clinical visit – the medical assessment and discussion.

It was often through the use of the discourse of medicalization that both participants and families accessed sexual health as a topic of conversation:

> Well, it's [sexual health] seldom ever brought up by the client. It seems as though very, very, seldom would a client or a family come up with that question. And usually, if they do, it's in relation to a side effect of the medication or physical issues/complications ... Well, for example, some of our kids are on deflazacort, a steroid. And one of the side effects is delayed puberty. Or it will come out as a toileting issue. If a boy needs a condom catheter, then we're talking about size of penis and that how it [sexual health] comes up. It's very functional or bio-medical, rather than the social aspect...It's a functional issue. There are very few cases, where it would be *just the client in the room. ...Many times when I offer to remove the client,* he/she seems to prefer that their mom/primary caregiver remains in the room with them. And it might be again related to just checking to see if their menstrual cycle is normal, or in relation to their spine, i.e. monitoring increase in spinal curve during two years after menstruation begins. So again, it's tied to the functional, the medical. So it's very functional. Very medical. (A2)

Here, participants asserted that even families and patients use a medical issue or topic to talk about sexual health, and that often this is the only time it comes up – in relation to a medical problem. Perhaps this speaks to the fact that parents and health care professionals use a medical approach because it seems most appropriate given the context. The use of medical topics as an access point for sexual health is also reflective of the nature of the clinical environment and its influence on what is shared and discussed within the clinical space. If patients, families, and health care providers, primarily identify the clinic as a medical space this will influence what is considered appropriate for discussion in this environment (i.e. medical issues versus psychosocial health).

It was interesting to note that the above participant separated a discussion of sexual health from a medical or functional perspective from a social perspective. This suggests that families and patients were more comfortable or more concerned with discussing sexual health as only a medical issue, while avoiding the social aspects of sexual health such as forming health relationships, dating, and the possibility of sexual relationships. However, the psychosocial portion of the nursing assessment was not ignored. As a component of my research I examined mute evidence. Among this evidence were blank versions of the nursing assessment form used by the nurses in the clinic environment. These forms guided the nursing assessment and varied from clinic to clinic, however they all include basic information: height, weight, blood pressure, family concerns, and attended to general aspects of health. The assessment form was usually organized into systems– neurological, cardiac, respiratory, gastrointestinal, bowel and bladder, and musculoskeletal. There was often also a space for "psychosocial":

> In our assessment we have a section that has a bunch of blank lines and it's called psychosocial, and it's a catch-all for everything. (A1)

This section of the assessment was used by nurses to capture a number of 'psychosocial' aspects, including family goals, relationships, home and school life, and involvement in the community. Relationships, either with friends or others, are a component of sexual health, as it provides opportunities for independence and making connections with other people. Clearly nursing work was attuned to the importance of a healthy social life in addition to a healthy physical body. On one of the clinic nursing assessment forms there was a section entitled: urinary system, under which was a small line that read "Girls: Menses yes/no". On another assessment form under Nutrition was a note to address "Folic acid & Family planning". Interestingly, both forms provide the nurse with cues for their head to toe assessment, but in doing so medicalize menstruation and family planning as aspects of either the urinary system or nutrition.

The discourse of medicalization also provided nurses with cues to integrate aspects of sexual health into their practice; some nurses took this one step farther. One nurse commented on how he or she had added to the assessment over time:

> And also we have our own little nursing assessment guidelines paper that we made up, and as time has gone on over the last year, I've added a few things myself, the folic acid, latex allergies, etc. (J5)

The initiative taken by this nurse to add information related to sexual health indicated that some nurses are taking steps to integrate these topics into practice.

In order to address sexual health, they may need to do so from a medical perspective, in order to gain access to the topic with families and patients. One participant spoke specifically about the affect of the medical model on the clinic environment and the health care system in general:

> We are still stuck in the medical model of disability, still, in this late age 2009. Still stuck in the clinic model of the doctor and the information going one way, from the professional to the client. So it's up to the teams to change ... I think that structurally, sexuality is not seen to be important, it doesn't get mentioned, what is the priority? The priority is one doctor sees, at one time it was 15 patients a day, in an afternoon. There is no time for this [sexual health]. And I guess it's also our own discomfort with the topic and really acknowledging the scope of sexuality. (J2)

This participant detailed how the discourse of medicalization has functioned, and has continued to influence the practice of the clinic. She or he noted that it was up to the teams to change, pointing to the fact that it is up to the individuals, within the institution, to resist and advocate for changing care environments. As this participant addresses, nurses may be put in difficult positions by conflicting messages and priorities from the institution. The institution enacts priorities regarding transitioning and preparing for adulthood, but the infrastructure to deliver these priorities at the level of the clinic remains dictated by priority medical issues and time constraints. Finally, participants addressed the issue of personal discomfort with sexuality as a barrier to engaging in sexual health care. This statement is consistent with the findings of many studies involving nurses that cite personal discomfort as a reason for avoiding sexual health care in the clinical setting (see Lewis & Bor, 1994; Haboubi & Lincoln, 2004; Magnan et al., 2005).

Medicalization, in the context of the clinic is a double edged sword. In some situations medicalization of the body limits conversations to physical changes and medical priorities, while at times neglecting the importance of the psycho-social aspects of care.

However, in other situations medicalization serves a positive influence in nursing work. Nurses utilize a medical approach as a starting point to launch a discussion around sexual. Using this approach sexual health was seen as an appropriate topic for clinic discussion, which could then be explored over time.

As detailed within this theme there are larger discourses at work which can be situated outside of the institution, that affect patients, families, and nurses and the ways in which these actors interact and behave in regards to issues of sexual health. Deviancy and asexuality are well established as factors which shape the identity of individuals with disability, within this theme they are positioned as discourses which inform specific actions.

5.4 - Theme Four: The Nursing Experience

The discourses that emerge within the themes of *Institutional Space*, *Professional Interactions* and *Engaging with Sexuality* inform and structure the way that nurses engage in exchanges with patients and families regarding sexual health. The themes identified above, contribute to the fourth theme: the *Nursing Experience*. This theme comprises a unique set of discourses: the discourses of nursing, normalization, and desexualization. It became evident that nurses saw themselves, and were seen by others, as individuals who were allowed to have access to very private moments and conversations. However, in relation to sexual health care there were many dilemmas that nurses encountered. These dilemmas inadvertently resulted in practices that reflected the desexualization of care and the normalization of routine care within the clinical environment.

5.4.1 - Discourse of Nursing

The discourse of nursing considers both the role of the nurse within the institution as well as an examination of nursing as a profession. It considers the way in which nurses are seen, and see themselves, through discursive practices.

Discourses inform and structure how individuals act or are expected to act/react in a given situation. The discourse of nursing relates to expectations around nursing practice, and the tasks that are included in nursing work. In order to fully understand the role of the nurse within the facility, the specific roles that nurses are expected to adopt within the out-patient clinic environment must be explored. On an institutional level, the job description of the out-patient nurse requires nurses to provide:

> holistic, client and family centred health promotion and primary prevention services to infants, children and adolescents and their families who are receiving habilitation and rehabilitation services in the ambulatory care setting. She/he assumes a leadership role in developing collaborative partnerships with clients, families, other health professionals and community providers, to ensure optimal care co-ordination and delivery. (Name of Hospital, 2009a)

The job description is an example of institutional knowledge, which guides nursing practice. As such, nursing practice involves the provision of care within a patient/family perspective and an emphasis on leadership and the creation/maintenance of collaborative relationships. More specifically, this job description outlines specific models for nursing practice. Nurses are expected to conduct their work within the:

> framework of the McGill Model of Nursing, and practices in a manner consistent with the Vision, Mandate and Core Values of the organization. She/he incorporates the Standards of Practice stated by the College of Nurses of Ontario in clinical practice. (Name of Hospital, 2009a)

Interestingly, specific models and frameworks of care were not raised by participants as guiding their practice. The priority of collaboration was evidenced by statements of participants when they described roles involving referrals and collaboration with other professionals.

As participants were from a variety of clinics, it is important to understand their specific roles. Nurses from different programs spoke differently about their roles in the clinical setting. Some participants described their roles in great detail, as can be seen in the following excerpts:

> I would say that we do assessments, while in clinic, and case management following clinic. We definitely coordinate care. At their clinic visits we go through a nursing assessment, involving most body systems. Teaching them about respiratory care, we do assessments around respiratory functioning tests, we do their vital signs. We do a lot of teaching ... A lot of referrals ...for any various number of things ...we liaise with the schools, principals, special needs teachers, respiratory support, emotional support. Some we do transition for. (A1)

> We would spend the time ... with the client and one and/or both of their parents, occasionally siblings. When you do a full assessment, basically a medical assessment, just to see how things are going. And we ask about general things school, health, social, and then get into some nutritional counselling, skin counselling, bladder bowel, and anything else that they want to talk about. And right now we have the Prepared to Grow Up initiative, for transitioning. (J5)

> ...a lot of case management. I would say it is case coordination, supporting an interdisciplinary approach, working with other professionals. Our scopes overlap ... As a nurse, I work with the pediatricians, therapists and social worker to provide family/client centered care. We work with community partners providing informational and emotional support, providing consultation and interventions specifically related to the client's special needs. (A2)

Nurses from these clinics clearly identified the facility values of collaboration and partnership both within the facility and within the community. Also there is an attention to the holistic aspect of care: assessing more than just the physical body.

The roles of nurses described above, were from a particular group of clinics, and were different from the roles described by nurses that worked within other clinics. For instance, nurses with the first group seemed to have more time with patients and their nursing practice had different priorities. The next few excerpts demonstrate what nurses from the other clinics had to share about their work.

> For me, I welcome them in, I'm doing blood pressure, heights and weights, and dealing with referrals, that sort of thing. I don't have an awful lot of contact with kids. (J3)

> They [patients] are coming, and in some cases going to be newly diagnosed... and generally with those visits, if I have time, I'll sit in [with the physician] as well. Other times, I'll leave the developmental pediatrician with a fellow or a resident, and they may do the full work up. And I'll see the patient initially, and put them in a room, give them my contact information.

> And then I may see them again at the end, just to reiterate contact information. My biggest role is with the follow-ups. I'm the main contact, in the centre for them [the family], and if they are confused about something they'll call me. And if we're relocating them to another facility in the community... I'm the bridge for that. We also do drug trials, particularly Ritalin. And I'm probably the main person doing the main work, and they'll come back on another day and I'll arrange the Ritalin trial for them. (J4)
>
> Basically, for everything except the other group of clinics, it's just sort of medical management, medications, trouble shooting sleeping issues, sometimes emotional support of the parents ... Basically, I do a nursing assessment. Any problems, nutrition, just the whole health assessment basically. And if there is anything that jumps out, any major issues, I will point that out to whoever is going in after. (J1)

There are a number of similarities between this group of participants and the first group. For example, the attention to holistic care was consistent across both groups, as was the emphasis on collaboration with other team and community members. However, between the two groups, nurses spoke differently about their work. These differences were most prominent in relation to the impact of the clinic structure on their work. The first group of participants had more time with patients and used words such as teaching, support, and counselling; whereas, the second group of participants used words like contact and assessment, and appear to be more task oriented.

The discourse of nursing work was clearly affected by institutional space, especially the mission statement of the institution. This became clear when nurses spoke about their approach to nursing work, especially as it related to family/patient centered care and caring:

> We try to be holistic in everything we bring up. (A1)
>
> We are not just talking about medications, we are looking at the child as a whole and what interventions can be put into place that are going to be most helpful. (J3)
>
> Starting with a nursing assessment it [a clinic visit] is a back and forth open ended conversation. It's holistic, it involves all aspects, from physical to psychosocial assessment ...We have a nursing assessment worksheet to guide and document the assessment. And then we would consult with the other professions, after, so that we are not asking the same questions. The

> pediatrician usually consults with the client and family at the end. (A2)

The emphasis on a holistic perspective was raised by most participants. Regardless of the specific clinic that nurses worked within, nursing work was seen as holistic, family and patient centered and was driven by the priorities of the patient and family.

In addition to the documented roles and responsibilities of nurses in the clinical setting, many participants also spoke about the unique role of nurses. One point in particular that participants continued to raise was that the view of nurses, held by family members and patients, provided nurses with access to events, care routines, and topics that other professionals may not be able to engage with.

> I think nurses are viewed as people that are allowed to talk about it [sexual health]. (A1)

This participant identified the way nurses were seen by others as individuals with whom it was okay or appropriate to talk with about sexual health. This same participant relayed a story about an incident at a school:

> *I worked in a different program and was called out to a school one day, and* it was another nurse and myself. We went out to the school and it [the issue] was around toileting a female student. There was an occupational therapist, a physical therapist, an occupational therapist student, a physical therapy student, the people from the school, whoever was in supporting internally at the school – a cast of many. And I think that day did a lot for me a far as what the public's view is of what nursing is and what their responsibility is. They [the school staff] were trying to figure out, how she [the student] was going to toilet in the space that she was given in the school, with the accessibility, or lack of, that was there ... as we were getting ready to go into this washroom, which was probably about the size of this room [5 x 10], "so now we'll actually go into the washroom". We had talked around how she [the student] was going to do it [toileting], but now we'll actually go in. And she [the student] said to everybody, and I was very proud of her "Only the nurses can come in". And I thought, wow, at that moment I felt kind of proud about this strange situation. But what I think, is that her family had probably taught her was that it's okay for nurses to see you and to help you, in regards to toileting and other private ways, but you say no to everybody else. And I think that was her families' way of protecting her. You can say yes to nurse, but anybody else you say no. (A1)

In sharing this story, the participant explored two very important aspects of nursing. First, in this situation, the nurses had the privileged position of assisting the student with her personal care. The second aspect was in that the participant felt that perhaps the family had taught the youth that toileting and personal care was something that nurses had exclusive access to. The participant expanded on this idea:

> I think that a lot of the public does think, that it's okay, it's not the occupational therapist. Although it is occupational therapists that deal with everything. But I don't think that the general public think that and I don't think that they would associate a physical therapist with that. But nurses obviously are people that are allowed to have access to that privacy. (A1)

The participant had an acute awareness of the acts that nurses typically have access to, without question, and that other health care professionals may not have access to in the same way. And often these acts are indeed private, or involve intimate care, such as bathing, and assisting with catheters. The public perception that this participant raised may be a result of the personal experiences with nursing care, directly or indirectly, which would increase the awareness of what nurses do.

Participants spoke about their unique access, as nurses, to a variety of sensitive topics. For example, nurses in many settings have access to intimate moments including discussions about the function and status of bowels, the smell and colour of urine, the explanations that are shared about end of life care, and the intimate nature of providing personal care. However, some participants felt that even sexual health fell outside of this realm. One nurse expressed the concern that if she/he brought up sexual health, the patient might think that they were prying for information, despite that fact that they discuss almost everything else:

> It's funny that we ask about everything else ...I know, I talk about shit and pee. Hey I'm a nurse tell me about your poo. (J1)

This excerpt suggests that nurses are "allowed" access to topics about the body in ways that perhaps other professionals are not. As this and the other passages above reflect, there is a sense of normalcy to these interactions, where nurses approach otherwise abject topics (excrement, interactions with the body that focus on bodily fluids and waste). These tasks and activities are very personal and involve the touch and communication around intimate/highly sexualized areas of the body. Practices such as these are the discursive practices of nursing, and are not questioned as being unusual by either nurses or their patients and families. The participants were aware of the special status of nurses in the eyes of society, as being members of a profession that are allowed to conduct work with the body in intimate ways. Despite this fact, the participants noted that sexual health, at the moment, still remains a difficult topic to broach with patients and families.

The therapeutic relationship between nurses and patients provides the space to have open and honest discussions about difficult topics. One participant spoke about this unique connection, suggesting that it was a result of the way the nursing image is internalized by the public:

> I think, from the patients' and families' perspectives, that they see that the nurses have a physical aspect as well as the communication aspect, and as well as the whole child aspect. So they [nurses] are an excellent resource. And when you have a population with differences related to bowel and bladder functioning, sexual functioning, nurses are an excellent resource for helping people. And it's because they deal with all different aspects of care. Bowel, bladder, skin trauma, they are in the trenches, where the kids really live. They know that is a person that you can trust. (J2)

The idea of seeing nurses "in the trenches" reflects the type of work that was alluded to in the first few passages – the kind of work that nurses undertake at the level of the patient and on the body itself. Nurses engage in nursing work that requires access to otherwise private areas, and it is not always glamorous. Other participants acknowledged that nursing work, especially around sexual health, can be messy. One nurse spoke about an experience on the in-patient ward:

> I'm the nurse taking care of this kid who has a big poo, and has her period and is very hairy and it's like - yuck. We [nurses] are the ones that are dealing with it. (J1)

While this passage was in regard to in-patient care, it illuminated not only the work that nurses do, but also the work that families and patients address on a daily basis. These are the types of activities that inform the discourse of nursing and in turn the straightforward way nurses approach their work.

Specific discursive practices of nursing work, such as holistic assessments, wound care, attending to priority issues, recording heights and weights, and acting as a liaison for families, were all supported by the creation of a specific clinical environment and were structured around institutional priorities and the time available to nurses. In addition to the institutional perception of nurses, what also emerged from discussions with participants was the importance of the way in which nurses saw themselves and their profession. The use of their knowledge of nursing as a "special" practice was also intriguing as it functioned to encourage open discussion of sexual health topics. This was done by framing sexual health as a medical issue. Sometimes issues such as menstruation had to be addressed. This provided nurses with an opportunity to frame a discussion about sexual health. However, how the topic was raised and who initiated the conversation may limit the ways that the topic could be addressed (i.e. problematic versus natural/normal). Nurses were able to utilize their position to help parents, families, and patients open up and discuss sexual health as something normal. These actions communicated that not only was the topic appropriate, but it was also an important issue that could be discussed in the clinic environment.

5.4.2 - Discourse of Normalization

Participants involved in this study provided detailed descriptions of how they could make addressing sexual health issues with patients and families easier. One of the ways that nurses approached sexual health was in a medical manner. Another perception nurses expressed was the view that it would be easier to address sexuality and sexual health if these topics were somehow normalized. This way sexuality and sexual health could be seen as normal and commonly addressed issues in the clinic environment.

The discourse of normalization is linked to the discourse of medicalization, but is different, as the former extends beyond medical frameworks and deals with issues of normalizing discourses of sex and sexuality throughout all health care systems. Often nurses spoke about the need to normalize sexuality and sexual health by linking it to the clinical environment.

> It's that atmosphere of "this is normal to talk about." Falling back on it's clinical, we talk about health, and sexual health should be included. (A2)

This participant expressed the need to address sexual health as a 'normal' part of care and a necessary inclusion when discussing the health of the whole person. Other participants offered the idea that sexuality and sexual health were challenging to address in general, not just within the context of disability:

> But you do wonder, what it's like, in regular, outside of the areas of disability, how pervasive is this with say pediatricians, well baby clinics or what have you. I don't think that just because of disability that it's down in the priority list. (J2)

As this comment reflects, the need to normalize sexuality, so that it can be discussed comfortably and seen as 'appropriate' to talk about, is something that is seen as required within the context of disability. This participant points to other facets of the health care system, contemplating the state of sexual health care within the able bodied population. This comment draws attention to the fact that the existence of a disability may not be the only reason sexuality falls low on the priority list, but rather the participant questions if an avoidance of sexuality is a systemic issue in health care.

Despite the fact that the institution did have a priority on preparing youth for the transition to adult services and on preparing them for the lives they would lead as future adults, issues around mature sexuality were not highlighted as essential for these young people. One participant identified that the organization as a whole was not emphasizing sexuality as an important aspect of the processes of maturation:

> We, as an organization not only a team, don't put enough emphasis on it, should there not be a poster on the wall, proclaiming something about sexuality? Demystify it, to make it a real factor in everybody's life. (J2)

This comment related to the organization as a whole. I did see some evidence that indicated otherwise, such as stickers proclaiming offices as "positive space" (spaces that were safe to talk about diverse sexualities and sexual health issues). These stickers were not everywhere, and I do not recall seeing any in the general public spaces or in the clinic.

Providing physical space, that dedicates safe environments to discuss sexuality and sexual health, is one step towards normalizing sexual health in the institutional environment. However, it may also limit the discussion, placing boundaries on where, when, and by whom these topics may be addressed. The benefits of normalizing sexual health were reflected upon by the participants, especially as it related to their nursing practice:

> I think it would be very good for us to be able to add that [sexual health] to the whole assessment. But the thing is, you get people who are oh, well "What area specifically" and they'll [the parents] say "well what are we talking about? Does he go out with girlfriends, or" ... it's such a big topic ...To add it somehow, ... "Do you have any friends at school" in that sense, "is there anyone you like playing with more?" "You know he's got a little friend Jody, who she comes over, and that's nice." It's interesting, and I never gave it much thought.... Like, you never think, oh yah okay ...everybody goes through it [sexuality/growing up]. (J1)

This participant thought that promoting the idea that sexuality and growing up is a common aspect of everyone's life would help families to understand that it applies to their children and youth also.

The normalization approach to sexuality was also discussed in practical terms. Participants suggested how normalization might be accomplished in a clinic environment:

> Ideally, if we could all just blend it [sexual health] in, as a questions, in the same way that we are asking other questions. "How's school going, how are the meds for seizures going, how's this going and that going, and how is sexual health stuff going." (S1)

The discourse of normalization involved identifying potential practices that would make sexual health topics easier to address and more accessible to nurses.

Normalizing sexuality was not limited to patients and families, some participants also spoke about the need to normalize sexual health and sexuality for the public in general, including staff and patients:

> Making everyone more comfortable, even using the word sexuality is a great start, Isn't it? ... It conveys a whole new message to kids, it's okay to talk about this. It's something I have, I have sexuality. Isn't that a great thing. (J2)

The discourse of normalization hinged on a perception that despite the prevalence of sexuality in the media and society in general, it was not okay to freely discuss sexual health. Given the fact that nurses were addressing very intimate issues with patients and families, sexual health was still seen as something that needed to be more formally supported by the institution so that it could be embraced as a valid topic by nurses and families.

Normalizing sexual health, in the eyes of the participants, would make it an acceptable topic to discuss and assess within the clinic. Participants were acutely aware of the difficulty of addressing sexual health and sexuality. Given the fact that participants were striving and working towards having sexuality and sexual health embraced as routine aspects of care, there was an outstanding issue as to how some aspects of care were approached, which gave way to a final discourse in the theme of The Nursing Experience – the discourse of desexualization.

5.4.3 - Discourse of Desexualization

The privileged access to the body provided to nurses, and associated nursing work, has been discussed above and throughout the four themes presented in this chapter. Many of the instances described suggest that nurses may not interpret this access and work as acts of intimate care, since the sexual nature of the genitals were rarely discussed. However, nurses frequently engage in care that is very intimate, such as catheterizations, discussing bowel and bladder movements, and educating caregivers and families on how to handle menstruation with youth who are in incontinence briefs.

Some discursive practices of nursing involve tasks that influence sexual identity, one participant reflected on this issue:

> I don't feel we really know enough about how the interventions for personal bowel and bladder care effect the child's perception of their own sexuality. We make kind of big assumptions, but it would be an area for lots more research, because we impose our own restrictions and values on being exposed in that way, and kids, kids find it hard to talk about. It is an influence, we just don't know how, but I do think it is a strong influence ... how they [the patient] see themselves – how the child is able to separate personal care from sexuality ... And I would say that up to 80 - 90% of kids do need assistance with toileting and catheter care, especially when they are younger, and perhaps by the teen years, if they've got lots of motivation, dexterity, mobility, and balance. There are so many things that you are dealing with and the problem is a huge one. The problem here is ownership of bowel and bladder issues by the young person/motivation to follow through with catheterization routines. (J2)

The participant acknowledged that as a group, health care professionals do not understand the extent to which their involvement in care may influence how individuals see themselves. The participant went on to say that the approach of health care providers must surely impact an individuals' sense of self. The assessment, care, and teaching around bowel and bladder health are primary focus areas for nurses working with youth with Spina Bifida and spinal cord injuries. Often children with Spina Bifida need to be catheterized intermittently throughout the day. It was interesting that while bladder and bowel care and catheterization were spoken about throughout my study, participants rarely acknowledged such practices as involving access to the genitals and the impact of this constant access on the individual patient. Instead, nurses spoke about these practices in very a desexualized manner.

The discourse of desexualization is enacted in everyday care and results in the desexualization of the patient's body. One participant spoke about patients wanting to masturbate, while the example provided was from a previous experience on an in-patient ward, it speaks to the issue of sexuality and the needs of patients. The situation discussed below describes an encounter when two nurses were required to change a patient's diaper.

> I guess it's not a going concern. But I think that nurse's attitudes towards touching and masturbation can be a little backwards. Not all, but a couple of times when I have been working with a client, and two of us are turning him, and he's touching himself, and you know it's [the reaction is] "you don't do this, this isn't an appropriate thing to be doing"... it's a judgment call. It's passing judgment, because when you've got 14 or 15 year old boys who are maybe not as aware cognitively that it's not an appropriate thing to be doing in public, but I mean. I don't know if that is lack of understanding about what teenage boys do ... I don't know if it's that a cultural thing, or an age thing ...it's mostly a matter of, it's not appropriate in public, to be doing. But it's not, not an okay thing to do. You know, you can do it, but probably not while I'm changing your diaper, but then, kids don't really understand that either. They don't really understand, and it's not really like it's in public, it's in his bed, and it's, you know, behind closed doors, and he has access to it [his genitals], whereas before it was done up [in a diaper]. For me, if it provides some relief and nice feeling than I don't really have a problem with it. With the kids that aren't cognitively aware, if they are aware then he [the patient] can wait till I'm gone. (J3)

In this passage, the participant acknowledged that for some individuals the fact that the child is masturbating is seen as completely inappropriate (reflects the discourse of asexuality or deviancy), despite the fact that the behaviour takes place in a space that could be considered as private. The participant also acknowledged the practical aspects of masturbation for some patients: if there are incontinence briefs involved, the patient may not have access to his or her genitals until the nurse is doing personal care. This reflects how health care providers may influence the sexuality or sexual expression of patients through the care that they provide. The attitudes of others, raised in the above quote, reveals that some health care providers may unintentionally desexualize their care, or may not understand that the patient is experiencing a lack of access to sexual exploration.

The theme of "The Nursing Experience" explored three distinct areas: the discourse of normalization, the discourse of desexualization and the discourse of nursing. Each of these discourses interacts with the previous three themes that have been presented. For instance the story that was shared about the patient who wanted to touch himself while being changed, reveals behaviours that are influenced by the physical space where a nursing action is taking place. The patient room may be a "private" space for the patient, but in the nurses' reality it is a shared space between the patients/families and health care providers. This example is illuminates the collision of two realities, that of the patient and family, with that of the nurse. Each reality encompasses its own set of symbols, meanings, and actions for this specific space and therefore the actions and discussions that may occur in this space.

The discourse of nursing provides nurses with the sense that they are in a unique, publicly trusted position, which confers upon them the unique responsibility for very intimate acts of care. Despite their awareness of the importance of sexual health, nurses often relayed stories which desexualized the bodies that they cared for. And, in other situations, nurses attempted to normalize sexual health, or make it more routine, perhaps in an effort to de-sensitize it for patients and families. Ultimately, the theme of the Nursing Experience is a result of the previous three themes coming together and depicts how nurses attempt to navigate sexual health in their day to day practice.

5.5 - Chapter Summary

The data analysis presented in this chapter explored four distinct themes: *Institutional Space, Professional Interactions, Engaging with Sexuality, and the Nursing Experience*. In exploring these themes, from an individual, institutional, and on a broader social level, specific discourses were identified that contribute to and shape the beliefs and actions of nurses, patients, families, and other health care professionals, such as social workers and physicians. In presenting the data, I hoped to show how these discourses functioned on an individual, institutional, and societal level. For instance the view of the nurse, as a professional who has been given the privilege of having access to intimate areas of care affects nursing work on multiple levels. First it delineates what is identified as appropriate and important nursing work, and how society interprets the nursing profession which affects interactions with nurses.

The discourses and discursive practices that are outlined in the four themes are all interconnected. Reading a single passage from a transcript reveals multiple discourses that frame nursing work with youth with disabilities around sexual health. When engaging with the data, I began to see how different ways of thinking led to specific discursive practices, from the language used to describe a situation, to how nurses (unknowingly) used specific opportunities to gain “access” to sexual health topics. The analysis of the data, presented in this chapter uncovers some very intriguing aspects of nursing care in regards to sexual health and youth with disabilities.

Nurses seemed to be caught in a paradox – asked to engage in holistic health care and institutional priorities around preparing for adult life/transitioning, and the social discourses that affect their practice and shape the identify of individuals with disabilities as asexual, deviant. Another component of this paradox is that nurses, along with other health care professionals, are mired in a system that continues to be structured by a medicalized view of the body and bodily functions, but at the same time it acknowledges that sexuality and sexual health is an important aspect of holistic care. While nurses seek to provide holistic care, as promoted by the institution, their concern for establishing trust and maintaining the respect of families, as well the lack of tools provided to them by the institution, prevent them from addressing sexual health properly. Far from nursing work functioning to control and suppress the sexuality of youth with disabilities, the data analysis painted quite the opposite picture – the participants demonstrated a desire to engage and support the sexual health of the youth they worked with.

The data analysis presented here addresses the thematic discourses as unique entities, my discussion will demonstrate that these discourses are woven into the others and together legitimate, support, contradict, and create specific discursive practices. My previous chapters outline the existing literature and present the theoretical foundations that inform this research project. My analysis reveals that while some discourses create opportunities for nurses to address sexual health with the target population, other discourses conflict with these objectives – which create a paradox, within which nurses attempt to provide the best holistic health care they can.

Chapter Six – Discussion

As outlined in the closing summary of Chapter 5, four distinct themes emerged during the data analysis: *institutional space*, *professional interactions*, *engaging with sexuality*, and *the nursing experience*. These themes and their discourses interacted with each other, in both limiting and supportive ways, and gave way to the development of three major findings, that I will outline as: (1) nurses as caring agents, (2) the perceived impossibility of sexual health care, and (3) the necessity of dangerous practices. Within this chapter, a summary of the major findings are provided alongside the current literature (presented in Chapter Two) and situated within the theoretical framework (addressed in Chapter Three). In addition to discussing the major findings of this project, this chapter also serves as a forum to identify the limitations of this research, and to address the broader implications of the project at the levels of professional practice, education, and research.

The major findings that have been generated from the data analysis can be summarized as follows. First, nurses are caring agents that utilize this position to engage patients in sexual health care. Second, there is a perception, on the part of the participants, of the impossibility of sexual health care. This impossibility is related to the structure of a total institution, as well as the influence of the larger discourse of asexuality on patients and family perceptions. The third major finding is that nurses, and other health care providers, engage in practices that in the short term enable conversations around sexual health, but in the long term may have negative consequences.

6.1 - Nurses as Caring Agents

Literature related to sexual health and nursing, regardless of diagnosis or disability, is heavily focused on the barriers that nurses encounter in providing sexual health care. For decades these barriers have been studied by researchers, and for decades, the same barriers have been identified by nurses: educational preparation and support, attitudes towards sexuality, and the roles of nurses in providing sexual health care are all common themes raised in the literature, many of which are also reflected in this research project. Overall, sexual health was acknowledged by participants in this study as an important aspect of care to address with youth with disabilities and their families. Also, participants did engage in some aspects of sexual health care, especially in relation to masturbation. This reflects that participants accepted that their patients were indeed sexual beings, and that sexual health care was an important component of providing holistic care to the whole person.

The recognition of the inclusion of sexual health, as an aspect of nursing care, is congruent with perspectives of the Canadian Nurses Association (2010) which includes the promotion of sexual health and safe sexual practices, as a health and wellness competency of practicing nurses. In addition, the importance of including sexuality and sexual health in the comprehensive care of patients is frequently raised across different areas of nursing including cancer and palliative care (Lemieux, Kaiser, Pereira, & Meadows, 2004; Hawkins et al., 2009; Higgins et al., 2006; Hordern & Street, 2007; Shell, 2008), general acute care settings (Dattilo & Brewer, 2005; Katz, 2005; Magnan & Norris, 2008; Magnan et al., 2005), and as stated earlier, is limited in relation to youth and adults with disabilities (Carr & Purdue, 1988; Di Giulio, 2003; Earle, 2001; Milligan & Neufeldt, 2001; Murphy & Young, 2005; Smith et al., 1995).

Health care professionals, in particular nurses, perceive sexuality as a component of care, and increasingly general society is envisioning nurses as professionals who could and should integrate sexual health into their responsibilities (Gamel et al., 1993; Lemieux et al., 2004). The fact that patients, health care professionals, and society in general, view nursing as a profession that could integrate sexual health care into practice, may be due in part to the rapport that is established between nurses, patients and their families.

Despite the fact that nurses endorse sexual health as a component of care and recognize its importance in the context of youth with disabilities there are many barriers to engaging in sexual health care. The same barriers that were raised in the literature were also apparent in this research study. Nurses acknowledge the need for additional education (Lewis & Bor, 1994; Haboubi & Lincoln, 2004). Specifically though, nurses in this project discussed a need for specialized knowledge and information that was focused on the unique needs of their patient populations, for instance increased knowledge about conception and pregnancy and Spina Bifida. Participants also spoke about the awkward nature of opening up a conversation about sexuality, and identified feeling as though they were prying for information. Participants expressed that asking about sexual health, or questions about intimate affairs, could be interpreted as snooping, and reflects being uncomfortable, a common barrier to addressing sexual health with patients (Lewis & Bor, 1994; Haboubi & Lincoln, 2004; Magnan et al., 2005). Twenty years ago, Kautz, Dickey and Stevens (1990) conducted a study on sexual health care with nurses in a hospital setting. They found that sexual health care was a low priority, was not a routine practiced by other nurses, and that nurses perceived that patients were too ill to address sexual health, or it was assumed that patients would initiate the conversation. Twenty years later, studies continue to discover similar themes, leading one to question if perhaps the real barriers to addressing sexual health in a clinical setting are more deeply rooted.

Some authors and researchers have started to shift their attention to specific aspects of the nurse-patient relationship which may influence a nurses' ability or willingness to broach the topic of sexual health with patients. Katz (2005) suggested that the rapport between patients and nurses is often interpreted as something that supports conversations about sexuality. Lemieux et al., (2004) interviewed palliative care patients and discovered that rapport with professionals made it easier to discuss issues of sexuality. This sentiment was echoed by participants in this study, professionals felt that the longer they had worked with patients the more familiar they became with the patients and their families, which allowed them to raise sensitive issues, including sexual health. However, the development of this relationship required nurses to be aware of the cultural and religious beliefs of the family, and understand that raising specific information may jeopardize the relationship with the family. Rarely, if ever, does research address these nuances of the nurse-patient relationship. Elements that may either facilitate or deter nurses from engaging in sexual health care. Within this study it became quite clear that the relationship with the patient and family was of primary and utmost importance. The nurse-family relationship was the cornerstone of all communication, teaching, and care that took place, and nurses were acutely aware of the implications of damaging the relationship by broaching 'sensitive' topics such as sexual health. Placing the patient and the family as the unit of care can present challenges in this context, and the dynamics within these relationships (parents/children/health care providers) can be an issue. For instance, if patients are interested in exploring sexual health, but the parents are less inclined to do so.

Within this study, participants gave much attention to the importance of the relationships that nurses form with patients and families. Elements of these relationships ultimately determine nursing actions in given situations in combination with the public view of nurses (both within the institution and in society in general); suggesting that nurses occupy the position of caring agents. In order to understand this concept and its connection to sexual health, it is helpful to turn to Foucault's later work which focused on the productive nature of power; beyond power as a repressive and limiting force.

Attending to a productive version of power, Foucault discussed ascetical practices, those practices which focus on the self, and move the self towards a new way of being (Fornet-Betancourt, Becker & Gomez-Müller, 1987).

Foucault termed this set of practices 'technologies of the self', technologies that are focused on the care of the self. They "permit individuals to effect by their own means or with the help of others a certain number of operations on their own bodies and souls, thoughts, conduct, and way of being, so as to transform themselves" (Foucault, 1988, p.18). Technologies of the self do not result from the liberation from power. In fact, Foucault remained sceptical and cautious to endorse the possibility for complete liberation. However, he did acknowledge that practices of freedom, related to the care of the self, exposed new relationships that could be engaged in, and controlled by power (Fornet-Betancourt et al., 1987).

In Greek and Roman times, to care for the self was a precondition for engaging with society; to care for the self meant knowing how to practice freedoms and behave 'properly' within the established truths and regulations. Care of the self requires knowledge of rules of conduct and societal truths; "to care for self is to fit one's self out with these truths" (Fornet-Betancourt et al., 1987, p. 116). Knowledge of these truths, norms, and the rules of "appropriate" behaviours, provides the individual with the information required to govern themselves within the established norms of a community, culture, or society. Awareness of these truths also provides an understanding of the consequences that may be associated with movement away from the norm (i.e. stigma, punishment). Caring for the self is an ethical act that involves the engagement of the individual with a complex network of relationships (all of which are mediated by power), and in this way becomes a way of caring for others (Fornet-Betancourt et al., 1987). That is, by acting in accordance with social norms, the status quo of the whole is maintained, the network of social relationships remains unchallenged and stable, and the behaviours of the norm are continuously reinforced. Care of the self has historically been linked to medical practice and thought (Foucault, 1986); this becomes evident in an examination of nursing work.

Nurses, in their professional role, engage in both the care of the self as well as the care of others. Care for the self is represented through the process of nursing education (guided by expert educators), ongoing professional development, and adherence to norms that govern the profession. Nursing students learn the competencies and scope of nursing practice. Subsequently, as professionals, they draw on these competencies, work within their scope of practice, and follow a code of ethics. These rules and codes of conduct are mastered throughout their education, but also during their integration into the profession. For example, within the context of the facility in the current study, nurses were guided by the McGill model of nursing, policies and procedures, and codes of care embedded in the facility's mission and vision – including the provision of family centred care and holistic care. These aspects represent norms and standards which the nurse is expected to practice within, and which inform how nurses are to govern themselves and others in given situations. In this sense, care of the self provides the nurse with an understanding of his/her place within a given work environment along with the rules, norms, and regulations that govern the environment and those within it.

While nurses engage in the care of the self, they are also caring agents. As caring agents, they are responsible for the care of others. Nurses occupy a position of authority or expert, as one who will guide another. For example, nurses guide the patient and family through a process of self-exploration. Foucault states that the ethos of caring for the self also implies:

> "a relation with others to the extent that care for self renders one competent to occupy a place in the city, in the community or in interindividual relationships which

> are proper – whether it be to exercise a magistracy or to have friendly relationships. And the care for self implies also a relationship to the other to the extent that, in order to really care for self, one must listen to the teachings of a master." (Fornet-Betancourt et al., 1987, p.118)

The nurse occupies a place in the community as one who develops therapeutic relationships with patients and families in order to provide nursing care that will promote health and prevent illness. This position, utilizes what Foucault (1978) refers to as pastoral power. Pastoral power originated with the organization of Christianity, but has extended beyond religion and is exercised through public institutions and disciplines, such as nursing and medicine (Foucault, 1983). Central to pastoral power is the concern for both the whole and the individual, and the caring agent as an expert has a moral influence on others and thus exercises their power discreetly (Holmes & O'Byrne, 2006).

The nurse, exercises pastoral power, using their position as a caring agent, and the expert status (power) this role confers to guide others to care for the self (Holmes et al., 2006). In the clinic setting, the nurse can ask questions that require the patient and family to reflect on their behaviours in a way that may elicit change the practices of patients and families. As nurses become more familiar with a patient or family, their relationship also changes, and behaviours may be easier to address. For example, the child who had been seen by the nurse for frequent wound care, eventually opened up to the nurse about the cause of the wound, and understood the implications of these actions.

Participants frequently referred to the general view of nurses held by the public, as being a profession that is allowed to talk about sexual health, a profession that works "in the trenches" with families and patients, as a result nurses come to occupy a position that engages patients and families in a relationship – a relationship within which the nurse occupies the role of the caring agent, a guide, a confidant. But in occupying that role, nurses must also consider the fact that an abuse of their power could result in the abrupt end of that relationship. In regards to sexual health, nurses were acutely aware of the delicate nature of this relationship. If discussing sex and sexuality might damage the relationship or isolate the patient, nurses chose to avoid the topic or use euphemisms, especially if damaging the relationship might result in families not raising concerns about serious health issues.

Nurses, as caring agents, engage in collaborations with patients and families in the clinical setting. They work with families and patients to address problems and health concerns. In this role, nurses utilize productive power; that is, power that transforms from the inside out (Weberman, 1995) through self-examination. The exam is a cornerstone of health care, and requires patients to disclose information about themselves, to the health care professional; in this instance, a nurse. For example, through the nursing assessment the nurse may ask questions related to privacy in the home, opportunities for peer interaction, and activities that represent the independence of the patient. In asking these types of questions the nurse encourages the family and patient to reflect on these issues. As a consequence, patients and families come to know themselves, and with interventions put in place by the nurse, patients/families may redirect their activities according to this newly acquired knowledge (i.e. activities may be engaged in that increase the independence of the patient). In other words, technologies of the self allow individuals to transform themselves into newly discovered ways of being, by acting on their own psyches, thoughts, and conduct (Foucault, 1986).

In this sense, the time a nurse spends with patients and families becomes a time for reflection, within which patients can reflect on their own (and others') behaviours and beliefs against a set of pre-established norms and assumptions. Through this process, individuals may identify themselves as a certain type of subject, and may gain a new knowledge of themselves and their actions, which may help move them towards a new a way of being and acting (guiding conduct by newly discovered truths).

Nurses balance their own desires and institutional priorities, to include sexual health as a dimension of care with the need to maintain the patient/family relationship. To abuse their position as a caring agent, would to be to abuse the power that this position has vested them with. Foucault (Fornet-Betancourt et al., 1987) defines the abuse of power in this way as the imposition of whims, appetites and desires. Rather the role of the caring agent must engage in an ethos of freedom represented through acts of self care and the care of others that involve engaging in relationships in a way that minimizes domination, while acknowledging that power will always exist within a relationship (Fornet-Betancourt et al., 1987). If participants in this study abused their powers in this way sexual health in the clinical setting would have been addressed regardless of the needs, priorities, or values of the patients and families. Nurses in this study seemed to recognize their role as caring agents, and understood that they had the potential, even by simply asking about sexual health, to alter the perceptions of patients and families. However, participants also realized that they must do so within the context of the caring relationship, which required them to attend to the relationship itself, and not to impose their own personal desires to force the topic of sexual health.

Power in the Foucauldian sense is not a physical entity. Rather, it resides in a network of social relations (Gordon, 1980) and nurses occupy a role within the institution that involves the maintenance of a number of relationships, beyond the patient-nurse interaction. As such they practice technologies of the self on their own persons; modifying their own behaviours and activities, and those of others, to remain in accordance with dominant regimes of truth. For example, despite the perceived need for more time with patients and families nurses often followed the flow of the clinic, rather than disturbing the clinic day. Issues that nurses could easily address, given their knowledge and desire, may not be followed up on due to the limited time they were given with patients, and the difficulty in seeing patients outside of assigned clinical time. This modification represents the presence of institutional barriers to addressing sexual health care.

6.2 - The Perceived Impossibility of Sexual Health Care

Despite institutional attempts to introduce sexual health care into the clinical experience through the "Prepared to Grow Up" program, there remained an overwhelming perception, on the part of participants, of the impossibility of integrating sexual health as a regular aspect of the clinical visit. In reviewing the themes and discourses that emerged, it became clear that there were attributes of the institution that needed to be contrasted with the characteristics of a total institution, as outlined by Goffman (1963). This contrast may aid in understanding the roots of this perceived impossibility. Specifically, the characteristics of scheduling, and the fulfillment of the overall goals of an institution, will be addressed. These aspects of the clinical experience are beyond the control of the participants, which could contribute to the perception of integrating sexual health as impossible in the current context.

Within the discourse of time (the theme of Institutional Space), a number of institutional barriers to sexual health care were identified. These barriers included lack of time with patients in the clinic environment during an appointment, the length of time in a specific position (as related to an unfamiliarity with the patients and families, as well as the specific clinical issues), and lastly, the need to develop a rapport or familiarity with patients and families (over time). These were all elements of the clinic experience that participants reflected on as being barriers to the implementation of sexual health. The issue of time raised by participants has been cited in other studies as a barrier to sexual health care across many areas of nursing. Lewis and Bor (1994) found that 70.9% of nurses surveyed felt that the ward schedule rarely provided opportunities to discuss sexuality issues with their patients. Similar findings have been demonstrated in other studies that focused on sexual health care provided by nurses, nursing students, and health care professionals (Jolley, 2001; Magnan & Reynolds, 2006; Magnan & Norris, 2008; Haboubi & Lincoln, 2003; Herson, Hart, Gordon & Rintala, 1999; Guthrie, 1999). Jolley (2001) addressed that lack of time not only impacts the discussion of specific health topics, but that it impacts all work that requires talking, listening, and teaching. This is reflective of the role of the caring agent; nurses require time, not only with the patient to attend to clinical needs, but time is also required to foster the nurse/patient/family relationship. Magnan and Norris (2008) identified that the limitation of many studies examining barriers to implementing sexual health care neglect contextual elements of the clinical environment, such as elements that affect the nurse-patient relationship and the length of time one is involved with caring for a patient.

Another contextual element that was presented as a barrier to sexual health care was privacy. The importance of private physical space was identified by participants. Physical space within the institution was seen as a limiting factor in the ability of participants to effectively engage patients and families in sexual health care. A lack of access to physical space prohibits discussions from taking place in a private environment, one that may be separate from the general public, or separate to families and caregivers. Privacy, like time, is also frequently cited as a barrier to sexual health care (Lewis & Bor, 1994; Jolley, 2001; Guthrie, 1999). Privacy extends to private space for examinations, personal care, and education regarding personal care. A lack of privacy can result in private activities being made public (Hingsburger & Tough, 2002; Smith et al., 1995). Participants, in this study, recognized the private nature of the clinic environment, specifically individual clinic rooms. However, access to private space outside of the clinic was limited.

The perceived need for increased amounts of time with patients and a lack of physical space reflects the challenges of the current clinical milieu. Increasingly the clinical space is becoming more fast-paced, technologically driven, task oriented, and often understaffed; this poses a challenge to practitioners who value a holistic approach to patient care (Magnan & Reynolds, 2006). In addition, a high paced, task oriented type of environment often involves the prioritization of tasks, which is reflected in participants' comments regarding addressing 'priority issues' with patients and families. Guthrie (1999) found that staff nurses noted that sexual health was not a priority of care because of the acute nature of patients and that there were more pressing patient concerns.

Notions of priority and time are discourses that become wrapped together: lack of time dictating the precedence of one issue over another, a precedence that may be established by the nature of the clinical visit, nursing priorities in relation to education, or patient and family expectations of the clinical visit and their own concerns. For instance the amount of time a nurse can spend with a patient and/or family, and the greater amount of rapport s/he can develop with them. Participants in this study frequently cited a lack of familiarity with patients as an inhibiting factor to addressing delicate subject matter. Guthrie (1999) noted that staff nurses often found that the lack of time and a busy workload affected a nurse's ability to build rapport with patients, and limited interactions to routine and priority issues. When working with patients and families, nurses attend to the needs of both parties, and balance these needs with existing institutional realities and goals. It is here, at the level of the clinical interaction that aspects of the total institution can aid in understanding the impact of time and space within the clinical environment and the perceived impossibility of sexual health care.

In the context of health care, specifically nursing, the concept of the total institution is typically utilized in reference to psychiatric treatment facilities and prisons (see Jacob, Holmes, & Buus, 2008; Holmes, 2005), as well as full time residential facilities, such as long term care facilities (see Malacrida, 2005;). As alluded to in Chapter 3 (Review of the Literature), many would argue that a facility, such as this, is not representative of the type of total institution that Goffman (1961) referred to in *Asylums*. Goffman outlined five types of total institutions from those designed to care for people who cannot care for themselves to retreats from the world that also hold a training purpose (i.e. monasteries). However, Goffman himself admitted that this list is far from exhaustive, and simply a starting point; used to distinguish common characteristics that a total institution may exhibit. Researchers have commented on the outdated notion of the total institution (see Weinstein, 1994), while others have extended Goffman's total institution and updated it to reflect a more current context (see Quirk, Lelliot, & Seale, 2006). However, what Goffman presented in *Asylums* is still applicable today, especially when the original context is considered. Of course, many institutions of today are 'permeable' (Quirk et al., 2006), in that the division between outside and inside has become more transparent, especially given the movements of deinstitutionalization. The characteristics of a total institution, as described by Goffman (1961), applicable in this situation are (1) the scheduling of activities and (2) that activities within an institution contribute to a larger plan designed to fulfill institutional goals.

The organization of the clinic schedule, which is imposed by a higher authority, reflects the routinization of events. In this study, this routinization could be seen in the ways in which participants spoke about the clinic environment; the set way that patients and families moved through the clinics and the time allotted to the various professions and tasks within the clinical environment. In order to maintain this timetable, nurses must ensure that patients and families move through the clinic environment on schedule. This may result in team members decreasing the amount of time they spend with patients. The tight schedule may also result in a structuring of the topics discussed in the clinic environment. Participants often spoke about addressing priority issues during time with patients and families. If sexual health is not a priority for the patient, family, or the nurse, than it may not be addressed or even mentioned. Inadvertently, this may reinforce any stigma related to sexuality and disability. If sexuality is never mentioned, it may be assumed that issues of sexuality and sexual health are not applicable to the patient.

The schedule, while devised with the needs and volume of the clinics in mind, are ultimately created by administrators. Goffman (1961) identifies the groups that are present in a total institution; supervisory staff, and the managed individuals. Supervisory staff create the schedule to 'manage' professionals in a given context. However, nurses also occupy the role of supervisory staff, when they enter into the clinic environment. Nurses are typically the professional that invites patients/families into the clinic environment, and are likely a point of contact with the institution after the clinical encounter. Thus, nurses become both 'the managed' and managers. The scheduling of activities, in this case the clinic schedule, and the fast paced environment that this schedule imposes, dictates the work that nurses are able to accomplish in a given period of time.

There is another level to the perceived impossibility of sexual health care, which is in line with the characteristics of the total institution; the actions and activities within a total institution are all aimed at achieving the larger overall goals of the facility. Recall that the vision of this institution was "A world of possibility" – which includes engaging the children, youth, and families within this "world of possibility". More recent priority items, within the institution, included the roll out of the "Prepared to Grow Up" program, which included attending to the sexuality and sexual health needs of the patient.

Participants identified that there was a stigma or taboo attached to sexual health. It was a topic that parents sometimes had strong moral and religious views on and that required more rapport to address. The impossibility in this case is twofold – not being able to meet institutional priorities because of the stigma attached to sexual health and disability. Goffman (1963) described stigma as a differentiating attribute that separates the individual from others, within a specific category, and signifies that attribute as less desirable. Stigma in this case has multiple sources. First, there is a general social stigma attached to children and sexuality; typically children are considered asexual beings. Second, along with children, another group that is generally perceived by society to be asexual are individuals with disabilities (Di Giulio, 2003; Szollos & McCabe, 1995). Finally, there also exists a stigma associated with professionals who cross the established boundaries of practice, especially around issues of sexuality. Stigma does not result from a physical attribute alone. Rather physical attributes encompass behaviours, and are connected to specific groups; as a result stigma results from a discrepancy between the perceived norm for these groups and reality (Curra, 2000). The stigmas that participants encountered resulted, in part, from the perceived norms that relate to the asexuality of people with disabilities.

There were clear examples of participants engaging in activities which inadvertently disturb these stigmas, solely in an effort to meet the priorities of the institution and practice holistic health care. These actions ranged from simple acts such as introducing sexual health as a topic, to nurses allowing a patient access to their genitals during a diaper change, and the incident involving the child who masturbated when over stimulated. Herson et al. (1999) pointed out that, when discussing sexual health with patients, professionals should take the time to provide a comfortable setting for the discussion and when feasible utilize private locations. However, given the clinical milieu, the tight schedule, and an overall lack of time and space, this can be very difficult in the current context. As such, nurses, and other health care providers needing to address this important aspect of care, may be inclined to introduce sexual health in a regular clinic visit, as just another topic to cover. Participants in this study also alluded to accessing the topic through "valid" medical questions – this met the needs of the professional, institutional priorities, and functioned to maintain the patient/family/nurse relationship. An example of this was accessing sexual health by relating it to nutrition (i.e. folic acid and Spina Bifida), by touching on relationships with others as an aspect of a psychosocial assessment, or as part of the "Prepared to Grow Up" program. These actions achieve the overall goals of the institution, the profession, and the care of the 'entire' patient, all the while keeping nurses in the role of caring agents. This role reveals new ways of being to the individual and family, but also fosters the relationship with the family and patient.

While the total institution of the 1950's is not representative of today's fast paced, non-residential healthcare facilities, there are aspects of Goffman's institution that linger, and continue to influence nursing work and patient care. Nurses encounter barriers to sexual health care that occur on an institutional level, versus at the level of the nurse, where most studies tend to focus. These barriers include the highly organized and schedule oriented nature of the clinical environment, as well as the situations that nurses encounter that exemplify the stigma attached to the sexuality of youth with disabilities. In addition, despite an institutional priority focused on the transition of patients from pediatric to adult care (which included items related to sexual health), there was no formal training for nurses on sexual health offered or initiated by the institution. The fast paced environment and accessing sexual health through different avenues, may lead nurses to engage in healthcare practices that while aiming to fulfill the goals of the institution could actually, over time, be detrimental to the youth they engage with.

6.3 - The Necessity of Dangerous Practices

In an effort to engage patients and families in sexual health care, participants shared a number of strategies that they employed. The most apparent strategy was the medicalization of sexual health. The medicalization of sexual health involved accessing the topic through medical avenues (such as nutrition, or in dealing with bladder issues). Interestingly, nurses did not seem to be aware of the fact that many of their tasks may have sexual health implications. In addition to medicalizing sexual health, participants also spoke about the necessity to make sexual health a "normal" topic to discuss. Putting sexual health on the agenda is an important strategic move for clinical staff; it makes it acceptable to discuss in the clinical milieu and would ultimately work to dispel the stigma attached to sexuality and people with disabilities. However, there are risks associated with the normalization of sexual health. Specifically these dangers may relate to the normalization of certain behaviours (i.e. heterosexuality, masturbation) at the expense of labelling other activities and behaviours as inappropriate or deviant (i.e. homosexual relationships, sexual intercourse, anal sex). The normalization of specific aspects of sexual health may also be influenced by the comfort level of health care providers and families with certain topics (i.e. holding hands and hugging versus oral sex). In addition, the normalization of sexual health may occur for some populations, including youth with mild developmental or physical disabilities, but may not be approached with youth with more complex disabilities.

A quality of modern biomedicine, whether population or patient focused, is that it is driven by strategies that aim to normalize, as represented in practice by the actions of measurements against the norm, assessments, and documentation (Shildrick, 1997). The clinical gaze, which Foucault (1973) refers to in *Birth of the Clinic*, becomes a disciplinary technique of control – both an outright form of surveillance, but also a technique which encourages self surveillance to fit into established norms. Sexual health, when normalized for a group, subjects the group to established norms against which people and behaviours can be measured and compared. This is an example of how the medicalization of sexual health could be detrimental to a larger group. However, there is perhaps a greater risk that has been brought to light by this research; the impact of a nurses' position as an individual who is 'allowed' access to the body.

In addition to his work on the characteristics of a total institution, Goffman also discussed the nature of work that staff of total institutions engage in; people-work, where patients are the object of the work that is being carried out. Much of nursing work involves the physical body of the patient; assessing the body, moving the body to measure height and weights, wound care, and bowel and bladder education.

It is essential that patients are understood in connection to their physical embodiment. Not only is the body a dimension of the person, it is often, in the case of health and illness, the aspect of the subject that is most visible. If we consider bowel and bladder care, the technical aspects of care may be the most relevant. However, Thorne (2001) reminds us that during health and illness "the subjective reality of an individual renders one part of that person more visible, more prominent, and more relevant than any other" (pp. 261). If the technical aspects of bowel and bladder care are continuously attended to, without acknowledging the deeper vulnerability that is revealed in moments such as this, there may be a danger to the subjectivity of the individual in the long term.

The body, while absent during times of health, becomes the centre of attention during times of illness or disability (Shildrick, 1997). Continued adherence to the medical model, in health care settings, emphasizes the centrality of the physical body, which is representative of the split between mind and body, resulting in a disembodied subject (Shildrick, 1997). The neglect of the corporeality of an individual, in the medical setting, corresponds to a focus on pathology and the influence of the medical model. This type of "reductionist concentration on the pathology of the body serves to dehumanize the 'patient' and reduce her to the status of a malfunctioning machine" (Shildrick, 1997, p. 15). The body then, becomes the site of intervention, and the focus of the practitioner shifts from a holistic concern with the person to the disease process (Shildrick, 1997).

Herson et al. (1999) pointed out that discussions related to sexual health should take place on their own, as independent topics of conversation rather than be linked to bowel and bladder issues. While this point is valid, it must also be recognized that bowel and bladder care involve intimate touch, and access to normally 'private' or 'sexualized' areas of the body. However, this aspect of personal care is often overlooked, even in the literature. Katrancha (2008) describing the process of clean intermittent catheterizations of youth with Spina Bifida in a school setting, highlights the importance of using anatomically correct language and the value of tools such as mirrors during the procedure so that the student can learn how to self-catheterize through participation. However, nowhere in this article does the author attend to the fact that the nurse in this situation is engaging the patient at the level of the physical body, and that these procedures involve a negotiation around touch and access to intimate aspects of care.

Goffman (1961) addressed the 'mortification of self' that occurs within total institutions, the stripping away of identity by removal of a person's clothes, possessions, and name: acts that ultimately result in a loss of personal safety. Certainly patients are not being stripped of their personal identify by means of such extreme examples, however the deeper meaning behind the mortification of self is relevant to this situation. Goffman (1961) writes: "territories of the self are violated; the boundary that the individual places between his being and the environment is invaded and the embodiments of self profaned" (p. 23). What is key here is the invasion of the boundaries of the self, whether unconscious (Kristeva's sujet en *procès*), or physical – the corporeality of the individual represented by the physical barrier of the skin. Often the influence of the medical model in health care settings may be the root cause of the medicalization of sexual health that participants in this study alluded too.

Shildrick (2002) speaks of the deeper meaning of touch: "to touch and to be touched speaks to our exposure to, and immersion in, the world of others, and to the capacity to be moved beyond reason, in the space of shared vulnerability" (p. 117). However, nurses frequently immerse themselves into the space of shared vulnerability, providing care to patients that require contact in intimate ways – skin and gloves, cleansing the body, procedures that invade personal spaces. We encounter patients and families at their most vulnerable times. In these times, nurses insert themselves into the world of others. Sometimes, this insertion is not only psychological but physical – utilizing the necessity of medical touch, and as such we may cross certain boundaries. Shildrick (2002) reminds us that not all experiences are ones of shared vulnerability, rather they may be a type of "corporeal colonisation" (p. 118), exploiting a specific vulnerability that exists within a less dominant partner. This corporeal colonisation maps the body as a medical landscape; a world in which the acts of inserting, prodding, poking, and leaking become normal and routine, and as a result the body becomes colonised by medical action.

In order to embrace the embodied self, embodiment must be recognized as a process, as a refusal to separate mind from body, a refusal to be normalized or defined as pathological (Shildrick, 1997). This is a danger of the medicalization of sexual health, as it risks separating the mind and body; the physical experience from the technical experience. While nurses engaged in medicalizing sexual health, it was with the purpose of reaching sexuality as a topic, not a malicious endeavour to deny the patient a sexual self. However, accessing the topic in this manner and failing to consider the intimate nature of nursing work could be detrimental in the long run; especially to younger children exposed to prolonged medical intervention and who will need to negotiate their personal care later in life.

The information and stories that participants shared through the interview process, as represented in the data analysis has now been connected to the literature and the theoretical findings. Major Finding 1. addresses the unique position of nurses in this clinical milieu. Nurses here engage in profound relationships with patients and families, relationships that have the potential to alter the subjectivity of those involved, including the nurse and the patient. This finding juxtaposes the importance of addressing sexual health but the necessity to protect this relationship. Major Finding 2. situated this relationship in the clinical setting and illuminated characteristics of Goffman's total institution that continue to shape clinical care. These included the scheduling of clinical time and the need to attend to institutional goals. Major Finding 3. addressed a sensitive topic; the impact of the medicalization of sexual health and the implications of medical touch. These are important, yet often overlooked aspects of nursing care. In combination these findings shed light on areas of nursing work that are not always given time in the literature, or captured in quantitative research studies.

6.4 - Limitations of the Study

As with all research, this study was subject to limitations that may have affected the outcome. First, the research project was conducted in a rehabilitative hospital located in an urban area, a facility that the researcher already had established connections with. The location of the project raises a number of issues. To begin with, the nature of the facility, as a pediatric rehabilitative centre, a teaching and research facility, and the focus of this particular institution on successful transition meant that sexuality and sexual health were already on the institutional agenda, as evidenced by the "Prepared to Grow Up" program. Participants were already aware of their potential roles related to sexual health, and spoke about the challenges espoused in providing sexual health care in this particular environment. While many challenges, as identified above, coincide with the findings in the literature, new information was discovered – particularly around the transient nature of participant's relationships with patients. Conducting the research in an environment where health care professionals had prolonged contact with youth and families may have yielded different information.

The second limitation that results from the research location was my familiarity with the institution and the nursing work that was being conducted. While still an outsider, my position within the institution was somewhat that of an insider. This was beneficial because it facilitated access to information and an understanding of the specific clinic work, and while I had a relaxed relationship with many of the participants, this was also a limitation. As a researcher, and a nurse with knowledge of the clinical encounter, I may have overlooked what to me would be standard or normal because of familiarity with it, whereas an outsider may have questioned word choices or descriptions of procedures.

This project has demonstrated the benefits that can be gained from employing critical ethnography as a research methodology. Inherent to critical ethnography are its overt political aims; to uncover generally unacknowledged ideas and beliefs. These aims require a different perspective on researcher bias and position. Reflexivity requires the researcher be aware of the influence of the setting, and personal values, on the researcher. Employing reflexive practice through journaling, allowed me to work through my own emotions, thoughts, and biases in order to understand how my own context and history shaped my perspective of the research questions, and my expectations of practice.

Another limitation of the study was the nature and results of recruitment efforts. Participants were recruited through purposeful and convenient sampling. There was a small pool of nurses to recruit from, and likely those participants that volunteered to take part in the study already felt somewhat comfortable discussing sexual health issues. Potential participants that were less comfortable with the topic or did not see the relevance or connection of sexual health to their patient population may not have come forth as participants, which may have resulted in the lower number seen. This is unfortunate, as likely the stories and perspectives of this group of individuals would have been invaluable to developing the discourses and themes that were generated. Despite, a small sample size (*n*=9), data saturation was accomplished, and similar themes and discussion points were raised by participants. In addition, the requirement to participate in an interview may have pushed away potential recruits. If potential recruits had a history of a negative experience with patients/families involving sexual health, or were not entirely comfortable with the topic they may not have been willing to come forth and participate in an interview.

6.5 - Implications for Research, Practice, and Education

As a critical ethnography, this research project addressed not only the nature of nursing work in the chosen clinical setting, but also the nature of this work with a specific population. As such, the implications of this research project range from considerations for practice to broader implications at both social and political level. Also as a result of the knowledge gained through this process there are a number of new directions that can be pointed to for possible research projects and educational initiatives.

6.5.1 - Implications for Research

Research always creates ideas for new research projects, and there are aspects of this project, that may have produced findings that would not be the same if conducted in different settings, or if slightly different questions were asked. The knowledge generated as a result of this project, must be understood within the context that it was generated within – a teaching hospital with a strong research component located in a major city centre. There is a need to extend this work, and similar projects, to locations and facilities in rural and remote communities, with a focus on working with youth in the environments that they live in.

The perspective of nurses and other members of the health care team contributed to the representation of the institutional experience presented in this research. These viewpoints supplemented the current understanding of challenges to integrating sexual health care into practice. However, what was not represented in this research were the voices and experiences of the most important people, the youth themselves. Further research that attends to the experiences of youth with disabilities and sexual health is necessary. These projects should move beyond measuring sexual knowledge and categorizing sexual behaviours and frequency of behaviours, and concentrate on the experiences of youth in accessing sexual health care, sources of knowledge, the challenges posed by the built environment (i.e. privacy), and negotiating personal care. Research should address the implications of medical touch on experiences of embodiment, and give voice to the needs of youth with disabilities from the perspective of these youth, rather than being focused on the perspective of the family, care provider, or health care practitioner. Also, while the perspectives of family caregivers has been documented in the literature, there is a need to attend to the challenges that caregivers encounter as their children become sexually mature beings, in order to better support the entire family.

6.5.2 - Implications for Practice

The results of this research are relevant to nurses, and other health care practitioners, who work with youth with disabilities and their families, especially in relation to issues of sexual health. At the level of the clinical environment, there are many practical implications that emerge from this study.

First, nurses described the need for space (physical), and time (in practice) to foster therapeutic relationships with patients and families and attend to sensitive issues. Space was especially important when working with older youth and their families, so that both parties could be provided with a private space, to talk about their health care questions and concerns. This physical space should also be highlighted as a 'safe space' where sexuality and diversity are accepted and embraced.

Second, participants expressed a desire for education and resources that focused on the unique needs of the patient populations that they engage with. This represented a reflection on participants own attitudes and needs in relation to the perceived sexual health needs of their specific patient populations. While participants expressed a need for this information for themselves, they also realized that there was a general lack of accessible, easy to understand information for families and patients to utilize, that addressed sexual health in relation to their specific disability. For instance, resources that addressed precocious puberty, Spina Bifida and sexuality, or managing menstruation with youth who are also incontinent, would be helpful for clinic staff to have access to. Third, on an assessment level, changes could be made to nursing assessment forms. At the moment these forms do not include sexual health as an aspect of care in the 'head to toe' assessment. Explicitly including sexual health on assessment forms provides this aspect of care its own space, separating it from being lumped in with other body systems and speaks to the value of sexual health as its own entity, and therefore works to disturb the stigma attached to sexual expression and people with disabilities.

Third, forming partnerships and links with local community agencies that provide services aimed specifically at individuals with disabilities in relation to sexual health may be beneficial for nurses, patients, and families. This information could be condensed into a pamphlet outlining available community services focused on sexual health (i.e. accessible health clinics, life skills programming). There was an existing pamphlet that could be added to and updated that then could be used by clinic staff, patients, and families. Existing councils at the facility could be involved in the development of resources, for instance the youth council could provide valuable information regarding practical issues that they themselves have encountered and would have appreciated answers to as children and adolescents.

Finally, the development of relationships with patients and families was emphasized in discussions with participants as an essential element of care. This requires attention to staffing, space, and the structure of work at the clinical level. Spending health care dollars requires administration to be accountable, and accountability involves justifying how and where money was spent. Nursing work, and the aspects of work that participants valued in this project, involved both the knowledge of disease and therapeutics, but also of the intimate nature of nursing care, the relationships with patients and families and the education and conscious raising that occurs within this relationship. Without a socially accepted understanding of the nature of nursing work, administrators do not have access to the funds required to staff clinics differently, in a way that would increase the number of practitioners to allow for increased attention to relationship building. While the allocation of resources is, in part, the responsibility of hospital administrators, it requires activism at the provincial and federal level, to raise awareness of the unseen aspects of nursing care. Funding formulas for nursing staff need to allow not only for direct patient care hours, but for the time that must be invested in building relationships.

6.5.3 - Implications for Education

This project raises a number of important issues that could be integrated into the education of students in programs of nursing (from undergraduate to graduate courses). One of the key issues that was raised, applicable to education, is the need to incorporate sexual health into the curriculum. Undergraduate nursing students explore a variety of areas of nursing throughout their education, and research shows that they do not experience positive instances of mentoring around issues of sexual health, especially in relation to illness and disability (Treacy & Randle, 2004). Students should be provided with educational experiences that allow them to explore issues of sexual health, such as the impact of acute illness and disability on the sexuality and sexual health of patients. This could occur as an integration of sexuality and sexual health into a variety of courses, which would be ideal, or through a specific course examining sexuality and sexual health in nursing across a broad range of settings. As well, students should also have practical and practice experiences during which they can practice talking about sexual health with real or simulated patients. Providing these opportunities in the safety of the classroom may encourage students to raise the issues in clinical settings. This project showcases the importance of critical theory in examining nursing work and marginalized populations. Exposing students to a wide range of theories and philosophies throughout their education may provide them with new and different ways to view the world.

6.6 - Conclusion

There is some concern in the literature regarding ethnography and the failure of ethnography, in general, to take into account the broader context. This research certainly provides evidence to refute this concern. By employing a critical ethnography, and utilizing discourse analysis, the larger context framing this work became evident, and as a result the implications for this research, as well as the future directions for research address multiple levels of health care and nursing; from practical clinical changes to the need for a broader social understanding regarding sexuality and disability. Also, the implications for research highlight the importance of capturing the voices of youth in potential projects.

Sexual health care in the context of nursing, should aim to promote sexual health and sexuality, through ongoing sexual health education, as well as through goal setting and planning related to independence and opportunities for social interaction. This type of approach would provide youth and families with the tools and knowledge to facilitate the formation of healthy relationships. As well, it would provide patients with the power to identify potentially dangerous situations, facilitate independence and dignity in personal care, and create an active acknowledgement and respect of individual sexual rights (i.e. body integrity, respecting decisions etc.). This research project has shed light on not only the practical barriers that challenge nursing engagement in sexual health care, but also addresses the complex ethical nature of the nurse/patient/family relationship.

Participants in this project were in a paradox – practicing within a profession that values providing care to the whole person, and working within an institution that aimed to prepare youth for the transition to adult life and adult health care services. However, nurses were attempting to carry out these priorities and holistic care in an environment and within a therapeutic relationship that were wrought with barriers. These barriers were not the typical barriers that nurses often describe in the published literature. Rather they are focused on both practical and relational aspects of care. From deficiencies in physical space and time, to being challenged by a society that continues to shape the identity of individuals with disabilities as asexual, and jumps to interpret sexual expression as deviant – nurses strived to include sexual health in their daily encounters with patients. At the end of the day, participants understood and prioritized the importance of building and maintaining a therapeutic relationship with the patient and family. Often times, prioritizing the relationship over issues that would jeopardize the trust that patients and families place in these nurses: nurses who occupy a space with them "in the trenches" of daily life.

This study addressed the impact of the unique nuances within the relationships forged between nurses, patients and families, and the influence of these relationships on sexual health care in the clinical setting. As a result of the perceived expert role of nurses in combination with the therapeutic relationship that is the basis of nursing care, nurses in this particular setting, were simultaneously positioned as both caring agents and agents of care. As a result they are faced with the challenge of balancing the demanding and high priority medical needs of patients, with institutional priorities aimed at transitioning patients to adult care, and their own professional views of holistic health care. This finding suggests that continued research focused on the typical barriers to sexual health care (i.e. lack of education, discomfort raising the issue), may not consider larger influences that restrict addressing sexual health. One of these influences is the need to maintain the relationship with the patient as the ultimate priority.

This project illuminated broader and often overlooked aspects of nursing practice, including the role of nurses as caring agents, the effect of the clinical milieu on nursing work, and the ways in which nurses utilize themselves and medical discourse to reach a goal. Nurses engaged in the role of caring agent, continue to foster the relationships they forge with patients and families. As a by-product of these relationships, the context for discussions of sexual health may be established as time goes by. However, there remains a perception that ultimately, the provision of sexual health care is not realistic in the current clinical milieu. In this study, this perception was linked to residual aspects of the total institution. Specifically, the characteristics of scheduling and the challenge of meeting the overall goals of the facility were identified, as well as the challenge of overcoming stigma that are associated to both sexual health and disability.

One of the most profound issues that emerged from this research was the need to understand the impact of nursing activities that are focused at the level of the body, and to consider the long term consequences of these interventions (especially when they begin at a young age). When nurses focus on the patient as an object of work, and distance themselves from a shared embodied experience, the activities that nurses engage in may become invisible and devalued (Benner, 1990). In other words, Benner was concerned with separating the physical actions of nurses from the embodiment of both patients and nurses. In doing so, she was attempting to highlight that nursing work with patients seen as disembodied tasks devalues the instances of care that expose vulnerabilities and intimacy, devaluing the basic care that nurses may provide. The environment in which nursing care takes place, in terms of hospitals and rehabilitative centres, often requires attention to priority issues. However, it is essential that the physical body of the patient is not forgotten and that the medical and nursing interventions enacted are considerate of the whole patient and not simply focused at the level of the disease or disability. The impact medicalization of sexual health emerged during this project. Nurses engaged in work at the level of the patient, but both the literature and this project reveal that nurses may inadvertently objectify the patient and minimize the impact of touch on the patient.

In conclusion, participants in this study recognized the importance of sexuality and sexual health as an aspect of holistic care, and identified this as an aspect of care that was often overlooked, in favour of higher priorities, in this particular setting. However, what was apparent was the desire of participants to engage in providing positive messages about sexuality and their willingness to engage their patients and families in sexual health care. Often, in attempts to maintain the relationships that had been established with patients and families, nurses medicalized sexuality and sexual health so that it was an acceptable topic. This tactic exemplifies the role of nurses as caring agents; as individuals who can engage patients and families in technologies of the self, and potentially use this as an opportunity to alter a patient's view of themselves. Drevdahl (1999) points out that "individuals are the *result* of social workings" (p. 5, emphasis in original), and that it is within discourses, such as nursing, that identities are created and differences established. Nurses have the potential to expand or alter how patients and their families interpret the subjectivity of the patient, one that ought to include sexuality.

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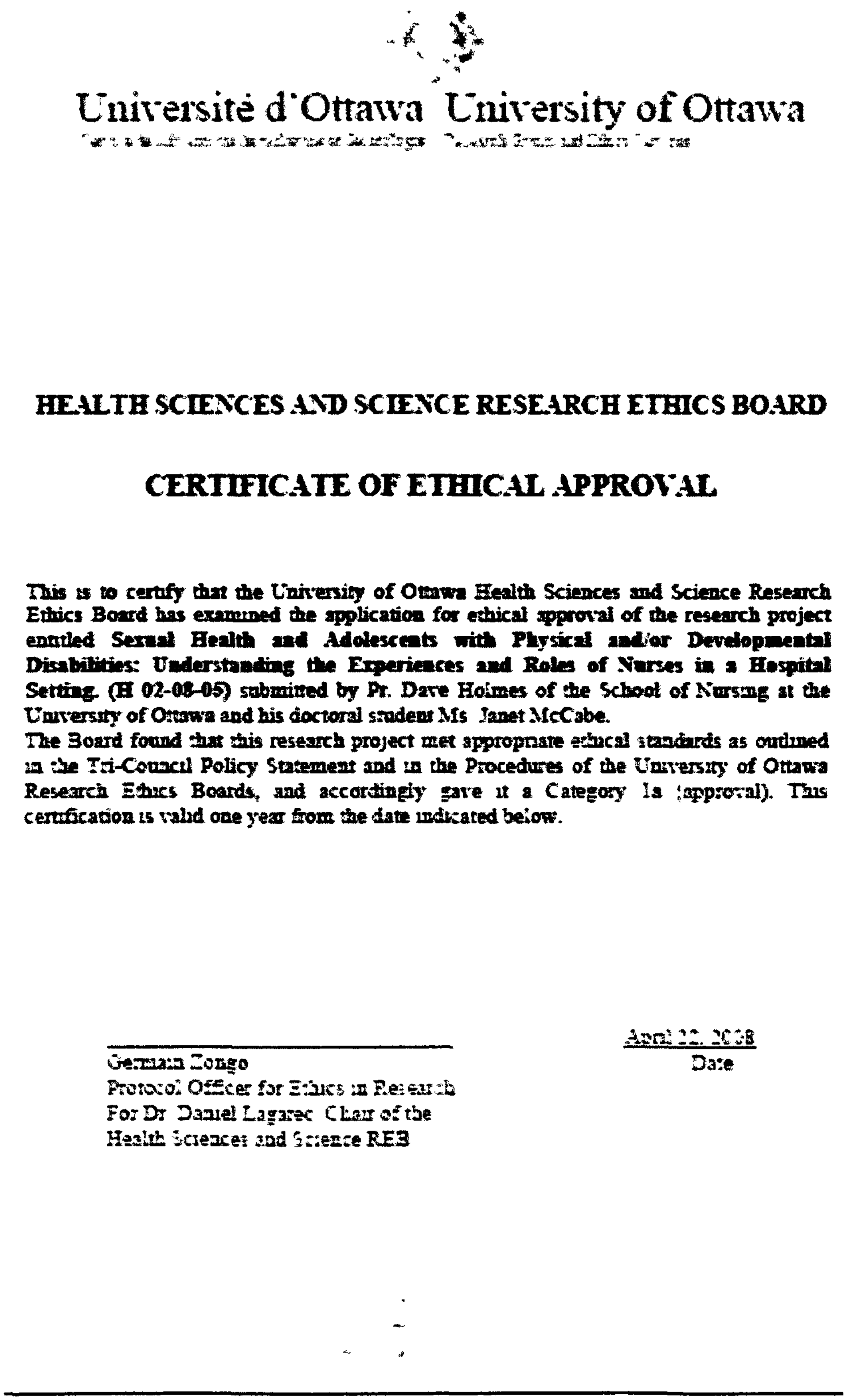
Appendix A: Ethics Approval



Université d'Ottawa University of Ottawa

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HEALTH SCIENCES AND SCIENCE RESEARCH ETHICS BOARD

CERTIFICATE OF ETHICAL APPROVAL

This is to certify that the University of Ottawa Health Sciences and Science Research Ethics Board has examined the application for ethical approval of the research project entitled **Sexual Health and Adolescents with Physical and/or Developmental Disabilities: Understanding the Experiences and Roles of Nurses in a Hospital Setting. (H 02-08-05)** submitted by Pr. Dave Holmes of the School of Nursing at the University of Ottawa and his doctoral student Ms Janet McCabe.

The Board found that this research project met appropriate ethical standards as outlined in the Tri-Council Policy Statement and in the Procedures of the University of Ottawa Research Ethics Boards, and accordingly gave it a Category 1a (approval). This certification is valid one year from the date indicated below.

Germain Zongo
Protocol Officer for Ethics in Research
For Dr Daniel Lagarec Chair of the
Health Sciences and Science REB

April 22, 2008
Date

Appendix B: Informed Consent

uOttawa

Université d'Ottawa
Faculté des sciences de la santé
École des sciences infirmières

University of Ottawa
Faculty of Health Sciences
School of Nursing

Consent Form for Participation in a Research Project

Researcher: Janet McCabe, RN, MEd, PhD(c)
School of Nursing
Faculty of Health Sciences
University of Ottawa

Supervisor: Dave Holmes, RN, PhD.
Co-supervisor: Christine McPherson, RN, PhD
8693

Title of Project: Sexual health and adolescents with physical and/or developmental disabilities: Understanding the experiences and roles of nurses in a hospital setting

Funding: **Social Sciences and Humanities Research Council of Canada**

Purpose of Research

This research project aims to gain an understanding of the roles and experiences of nurses in providing sexual health care to adolescents with physical and/or developmental disabilities, and to uncover what factors affect these actions. Specifically, this study will examine if or how nurses are affected by institutional contexts in relation to the provision of sexual health care. This research project will address the crucial gap between knowledge around the role of nurses in terms of sexual health and the body of knowledge focused on the sexual health, sexual knowledge and experiences of individuals with physical and developmental disabilities.

Nature and Expectations of Participation

Participants that agree to be involved in the study will be contributing approximately three hours of their time. One hour to complete an interview and demographic questionnaire, and approximately two hours to review the transcript of the interview. The interview material will focus on your experience, as a nurse, physician, or social worker, employed at Bloorview Kids Rehab, as it relates to the roles and experiences of nurses and their provision of sexual health care to adolescents with physical and/or developmental disabilities. If the participant agrees, the interview will be audio-taped, if the participant prefers not to the audio-taped then the researcher will take notes instead. Participants are reminded that they must respect the privacy and confidentiality of their patients. During interviews please refrain from directly identifying individual patients. All participants will be asked to sign two copies of an informed consent form prior to any data collection commencing (one copy will be kept by the participant, and one copy will be kept by the researcher).

☎ 613 562-5473
📠 613-562-5443

451 Smyth (3051)
Ottawa ON K1H 8M5 Canada
www.uOttawa.ca

Risks

Due to the subject matter being discussed participants may experience emotional or psychological discomfort. Participants may be embarrassed or ashamed about some of the topics discussed during the interview, and may question the roles of nurses in relation to the sexual health of youth with developmental and/or physical disabilities. Also, participants may experience concern discomfort when discussing the sexuality and sexual practices of this population. It is the right of the participant, to stop the interview at any time and to refuse to answer questions, or to request a different line of questioning. The phone number of a support line will be provided if participants request counselling, and the phone number of the College of Nurses of Ontario will be provided if participants require additional information about the role of nurses as it relates to sexual health.

Benefits of Participation

Participants will not be compensated for their involvement in this research. However, participants involved in this research will contribute to the knowledge base of the nursing profession, and provide an opportunity to discuss issues related to the research topic, which may assist in identifying new roles and potential learning opportunities for participants and for the profession. Interviews will provide participants with an opportunity to discuss these issues, explore the current and potential professional roles and contribute to a broader understanding of the challenges and difficulties (personal, social, political) that affect a nurses' ability to address the sexual health of youth with physical and/or developmental disabilities.

Privacy, Confidentiality, and Anonymity

Due to the small sample size being utilized, and despite all efforts taken by the researcher, full anonymity will be difficult to guarantee. However, the following measures will be taken to protect anonymity, privacy and confidentiality.

The privacy, confidentiality, and anonymity of participants and of information discussed during the interviews will be protected in a number of ways. First, a private and secure space for interviews will be used, with no one having access to the room during the interview. Second, the research material (i.e. information, recordings, notes, and written transcripts) will not be shared with anyone, except with Dr. Dave Holmes [supervisor] and Dr. Christine McPherson [co-supervisor]. It is important that participants know that data will not be available to managers or directors and that the participation of individuals and information gathered during the research project will not affect performance appraisals. To protect confidentiality and anonymity, each participant will be assigned an alphanumeric code (found on the consent form); this code will be used to label any tapes or transcripts. In addition, all locations, names, and identifying features will be removed during the transcription process.

Use of Research Findings

The primary purpose of this research is the completion of the researcher's (Janet McCabe) dissertation. However, the information and research findings will be used for a presentation to Name of Hospital staff and may later be used as teaching material, or presented during conferences and reported in publications (journals, books etc.). However, all identifiable features of the text will be removed, and actual names or locations will never be identified.

Withdrawing from the Study

If at anytime, a participant wishes to withdraw from the study they must contact the researcher and provide the assigned alphanumeric code. At this point all documentation related to this participant will be destroyed. There is no penalty for choosing to withdraw from the study.

Questions about the Study

If the participant has any questions about the study, please contact one of the following individuals:

- Researcher - Janet McCabe (jmcca009@uottawa.ca / phone number)
- Dr. Dave Holmes – Supervisor (dholmes@uottawa.ca / 613.562.5800 ext. 8341)
- Dr. Christine McPherson – Co-supervisor (613-562-5800 ext. 8693).

Ethics

This is an independent research study; it has not been requested by Name of Hospital. The data collected will not be made available to anyone. The role of managers within this study is to facilitate access to the premises and the nurses. Participants should not feel pressured to participate, and nothing discussed during interviews or throughout the course of the research will be utilized to evaluate individual performance of the involved participants. The provision of a private room on site will allow for privacy for participants, as the room will not be open to anyone else during interviews. In order to avoid any coercion to participate, the role of managers has been limited and nurses must make contact with the researcher directly, they cannot be signed up to participate by their supervisor. Participants will not receive compensation for their role in the study.

It is anticipated that the researcher will store the data generated throughout the study for five years after the defence of her dissertation. Throughout the project and afterwards, the only individuals who will have access to the data are Janet McCabe, Dr. Dave Holmes (supervisor), and Dr. Christine McPherson (co-supervisor). The research data will be kept in a locked filing cabinet in Dr. Holmes' office at the University of Ottawa. At the end of storage, printed data will be destroyed via shredding and any electronic data will be destroyed by deleting all files from the discs that it was originally saved onto.

This project was approved by the Research Ethics Board (REB) at the University of Ottawa and by the REB at the Name of Hospital Research Institute. If you have any concerns or questions regarding the ethics of this project please contact the REB protocol officer at the University of Ottawa (613.562.5841 or ethics@uottawa.ca) University of Ottawa, Research Grants and Ethics Services, Tabaret Hall Room 159, 550 Cumberland Street, Ottawa, Ontario, K1N 6N5.

Consent of the Participant

I, ______________________________ (print name), have read and understand the terms outlined by this consent form.

I agree for this interview to be audio-taped: ☐ YES ☐NO
I agree to be quoted, as long as quotes reflect their original context: ☐ YES ☐NO

I agree to take part in this study. There are two copies of this consent form, one of which I will keep and the other will be kept by the researcher.

_______________________________________ _______________
Participant Date

_______________________________________ _______________
Researcher Date

Appendix C: Demographic Questionnaire

The following questionnaire was self administered by participants.

Gender:

Female ☐
Male ☐

Age:

Between 20 and 30 years of age ☐
Between 31 and 40 years of age ☐
Between 41 and 50 years of age ☐
Over 50 years of age ☐

Profession:

☐ Nurse
☐ Physician
☐ Social Worker

Education:

(Please check the box of all degrees you hold):

☐ College Diploma (please specify): ____________________
☐ University Degree (please specify): ____________________
☐ Masters Nursing (please specify): ____________________
☐ PhD (please specify): ____________________
☐ Other (please specify): ____________________

(Please check the box of any degree that you are currently working towards)

☐ College Diploma (please specify): ____________________
☐ University Degree (please specify): ____________________
☐ Masters Nursing (please specify): ____________________
☐ PhD (please specify): ____________________
☐ Other (please specify): ____________________

Do you have any special training in sexual health specific to individuals with developmental and/or physical disabilities?

YES ☐ No ☐

If yes please indicate what type of training:

-

Experience:

(Please indicate your years of experience in each section)

Experience in pediatrics: ____________________
Experience in rehabilitation: ____________________
Experience in other fields (please indicate years & area): ____________

Appendix D: Results of Demographic Questionnaire

The following table represents the results of the self-administered demographic questionnaire that each participant completed (n=9).

Category		Number (%)
Gender	Male	0
	Female	9 (100%)
Age	20 - 30 years of age	1 (11%)
	31 - 40 years of age	1 (11%)
	41 - 50 years of age	3 (33%)
	Over 50 years of age	4 (44%)
Profession	Nurse	7 (78%)
	Physician	0 (0%)
	Social Worker	2 (22%)
Education (highest degree attained):	College Diploma	1 (11%)
	University Degree	6 (67%)
	Masters Degree	3 (33%)
	PhD	0
	Other	0
Education in progress	College diploma, University degree, Masters degree, PhD, or other	0
Specific Training related to sexual health and individuals disabilities	Yes	3 (33%)
	No	6 (67%)
Related work experience	Pediatrics	Not stated: 0 (0%) 0 – 5 years: 3 (33%) 6 – 10 years: 1 (11%) 10 - 20 years: 2 (22%) 21 – 30: 3 (33%)
	Rehabilitation experience	Not stated 4 (44%) 1 – 5 years: 3 (33%) 6 – 10 years: 1 (11%) 10 - 20 years: 1 (11%) 21 – 30 years: 0(0%)
	Experience in other areas	Not stated: 3 (33%) 1 – 5 years: 2 (22%) 6 – 10 years: 2 (22%) 10 - 20 years: 1 (11%) 21 – 30: 0(0%) Over 30: 1 (11%)

Appendix E: Letter Accompanying Transcript for Review

Researcher:	Janet McCabe, RN, MEd, PhD(c) School of Nursing Faculty of Health Sciences University of Ottawa
Supervisor:	Dr. Dave Holmes, RN, Ph.D.
Co-supervisor:	Dr. Christine McPherson, RN, PhD
Title of Project:	Sexual health and adolescents with physical and/or developmental disabilities: Understanding the experiences and roles of nurses in a hospital setting
Funding:	Social Sciences and Research Council of Canada

To Whom It May Concern:

Thank you for participating in the above mentioned study. Please find enclosed the transcript of your interview for your review. Below are detailed instructions for this review. Please review the transcript during the next month, when you have completed the review please contact Janet McCabe At this point, a convenient time will be arranged to pick up the transcript.

During your review, should you find any areas in which you feel that additional comments are necessary to explain what you stated please add these comments in the margin and clearly indicate the block of text that they are related to. If, for any reason, you would like a section of text removed from the transcript, please cross out every line that you are requesting be deleted.

If you have any questions or concerns, do not hesitate to contact the researcher Janet McCabe the researcher's supervisor Dr. Dave Holmes or co-supervisor Dr. Christine McPherson

Sincerely,

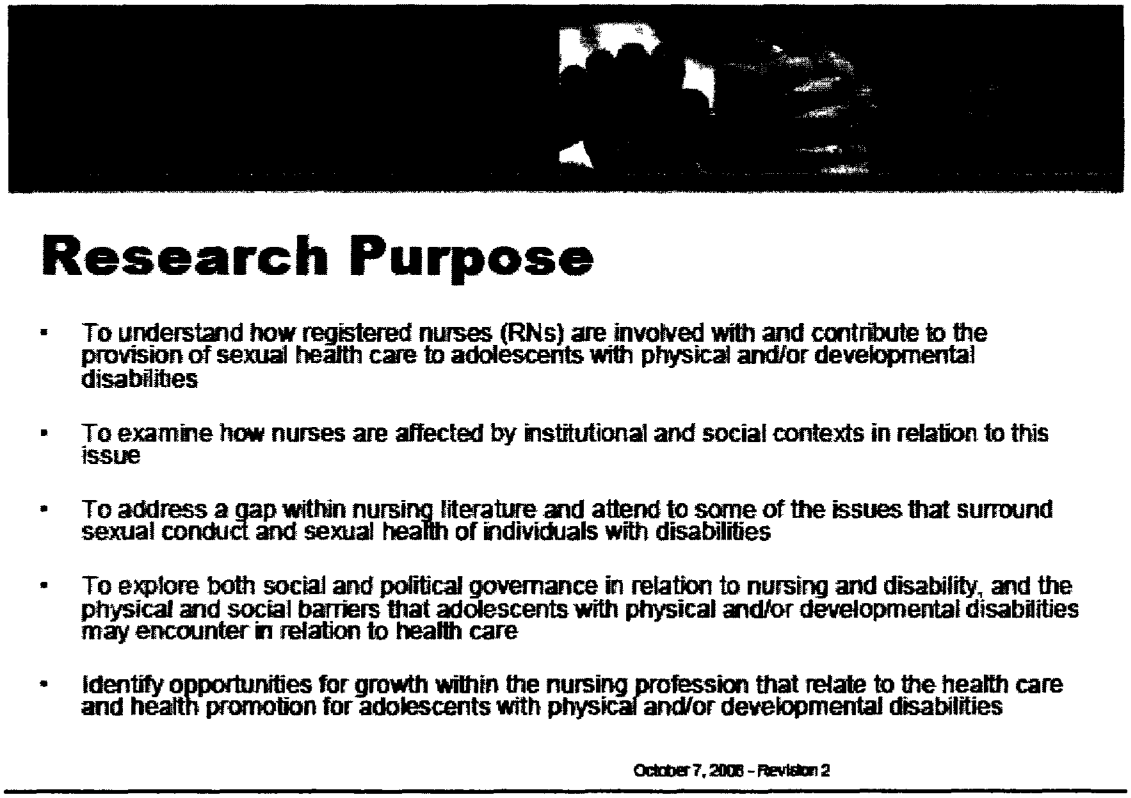
Janet McCabe, PhD (cand.), M.Ed., RN
School of Nursing/Ecole des sciences infirmieres
University of Ottawa/Universite d'Ottawa

Appendix F: Qualitative Interview Guide

The following questions were used as probes during the open-ended interviews.

1. Tell me about your role as a Registered Nurse/Physician/Social Worker here at the facility.
2. Nurses: Can you describe any instances when your adolescent patients or their families have asked you questions about sex, sexuality, or sexual health (e.g. menstruation, or masturbation)?
    a. What were your reactions to these questions, how did you handle these questions?
    b. How do you feel about answering these types of questions?
3. Physicians/Social Workers: Can you describe any instances when you have referred patients/families to speak to a nurse in regards to sex/sexuality/sexual health?
4. What do you think the roles and responsibilities of the out-patient nursing staff are in relation to the sexual health of adolescent clients with physical and/or developmental disabilities?
5. Are you aware of any policies in relation to sexual health, sexual rights and/or sexual conduct at this facility?
6. What do you think facilitates or hinders your ability (the ability of nurses) to address the sexual health of adolescents with disabilities at this facility?
7. Do you know of other professionals at the facility that are working on issues related to the sexual health of young people with physical and/or developmental disabilities? How did you find out about these projects?
8. Are you aware of any research that is being conducted, or materials that are available through other departments or professionals that relates to the sexual health and sexual rights of youth with physical and/or developmental disabilities (aimed at clients/caregivers/professionals)?

Appendix G: Recruitment Presentation



Research Purpose

- To understand how registered nurses (RNs) are involved with and contribute to the provision of sexual health care to adolescents with physical and/or developmental disabilities
- To examine how nurses are affected by institutional and social contexts in relation to this issue
- To address a gap within nursing literature and attend to some of the issues that surround sexual conduct and sexual health of individuals with disabilities
- To explore both social and political governance in relation to nursing and disability, and the physical and social barriers that adolescents with physical and/or developmental disabilities may encounter in relation to health care
- Identify opportunities for growth within the nursing profession that relate to the health care and health promotion for adolescents with physical and/or developmental disabilities

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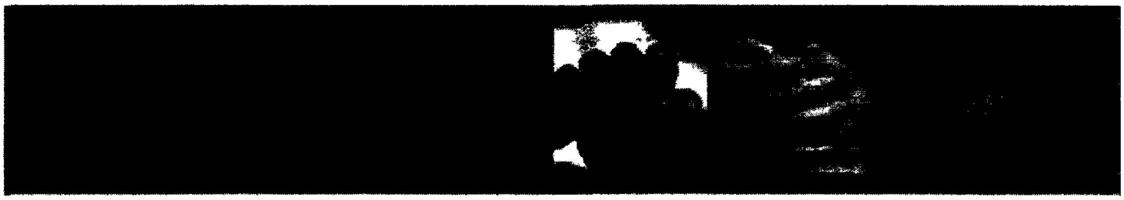
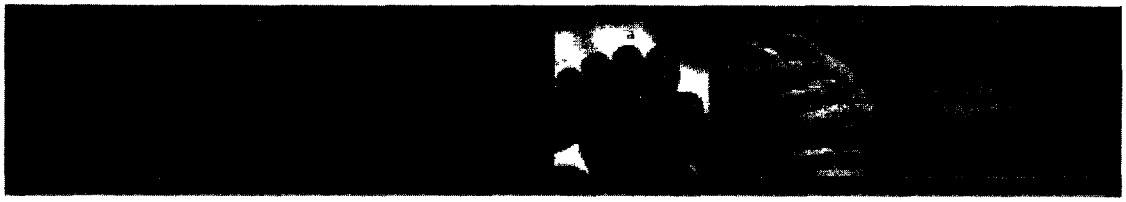
Data Collection

- Interviews with RNs, physicians, and social workers
- Observation of the setting
- Examination of educational materials and policies



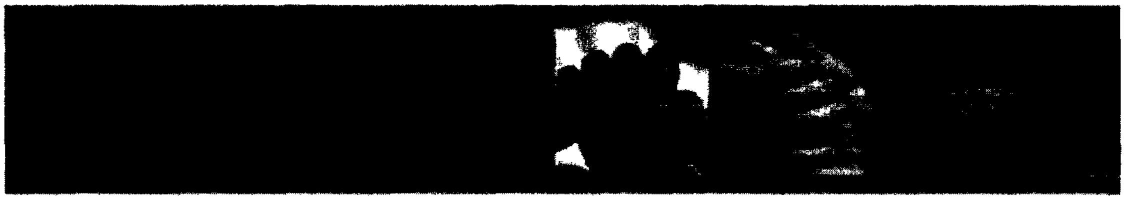
Roles of Research Participants

- Interviews
  - Recruiting interested individuals to participate in 1 hour interviews and to review this transcript at a later date
  - Participants will also be asked to complete a 1 page questionnaire about themselves (i.e. age, gender, position at the facility)
  - Time Commitment: maximum 3 hours in total



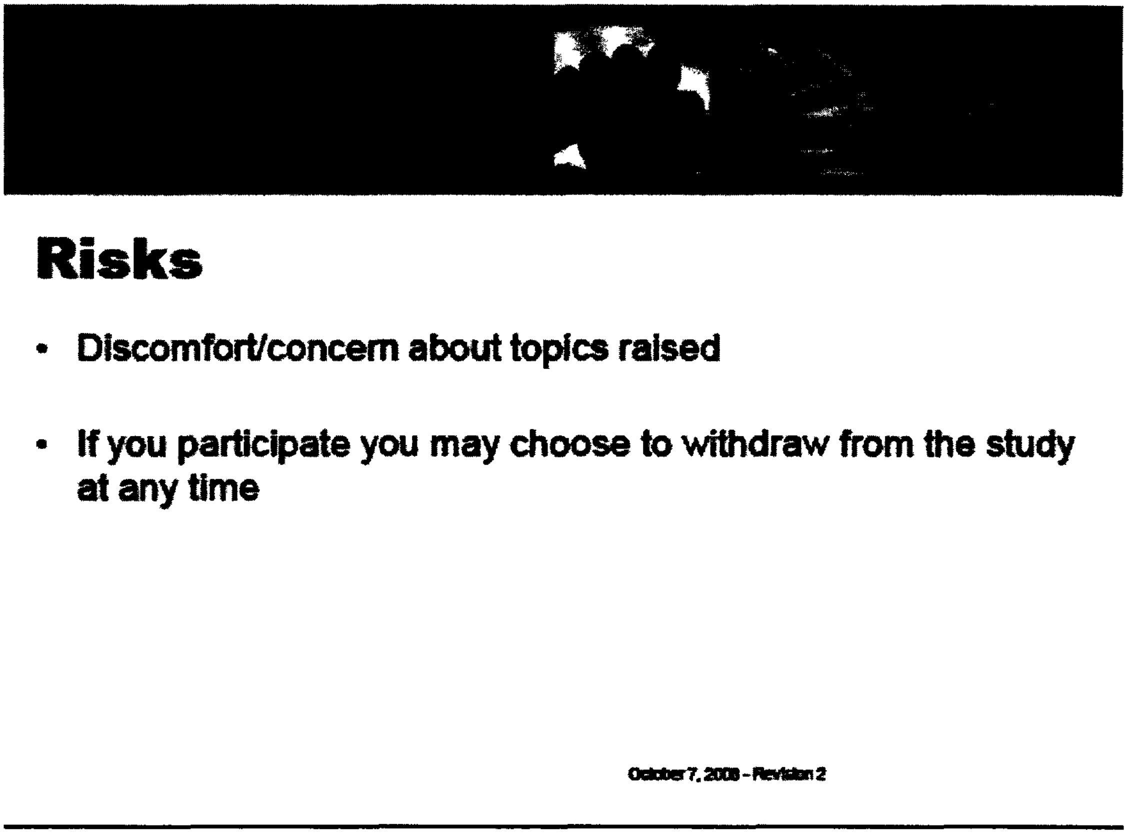
Privacy & Confidentiality

- Access to transcripts, tape-recordings, research material is limited to the researcher, her supervisor, and co-supervisor
- Administration will have NO ACCESS to research materials
- Information discussed in the interview will not be discussed with others
- All identifying names and features will be removed from transcripts and will not be included in any publications or presentations after the research is concluded



Informed Consent

- **Participation is voluntary**
- Participants will be asked to sign an informed consent form
- This form acknowledges that the individual agrees to participate in the study, and informs them of their rights as well as risks and benefits of participation



Risks

- Discomfort/concern about topics raised
- If you participate you may choose to withdraw from the study at any time

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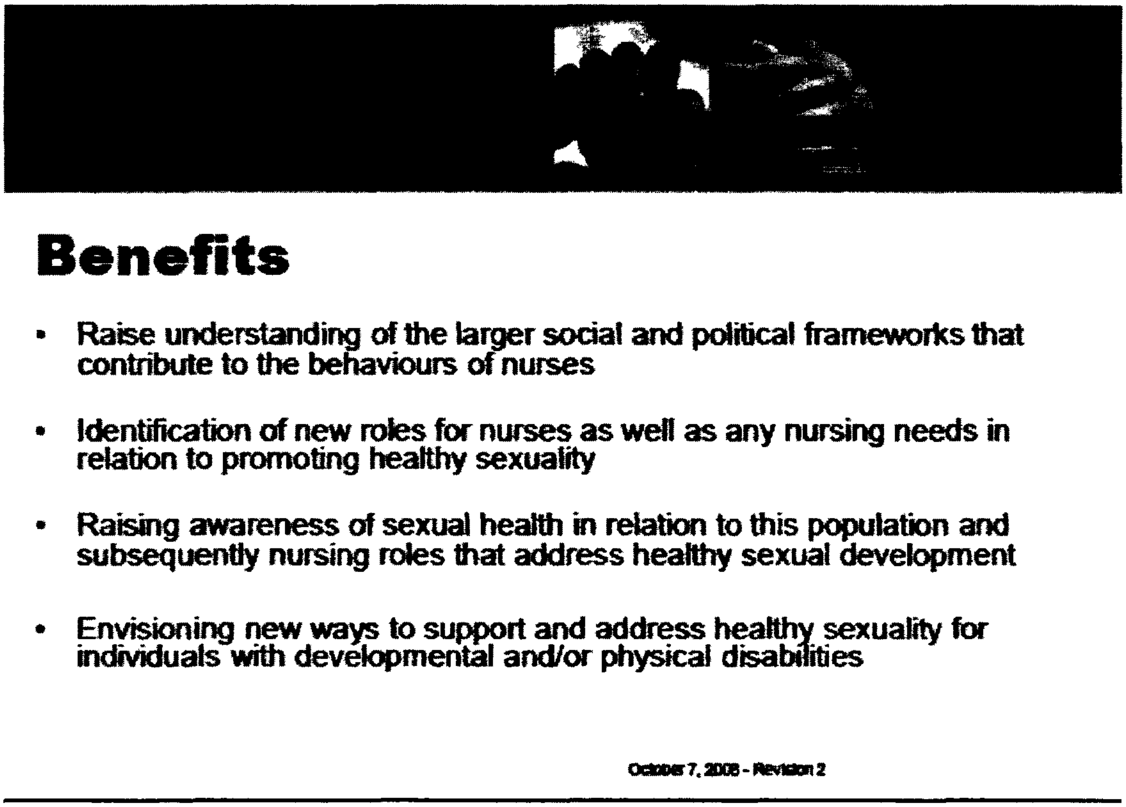

Benefits

- Raise understanding of the larger social and political frameworks that contribute to the behaviours of nurses
- Identification of new roles for nurses as well as any nursing needs in relation to promoting healthy sexuality
- Raising awareness of sexual health in relation to this population and subsequently nursing roles that address healthy sexual development
- Envisioning new ways to support and address healthy sexuality for individuals with developmental and/or physical disabilities

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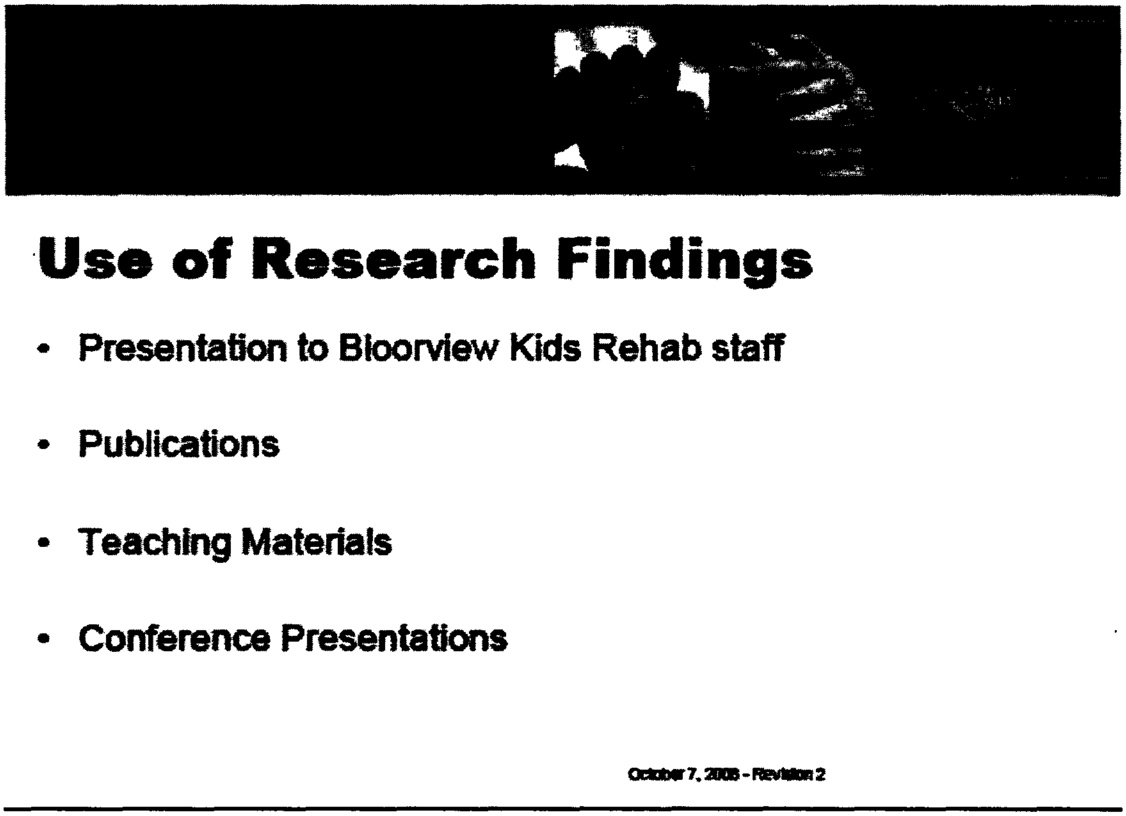

Use of Research Findings

- Presentation to Bloorview Kids Rehab staff
- Publications
- Teaching Materials
- Conference Presentations

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Appendix H: Observation Data - Collection Grid

General Categories	Specific Elements of Observation
Characteristics of the facility	• Geographical and historical location of the facility • Identification/obviousness of the facility to an outsider • Accessibility (i.e. how do individuals access the facility) • What is the facility used for (i.e. what services are offered)?
Physical appearance within the facility (architecture, space, decoration)	• Physical architecture • Physical barriers (i.e. doors, locked doors) • Surveillance technology utilized by staff (i.e. cameras, intercoms) • Structure & design of the environment - division of work areas - organization of space - utilization of space (what spaces are restricted, and to whom) • Décor (i.e. decoration)
Policies and procedures of the facility	• Regulation of actors and groups (circulation of the people, modes of interaction) • Modes of informing staff of policies, procedures, roles, and responsibilities (i.e. locations of policies and procedures, job descriptions) • Privacy provided by patient rooms, treatment rooms etc.
Actors/groups	• Individuals present in out-patient and in-patient settings • Presence of an invisible authority (i.e. memos and documentation from administrators)

Adapted from Peretz (2004)