



Making Sense of Sex with People with Cerebral Palsy

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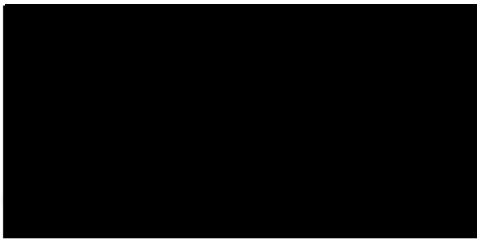
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Author's Certification

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Tinashe Moira Dune, B. A. (Honours) Psyc.

This dissertation is dedicated to my mother, Janet Mpopu Dune who taught me the value of education, and my beloved friend Andrew St Kitts who reminds me that everything in life should be appreciated and cherished.

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Abstract

Constructions of sexuality and disability have been discussed widely by scholars across a number of fields. However, there has been relatively little research on how people with Cerebral Palsy construct their own sexuality and the salience of the socio-sexual schema which are involved in this process. As such this study aimed to address three questions; 1) the relative salience of public, interactional and private sexual schema in the construction of sexuality for people with Cerebral Palsy, 2) how people with Cerebral Palsy construct sexual participation, and particularly sexual spontaneity and, 3) how people with Cerebral Palsy describe their sexuality. This project utilized a hermeneutic phenomenological approach to explore these questions. In doing so, this study helps fill the gap between how sexuality and disability is constructed external to the individual and how the individual constructs their own sexuality. For this research, seven in-depth, semi-structured interviews were conducted with five men and two women with moderate to severe Cerebral Palsy.

Participant data indicated that how people with Cerebral Palsy perceive sexual experiences with others (interactional) is the most influential factor in the construction of their sexuality. Public influences were cumulatively the second most important factor in the construction of sexuality by people with Cerebral Palsy. Finally, private influences were cumulatively the least influential factor in the construction of their sexuality. Sexual spontaneity primarily was a derivative of sexual exploration. Furthermore, participants defined sexual spontaneity as liberating and allowed them to experience their sexuality with others relatively independent of normative sexual scripts. Participants also described their sexuality primarily in terms of major transitions and experiences which involved others.

Based on the findings sexual theory needs to be more cognizant of sexual agency as primary in the construction of sexuality with significant disability. In addition, healthcare providers and people with Cerebral Palsy are likely to be successful partners in sexual health when they promote positive and agentic constructions of sexuality with significant disability. The findings emphasize that people with Cerebral Palsy are cognizant and intelligent agents in the construction of their sexuality. Their articulations, understandings and descriptions of their sexuality demonstrate their interest and awareness in their sexuality and issues related to it. People with Cerebral Palsy are sexual agents and beings who empower themselves.

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Chapter 1: Introduction

Alex (not real name) and I were watching television in his relatively accessible, technologically-enhanced and fully mechanized dorm room. As we chatted over the buzzing of the television our attention was suddenly drawn to a heated and passionate sex scene. The characters had only just met and seemed to be having the best sex of their lives. “Do people really have sex like that?” Alex asked. “I don’t think so... No... Of course not” I replied. Alex and I were silenced as both characters simultaneously reached orgasm in a very complicated physical configuration. “Would you want to have sex like that?” I asked. “You must be joking” Alex replied. Alex, who has severe Spastic Quadriplegic Cerebral Palsy, explained to me that sex (for him) was about working with what you had. With a wink he assured me that no one had ever complained.

The media often presents the most satisfying sex as occurring without the need for sexual communication or negotiation (Chapin, 2000). Sex is also portrayed as an instantaneous and mutually gratifying experience that elicits feelings of intimacy and romance. As Offman (2007) observed, sexual spontaneity is presented as “the expectation that intimate partners can become aroused and initiate sexual activity upon a moment’s notice”... [and] “sexual behaviour follows desire and arousal (lust) without a conscious awareness of the process, such that satisfying sex is the result of reflexive bodily impulses and not conscious communication” (personal communication, September, 25th). People with Cerebral Palsy may find it difficult to live up to the expectations of normative functioning and hegemonic sexual scripts and this can exacerbate barriers to the expression of their sexuality.

The assumption that good sex is spontaneous is also indicated in research literature which focuses on contraceptive use, sexual dysfunction, illness and physical impairment (Schover, 2000; Siegel, Schrimshaw & Lekas, 2006; Torabi & Yarber, 1992). In this literature, sexual spontaneity seems to be linked to sexual satisfaction. These terms are often presented together which may lead the reader to assume a causal relationship between the two (Crosby, Sanders, Yarber, Graham & Dodge, 2002; Gurevich, Mathieson, Bower, & Dhayanandhan, 2007). For people with atypical mobility, sexual spontaneity may be relatively difficult because of the need to plan their sexual encounters, often in intimate detail (Gossman, Mathieu, Julien, & Chartrand, 2003; Mona, 2003; Mona & Gardos, 2000).

People with Cerebral Palsy who require daily personal care may be dissuaded from initiating or engaging in sexual activity. For example, a caregiver may be required to assist in the removal of their clothes or the application of contraceptives (Earle, 1999; Earle, 2001; Mona, 2003). Importantly, asexualizing attitudes from care providers, family members and peers may create an environment in which people with Cerebral Palsy could perceive that it is inappropriate to discuss or exert their need for sexual expression (Antle, Mills, Steele, Kalnins & Rossen, 2008). Asexualizing attitudes refer to the internalized misconception that people with disabilities are incapable of and are not interested in sexual intimacy and relationships. Milligan and Neufeldt (2001) suggested that asexualizing attitudes are based on the erroneous premise that for "people with physical disabilities, because of actual or presumed sexual dysfunction, gratification opportunities are considered so limited that sexual needs are either deemed to be absent or subjugated" (p. 92).

Furthermore, the difficulty people with Cerebral Palsy may have in securing some privacy can impede the ability to spontaneously engage in sexual activity, and this can be true for persons residing, with family, in institutional or group home settings (Nosek et al.,

1996). The discrepancy between the desire to fulfill sexual expectations and the “real world” of intimate relationships can be detrimental to sexual self-concept when people with Cerebral Palsy internalize asexualizing attitudes. As such, people with Cerebral Palsy may attribute sexual difficulties to a personal inability to act as prescribed in terms of this internalized script (Taleporos & McCabe, 2003). A related question of interest is how people with Cerebral Palsy construct sexuality.

Background

A large portion of research has explained sexual behaviour and sexual functioning using a medical model (i.e., Ahtari & Dwyer, 2005; Monyihan, 2003; Schover, 2000). However, human sexuality is also a product of cultural socialization. Studies in sexual psychology suggest that sexuality is constructed via the interaction of psychological and social processes within a particular culture (i.e., Leiblum, 1990; Mona & Gardos, 2000; Schooler & Ward, 2006; Szasz, 1998).

For instance, in their seminal work Simon and Gagnon's (1986) sexual script theory posits that the way individuals express their sexuality is based on socially imprinted schemas which outline how they should sexually interact with others, with whom to interact (socially “appropriate” sexual partners), what sexual activities are socially permitted, where and when these activities can transpire and why it would benefit to act in accordance with these schemes (see also McVee, Dunsmore & Gavelek, 2005). Sexual script theory proposes that sexual behavioural dispositions are created through a person’s involvement in cultural, interpersonal and intrapsychic schemas.

Script Theory and Sexuality

Cultural schemas guide the individual within collective life—meaning that they dictate the requirements needed to fulfill specific roles including the process by which a

person enters those roles and how they should behave within them (Pryor & Merluzzi, 1985; Ronen, 2010; Serewicz & Gale, 2008). Cultural schemas therefore instruct individuals on the topics of time, place, gestures, utterance and what people engaging in sexual behaviour are supposed to be feeling; “qualities of instruction that make most of us far more committed and rehearsed at the time of our initial sexual encounters than most of us realize” (Simon & Gagnon, 1986, p. 105). For example, being a man in a Western culture may mean fulfilling the expectation that one is the sexual aggressor, knows what their partner enjoys, and is able to do so flawlessly (Kim, Sorsoli, Collins, Zylbergold, Schooler & Tolman, 2007; Szasz, 1998; Zilbergeld, 1999).

Interpersonal schemas define people as being both the actors of scripts and agents of their formulation. The construct of interpersonal schemas reinforces the relevance of cultural schemas because people act out their perceptions of appropriate identities and the desired expectations from playing such roles (Chapin, 2000). By legitimizing and lowering uncertainty for oneself and others involved in a sexual encounter, a person who has been scripted as the sexual aggressor could be reinforced by his/her partner who is habituated to play the passive role (L’Engle, Brown & Kenneavy, 2006; Ward, 2003). Although actors may experience sexual feelings throughout the interaction, they may only express or allow themselves to become aware of the feelings that are appropriate to the situation (L’Engle, Brown & Kenneavy, 2006) which can cause “inappropriate” thoughts to halt, or be repressed. Presumably, individuals must think about how they are going to express and execute these scripts with others through the interplay of interpretation and mental rehearsal of sexual expectations.

Intrapsychic schema are a significant factor in personal mental processes which involve inner dialogue (Brown, 2002; Emerson, 1983). They influence the way individuals

internalize the script of what is sexually desirable and how they fit into that scenario. As described by Simon and Gagnon (1986), intrapsychic schemas are “the symbolic reorganization of reality in ways that makes it complicit in realizing more fully the actor’s many-layered and sometimes multicoated wishes” (p. 99; see also Markle, 2008). Even through the mental world of private desires and wishes one’s thoughts are socially bound (Kant, 1958). For example, the same man who is expected to be sexually aggressive may wish to be cuddled and submissive but may not ask for such things (Markle, 2008; Zilbergeld, 1999).

Interpersonally, individuals try to act out what has been culturally scripted (Chiu, Gelfand, Yamagishi, Shteynburg, & Wan, 2010). In thinking about their sexual experiences people may contemplate how they fit or do not fit into this expectation. To achieve ultimate sexual satisfaction through sexual activity the script of sexual spontaneity follows three basic “Acts”:

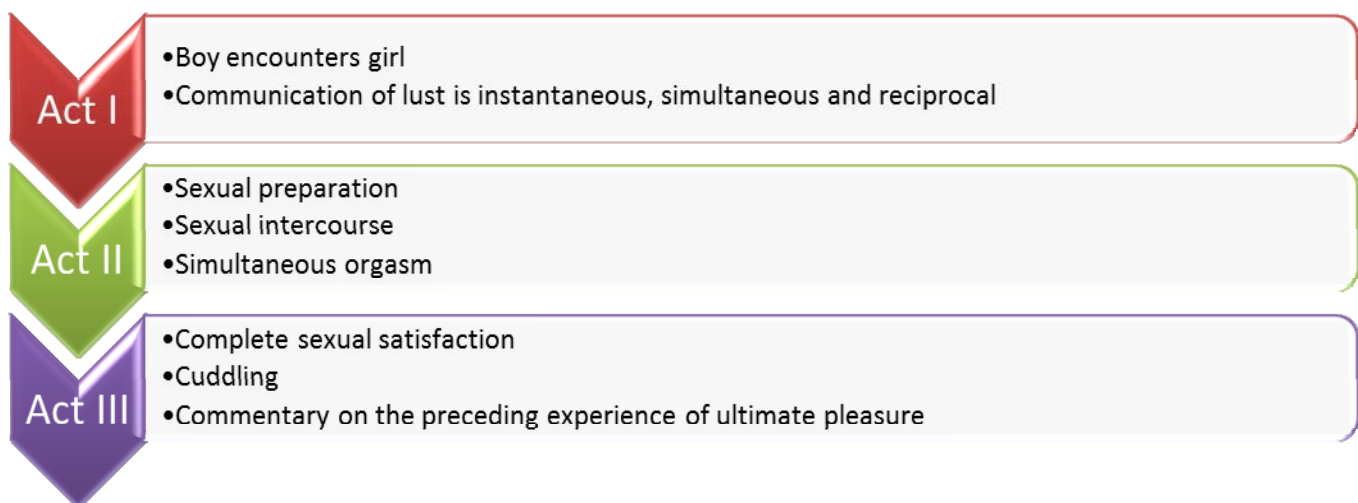


Figure 1.1. Script of Sexual Spontaneity (Dune & Shuttleworth, 2009)

Figure 1.1, illustrates the script of sexual spontaneity as characterized by three acts (much like the script from a play). In Act I, a heterosexual situation is set-up to facilitate the communication of instantaneous and simultaneous desire and arousal (lust) which is

unquestionably reciprocated. Act II, begins with the actors preparing for sexual intercourse. Here the actors engage in flawless foreplay which includes kissing, fondling, heavy petting and possibly oral sex - only if their lust is patient enough to facilitate it. The foreplay is then followed by sexual intercourse in which both partners are in their favourite position which provides enough stimulation for both partners to experience simultaneous orgasm via vaginal penetration by an erect penis. Finally, Act III includes the feeling of complete sexual satisfaction followed by cuddling which is an indication of romance, love and intimacy as a result of an unspoken understanding between sexual partners which has been expressed through the preceding sexual experience. At the end, both partners breathlessly allude to one another how completely pleased and sexually satisfied they are due to their sexual encounter. Although sexual gratification is presumed to be a linear process, people with Cerebral Palsy may conceptualize the public, interactional and private aspects of the script of sexual spontaneity in ways influenced by their atypical experience as social actors.

Considering Simon and Gagnon's sexual script theory, the myths surrounding sexual spontaneity as portrayed by popular media are internalized and perpetuated within a social context. However, much of the sexual behaviour the mass media presents is not necessarily representative of human diversity and the variance within people's actual sexual lives. As such, provisions are not adequately provided to include people with significant physical disabilities in the social or sexual arenas of everyday life. Socio-sexual exclusion for this population thereby perpetuates the idea that they should not partake in mainstream social and sexual activities with others.

When people with Cerebral Palsy do engage in sexual relations, contradictions between their experiences and internalized social scripts of idealized "appropriate" sexual relationships may occur. If social expectations of sexuality are internalized, then sexual

difficulties may result. When expectations are not met people may experience a negative impact on their sexual health and well-being. The influence of idealized sexual scripts is important to consider for people with Cerebral Palsy because expectations of normative function, bodily movement and the body beautiful can make access to sexual relationships difficult for many people in this group (Gossmann et al., 2003; Shuttleworth, 2000; Shuttleworth, 2006). As such, the specific ways in which people with Cerebral Palsy personalize sexual scripts is a matter for study.

Pertinent Concepts

Public, interactional and private events influence individual constructions, and inevitably expression of sexuality (Barbour, 2008; Caplan, 1987; Simon & Gagnon, 1986; Weeks, 2010). Public events include the consumption and engagement of media. This includes the purchasing and reading of magazines, watching movies or television and using the internet. Public events, like cultural schemas, may impact the expression of sexuality as they expose people to images of what is sexually desirable and/or “appropriate.” Interactional events are characterized by the negotiation of interpersonal relationships (i.e., flirting, courting and dating).

These events are important to expressions of sexuality as individuals may choose potential sexual partners based on their perceptions of what is socially acceptable. Private events, like intrapsychic scripts, are characterized by the interplay between individual perceptions and mental rehearsals (i.e., fantasies) of sexual expectations (Sanders, 2008). Private events impact sexual expression by consolidating or internalizing certain constructions of sexuality while rejecting others. The influence the script of sexual spontaneity has on constructions of sexuality is of interest. While many questions remain

unanswered about how the script of sexual spontaneity is constructed significant issues within the script of sexual spontaneity itself must be addressed.

Sexual Spontaneity: Inherent Tensions

Notwithstanding the influence of expectations of sexual spontaneity in the cultural context of instant gratification, there are some tensions inherent in this belief. For instance, tensions appear to arise from the contradiction between initiating sexual activity, which requires forethought to some extent, while maintaining an element of “surprise” for both partners. A study using the Sexual Initiation Scale explored this sexual expectation (Gossmann et al., 2003). These researchers studied the link between the initiation of sexual activity and other relationship factors. They defined the term sexual initiation as “the first step by one partner to convey verbally and/or non-verbally to the other partner an interest or desire for sexual activity” (p. 169).

The study by Gossmann and colleagues provided evidence to suggest that sexual initiation was to provide partners with a sense of sexual satisfaction and feelings of romance and intimacy. They further observed that couples who were dissatisfied with their relationship were less likely to initiate sex or respond to a partner’s initiation of sexual activity. Since sexual spontaneity presumably requires initiation from one of the partners, those who feel like they cannot express their intimacy in this way may shy away from engaging in sexual activity (Dune & Shuttleworth, 2009). Hence, emotional distress in regards to oneself or one’s partner may impact the initiation of sex, sexual interactions, sexual satisfaction and therefore, sexual wellbeing (Zimmer, 1987; Zilbergeld, 1999; Yadav, Gennarilli & Ratakonda, 2001). However, the full range of initiation behaviours is not known, particularly in atypical others.

Communication.

Levels of communication between intimate partners can impact the outcome of sexual interactions (Metz & Epstein, 2002; Ward, 2003). In this sense communication involves intimate partners conveying information with one another and thereby facilitating a connection which allows access to each other's thoughts, emotions and desires. Poor communication can exacerbate sexual issues when partners try to have idealized "good sex." For example, if the experience is negative subjectively partners may avoid the initiation of sexual activity in the future (Gossmann et al., 2003; Leiblum, 1990; Yadav et al., 2001).

If one partner is no longer initiating sex then the other partner may also reduce his or her attempts at sexual initiation. "Zest begets zest, potentially leading to more frequent sex and higher sexual responsiveness" (Gossmann et al., 2003, p. 178). While it is possible for "good sex" (i.e., mutually satisfying for both partners) to be spontaneous, the internalized belief that spontaneity is necessary for satisfying sex may lead to dissatisfaction or dysfunction (Swindle, Cameron, Lockhart & Rosen, 2004).

Adjoined with this misconception about sexual satisfaction is the problematic assumption that satisfying sexual experiences must involve and therefore be qualified by another individual. In this way, individual expressions of sexuality like masturbation (see Walthall, 2009) or sexual experiences with sexual surrogates and sex workers are categorized as a meager substitute for "good/real sex" (Giusta, Di Tommaso, & Strøm, 2007). Moreover, the present process by which expectations of sexual spontaneity are portrayed, internalized and perpetuated does not acknowledge individual or alternative constructions of sexuality, spontaneity and resultant sexual satisfaction (Dune & Shuttleworth, 2009). Hence, using sexual spontaneity as the sole ingredient to maintain

intimacy and romance ignores the dynamic interplay that occurs within sexual relationships. More importantly however, sexual spontaneity in atypical others, like people with Cerebral Palsy, is not well understood.

Exploration of Sexuality and Cerebral Palsy

While the exploration of sexuality and disability encompass a large variety and spectrum of physical and mental impairments, this thesis focuses only on Cerebral Palsy. As an understudied population (Shuttleworth, 2006) many qualities which mark the development of sexuality for people with Cerebral Palsy is unknown. First, Cerebral Palsy often causes physical impairment early in life. Thus, adults with Cerebral Palsy have a rich developmental history of experience. As adults with Cerebral Palsy have lived with its implications through the developmental period, their sense of sexual self is distinctively influenced by their disability.

Second, people with Cerebral Palsy are heterogeneous in their functional abilities. Some may experience minor impairments of motor function which result in mild spasms or a slight limp when walking (Dobson, Morris, Baker & Graham, 2007). Such individuals may “pass” as a typical other when sitting, standing still or during certain activities (i.e. talking, eating, writing or typing) and may have typical population competencies. In this way people with mild Cerebral Palsy may not experience the same barriers or at the same level and frequency. However, those with moderate to severe Cerebral Palsy who, for most or all of their lives, required the use of a wheelchair to get around and/or daily assistance from others could have significantly different developmental history. People with moderate to severe Cerebral Palsy are not able to move (i.e., walk, write, sit up, eat and/or dance) and often speak in the same way as individuals with mild cerebral palsy and/or typical others.

These differences have significant implications for the sexual participation of individuals with Cerebral Palsy.

Cerebral Palsy

In order to better understand the special circumstances for this group an overview of Cerebral Palsy and its epidemiology will be presented. Cerebral Palsy is a term which encompasses a group of non-progressive (National Center on Birth Defects and Developmental Disabilities, 2011) and non-contagious motor conditions that create physical impairments during human development, primarily in regards to the various areas of mobility (Beukelman & Mirenda, 1999). Complications are attributed to disturbances that occurred in the developing fetal or infant brain which occurs in 2 – 3 of 1000 live births in Western nations (National Center on Birth Defects and Developmental Disabilities, 2011). These physical impairments cause permanent disorders of movement and posture resulting in activity limitation. Motor disorders associated with Cerebral Palsy can also be accompanied by issues with spatial perception, communication, behaviour, epilepsy, disturbances of sensation, cognition, and by secondary musculoskeletal problems (National Center on Birth Defects and Developmental Disabilities, 2011). As such, individuals with cerebral palsy may be diagnosed with learning difficulties. Sometimes, however, it is the sheer magnitude of problems caused by the underlying brain injury that prevents the individual from expressing what cognitive abilities they do possess (Pennington, Goldbart & Marshall, 2004).

Primary Symptoms

Cerebral Palsy is most often characterized by abnormal muscle tone (i.e., slouching over while sitting), poor reflexes, motor development and coordination. Tight muscles and joints are often reported due to permanently fixed joints and bone deformities. Classical

symptoms also include spasms, involuntary facial movements, unsteady gait, problems with balance, and decreased muscle mass. The effects of Cerebral Palsy fall on a continuum of motor dysfunction and may range from mild clumsiness to impairments so severe that they render coordinated movement virtually impossible (Dobson et al., 2007).

Spastic. Spastic Cerebral Palsy causes the muscles to be tense and rigid and movements are slow and difficult. This can be misinterpreted as cognitive delay due to difficulty of communication (Liptak, 2008). Spastic Cerebral Palsy is by far the most common type, occurring in 70% to 80% of all cases (The Spastic Centre, Australia, 2009). Moreover, spastic Cerebral Palsy accompanies other types of Cerebral Palsy in 30% of all cases (The Cerebral Palsy Alliance, Australia, 2011). Spastic Cerebral Palsy is further classified by the region of the body most affected (see Figure 1.2):

- Spastic hemiplegia (one side of the body being affected).
- Spastic diplegia/paraplegia (the lower extremities are affected with little to no upper-body spasticity).
- Spastic quadriplegia (all four limbs affected equally). People with spastic quadriplegia are the least likely to be able to walk. If they can and/or want to walk, because their muscles are too tight, it may be too much effort to do so.

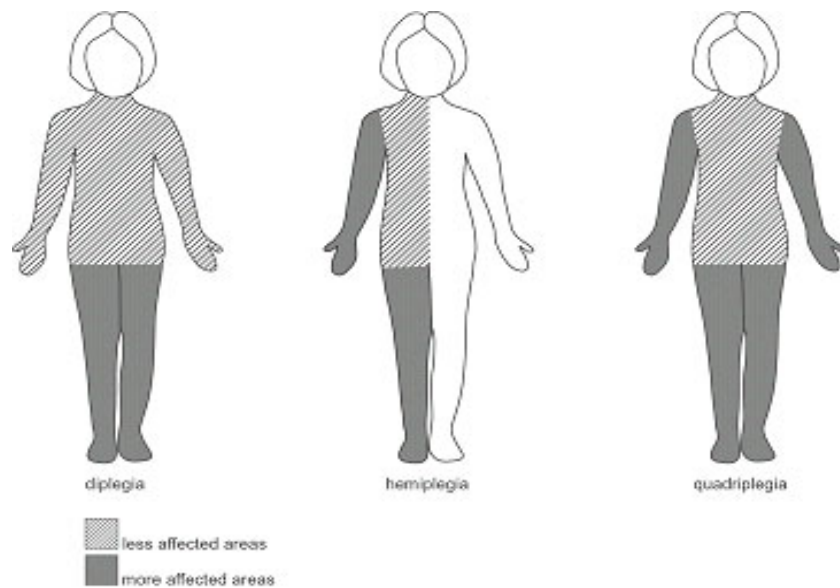


Figure 1.2. Regional Classification of Spastic Cerebral Palsy (The Spastic Centre, Australia 2011)

Ataxic. Ataxic forms of Cerebral Palsy are less common, occurring in no more than 10% of all cases (Andersen, Irgens, Haagaas, Skranes, Meberg & Vik, 2008). Motor skills such as writing, typing, or using scissors might be affected, as well as balance, especially while walking. It is also common for people with ataxic Cerebral Palsy to have difficulty with auditory and visual processing.

Athetoid/dyskinetic. About 20 – 25% of people with Cerebral Palsy exhibit athetoid symptoms. People with athetoid Cerebral Palsy have trouble holding themselves upright, for sitting and/or walking, and often exhibit involuntary movements. People with athetoid Cerebral Palsy may find fine motor control arduous (Andersen et al., 2008). As such, moving their hand(s) to scratch their nose or reaching for a cup, for example, becomes tiring and difficult. Ultimately, people with athetoid Cerebral Palsy may not be able to hold onto objects such as a pen or a fork.

Hypotonic. Only 10% of people with Cerebral Palsy (Yeargin-Allsopp, Van Naarden Braun, Doernberg, Benedict, Kirby, & Durkin, 2008) have the hypotonic variation and it is

therefore considered a rare subtype of Cerebral Palsy. People with hypotonic Cerebral Palsy appear limp and can move only a little or cannot move at all. As such, people with hypotonic Cerebral Palsy might seem floppy or unsteady when they walk (Yeargin-Allsopp et al., 2008). Hypotonic Cerebral Palsy causes posture problems and those affected often have difficulty in maintaining an upright posture while sitting or standing. The condition may also cause breathing and swallowing difficulties resulting in speech impediments.

Secondary Symptoms

Secondary symptoms are primarily characterized by speech and language disorders (dysarthria). Dysarthria is common in people with Cerebral Palsy and estimated to range from 31% to 88% (Pakula, Van Naarden Braun, & Yeargin-Allsopp, 2009). Speech problems are associated with poor respiratory control as well as oral articulation disorders caused by restricted movement in the oral-facial muscles. There are three major types of dysarthria in Cerebral Palsy; spastic, ataxic and athetoid/dyskinetic:

- Speech impairments in spastic dysarthria involve four major abnormalities of voluntary movement: spasticity, weakness, limited range of motion and slowness of movement.
- Uncommon in Cerebral Palsy, ataxic dysarthria is characterized by imprecise consonants, irregular articulatory breakdown, distorted vowels, excess and equal stress, prolonged phonemes, slow rate, mono-pitch, mono-loudness and harsh voice (Chen, Chen, Wong, Yang, Yang, & Wu, 2010).
- Athetoid dysarthria leads to the generation of faulty movements of the face and mouth that are involuntary. As such, speech mechanism impairment in athetosis involves a disorder in the regulation of breathing patterns which creates mono-pitch, low, weak and breathy voice quality.

Children with Cerebral Palsy are at risk of learned helplessness and becoming passive communicators, initiating little communication (Beukelman & Mirenda, 1999). Early intervention often target social contexts and encourage the child to be social agents who can control people and objects in their environment through making choices, decisions and mistakes (Beukelman & Mirenda, 1999).

Sexual Development

Although the majority of people with physical disabilities go through puberty at the same time and rate as their typical peers, Wiegerink, Roebroek, Donkervoort, Cohen-Kettenis and Stam (2008) explained that for some people with Cerebral Palsy puberty begins earlier and lasts longer. Early onset sexual development may be particularly confusing for adolescents as they may not understand what is happening to their bodies. Furthermore, young people with Cerebral Palsy may not be provided with information about human sexuality or sexual relationships that acknowledge them as sexual beings and agents (i.e., Hardoff & Millul, 1997; Rurangirwaa, Van Naarden Braun, Schendel, & Yeargin-Allsopp, 2006). This lack of sexual education and relationship information may result from the erroneous assumption that sexuality is of little importance to people with physical disabilities.

While research and literature about how people with Cerebral Palsy engage in and conceptualize sexual intimacy is limited, people with Cerebral Palsy do flirt, go on dates, have sex and negotiate sexual intimacy and relationships. A lack of adequate sexual health education and relationship information and among people with Cerebral Palsy (among many other disabilities) may influence them to engage in unsafe sexual practices and relationships (i.e., Wazakili, Mpofu, & Devlieger, 2009; Xenakis & Goldberg, 2010). They may be less able

to ask for sex or intimacy (i.e., Lease, Cohen & Dahlbeck, 2007; Davis et al., 2009) or refuse sexual activity (i.e., Alouf, 2007; Jemtå, Fugl-Meyer & Öberg, 2008).

While Cerebral Palsy primarily affects normative movement and functioning of the body sensory pathways and sexual functioning is almost invariably intact (unlike some instances of Spinal Cord Injury for example) (Shuttleworth, 2000). Hence, normative physical sensations and responses during arousal and sexual activity like touch, taste, smell, vasocongestion and lubrication of the genitals remains undisturbed. As such, the barriers people with Cerebral Palsy experience during their attempts to negotiate sexual relationships and intimacy may primarily be caused by the (mis)perceptions others have about atypical physical qualities.

Research Issues

A review of the literature published from 1951 to 2010 using PsycInfo and Scopus was conducted. "Cerebral Palsy" and "sexual spontaneity" did not produce any results. Searches using the terms "Cerebral Palsy" and "sexuality" produced 18 results with PsycInfo and 13 with Scopus. I then searched for "physical disability" and "sexuality" and "Cerebral Palsy" in all fields (see Table 1.1). In the following searches I exchanged the word "sexuality" for the word "sex", then "sexual", then the term "sexual spontaneity", "sexual negotiation", "sexual participation" and "sexual activity" (Table 1.1). I then changed the term "physical disability" for "physical impairment" and "mobility impairment" then cycled through the words "sexuality", "sex", "sexual" then the terms "sexual spontaneity", "sexual negotiation", "sexual participation" and "sexual activity" again.

Table 1.1 Systematic Literature Search

Within the Abstract	Within the Abstract	Within All fields	PsycInfo Results	Scopus Results
Cerebral Palsy	Sexuality	-----	18	13
Physical disability	Sexuality	Cerebral Palsy	3	18
Physical disability	Sex	Cerebral Palsy	6	39
Physical disability	Sexual	Cerebral Palsy	5	30
Physical disability	Sexual spontaneity	Cerebral Palsy	0	0
Physical disability	Sexual activity	Cerebral Palsy	2	10
Physical disability	Sexual negotiation	Cerebral Palsy	0	1
Physical disability	Sexual participation	Cerebral Palsy	0	0
Physical impairment	Sexuality	Cerebral Palsy	1	4
Physical impairment	Sex	Cerebral Palsy	4	20
Physical impairment	Sexual	Cerebral Palsy	1	7
Physical impairment	Sexual spontaneity	Cerebral Palsy	0	0
Physical impairment	Sexual activity	Cerebral Palsy	0	2
Physical impairment	Sexual negotiation	Cerebral Palsy	0	0
Physical impairment	Sexual participation	Cerebral Palsy	0	0
Mobility impairment	Sexuality	Cerebral Palsy	0	1
Mobility impairment	Sex	Cerebral Palsy	1	4
Mobility impairment	Sexual	Cerebral Palsy	1	2
Mobility impairment	Sexual spontaneity	Cerebral Palsy	1	1
Mobility impairment	Sexual activity	Cerebral Palsy	0	1
Mobility impairment	Sexual negotiation	Cerebral Palsy	0	0
Mobility impairment	Sexual participation	Cerebral Palsy	0	0

From the 85 articles found, 8 were excluded due to duplicity while 18 were excluded because they did not meaningfully discuss the psychosocial/sexual relationship that physical impairment/disability has with experiences and constructions of sexuality. A total of 12 articles were excluded because they discussed specific physical impairments/disabilities (i.e., Spinal Cord Injury, Spina Bifida, Multiple Sclerosis, etc.) other than Cerebral Palsy. This exclusion process (Table 1.2) also removed 10 papers which studied cognitive impairments, mental disabilities or performed assessments on intellectual or developmental ability.

Table 1.2 Exclusion Criteria

<ul style="list-style-type: none"> • Duplicates • Does not discuss the psychosocial/sexual relationship between physical impairment/disability and sexuality. • Articles specific focused on physical impairments/disabilities (i.e. Spinal Cord Injury, Spina Bifida, Multiple Sclerosis, etc.) other than Cerebral Palsy or physical disabilities generally • Articles primarily focused on cognitive impairments, mental disabilities or performed assessments on intellectual or developmental ability
--

Ultimately, 37 papers (see Appendix A) which focused on physical disability and/or impairment, discussed sexuality and made mention of or used participants who had Cerebral Palsy were identified for inclusion and in-depth analysis. Of the final 37 (from 1974 to 2010) articles identified, 23 discussed the psychosexual and social aspects of sexuality and physical disability/impairments and/or mobility impairments in a more general context. The remaining 14 discussed the psychosexual and social aspects of sexuality in relation to Cerebral Palsy examined Cerebral Palsy as a significant part of their study sample. Cumulatively these articles present important information about Cerebral Palsy in relation to disability, sexuality and psychological well-being, sexual and intimate relationships and facilitated sexual experiences. I discuss the key findings from these studies below.

Disability, Sexuality and Psychological Well-being

Due to societal expectations of the typical human body (Shuttleworth, 2000) research suggests that people with mobility or physical impairments (like Cerebral Palsy) perceived their bodies to be a source of contention in their social lives (Shuttleworth, 2002; Taleporos & McCabe, 2005). As such, people with Cerebral Palsy may have negative feelings about their bodies presumably from the difficulty they experience when trying to initiate or engage in sexual relationships. Consequently, levels of sexual esteem in people with Cerebral Palsy may be lower than typical others (i.e., Chance, 2002; Lease et al., 2007; Taleporos & McCabe, 2002).

The research identified indicates that reduced levels of sexual esteem, body esteem, and sexual satisfaction were strong predictors of self-esteem and depression among people with physical disability (i.e., Chance, 2002; Lease et al., 2007; Taleporos & McCabe, 2002). In addition, the relationship between self-esteem and depression was stronger among people with physical disability than typically developing others (i.e., Nosek, Hughes & Robinson-

Whelen, 2008). However, few studies (i.e., Chance, 2002; Lease et al., 2007; Taleporos & McCabe, 2002) have examined sexual self-concept in people with Cerebral Palsy (i.e., body image, sexual esteem and sense of sexual desirability) in relation to their construction of their own sexuality. Furthermore, literature on psychological well-being, sexuality and Cerebral Palsy emanates mostly from Western countries and leaves speculation about whether or not the incidence of low sexual self-concept and its connection to depression is a universal experience.

Sexual and Intimate Relationships

While people with physical disabilities are presumed to experience negativity towards their bodies, there is evidence to suggest that this may not necessarily be the case. For instance, the longer people live with physical impairments, the more they begin to feel positive about themselves and their level of physical functionality (i.e., Stevens et al., 1996; Taleporos & McCabe, 2005). Subsequently, the acceptance of their body often facilitated finding creative ways to engage in and enjoy their sexuality with others. Despite significant barriers to sexual initiation and negotiation which may exist for people with Cerebral Palsy and other physical disabilities, they may enjoy satisfactory sexual activities, negotiating sexual intimacy and participating in intimate relationships (i.e., Sanders, 2007). What the literature has not explained, however, is how people with Cerebral Palsy (and other physical disabilities) are doing so.

Facilitated Sex

The role of personal care assistants in facilitating intimacy in people with physical disabilities has been considered in the literature (i.e., Earle, 1999; Sanders, 2007). In this case, facilitating sexual activity may include helping clients with the use of contraceptives and safer sex products and undressing clients in preparation for sexual activities. Other

facilitations may include helping clients masturbate or engage in sexual activities with others. However, clients who legitimately fear asexualizing comments or opinions may feel that asking for sexual aid may create tension within their client-carer relationships (Sanders, 2007; Tepper, 1999). Interestingly however, the level to which people with physical disabilities request or abstain from requesting sexual assistance is not known.

Alternatively, people with Cerebral Palsy and other mobility impairments have been engaging the services of sexual surrogates and sex workers (Joseph, 1991; Sanders, 2007). Joseph (1991) and Sanders (2007) explained that sexual service providers do not overtly pass judgment or expose people with Cerebral Palsy (or other physical impairments) to as much negativity about their mobility differences and their need for sexual activity and intimacy as they may receive from typical others. Considering the importance placed on sexual spontaneity as a means to achieve optimum levels of sexual satisfaction, sexuality and disability literature does not indicate whether or not the planning involved when arranging a visit to or from a sexual services provider means that clients experience lower levels of sexual satisfaction.

Statement of the Problem

The script of sexual spontaneity as a social construction does not encompass the range of individual conceptualizations, experiences and ultimately constructions of sexuality. As such, this thesis aims to understand how people with Cerebral Palsy conceptualize the script of sexual spontaneity and whether or not that conceptualization plays a role in their construction of their sexuality. As previously mentioned, sexual script theory outlines the significance of the influence public, interactional and private constructions of sexual experiences have on individual constructions of sexuality (Simon & Gagnon, 1986, 1987, 2003) (see Figure 1.3).

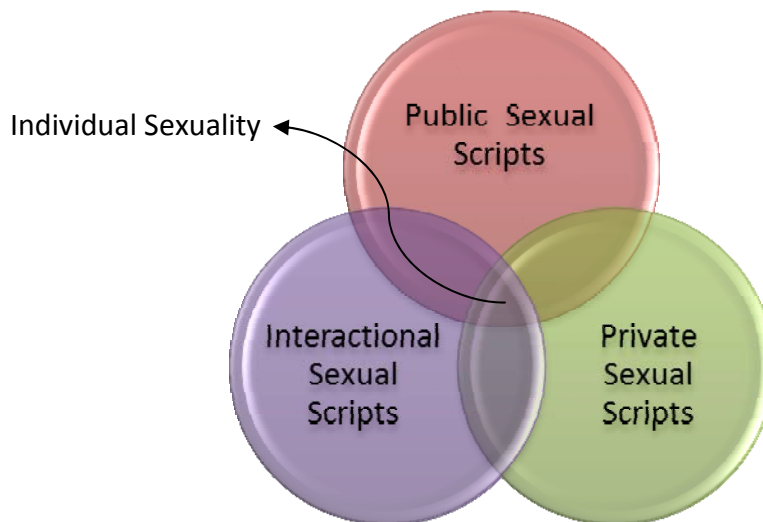


Figure 1.3. Influence of Public, Interactional and Private Sexual Scripts on the Construction of Individual Sexuality

Figure 1.3 illustrates that an individual's sexuality (in the centre) is a product of public, interactional and private sexual scripts. Using sexual script theory then, can help to explore the proportion particular sexual scripts (i.e., script of sexual spontaneity) occupy in individual constructions of sexuality. In order to explore these sexual scripts this thesis adopts a hermeneutic phenomenological approach to investigate how people with Cerebral Palsy construct their sexuality based on their conceptualizations and understandings of public, interactional and private sexual scripts.

Methodological Approach

Sexuality is an interpretive experience (Edley, 2001; Risner, Godfrey & Simmons, 2004; Jackson & Scott, 2007). This study explores the utility of a hermeneutic phenomenological approach in order to gain a better understanding of how people with Cerebral Palsy interpret sexual scripts and construct their sexuality (Heidegger, 1927/1962; Husserl, 1952, 1980). Hermeneutical phenomenology studies interpretive structures (in this thesis sexual scripts and sexual constructions) of experience, how people engage with and

understand these experiences in relation to ourselves and others (Stanford Encyclopedia of Philosophy, 2008). With its foundations in philosophical studies, hermeneutic phenomenology is useful for examining how public, interactional and private meanings are deposited and mediated through myth (i.e., myth of sexual spontaneity), religion (i.e., constructions of heterosexuality), art (i.e., erotica), and language (i.e., popular culture and interactional discourse). Ultimately, hermeneutic phenomenology aims to answer questions about the meaning of being, the self and self-identity (van Manen, 2002).

There are many approaches to qualitatively investigating social constructions and their influence on human sexuality (i.e., participatory action research, grounded theory, ethnography) (Denzin & Lincoln, 2000). Phenomenology however is preferred because it aims to understand human life from the inside “rather than pretending to understand it from an outside, ‘objective’ point-of-view” (Boeree, 2000 p. 72). Generally phenomenological approaches study conscious experience as it is experienced and analyzes the structure (the types, intentional forms and meanings, dynamics, and enabling conditions) of perceptions, thoughts, imagination, emotions, volition and actions (Stanford Encyclopedia of Philosophy, 2008).

More specifically, hermeneutic phenomenology and phenomenology in general are often referred to interchangeably, without any distinction made between them (Lavery, 2003). While this may be the case there are several types of phenomenological approaches which are useful to qualitative social research. It is important then to designate their differences and indicate their major theoretical foci (see Table 1.3) as some phenomenological approaches are not suited for the aims of this thesis. Appropriateness is coded 0 to 3 (0 = least appropriate, 1 = somewhat appropriate, 2 = appropriate and 3 = very appropriate, as indicated in Table 1.3).

Table 1.3 Phenomenological Approaches Used in the Study of Human Experience

Phenomenological Approach	Typical Applications	Description	Appropriateness Rating
<i>Transcendental constitutive phenomenology</i> ; studies how objects are constituted in pure or transcendental consciousness, setting aside questions of any relation to the natural world around us.	Particularly useful for theoretical analyses of phenomenology itself (Scanlon, 2002) and the analysis of philosophies of information (Kervaishvili, 2008).	Transcendental phenomenology is an abstract study which is concerned with how ideal, verbal and non-verbal meanings exist for consciousness in its social habitat. It is allegedly devoid of influences from specific worlds of meaning. The word “transcendental” means finding the enabling conditions of possibility for meaning to exist in a shared cultural world (Owen, 2009).	0
<i>Naturalistic constitutive phenomenology</i> ; studies how consciousness constitutes or takes things in the world of nature, assuming with the natural attitude that consciousness is part of nature.	Often used for theological research primarily phenomenology of religion and spirituality (Barua, 2008)	All that is, and every property of what is, is natural. There are no abstract entities there is only one kind of thing, namely, things with natural (efficient or material) properties. In turn, all explanations are in the end, causal explanations (Aikin, 2006).	0
<i>Existential phenomenology</i> ; studies concrete human existence, including our experience of free choice or action in concrete situations.	Often used in the humanities and social sciences to explore consumer experiences (Thompson, Locander & Pollio, 1989), feminist experiences (Garko, 1999), psychiatric phenomena (Ratcliffe, 2008), etc.	Although the specific terminology has varied among existentialists, common to all is the insistence that human reality is situated in a concrete world-context. In short, man is only man as a result of his actions which are worked out in the world. But there is still the reciprocal relationship that phenomenology insists on: The total ensemble of human actions--including thoughts, moods, efforts, emotions, and so forth--define the context in which man situates himself. But, in turn, the world-context defines and sets limits to human action (Robbins, 2008).	1
<i>Generative historicist phenomenology</i> ; studies how meaning, as found in our experience, is generated in historical	This type of phenomenology is used, for example, in metaphysics, facticity and interpretation	This type of phenomenology reveals valuable information about the nature, ideology, linguistics, cultural background, author, intent and meaning of	1

processes of collective experience over time.	(Zahavi, Heinämaa & Ruin, 2003) and phenomenology in medical institutions (Tanner, Benner, Chesla & Gordon, 1993).	a actions and experiences, as well as their historical place in human existence, sequentially (Sherfey, 2005).	
<i>Genetic phenomenology</i> ; studies the genesis of meanings of things within one's own stream of experience.	Often used in graph interpretation studies (Roth, Bowen & Masciotra, 2002) to theories of intersubjectivity (Depraz, 2001).	By investigating the development of the ego itself and of the transformation of meaning through time genetic phenomenology, the approach involves a regressive inquiry into the genesis of the ego and of meaning(s) (Donohoe, 1998).	2
<i>Realistic phenomenology</i> ; studies the structure of consciousness and intentionality, assuming it occurs in a real world that is largely external to consciousness and not somehow brought into being by consciousness.	Popular in the study of science, for example, statistical physics (Landau & Binder, 2001) particularly localized supersoft supersymmetry breaking (i.e., Chacko, Fox & Murayama, 2005; Chen, Li, Mayes & Nanopoulos, 2008; Csáki, Hubisz & Lee, 2007)	It is based on the actual experience of “being in the world” and what that means for human experience. Another pillar of this theory is that idealism, since it lacks a genuine account of the real finitude of individual ego fails to account for communication between human beings, as well as an existence of a plurality of minds (Edie, 1989).	0
<i>Hermeneutic phenomenology</i> ; studies interpretive structures of experience, how we understand and engage things around us in our human world, including ourselves and others.	This type of phenomenology is often used in tourism studies (Pernecky & Jamal, 2010), nursing research (Charalambous, 2010; Charalambous, Papadopoulos, & Beadsmoore, 2008), intensive care and hospital research (Storli, Lindseth & Asplund, 2008).	The focus is toward illuminating details and seemingly trivial aspects within experience that may be taken for granted in our lives, with a goal of creating meaning and achieving a sense of understanding (Wilson & Hutchinson, 1991).	3

Hermeneutic phenomenological inquiries emphasize the importance of the individual's participation in his or her own creation (Lavery, 2003). Heidegger (1927/1962) believed that understanding is a basic form of human existence in that understanding not only helps us know the world, but also makes us the way we are (Polkinghorne, 1983). For instance, Koch (1995) emphasized that our cultural and social history informs understandings of one's background or positionality in the world. Historicity, a person's history or background, includes cultural scripts and social influences which impact how an individual understands the world. Cultural scripts determine in part, what is "real." In this way, hermeneutic phenomenological inquiry can facilitate the aim of this thesis as it acknowledges that people and the world are indissolubly related through cultural, social and historical contexts.

Applying a hermeneutic phenomenological approach to this study can help to answer questions about how people with Cerebral Palsy conceptualize (perceive and understand) the script of sexual spontaneity (as a socio-cultural construct), the role that script has in the construction of their sexuality (self-identity) and ultimately how they construct their own sexuality (participation in their own creation) in relation to public, interactional and private schemas. Ultimately, the use of the hermeneutic phenomenological approach within this study is most appropriate as it is most interested in human "creative processes far more than our adherence to laws, be they human, natural, or divine" (Boeree, 2000 p. 72).

Preliminary Conceptual Model

Considering that sexuality and how people with Cerebral Palsy construct their sexuality is influenced by several explicit and implicit factors (as outlined above) a preliminary model for these interactions will be presented (see Figure 1.4). This model aims

to inform and support the hermeneutic phenomenological approach for the collection and analysis of data. As such, this model may then be transformed by the evidence gathered from this thesis.

Figure 1.4 illustrates the overlap of public, interactional and private scripts influence the creation of individual sexuality. The preliminary model above, however, includes specific elements of public, interactional and private scripts which influence constructions of sexuality and sexual identity in people with Cerebral Palsy. This model illustrates that sexual scripts are not directionally influential but are interdependent and constantly informed by factors like history, media, interactive sexual scripts and sexual self-concept(s). While this may be the case for all populations, this thesis is particularly interested in the influence and experiences of disability on individual constructions of sexuality.

This model proposes that the severity of one's disability, through experiences of exclusion, the expectation to experience life like typical others and interactions with parents, family and peers, has an interdependent effect on the influence public, interactional and private scripts have on constructions of sexual scripts and sexuality in people with Cerebral Palsy. Although public and interpersonal scripts influence constructions of sexuality, individual factors imply heterogeneity between people with Cerebral Palsy and their resultant levels of social and/or sexual participation and preferred social and/or sexual activities (social and/or sexual negotiations).

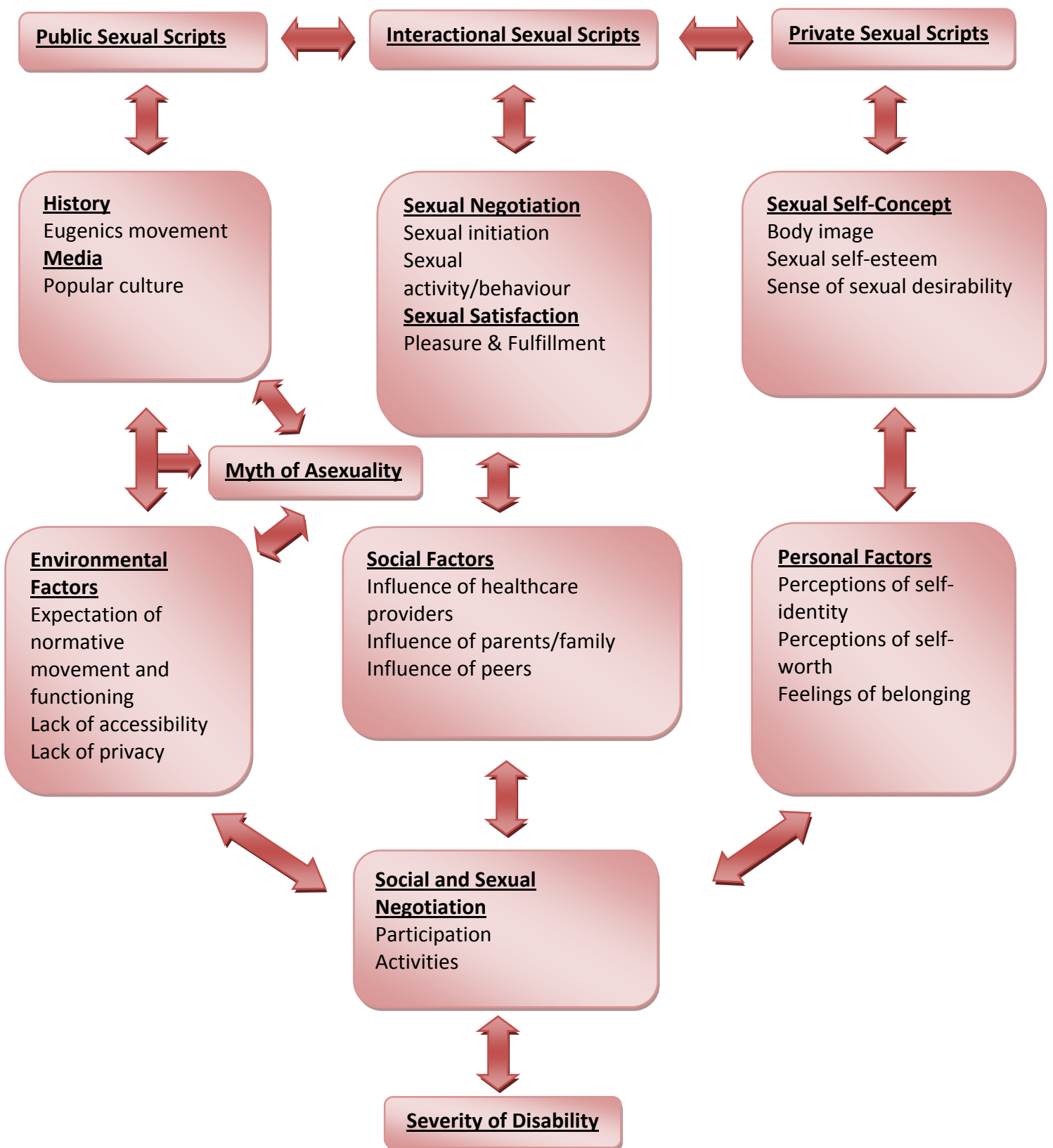


Figure 1.4. Preliminary Model for the Construction of Individual Sexuality in People with Cerebral Palsy

Research Objectives

In light of the sexual constructs and phenomenological approach used in this study this thesis aims to:

- 1.** Use hermeneutic inquiry to collect information from people with Cerebral Palsy about; how they construct the concept of sexual spontaneity, how they construct their individual sexuality and what sexual scripts are prioritized within that construction.
- 2.** Construct a conceptual model of sexuality which takes into account the phenomenological experience of people with Cerebral Palsy.

Research Questions

In order to achieve these aforementioned objectives this thesis adopts a hermeneutic phenomenological approach to explore how people with Cerebral Palsy construct their sexuality based on their conceptualizations and understandings of public, interactional and private sexual scripts.

- 1.** What is the relative salience of sexual schema in the construction of sexuality for people with Cerebral Palsy?
 - 1.1.** What public schema are integral to how people with Cerebral Palsy construct their sexuality?
 - 1.2.** What private schema are integral to how people with Cerebral Palsy construct their sexuality?
 - 1.3.** What interactional schema are integral to how people with Cerebral Palsy construct their sexuality?
 - 1.4.** How do these schema compare in their relative significance?
- 2.** How do people with Cerebral Palsy construct the term sexual spontaneity?

- 2.1. How do people with Cerebral Palsy conceptualize the script of sexual spontaneity in their lives?
 - 2.2. What role does their conceptualization of the script of sexual spontaneity play in how people with Cerebral Palsy construct their sexuality?
3. How do people with Cerebral Palsy describe their sexuality?
 - 3.1. Overall what are the defining characteristics of sexuality in people with Cerebral Palsy?
 - 3.2. How are these constructions influenced by individual circumstances?

Significance

People with Cerebral Palsy may experience their sexuality in atypical ways. Methodologically the exploration of how people with Cerebral Palsy interpret the meanings of sexual scripts and construct their sexuality provides an important phenomenological understanding of how sexuality is constructed and experienced in this population. Practically, discerning the ways in which people with Cerebral Palsy conceptualize sexuality contributes an important building block in understanding the influence sexual expectations have on constructions and conceptualizations of sexual self-concept, activity, intimacy, relationships and satisfaction within this population. As the expression of sexuality is important to health and wellbeing (i.e., Kellett, 1990; Michaels & Johnson, 2008; Pattman, 2005; Schnarch, 2008), findings from this study can provide important information which will further contribute to the construction of a more comprehensive model of sexuality that acknowledges people with physical disabilities as sexual beings and more importantly sexual agents. Theoretically, this thesis aims to contribute information on the relevance of script theory in the exploration of and/or descriptions of individual constructions of sexuality.

Assumptions

This study is framed on a number of assumptions. First, the assumption is made that sexuality is culturally constructed. It is also assumed that sexual scripts influence sexual experiences and individual constructions of one's own sexuality. In addition, it is assumed that people (atypical or otherwise) play an agential role (implicit and/or explicit) in the construction of their own sexuality. As such, the script of sexual spontaneity is conceptualized differently for each person and is therefore experienced differently by different people. It is also assumed that individuals may not value sexual spontaneity in the same way. For certain individuals then, their interpretation and understanding of the script of sexual spontaneity may be very important to their construction of their sexuality while for others this may not be so.

Limitations

Although this thesis aims to provide information about an understudied population it is therefore limited by it. The purpose of this research is to describe or understand sexuality from the participants' point of view. As such participants are the only ones who can legitimately judge the credibility of the results (Trochim, 2006). Resulting data in its raw authenticity can inform further research about people within this population in a unique way. This thesis is limited by its focus on sexual spontaneity versus a broader exploration of sexual expectations in general. However, studying sexual expectations in general (within this thesis) could diffuse information about the effect particularly unsustainable conceptualizations of sexuality have on individual constructions of sexuality.

Definition of Key Terms

Central to this thesis are key terms and concepts which help to inform the basis for this project. Although more and perhaps new concepts and constructs may emerge from the information acquired from people with Cerebral Palsy the description of terms (alphabetically ordered) included here are informed by existing research and literature.

Sexual concept and conceptualization of sexuality. A sexual *concept* is defined here as a word or set of words that expresses a general idea about the nature of human sexuality. For example, the term 'sexual spontaneity' implies a type of sexual activity which does not require thought or planning. Within this thesis a *conceptualization of sexuality* then, is the inventing or contriving of an explanation and formulating it mentally thereby creating a meaning for a human sexuality (experiences, thoughts and behavior). For example, the idea that spontaneous sexual activity is the most gratifying.

Constructions of sexuality. This refers to what individuals perceive as important and/or influential variables in their understanding of their sexuality (Seidman, 2003). This construction and understanding of their sexuality could very well include predefined constructions of sexuality, like sexual orientation, anatomy, gender, culture and ethnicity, which come with their own set of concepts, assumptions, conceptualizations, questions and implications.

Mobility impairment. The term refers to a condition limiting physical ability; generally considered to include lack of a limb or loss of limb use (United States Department of Transportation, 2009).

Physical disability and impairment. As indicated on their website the World Health Organization (2011) indicates that "disabilities is an umbrella term, covering impairments, activity limitations, and participation restrictions. An *impairment* is a problem in body

function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations. Thus *disability* is a complex phenomenon, reflecting an interaction between features of a person's body and features of the society in which he or she lives".

Sexual activity. The term *sexual activity* is oft used and discussed in modern academic literature on sexuality yet it is vaguely defined. This thesis describes sexual activity as the part of human sexual behavior which is aimed at arousing oneself and/or another through various stimuli (i.e. masturbation, coitus, cyber-sex, kissing, phone-sex and hand-holding). Experiences of sexual activity may often involve all, a combination of a few or just one of the human senses; touch, taste, smell, sight and sound.

Sexual agency/agent. *Sexual agency* is the ability to make sexual choices according to one's will, free from coercion. Experiencing oneself as a *sexual agent* means feeling in control of one's sexual decisions and experiences (Pittard & Robertson, 2008).

Sexual being. Although the use of the term *sexual being* in reference to humans has been used across a spectrum of literature a definite description of this term is limited. The term *sexual being* within this thesis refers to an inherent feature of being human characterized by psychological and biological needs, desires, responses, thoughts and feelings which construct an individual's sexuality.

Sexual expectation. According to the Merriam-Webster Dictionary Online (2011) "to expect is to consider reasonable, due or necessary". Expectations then are collective beliefs about how things ought to be (Rapp, 2004). A *sexual expectation* is characterized by behaviours, activities, experiences, feelings and thoughts which are collectively believed to

be imperative to experiencing human sexuality in accordance with social and/or cultural values.

Sexual expression. *Sexual expression* refers to the way in which an individual chooses to express his or her sexual needs, desires, feelings and thoughts through sexual activity and behaviour. The range of sexual expression is limited only by the extent of human creativity (Stanford Sexual Health Peer Resource Center, 2010).

Sexual intimacy. In popular and academic literature which discusses human sexuality the use of the term *sexual intimacy* is rarely accompanied by a comprehensible description of its characteristics. This may be because experiences of intimacy (sexual or otherwise) are quite subjective. Intimacy is often defined as a feeling or atmosphere of closeness and openness towards someone else which does not necessarily involve sexuality (Miller, Perlman & Brehm, 2007). For the purposes of this thesis, *sexual intimacy* is described as a feeling or an atmosphere of closeness and openness resulting from experiences of sexual expression and/or behaviour with oneself or other individual(s).

Sexual negotiation. According to the Merriam-Webster Dictionary (2011) to negotiate refers to the act of conferring with others in order to come to terms or reach an agreement, to arrange or settle something by mutual agreement and to succeed in coping with or getting over something. *Sexual negotiation* then is defined in this project as the process individuals undertake with themselves and others to come to terms or reach an agreement, to arrange or settle the boundaries or terms of sexual behaviour and activity in order to exert expressions of their sexuality.

Sexual relationship. The term *sexual relationship* is not clearly defined in literature about sexuality (possibly due to its relatively subjective nature) but is simply eluded to as an interpersonal relationship which involves, includes or is based on sexual activity and/or

sexual intimacy. Following this definition, this thesis will further include expressions and experiences of sexual activity and intimacy that individuals have with themselves as well as with others as potential characteristics of sexual relationships.

Sexual satisfaction. As defined by Lawrence and Byers (1995) *sexual satisfaction* is “an affective response arising from one’s subjective evaluation of the positive and negative dimensions associated with one’s sexual relationship... and distinguishes satisfaction from purely affective constructs such as happiness and purely evaluative constructs such as success” (p. 268).

Sexual script/schema. A *sexual script* is the way individuals express their sexuality based on cultural, interpersonal and intrapsychic influences which outline how people should sexually interact with others, with whom to interact (socially “appropriate” sexual partners), what sexual activities are socially permitted, where and when these activities can transpire and why it would benefit to act in accordance with these schemes (McVee et al., 2005).

Sexual self-concept. Self-concept is described as individuals' perceptions of themselves in regards to who they are, how they feel and how they act (Vickberg & Deaux, 2005). *Sexual self-concept* as one element of individual self-concept is defined as “an individual's perception of his or her 'qualities' in the sexual domain” (Buzwell & Rosenthal, 1996, p. 490). This perception is “derived from past experience, manifest in current experience, influential in the processing of sexually relevant social information, and gives guidance for sexual behavior” (Andersen & Cyranowski, 1994, p. 1092).

Sexual spontaneity/spontaneous sex. These terms are used interchangeably. They refer to “the expectation that intimate partners can become aroused and initiate sexual activity upon a moment’s notice” ...[and] “sexual behaviour follows desire and arousal (lust)

without a conscious awareness of the process, such that satisfying sex is the result of reflexive bodily impulses and not conscious communication” (Offman, 2007, personal communication).

Sexuality. *Sexuality* is defined here as the means by which people experience and express themselves as sexual beings. Human sexuality is frequently driven by the desire for sexual pleasure and is characterized by the interaction between biological, physical, and emotional aspects. Biologically, human sexuality refers to the reproductive processes and anatomy as well as the basic biological drive that exists in all species. This may encompass sexual intercourse and/or sexual contact, activity and behaviour in all its forms. Emotional aspects deal with the intense emotions relating to sexual acts and associated social bonds, such as intimacy, excitement and love. Physical issues around sexuality range from purely medical considerations to concerns about the physiological (i.e., male erectile dysfunction and vaginismus) or even psychological (i.e. sexual self-concept) and sociological aspects of sexual behaviour.

Summary and Conclusion

Sexuality in people with Cerebral Palsy is not well understood. The myth that sex should be spontaneous and the concept that planning for sex is unsexy is pervasive. This can act as a barrier to sexual intimacy partly due to the expectation that partners do not need to communicate in order to achieve optimum levels of sexual satisfaction. Primarily, people with Cerebral Palsy who may require mobility aids, communication technology and/or personal care assistance may find common conceptualizations of spontaneous sexual activity difficult to achieve. However, whether or not this sexual expectation is as important as modern media presents it to be has not yet been addressed in research literature. Sexual

script theory (Simon & Gagnon, 1986) has the potential to explain the socio-cultural influence the script of spontaneity as experienced by people with physical disabilities.

Barriers to sexual expression that people with Cerebral Palsy experience include asexualizing attitudes towards people with disabilities, lack of social and environmental accessibility and the impact of disability on psycho-sexual well-being. People with Cerebral Palsy and other physical disabilities are at risk for stigmatization and exclusion from social activities and sexual participation. Normative sexual scripts construct people with disabilities as undesirable and asexual (Shuttleworth, 2006). This perspective may make it difficult for people with disabilities to fulfill the requirements of normative functioning, hegemonic sexual expectations and romantic expectations.

Much of the research with people who have Cerebral Palsy focuses on their experiences (or lack there of) of sexuality but has yet to explore how they conceptualize sexuality in general and their sexuality specifically. Part of sexuality, however, also includes conceptualizations of sexual expectations and their role in an individual's sexual expressions and activities. As such, people with Cerebral Palsy may construct their sexual experiences and relationships in ways that are different from traditional sexual expectation(s). This thesis will apply a hermeneutic phenomenological inquiry to test the explanatory value of a preliminary conceptual model on 'constructions of sexuality' from a social (i.e. Bay-Cheng & Lewis, 2006; Seidman, 2003) and cultural (i.e. Attwood, 2009; Few & Stephens, 2009) standpoint which implies that constructions of sexuality are created peripherally and therefore exist outside the parameters and out of the control of the individual.

Ultimately, this chapter expresses that sexual experiences and behaviour are products of human agency as well as constructions of sexuality through public, interactional and private scripts. Determining which social, sexual and cultural factors influence individual

constructions of sexuality serves as a building block towards understanding sexuality as something humans actively engage with and influence rather than simply being influenced by constructions of it.

Chapter 2: A Review of Historical Constructions of Disability and Sexuality

Sexuality and sexual expression is a universal phenomenon. Nonetheless some individuals (i.e., people with disabilities) may not be accepted as full sexual members in the societies in which they live (Rojek, 1995). The exclusion of people perceived as atypical may be due to public misconceptions about the entitlement of sexual rights and sexual inclusion (World Health Organization, 2011). Those who are perceived to be atypical (i.e., some people with Cerebral Palsy or other disabilities) may be perceived as ineligible candidates for sexual activity and expression. However, the assumption that people who have disabilities are not sexual candidates, do not think about or want sex and cannot engage in sexual activities is a myth (Milligan & Neufeldt, 2001). Ultimately, the exclusion of people with disabilities from being acknowledged as sexual beings may influence how sexuality within people with disabilities is constructed. People could be socialized to perceive others with significant disability differently in regard to sexuality. In their self-understanding as sexual beings, people with significant disability may be influenced by prevalent sexual attitudes towards them.

This chapter aims to analyse and discuss literature which provides insight into constructions of disability and sexuality for people with Cerebral Palsy. As little research exists concerning sexuality and Cerebral Palsy an analysis of research in regards to disability and other sexually marginalized groups will inform the discussions about Cerebral Palsy and sexuality in this chapter. As such, this chapter reviews historical constructions of disability and their influence on contemporary understandings of disability and sexuality throughout Antiquity, the Middle Ages, the Early Modern period and the Late Modern period (see Table 2.1).

Table 2.1 Historical Constructions and Implications of Disability and Sexuality Summary

Period and dates (approximate)	Major Milestones	Historical Constructions of Disability		Implications for Sexuality
		Digressions	Progressions	
Antiquity (pre-5th century)	Prehistory	- Disability as punishment for sins	- Disability has always been part of society	As impairment had always been a part of life people with disabilities continued to participate in social and sexual activities. They were also provided with support by their families and communities in order to adapt and integrate.
	Early Biblical Times			
	Ancient Greece and Rome	<ul style="list-style-type: none"> - Disability as a reminder of human “imperfection” - Infanticide - Impairment restricted participation in normative (sex) roles - Impairment used as entertainment 	<ul style="list-style-type: none"> - Support for people with disabilities - Romans laws aimed to support citizens with disabilities - People with disabilities were not segregated from the societies in which they lived. 	
Medieval Times/Middle Ages (5th century – 15th century)	Demonism	<ul style="list-style-type: none"> - People with mental disabilities presumed to be minions of the devil 	<ul style="list-style-type: none"> - People with disabilities receiving psycho-social support within poorer communities 	People with disabilities were considered dangerous and infectious. Through witch hunts and relegation to poverty people with disabilities were segregated from their families and communities and were not allowed to participate in typical social and sexual activities. The use of impairment as a threat to restrict sexual behaviour people with disabilities were presumed to be like a sexually transmitted disease.
	Compassion and Support	<ul style="list-style-type: none"> - Christianity reinforced disability as abhorrent with the threat of impairment as punishment for unmitigated sexual expression - Witch hunts aimed at 	<ul style="list-style-type: none"> - Support provided by the Christians for people with impairments - Differentiating between disabilities - Support for people with 	

	Emergence of Institutionalization	<p>executing people previously thought to be impaired due to divine intervention</p> <ul style="list-style-type: none"> - People with disabilities relegated to poverty - People with disabilities forced to beg for their living - People with disabilities were thought of as a social nuisance - Segregating people with disabilities from the societies they had lived in - Forcing out people with disabilities from their communities through the Poor Law 	<p>disabilities given within communities</p> <ul style="list-style-type: none"> - Disease evened the social playing field - Emergence of institutions to support and accommodate people with disabilities - The beginnings of a “disabled” community - Enabling independence and affluence with the establishment of the Poor Law 	
Early Modern Period (16th century – 19th century)	Poverty and Disability	<ul style="list-style-type: none"> - Formalization of the connection between disability and poverty - Disability as socially and financially inferior - People with disabilities used in workhouses 	<ul style="list-style-type: none"> - Reinforcing social responsibility - Scientific advances in the etiology and variations of disability - The development of treatment programs 	Societies supported people with disabilities. However, efforts to normalize people with disabilities through scientific experimentation constructed them as damaged or as failures. People with disabilities were constructed as inappropriate social and sexual partners.
	Science and Disability			
	Adaptation			

		<ul style="list-style-type: none"> - Dehumanizing people with disabilities through scientific experimentation - People with disabilities as unimportant or disposable - Expectation of the perfect human/body/mind 	<ul style="list-style-type: none"> - Change in understandings about disability and its origins - The provision of adaptive skills - Introduction of education systems 	
Late Modern Period (19th century – 20th century)	Education	<ul style="list-style-type: none"> - Industrial training which exploited people with disabilities - Teachers with disabilities deemed incompetent and unnecessary - Overcrowding institutions - Abuse of people with disabilities - Formalization of the “doctor-knows-best” relationship with disability - Movements towards eradicating disability through eugenics 	<ul style="list-style-type: none"> - Formalized implementation of education programs - People with disabilities being educated based on their needs - Acknowledgement of the importance of “disabled” community - Impairment advocated as a form of social disadvantage - Movements against the inhumane and unequal treatment of people with disabilities 	The formalization of education and advocacy for people with disabilities acknowledged that they could learn if provided with a multidisciplinary and adaptive approach to pedagogy. Disability as human failure persisted as efforts to eradicate disability through sanctions on who could procreate or experience sexuality constructed disability and sexuality and incongruent.
	Overcrowding			
	Eradicating Disability			

Historical Constructions of Disability and Sexuality

Historical understandings of disability have an important influence on contemporary constructions of sexuality for people with disabilities. Throughout history constructions of disability and sexuality have been influenced by many socio-cultural factors such as religion, scientific/medical advances and the economy. For example, many of the world's major religions serve(d) as arbiters of sexuality through the moral systems they promote (Bullough, 1995; Endsjø, 2009; Stopes, 1929). For Instance, many religions have informed legislations which promoted sexual activity within the parameters of marriage between typical others (Eggebeen & Dew, 2009; Maynard, 1993; Stopes, 1929).

The increasing medicalization of disability has also been influential to contemporary constructions of disability and subsequent understandings of sexuality for this group. Historically, the medicalization of disability initially served to segregate people with disabilities from common society and reinforced the stigma of disability by typical others (Hayes & Hannold, 2007).

Through these experiences of segregation, medicalization and stigmatization people with disabilities developed a group identity. For instance, the consolidation of this group identity facilitated activism and promoted the acceptance and acknowledgment of people with disabilities and their entitlement to equal rights in contemporary contexts (Hayes & Hannold, 2007; Shuttleworth, 2007). Economically, perceptions of disability have evolved from that of economic burden to economic integration through attempts to promote equality within societies which are constructed for and by typical others. As such, people with disabilities were afforded more financial and social freedom to pursue employment and therefore social interaction more readily.

Modernization influenced notions of sexuality differently than did historical socio-cultural influences. The following chapter explores historical milestones and addresses socio-cultural influences on understandings of disability and sexuality. This section also highlights historical changes towards the acceptance of (people with) disability up until the 20th century and the historical implications of these changes for (contemporary) constructions of disability and sexuality.

Antiquity

The period from 500BC to 500AD is often referred to as antiquity and is often discussed in tandem with Greek and Roman societies (Neugebauer, 1969). Since the beginning of humanity there has undoubtedly been disability. While disability may not have been defined or understood in the same ways as it is in contemporary contexts, some early ideas and attitudes towards disability resonate in contemporary societies. The following section briefly discusses disability in the context of sexuality from ancient times; how it was dealt with in prehistory, early biblical times and Ancient Greece and Rome. This discussion includes an analysis of constructions on sexuality for people with disabilities.

Prehistory.

Disability and individuals with various impairments have been part of all societies since well before the evolution of humans (Berkson, 1974). Anthropological evidence indicates that some members within prehistoric subhuman primate groups lived with physical impairments well into adulthood (Berkson, 1974). Berkson, whose meta-analysis on research involving children with disabilities noted that many impaired subhuman primates included individuals who had fallen from trees or who had been injured by predators. Through adaptation and the help of others some survived with their injury as they were still able to assist with foraging and could escape from predators (Berkson, 1993).

According to Berkson mother monkeys provide compensatory care which makes up for even severe injuries. In addition, "other members of the primate community may 'baby sit' injured babies, as they do other young of the group ... where predation pressure is low and food is plentiful, handicapped animals may live to be adults" (Berkson, 1993, pp. 5-6). Citing Solecki (1971), Berkson (1993) describes a published description of an adult Neanderthal male who had sustained severe head and arm injuries which were acquired at an early age. To adapt he used his teeth and feet to hold objects. While the case of the Neanderthal may be unique, Berkson also discussed the incidence of chronic impairments and disabling arthritis as common amongst Neanderthals (see also Strauss & Cave, 1957). Berkson (1993) concluded that individuals with both minor and even highly significant impairments were part of primate societies "even before the evolution of modern homo sapiens" (p. 6).

Following Berkson's discussion of disability as a "matter-of-fact" part of primate and early human societies, those with impairments who could adapt or received assistance continued participating in quotidian activities with the rest of their community (Groce & Marks, 2000; Jamieson, 1993). While many of these activities would have included foraging and escaping predators other activities may have included mate-selection and mating. While community members with impairments may not have been selected as primary mates they may still have participated in sexual activity for pleasure and/or social interaction (Dixon, 1998; Gouzoules, 1984). Berkson's discussions about disability in prehistory signify that while impairment may alter social participation impairment does not necessarily exclude an individual from it. However, this has not always been embraced throughout history. While Berkson stated that disability has always been part of humanity what has changed are the socio-cultural factors, like the introduction of formalized religions (Bishop, 1995), which

influenced how disability was treated and the impact these changes have on contemporary constructions of disability and sexuality.

Early biblical history.

In Judaism and Christianity the biblical scripture acts as doctrine for its followers and informs them of how they should live their lives. While Judaic doctrines are primarily based on the Old Testament (the Torah) most Christian denominations use both the Old Testament and New Testament (the Bible) as their primary scripture. Within both Testaments impairments were often assumed to be the result of sin and became the basis for charity or the subject of miracles. As such, early biblical history exemplifies the contention between disability as grounds for pity or penitence.

Charity and protection. Passages within Hebraic scripture which discuss impairment offer insight into the prevailing attitudes about disability during pre-Christian times. For instance, The Old Testament commanded, "Thou shalt not curse the deaf nor put a stumbling block before the blind, nor maketh the blind to wander out of the path" (Leviticus, 19:14). In this passage readers are explicitly instructed against the abuse of people with disabilities. In Daniels' (1997) book on the Benedictine roots of constructions of people with hearing disabilities she argued that this Judaic command in Leviticus was one of the first recorded acknowledgements that people with disabilities should not be subject to abuse and therefore legislated for their protection. While protections were commanded against the abuse of people with disabilities, those who did not heed the Lord's rules were condemned to live their lives with impairment; "all these curses will come upon you and overtake you: the Lord will afflict you with madness, blindness and confusion of mind. At midday, you will grope around like a blind man in the dark" (Deuteronomy, 28:15). These

contradictory passages reflect the competing attitudes and constructions of disability during early Judaic times.

Sin and punishment. At the same time that society acknowledged disability and the need to protect those with impairment, disability was also perceived as a punishment for sins by God. Not only was disability a matter of charity or sin, the implication of these attitudes resulted in paternalism/infantilization and stigmatization of people with disabilities (Bishop, 1995). For example, Daniels asserted that people with physical disabilities were often considered children under Hebrew law and therefore protected much as a child would be. This often involved restrictions on social interactions, perhaps in order to minimize the potential of abuse from others (Anderson, 2006). In doing so however, people who may have been stigmatized due to impairment and therefore excluded from social interactions may not have had the opportunity to mature socially and/or sexually. In this way, being treated as a child and therefore being restricted from participation in adult social settings, people with impairments were denied equal access to social opportunities and the selection of adult (sexual) partners. This social exclusion and stigmatization was also characteristic of impairment as punishment.

Hebrew scripture continues to perpetuate the belief that illness/impairment is inflicted upon an individual or his or her family members by a vengeful deity in response to (non-penitent) sins committed by oneself or one's family members (Rosen, 1968). In this way, the "curse" of impairment could be passed on from mother to child or father to son depending on who God wanted to punish the most (Warkany, 1959). As such, those with disabilities were mentally, physically and spiritually unclean and therefore could not participate in sacred social activities (Anderson, 2006). For instance, The Old Testament informs its readers that "people with disabilities were classified with prostitutes and

menstruating women as unclean and were thereby prohibited from making sacrifices as priests” (Braddock & Parish, 2001, p. 14).

Some people with disabilities were permitted to participate as religious observers only (Stiker, 1999). However, depending on the disability (i.e., leprosy) some patrons were denied access to religious gatherings altogether (Stiker, 1997). As religion was often the basis for social interaction those who were excluded from religious gatherings were further stigmatized by those who they wished to accept them. For instance, the early Christian church, believed that faith came from hearing (Romans, 10:17), and therefore people who were hearing impaired could not be holders of the Christian faith (Daniels, 1997). In this way, being excluded from religious observance or membership constructed disability as the cause of sin, the source of pity and the grounds for stigma. Ultimately, these exclusive attitudes denied some people with disabilities access to social interactions with their peers and therefore the potential to mate. Through penitence one’s only hope of regaining a typical life was a miracle.

Miracles. Scripture from the New Testament indicates that miracles were both an improbable source of redemption and the means for restoring faith in the Lord by witnessing his work. For instance, when Jesus was asked whether a blind man's sin or his parents' sin had caused the man's blindness, Jesus replied that it was neither but rather the disability was a mechanism for "God's work [to be] revealed in him" (John, 9:3; Black 1996, p. 29). As such, the New Testament incorporates the curing of disabilities in order to highlight the power of God. For example, Mark recounts the healing of a blind man when Jesus spat on his hands and laid them upon the eyes of the blind man (Marcus, 1999; Mark, 8:22-26). Mark and Matthew write of the healing of a man with paralysis (Black, 1996; Mark, 2: 1-12; Matthew, 8:5-13).

Furthermore, the New Testament houses a multitude of stories about people with leprosy, epilepsy, mental illness, hearing and visual impairments being healed by Jesus (Black, 1996). These healing tales may be interpreted to mean that people who "have disabilities ... show the power of God" (Black, 1996, p. 29). However, within these stories, the disciples highlighted situations in which the person with a disability or their family sinned or did not repent for their indiscretions (Otieno, 2009). Even though Jesus indicated that the person with a disability was a vessel of/for God's work his followers continued to believe that disability was caused by sin.

This perception of disability as the result of sin often persists in contemporary settings. For instance, when running errands in Ottawa, Ontario, Canada with my friend Alex, who has severe Spastic Quadriplegic Cerebral Palsy, people would spontaneously approach him, put their hand on his shoulder and say; "may God bless you" or simply "God bless you." This experience of unsolicited prayers from others towards people with disabilities may indicate their presumption that impairment was caused by divine damnation which can be diminished through prayer. However, the unlikelihood of miraculously being "cured" of disability or impairment implies that people with disabilities were doomed to the fate of exclusion, stigma, pity and penitence. As such, the perpetuation of disability and its etiology as divine intervention within early Judaic scripture sets the stage for the proliferation of these attitudes and constructions of disability for the societies and civilizations which followed (Loefler, 2003).

Ancient Greece and Rome.

In ancient Greece and Rome life expectancy did not generally exceed 37 years for women and 44 years for men (Engels, 1980; Hayflick, 2000). Lowered life expectancy (in relation to contemporary statistics) for the ancient Romans and Greeks was attributed to

the high incidence of disease, the prevalence of war, paltry prenatal care, starvation or malnutrition and injuries sustained during manual labor (Hope, 2009). In Garland's (1995) book about disability within the Graeco-Roman world he noted that life for people in the ancient world was "nasty, brutish, and short" (p. 11). As such, many of life's day-to-day activities could easily result in early death, sickness or permanent impairment. This was often due to inaccessible, unaffordable or inadequate medical care (Garland, 1995). Considering the high incidence of disability amongst ancient Greeks and Romans several interpretations and constructions of disability evolved.

Greco-Roman beliefs. Much like the followers of Hebraic scripture some ancient Romans and Greeks were led to believe that physical impairment was a punishment for having displeased the gods (Stamm, 2004). For example, babies born with congenital deformities were thought of as signs which indicated that their parents had displeased the gods and were being punished by bearing a child with a disability (Kuriyama, 1998). While this may have been the belief of some Romans and Greeks their local governments often offered support to individuals (and/or their families) whose impairments made participating in employment activities difficult or impossible (Abrams, 2010).

Some people with disabilities who could not engage in physical labor took up an office or a trade which did not involve manual labor (Berkson & Taylor, 2004). In fact, the Roman Emperor Claudius had significant congenital deformities, and Spartans elected Agesilaos, a short-statured man, as their king (Braddock & Parish, 2001). These exceptional cases of people with disabilities in positions of power were reserved for those who were wealthy enough to afford advanced education for their children and were well connected with existing government officials or royalty (Walden, 1909). As such, the majority of Romans and Greeks who lived with a disability were marginalized and excluded from society

and relegated to living in inappropriate accommodation and inadequate economic conditions (Garland, 1995). During a time when one's value was based on the ability to fulfill social expectations, like child-rearing, farming or other manual labor, people with disabilities may have found it difficult to access adaptations which would have allowed them to participate equally in social and financial activities.

Gender issues. According to the Ancient Greeks and Romans people with disabilities were responsible for securing their own livelihood (Hasebroek, 1965). For the average Greek or Roman this may have meant that someone with a disability may not have been chosen or encouraged to mate as the government support they received was not enough to support more than themselves. While the provision of financial support was important to the survival of some ancient Greeks and Romans, for people with disabilities not having access to one's own income may have limited social and sexual options for this group.

While an individual (particularly male) may have a disability he or she may not have been excluded as a viable sexual partner. As long as a man was able to support a wife and children he may not have been disqualified as a sexual partner due to impairment. Ancient Greek and Roman women on the contrary were mostly defined by their ability to bear and rear children (Blundell, 1995; Licht, 2001). Women with disabilities which restricted participation in these activities may not have been chosen as sexual partners or mates. This perhaps was due to the perception that women with disabilities were incapable or improbable mothers. This construction of female sexuality and disability prevails in contemporary societies. Even though medical advances and adaptive technology make child bearing and rearing viable for many women (not just those with disabilities) typical others continue to assume that women with disabilities either cannot or should not procreate (Shaul, Dowling & Laden, 1985; Prilleltensky, 2004). Thus, some parents who bore children

with a disability and feared that they or their child would experience social or economic disadvantage took matters into their own hands (Schidel, 1995).

Infanticide. Infanticide, the killing of an infant, was conducted by some parents soon after they realized they would not be able to cater to the social and economic requirements of rearing a child with a disability (Mackelprang & Salsgiver 1996; Scheerenberger 1983; Woodill & Velche 1995). While this was the case for some parents Garland (1995) noted that the practice of infanticide as a way of dealing with disability was not as prevalent as previously believed. Garland goes on to explain that for ancient Romans and Greeks infanticide was more readily practiced to relieve the economic pressure of having too many children. For most Greaco-Roman family's infanticide was a choice left up to the parents to make. In Sparta however, children born with obvious physical deformities were put to death regardless of a family's economic resources or personal wishes (Stiker, 1997; Warkany, 1959).

Infants with deformities were sometimes perceived to represent the anger of the gods, and murdering such babies was a sacrifice intended to mollify them: "Aberrancy within the species not only threatens the future and continuation of this species, but also announces, threatens, signifies a condemnation by the gods: a condemnation of the group ... an aberrancy within the corporeal order is an aberrancy in the social order" (Stiker, 1997, p. 40). As such, Stiker noted that the death of a child with a disability acknowledged the power of the gods over their subjects. Much like the eugenists of later centuries, the Spartans believed that by removing the presence of disability they had nullified the possibility of proliferation of the impairment thereby purifying the Spartan community.

On the contrary Garland (1995) indicated that some Graeco-Romans, like the Athenians, would have been more inclined to raise their children regardless of number or

impairment. Stiker (1997) noted that while some children with visible physical disabilities were put to death children whose impairments were not visible or detectable at birth or soon after were not categorized as deformed and therefore spared from execution (see also Gaw, 1906). The exception, however, were those children who were perceived to have profoundly limited cognitive abilities and were detected early on. Considering that all children with disabilities may not be symptomatic early on adults with congenital physical or mental impairments were present in ancient Greece and Rome (Stiker, 1997). While the execution of babies with apparent disabilities was practiced those who made it to adulthood were not treated negatively. For instance, in ancient Greek society having a disability did not always signify marginalization or stigmatization (Edwards, 1996).

Ancient Greece. From Edwards' (1996, 1997) review of records from ancient Greece she indicated that disability was not perceived as wholly negative by the ancient Greeks. In addition, she noted that disability was not necessarily associated with economic burden as many people with disabilities were gainfully employed and/or took up an office or government post. For example, men in the Greek army who had a congenital disability or had sustained injuries while on the battlefield were expected to continue with their regimental appointments (Hansen, 1991). In addition, court records indicate that financial support was not given to all people with disabilities as some were deemed able to work within their abilities (Braddock, 2002). As such, people with disabilities in ancient Greece had to prove that they truly were in need of economic assistance due to other factors aside from disability in order to be granted any money (Edwards, 1997).

For those who were deemed unable to work Greek records show the acknowledgment of their need for financial and social support. For example, from the 6th century B.C.E. Athens offered citizens who were unable to work due to their impairments

small amounts of social support for food and living requirements. Furthermore, in support of military veterans the ancient Greek constitution provided medical support and granted pensions to soldiers who had been severely injured in battle (Stiker, 1997). In this way, disability did not equate to pity or charity. Instead people with disabilities were provided with short and long-term support in order to facilitate equality and social inclusion.

Ultimately, ancient Graeco-Roman civilizations had mixed feelings, beliefs, attitudes and constructions of disability which are evident in contemporary understandings of disability. In this way, impairment was not wholly negative or positive but instead people with disabilities were accommodated and supported more often than not. Edwards (1997) concluded that:

The consequences of physical handicaps varied according to the context and to the individual. Without a codified notion of “able-bodied” on one hand and “disabled” on the other, people were not automatically assigned to one category or the other on the basis of medical diagnosis or appearance...We see very few instances in which people with physical handicaps were banned a priori from certain roles ... people with disabilities in Greek society were integral to the society. There is no indication that people with physical handicaps in the ancient Greek world identified themselves or were identified as a distinct minority group. (p. 43-44)

A similar arrangement is noted in Ancient Rome.

Ancient Rome. Indications of the integration of disability as seen in Ancient Greece were also evident in Ancient Rome. Ancient Roman historical and literary accounts indicate that some people with disabilities used prosthetic devices after having sustained injury during battle or had limb deformations due to congenital disabilities (Bliquez, 1983). For

instance, the ancient Greek historian Herodotus recounted a Roman warrior in 479 B.C.E. who had amputated his own foot after freeing himself from executioner's shackles. Herodotus stated that the warrior continued to fight in battles with the help of a wooden foot (Beloe, 1831). In a tomb dating to 300 B.C.E., a skeleton was found with an artificial lower right leg (Albrecht, Seelman & Bury, 2001). This prosthesis was made of bronze, indicating that its owner was a person of some wealth.

These examples may serve as indications that ancient Roman society facilitated adaptation in order to support people with disabilities and to promote equal participation. In doing so those with prosthesis could "pass" as a typical other and reduce the potential of marginalization influenced by lack of access or others' perceptions about disability. In this way, people with acquired physical impairments were able to continue their daily tasks and social/sexual roles. However, those who could not adapt may have found themselves without an income, due to the inability to work, and without their families (Wilson, 2006). As women and children were passed on to their husband's closest male relative, in the event of his death, a man's wife and children may have become his brother or uncle's responsibility in the event of severe impairment.

Ancient Roman law. In order to delineate which rights people with disabilities were entitled to Roman law in the 6th century A.C.E. used the Justinian Code. This code was based on the detailed classification of people with disabilities and their rights in relation to different types and degrees of disability (Howe, 1983; McGuinley, 1927). For instance, some people with physical disabilities, like people with hearing impairments who spoke, were treated as adults and therefore given the same rights as other Romans (McGuinley, 1927). In addition, early Roman law protected the property rights of some people with disabilities whether they had acquired the property through inheritance or purchased it outright

(Berkson & Taylor, 2006). Roman law also permitted marriage for some people with disabilities with the exception of those with mental impairment (Berkson & Taylor, 2006).

These regulations often inhibited equality for people classified as mentally disabled. For example, people with hearing impairments who did not speak were categorized as mentally disabled and therefore forbidden to perform any legal acts (Gaw, 1906a, 1906b, 1907; Hodgson, 1953). As such, individuals who were deemed as intellectually deficient in early Roman times were designated guardians to assist them with the management of their affairs (Braddock & Parish, 2001). This paternalistic approach to disability may have included the restriction of activities in order to ensure that those with certain disabilities were “protected”. In doing so however, those individuals may have been excluded from participating in adult activities and were denied adult relationships and sexual expression. As marriage was advocated as the basis for procreation (Treggiari, 1993) people with disabilities who were denied the right to marry were sanctioned from procreating for fear that their impairment may be passed on to their offspring. While ancient Roman law sought to facilitate equality and support for its constituents with disabilities those people with disabilities who were not deemed to be legal equals by Roman law did not experience social and sexual equality or freedom.

Disability and ridicule. In ancient Rome equality and freedom for people with disabilities was marred by the incidence of ridicule. For the entertainment of wealthy men within the ancient Roman Empire slaves who had dwarfism or were atypically short-statured and those with intellectual disabilities were “kept” (Willeford, 1969). This practice was exemplified in many ancient civilizations as it was believed that “keeping” such individuals was good luck. For instance, it is estimated that the presence of courts jesters dates back to Egyptian pharaohs of the Fifth Dynasty who kept short-statured slaves within their courts

instead of with their other slaves (Welsford, 1935). In addition, ancient Chinese and American civilizations (before the times of Columbus) kept short-statured people as court jesters (Willeford, 1969). As short-statured people may experience difficulty with normative limb function their movements may seem exaggerated or animated (Boneh, Glick, Gutman & Mogle, 1996). As such, when asked to dance or lead a procession people in ancient civilizations may have found it humorous that their mannerisms were different to their own. While short-statured slaves may have experienced a more comfortable existence within the court, in relation to their typical counterparts (who were largely excluded from activities of the court), they were perceived to be novelties and not people.

The interpretation of disability as humorous continues to trivialize and exacerbate barriers to equal participation, respectful treatment and dignified employment opportunities for people with disabilities. From court jesters in ancient times, the specimens of freak shows throughout the Middle Ages and the focus of some fetish pornography in the 21st century the use of impairment as a source of entertainment seems consistent throughout history.

Middle Ages

As disability was poorly understood during prehistoric and ancient times some people with disabilities were dehumanized. With the fall of the Roman Empire and the increasing influence of Christianity biblical interpretations of disability, its etiology and how to deal with it were informed by religious ideology (Le Goff, 1988). During medieval times (5th to 15th century) this was characterized by the belief that people with disabilities, particularly those with mental illness or impairment, were minions of the devil who needed to be exorcised or destroyed (Cohen, 1995; Throop & Hyams, 2010). As some impairments, which were inadequately addressed progressed social support structures failed to provide

families with the means to assist members with disabilities (Braddock, 2002). With the urging of the Church people with disabilities were formally institutionalized (Braddock, 2002).

During the Middle Ages it was thought that institutionalization of people with disabilities would decrease the incidence of impairment in society. Institutionalization of people with disabilities also would provide the number of “cases” needed in order to gain a better understanding of disability and how it should be dealt with (Woodill & Velche, 1995). In relation to constructions of disability and their implications for sexuality for people with disabilities this section will discuss; disability as a manifestation of the devil (demonism), the implementation of support systems for people with disabilities and finally the move toward the institutionalization of atypical individuals.

Demonism.

During the Medieval period many disabilities were thought to have demonic or supernatural origins (Alexander & Selesnick, 1964). The common belief that people with mental illnesses or disabilities were possessed by demons led to religiously focused attempts to exorcise them (Hail, 1934; Neaman, 1978). These attempts to cure people with disabilities through religious exorcisms supported the Church, God and pagan magic as omnipresent (Moreira-Almeida, Neto & Koenig, 2006). Like early Judaic scripture medieval Church congregations were expected to believe that religion, God or supernatural forces controlled all earthly experiences including disability (Platt & Diamond, 1965). For example, Catholic doctrines in the Middle Ages tightened connections between sexual expression, procreation and marriage. As such, the Catholic Church campaigned against all extramarital and non-procreative expressions of sexuality.

Medieval Christian attitudes to disability and sexuality. During the Middle Ages Christianity controlled even the most intimate aspects of life. For instance, parents were warned against the risks of copulating on holy days. If people did have sex on these days they were informed that children with impairments would be conceived as a result (Metzler, 2006). For example, having sex on Sundays, saint's days and during Lent would result in hereditary congenital disabilities (Metzler, 2011).

If an individual did engage in illegitimate sexual intercourse, Judaic scripture indicates that parents may have been punished by conceiving a child with physical or mental impairment. In 13th century France, Christian priests proclaimed that children conceived from illicit sex would be born humpbacked, crippled or deformed in some way (Freedman, 1999). In addition, those children born with impairment were sanctioned from themselves "taking root" and procreating (Metzler, 2006). In this way, the child's parents, the sinners, were further punished by not being able to leave their legacy through descendants. However, Judaic scripture or ancient anatomist's and biologist's logs do not indicate that impairment could be conceived during hetero-normative sexual activities within a legitimate marriage if partners engaged in coitus during specific times of the year or on "holy" dates. As such, medieval scholars believe that many of the rules enforced upon sexuality were purely based on medieval interpretations of the Bible (Metzler, 2011). The threat of disability as a punishment for illegitimate sexual relations or disregarding Church rules perpetuated the belief that disability (and sexuality) was dirty, vile, infectious and monstrous.

In addition to abstaining from sexual intercourse outside of marriage or on holy dates the Church sanctioned sexual activities during pregnancy, menstruation or when breastfeeding. For instance, Robert of Flamborough (1213), author of a penitential (a book

of Church rules concerning the Christian sacrament of penance), warned that children conceived during pregnancy (now considered highly improbable), menstruation, and before a previous child was weaned, would be lame, leprous, given to seizures, deformed or short-lived (Kieckhefer, 2000).

By restricting sexuality to procreation, thereby constructing sexual pleasure as primitive and disgusting Christian doctrines used the threat of disability to ensure compliance from parishioners. In the 13th century for example, von Regensburg insisted that physical impairments such as hearing impairment, “meanspiritedness,” and demonic possession (mental illness) would be the result if parents engaged in coitus during the forbidden times or within the 6 week period after giving birth (another naturally contraceptive time) (Caciola, 2003). It was also feared that babies would be born with leprosy, lunacy or demonic possession. Propagating the idea that disability was the result of punishment due to sexual indiscretions relegated (positive) experiences of both impairment and sexuality to marginalized status. Of all the punishments however, demonic possession (mental disability) was soon considered the worst punishment as its manifestations and etiology were very unpredictable.

Mental illness and witch-hunting. During the Middle Ages people with disabilities came to signify failure and sin. As Christianity monopolized Europe around the 1450’s the Church insisted that people with mental disabilities were not simply possessed by the devil but were in fact his minions. As such, people who were presumed to be supernatural in some way were classified as witches and subsequently executed (Russell, 1986). Although the Catholic Church led the wave of persecution Protestant European countries also followed (Kemp & Williams, 1987). In the process people whose impairments were not

amenable to medieval treatments, particularly those with mental illness were tortured, imprisoned and executed as they were believed to be minions of the devil (Winzer, 1993).

In colonial New England, for instance, people with mental illness and/or disability were persecuted for witchcraft during the Middle Ages (Szasz, 1961; Szasz 1997). Erikson (1966) noted that the confusion between witchcraft and mental illness was the result of fear and a lack of education about hallucinations and other atypical neurological behavior. As such, the power that was associated with witchcraft and people with mental illness who saw or heard things that others perceived as nonexistent created fear based on ignorance. In this way, people with mental illness were sent off to prisons or killed as a way to remove them from interacting with common society.

The medieval construction of mental illness as the breeding place for evil resonates in contemporary societies (Chadha, 2008). For example, in Chadha's review of Canadian Immigration Law from the 19th to 20th century, she stated that people with mental illness were refused admission and residency in Canada as a means to reduce "social evils" (Chadha, 2008, p. 3). Fear that people with mental disabilities would pollute society and possibly the gene pool reinforced the presumption that people with mental disabilities were not viable sexual partners or mates. The exclusion and intolerance of people with mental illness demonstrates a misunderstanding of disability which continued throughout the ages.

Physical disability and poverty. Physical disability however, was not treated as poorly as mental disability. According to Stiker (1999) people with physical disabilities blended into medieval society. It has been noted that children with congenital disabilities existed in wealthy families (Metzler, 2006). As there is little research about people with physical disabilities in Medieval times Stiker concluded that they may have lived amongst the poorer communities. This may have been due to limited access to employment or

structural adaptations (Mollat, 1986). The incidence of people with physical disabilities living in poorer communities may have also been influenced by negative perceptions about mating with someone with a disability and the fear of passing the impairment on to future generations (Brundage, 1990).

As the Catholic Church did not condone abortion or infanticide people with physical disabilities were accepted as a message from God and were to be treated respectfully (Stiker, 1999). For instance St. Augustine advocated that physical anomalies were the way of God and contributed to necessary social diversity (Evans, 1991; Finucane, 1995). In this way, people with disabilities received familial and social support within whatever echelon of society they belonged. As such, people with physical impairments were integrated into the societies in which they lived and may therefore been more likely to experience social and sexual freedom.

Compassion and support.

Experiences of social and financial support were not only given to people with physical impairments but also to some people with mental impairments. As such, the commonplace belief that disability was due to demonic possession was not universally held (Kroll, 1973; Neugebauer, 1979; Rosen, 1968). For instance, in Kroll's (1973) discussion of psychopathology in the Middle Ages, he indicated that the medical texts from medieval times did not include discussions of demonology. Kroll also stated that during the Middle Ages some medical practitioners actively sought to discover and understand the natural causes of mental illness. In this way, understandings of disability in the Middle Ages were comprised of a complex landscape of religious, medical and social ideologies.

Financial support. Some people with mental disabilities were protected and supported by their families and communities. For example, some families who believed that

disability was due to God's will came together to organize and fund pilgrimages to distant religious sites in order to pray, repent and seek divine intervention (Rosen, 1968). In the records from the canonization of St. Louis people with disabilities during the late 13th century went to his tomb in search of cures for their impediments (Finucane, 1975). People with disabilities sought divine intervention in order to live as typical others and provide for themselves. Even without divine intervention people with disabilities survived via the support of family members, neighbors, employers and charity (Farmer, 1998). Albeit charity or charitable institutions were often the least supportive as they did not provide sufficient short or long term assistance (Cohen, 2005). However, charitable institutions would often provide basic medical attention after injury until the patient was just well enough to start begging for alms on the street.

Seeking alms. While small scale efforts were made to support people with disabilities without government or community support malnutrition and infectious disease took over (Chakrabarti, 2006). In addition, not receiving financial support or not being able to work meant that some adults with disabilities who still lived with their families were often perceived as burdens (Cusack, 1997; Guerra, 2006). In order to offset the inability to find employment some people with disabilities resorted to begging (Eyler, 2010). As such, begging for people with disabilities was more likely related to difficulty securing adequate employment or finances rather than having a disability in itself.

Without a steady income or employment people with disabilities may not have married. Considering the high costs of raising a family beggars (with disabilities or otherwise) may not have been viable options for potential mates. In this way, people with disabilities may have been excluded from formalized or sacramental experiences of adult relationships and intimacy. While poverty or begging may be constructed negatively in

contemporary societies people during the Early Middle Ages believed that poverty was part of the natural social order (Dyer, 1989; Foucault, 1991). As such, the poor and disabled were perceived as opportunities for wealthier community members to provide charity (Spierenburg, 1984). However, the perception that poverty was a means by which wealthy citizens could demonstrate their piety may have been the roots of paternalistic behaviour towards people in lower socio-economic brackets, particularly those with disabilities. While almsgiving facilitated survival for some people during the Middle Ages it did not give people the opportunity to move up the socio-economic ladder. There were times during the Middle Ages however, when disease and impairment somewhat equalized the social playing field.

Disease and disability. Stiker (1997) argued that the wide-reaching effects of the plagues significantly de-emphasized difference and disability during the Middle Ages. As such, people with disabilities relied on networks of community support in order to survive during a time that was unforgiving. Consequently, people with disabilities were accepted and integrated into poorer communities as they shared the same hardships (Quigley, 1998). Those, people with disabilities who were integrated may have encountered less stigma and more equality which may have afforded them more access to social interaction and sexual opportunities. Not all people with disabilities however, were as fortunate. Those people with disabilities who had been abandoned or could not be cared for by their family, those who did not have any means of financial stability and those people with disabilities who were not receiving adequate treatment were institutionalized.

Emergence of institutionalization.

The institutionalization of people with disabilities is said to have begun in Arab nations prior to the Middle Ages (Bhatty, Moten, Tawakkul & Amer, 2009). For instance, asylums for people with mental disabilities had been established by the Arabs in Baghdad,

Morocco, and Cairo in the 8th century and subsequently in Damascus and Aleppo in 1270 (Alexander & Selesnick, 1964). Finally institutions for people with disabilities were introduced in Europe and the Americas during the Middle Ages. As the Arabs believed that disability, particularly mental disability, was divine and not demonic early facilities and care staff who catered to people with disabilities were accommodating and benevolent (Bhatty, Moten, Tawakkul, & Amer, 2009).

Institutionalization in Europe. In Europe some of the first institutions for people with disabilities became the longest lasting. For instance, In England, the Priory of St. Mary's of Bethlehem was founded in 1247 in London with the explicit purpose of supporting people with disabilities through the collection of alms (MacDonald, 1981). As families found it difficult to provide care and support for family members with disabilities institutions like St. Mary's of Bethlehem began supporting both the physically and mentally ill in the 1330's (Underwood, 1953). With the impetus of the Catholic Church families were encouraged to institutionalize members whose impairments could no longer be accommodated socially or financially. While institutionalization separated people with disabilities from their families and communities institutions provided much needed support and care for people with disabilities. As such, institutions often had more occupants than they could accommodate.

By 1403 many institutions aimed at the rehabilitation or the stabilization of disabilities could no longer accept people with physical disabilities as it was believed that they were capable of contributing to their families and their families were capable of supporting them (Drimmer, 1993). Following the end of the 14th century people with mental disabilities became the primary focus of formalized institutions for people with disabilities but "it was nearly a hundred years later before there is evidence that London's magistrates thought that only the mad should be admitted" (Andrews, 1997, p. 90).

During the Middle Ages however institutionalization was not perceived negatively. Instead it was considered a useful social and financial resource. In this regard, impairment and institutionalization did not encounter the same level of stigma as it does in some contemporary ideologies of disability. Instead institutionalization in the Middle Ages allowed people with disabilities to interact with people who were like themselves. In doing so, people with disabilities may have been more likely to experience adult social and sexual interaction without fear of marginalization due to impairment. In this way, people with disabilities who were institutionalized may have had better access to socio-sexual development opportunities.

The institutionalization of mental impairment. Due to the lack of specialized institutions for the care of people with disabilities, (particularly mental disabilities) during medieval times, some continued to be a common fixture within communities (Wright & Digby, 1996). However, as people perceived that having less people with mental illness (in particular) “improved” the community purpose-built institutions were erected (Braddock & Parish, 2001). Asylums then opened in Barcelona (1412), Spain in Zaragoza (1425), Seville (1436), Valladolid (1436), Palma Majorca (1456), Toledo (1480), and Granada (1527) (Bassoe 1945). For communities who received limited government funding psychiatric wards were built onto or designated within hospitals (Rosen, 1968). For instance, in 1326 a “madhouse” was built onto part of the George hospital in Germany (Braddock & Parish, 2001). In 1385 a “madhut” was constructed within the Grosse Hospital in Erfurt, Germany (Braddock & Parish, 2001). As some found the institutionalization of people with mental disabilities was beneficial to society this line of thinking may be the seed from which contemporary exclusive behaviour towards people with mental disabilities grew. While institutions during

the Middle Ages became popular for the care and confinement of people with mental illness people with physical disabilities were not fully excluded from commission.

Institutionalization of physical impairments. As disease and plague were rampant during the Middle Ages it was common for people to acquire disabilities due to illness and lack of adequate medical treatment (Thorndike, 1928; Winston-Allen, 2005). In his efforts to reduce the spread of leprosy de Souza-Araujo (1937, 1946, 1948) discussed the extensive damage caused by leprosy as it swept through Portugal, Spain, France, Holland, and Africa through to Brazil and North America in the 15th century. Without sufficient resources to treat illnesses or stabilize physically disabling infections people were quarantined (Bloch, 1992; MacDonald, 2005). For example, when Hansen's disease (also known as leprosy) was on the rise during the 12th century institutions for the quarantine of people affected by the disease emerged (MacArthur, 1953). Howard (1789), who chronicled the treatment of the ill and the unsanitary situations in which people lived during the Middle Ages, observed that due to limitations for the treatment of leprosy and the contagious nature of the disease numerous leprosariums run by religious groups emerged across Europe (Kipp, 1994). As fewer people contracted leprosy due to the removal of community member who were infected communities began funding confinement more avidly (Bloch, 1992).

In this way, removing people who were presumed to be social, financial or health burdens became the primary solution to illness and impairment. As such, the quarantine of people with physical illnesses marked the beginning of segregated confinement for people with physical disabilities and those with mental disabilities. While formalized institutions for other physical disabilities were few and far between support for the isolation and removal of people with disabilities in medieval times grew (Blanchard, 2001; Drimmer, 1992; Thayer & Rice, 1990). As leprosy began to disappear by the 16th century (Weymouth, 1938) the

majority of privately owned leprosariums were converted into care facilities for people with mental illness or hospitals which accommodated people with various disabilities (Alexander & Selesnick, 1964). Throughout the lack of systematic efforts to support people with disabilities or develop ways in which society could adapt people with disabilities became a social problem (Allderidge, 1979; Jelliffe, 1930). In doing so, communities no longer had to challenge negative perceptions and assumptions about disability in an attempt to facilitate tolerance and integration. As such, anyone presumed to be different was encouraged to receive institutional care or custody.

Empowering people with disabilities. For some people with physical disabilities who were refused admittance to institutions, could not be supported by their families or could not secure gainful employment, guilds and brotherhoods were organized (Ruesch & Brodsky, 1968). These guilds were often run by the Catholic Church and would house people with disabilities in the evening whilst encouraging them to go out for alms during the day (Garvia, 1996). For instance, the Brotherhood of the Blind Beggars organized in the 14th century addressed issues of competition and conflict between beggars through the provision of equal accommodations by the Church (Covey 1998; French 1932). In Italy during the 14th century blind beggars guilds regulated begging times and places as well as organized pensions for elderly beggars (Covey, 2001; Gowman, 1957).

Through the organization of guilds people with disabilities formulated a sense of belonging and group identity. In this way, some medieval institutional frameworks served as opportunities for people with disabilities to find support, understanding and advocacy. From these experiences of empowerment and relationship building people with disabilities may have had a better chance at securing financial independence and possibly the provisions necessary to secure a spouse and support dependants. Hence, this particular construction of

disability in the medieval context facilitated independence, acknowledgment and social connectedness.

Changing the rules. With the Reformation of Christianity the Catholic Church lost its power and also lost their philanthropic ventures by the 17th century (Braddoch & Parish, 2001). This meant that many of the institutions built for people with mental and physical illnesses owned by the Church were seized and/or decommissioned by the government (Banner, 1973). With the demise of the Catholic influence on charity, "little of the medieval fabric of hospices, almshouses and refuges" was left for care of "unfortunates" (Porter, 1987, p. 121). With the closure of asylums and philanthropic pursuits, people with disabilities were turned back to the communities from which they came resulting in an increase of begging (Sinha, 1971). In response to the increase of people with disabilities on the street Britain passed the Elizabethan Poor Law in 1601 (Covey 1998). The Elizabethan Poor Law divided those experiencing poverty into categories and distinguished what level of support or assistance the government would provide:

- The "impotent" poor (people who were unable to work) were to be cared for in an almshouse or poorhouse. The law offered relief to people who were unable to work: mainly those who were "lame, impotent, old, blind" (Townsend, 1788).
- The "able-bodied" poor were to be set to work in a House of Industry (factories). Materials were to be provided for the poor to be set to work (Townsend, 1788).
- The "idle" poor and "vagrants" were to be sent to a House of Correction or even prison (Laybourn, 1995).
- Pauper children were to become "apprentices" to trades people (Poynter, 1960).

Similar laws were also passed all over Europe (Foucault, 1965). In this way, people with disabilities were not left to commit crime or beg. Instead they were provided with opportunities for self-reliance and stability. In this regard, impairment was acknowledged as a factor which contributed to financial disadvantage and social marginalization. Through the passing of laws aimed at protecting people who were disadvantaged, as well as providing them with opportunities for independence, medieval societies formally acknowledged the relationship between impairment, social stigma and disability. This framework of social support would later inform contemporary constructions of poverty, disability and disadvantage.

Early Modern Era

During the Early Modern period (1500 – 1800) disability as influenced by impairment, poverty and disadvantage became an important social issue. In response notable efforts towards better systems of support for dealing with impairment and understanding the etiology and treatments for certain illnesses were made. In this regard, the following section discusses constructions of disability in relation to poverty, science and the focus on adaptation throughout the Early Modern period.

Poverty and disability.

A primary contributor to contemporary constructions of people with disabilities and ultimately their “place” in society was the change in attitude to poverty and/or low economic status during the 13th to 17th centuries (Allen, 2004). Up until the 13th century poverty had been associated with Jesus and a life of simplicity in Christian European countries (Alexander & Selesnick, 1964). Societies therefore believed that those who were poor gave people with money an opportunity to appease God through almsgiving (Spierenburg, 1984). With the change in ideology about poverty from blessed to

burdensome from the 13th century came stigmatization for those whose primary income was begging. By the 16th century the Poor Law meant that people who did not have gainful employment due to illness, disability or who were disadvantaged due to circumstance were ostracized and deemed suspect (Jutte, 1994). As the poor were no longer being provided with alms from wealthier society members they began stealing for money or food (Menning, 2000). This transformation to the experience and perception of poverty resulted in the development of incarcerating facilities to deal with the increase of criminality from members of poorer populations (Spierenburg, 1984). As large numbers of people who were poor were imprisoned European societies began to acknowledge that the provision of support would facilitate independence and lawful behaviour (Jutte, 2000).

Support. With the passing of the Poor Law of 1601 in England many people with disabilities or who were impoverished were prohibited from begging or living on the street and encouraged to acquire productive occupations (Slack, 1995). Outsiders however, were not extended the same courtesy. In colonial America for instance, migrants who were likely to become a public charge would be "warned out" of town, with the threat of a public whipping for not leaving. However, community members who were poor and/or had a disability did receive public support. For example, following the Poor Law, the Pennsylvania colony provisioned for the maintenance of a people with mental disabilities which dates back to the 1600s. The Poor Law provided "a small Levy be Laid to pay for the buildings of ye house and the maintaining of ye said madman according to the laws of ye government" (Morton, 1897, p. 4). Although support was provided to some individuals the perception that people who needed financial and social assistance were social burdens prevailed.

Furthermore, the Poor Law delegated responsibility for the poor and those unable to provide for themselves. For instance, adults who were unable to secure employment were

to be taken care of by family members (Melling, Forsythe & Adair, 1999). If an individual's family was unable to provide support or if they did not have any relatives, local communities were charged with providing social and financial support (Rushton, 1988, 1996). As such, "competent sums of money for and towards the necessary relief of the lame, impotent, old, blind, and such other among them" were to be set aside by the local community (Elizabeth, 1601 as cited in Axinn & Levin 1982, p. 10).

With fewer people on the street, less reliance on charity and more productivity the English Poor Law facilitated a means for the disadvantaged to re/establish independence (Rushton, 1988). In doing so, the Poor Law became the basis for social/financial support systems worldwide (Botelho, 2004; Clark, 2003). For example, the Poor Law was implemented within American colonies for Caucasian settlers during the 17th and 18th century in order to make communities more accountable for their members with disabilities who were unable to support themselves (Axinn & Levin, 1982). In this way, communities seemed to acknowledge that while impairment and poverty had become social issues it was their responsibility to provide the support disadvantaged individuals needed in order to integrate and adapt to the societies from which they came.

Reinforcing social responsibility. As some people acquired physical impairments in service to their countries financial and social support was provided. For example, in the United States the Veterans of the Revolutionary War were of the first people with disabilities to receive a pension which compensated for war related disabilities in the late 1700's. By the end of the 18th century the Continental Congress adopted the first national pension law. In doing so, the stigma of impairment as an identifier of poverty and uselessness for war veterans was viewed with compassion and understood as a sacrifice for the United States; "permit not him, who, in the pride and vigor of youth, wasted his health

and shed his blood in freedom's cause, with desponding heart and palsied limbs to totter from door to door, bowing his yet untamed son!, to meet the frozen bosom of reluctant charity” (Obermann, 1968, p. 137).

As such, people with acquired physical disabilities were met with compassion and charity whilst people with congenital or mental disabilities were often treated like social burdens. This differential treatment contributes to negative constructions of disability for both groups. While acquired disability may not be considered a social burden it is often met with pity and sympathy. Congenital and mental disabilities are often treated as something which is best hidden as much as possible. These efforts to hide disability contribute to the bio-psycho-social expectation and challenge for atypical people to pass as typical.

In 1793 the Commonwealth of Kentucky passed legislation which ensured that communities were financially responsible for families who were too poor to continue caring for kin with mental illness or intellectual disability (Estabrook, 1928). This pension system continued throughout the nineteenth century and was still in existence in 1928. “Bidding out” was another American response to the financial difficulties some families experienced in efforts to care for members with disabilities. Through the process of “bidding out” an individual with a disability was auctioned off to the lowest bidder who would then receive the bid amount to provide care for a year. This practice of "bidding out" was administered until the 1820s, when it was perceived as too expensive to maintain (Breckinridge, 1939). Ultimately, some physicians and politicians felt that these provisions encouraged idleness amongst people with disabilities who they believed would be better cared for in formalized institutions (Estabrook, 1928).

Social and economic inferiority. While welfare systems were integral to the survival of some individuals the provision of social and financial assistance became irreversibly

linked with social stigmatization and financial disadvantage (Spicker, 1984). This was due to perceptions of people who received social and financial assistance as inferior and incompetent (Fairchild, 2007). Cavallo (1998) asserted that social and financial support during the Early Modern period "was usually within the context of structures likely to produce a sense of social stigma and alienation" (p. 91). Through the process of segregation disadvantaged individuals (i.e., those with disabilities and no to low income) were excluded from typical experiences of human interaction. Instead these individuals were dealt with much like children or animals. Thus, without financial independence disadvantaged individuals were denied social independence.

In order to maintain the impression of societal affluence many European societies removed disadvantaged people from the streets and into poorhouses and/or hospitals (Albrecht, Seelman & Bury, 2001). In 15th century Italy for instance, large numbers of people who were shunned from the streets were sheltered at poorhouses or hospitals (Gavitt, 1990). Based on the European model of institutionalization some states in America began developing almshouses which catered to a heterogeneous population of "invalids" who were unable to contribute to their own care. In Boston in 1662, for instance, the first documented almshouse in the United States was established and accommodated people with physical and mental disabilities as well as the poor, the elderly and orphaned (Rothman, 1990). People who were admitted to hospitals or almshouses were perceived as lazy and/or socially inferior due to their inability to successfully integrate into society (Jutte, 1981).

The exception to this experience of stigmatization where people who had intellectual disabilities (Braddock & Parish, 2001). For example, British administrative records from the 17th century indicate that people with intellectual disabilities were

unquestionably supported by the Poor Law (Fabrega Jr., 1991). However, the relatively well organized social and financial support system which assisted people with mental disabilities during the Early Modern period was not extended to people with mental illness (Rushton, 1996). In his examination of welfare records from the Early Modern period Rushton (1996) explained that while the majority of people with mental and physical disabilities were supported by their families or community people with mental illness continued to be incarcerated in jails or corrective facilities.

This method of dealing with mental illness was based on the misconception that individuals in this group were possessed by demons and therefore inherently evil. This construction of mental illness continues to stigmatize people with mental disability in modern times. For instance, criminals are often alluded to as mentally ill or disturbed by sensationalist media outlets (Byrne, 2000; Corrigan & Watson, 2002). In this way, mental illness, criminality and incarceration are presumed as correlative. As such, people with mental illness were thought to be dangerous and subsequently locked away.

Exploiting people with disabilities. People with disabilities who were able to contribute to their own income or care for themselves were removed from the general workforce and placed in workhouses. Soon after the first workhouse was established in Bristol, England in 1697 workhouses became a staple of Early Modern Europe (Gestrich, King & Raphael, 2006). In this way, people with mental and physical disabilities were segregated from the typical population thereby further contributing to their stigmatization. While people with disabilities experienced disadvantage and exploitation due to segregation, their placement in workhouses facilitated a sense of commonality and community. Due to the efficacy of the workhouses acquisition of cheap labor, segregation of the disabled

population and the ability to facilitate a sense of usefulness amongst workers workhouses spread across Europe until the beginning of the 19th century (Foucault, 1965).

While disability and disadvantage were being accommodated through institutionalization and the provision of small social and financial assistance many questions about how to understand disability remained unanswered. For instance, from where did impairment truly originate? In order to answer this question as well as understand the effect of impairment or illness on the human body Early Modern scholars, scientists and physicians aimed to explore and experiment with the human body.

Science and disability.

During the 14th through 16th century explorations of the human body was of great interest to scholars, artists, scientists, physicians and theologians (Metzler, 2011). In Italy for instance, the study and presentation of the human body was integral to da Vinci's masterpieces (Keller, 1952). Versalius' study of the body advanced and contributed to contemporary understandings of human anatomy and physiology (Edwards, 1996). In order to understand and treat disabilities healthcare practitioners began experimenting (Lederer, 2005).

Experimentation. The medicalization of disability during the Early Modern era had a major influence on constructions of disability. Most notably, people with disabilities were reduced to a medical label and their futures were defined by medical prognosis. Through the process of experimentation people with disabilities were dehumanized. The establishment of asylums, poorhouses, workhouses and hospitals for people with disabilities formally removed atypical individuals from society while at the same time providing science with its subjects. Through this process of dehumanization, the Early Modern period has

been noted as the era in which “cripples” disappeared and “disability” was created (Braddock & Parrish, 2001).

Of particular interest were people with mental illness and/or disability. As the causes of mental disability were difficult to identify healthcare practitioners and scientists began testing treatment options. For example, during the 16th century patients volunteered to be beaten upon the head in attempts to treat mental disturbances such as depression, paralysis, and intellectual disability (Bromberg, 1975). For some patients with mental disabilities holes in the skull were prescribed in order to purge individuals of their mental impairments or to release the "stones" or "black bile" which was thought to cause illness (Gilman, 1985). The treatment for epilepsy consisted of the ingestion of a mountain goat's brain or the still-warm gall of a dog killed at the moment of the seizure (Tuke, 1878, 1882). Hearing impairments were treated by frying earthworms in goose lard and then pouring the solution into the ear canal (Winzer, 1993).

By the 18th century people with mental disabilities at the Pennsylvania Hospital endured several experimental treatments. For instance, in Morton's (1897) comprehensive history of the Pennsylvania hospital he explained the treatment for "phrenze" in 1791; “...being drenched or played upon, alternately with warm and cold water (which may have accounted for some of the pulmonary fatalities elsewhere mentioned). Their scalps were shaved and blistered; they were bled to the point of syncope; purged until the alimentary canal failed to yield anything but mucous, and, in the intervals, they were chained by the wrist, or the ankle to the cell wall” (p. 125). While treatments for disabilities during the Early Modern period have been described as primitive (Gaukroger, 2001; Zilsel, 1942; Zilsel, 1945) these attempts provided information about the physicians' ability to intervene and address bodily difference and dysfunction. However, the process of inhumane and unethical

experimentation may have perpetuated the misconception that people with disabilities were not important or were disposable.

Competing beliefs about disability. Some societies however, continued to believe that disability was caused by God's displeasure. On the one hand, Puritans in colonial America believed that disability was a result of God's divine displeasure (Covey, 1998). In fact, Increase Mather, the president of Harvard University from 1685 to 1701 and avid witchcraft zealot, wrote that children with disabilities were evidence of God's retribution upon humankind (Covey, 1998; Winship, 1994). Mather, a puritan minister, believed that impairment could only be absolved through prayer and penitence. On the other hand, the fantastical (by contemporary standards) ways of dealing with disability marked the birth of medical advances in understandings of disability.

For example, Francis Bacon (1605), a British statesman and philosopher was of the view that disability as divine intervention or satanic possession did not contribute to understanding of why and how things worked in the body. Bacon suggested that experiments needed to be conducted in order to collect empirical data based on the systematic observation of regularities amongst typical and atypical individuals (Park & Daston, 1981). Within his book he refuted divinity or demonism as a cause of impairment and instead suggested that four factors were necessary in order to understand impairment: 1) studies of mental faculties and the interaction of body and mind, 2) individual case studies, 3) anatomical inquiry and postmortem studies, and 4) the interaction between society and the individual.

According to Bacon (1605) understanding all the factors which influence experiences of disability assist in the provision of treatment and adaptation. As such, the etiology of disability was no longer divine or supernatural and instead became linked to anatomical and

physiological anomalies during pregnancy, birth or throughout the lifespan. For instance, in Early modern England, society came to believe that intellectual disability was a congenital impairment which was relatively fixed throughout the lifespan while mental illness was understood as improbable and transitory (Fabrega Jr., 1990, 1991).

Adapting to disability.

With a better understanding of the physiological functions and anatomical composition of the human body Early Modern health practitioners began implementing strategies to allow people with disabilities to adapt to typical life. In doing so however, disability was problematized and individualized. For example in 1798, Thomas Malthus (1766-1834), a British clergyman and economist, argued that the population would outnumber the food supply. In addition to reducing the birth rate by sexual restraint and birth control, Malthus advocated that people, who were “defective” in any way; behaved or functioned differently than the rest of society, should be identified and eliminated. In this way, only those who were "normal" and could make the greatest contribution to society would survive.

As attitudes towards people with disabilities, particularly those with a mental disability, became more negative physicians believed that people with disabilities needed to be separated from common society and placed in hospitals. According to Early Modern physicians the benefits were twofold. First, people with disabilities would no longer be a public problem and second, the more patients they had the more observations and experiments they could conduct. For instance, in colonial America In 1752, the first general hospital was established in Philadelphia. The hospital was built to address a petition filed with the Pennsylvania Provincial Assembly on May 11, 1751 in order to address the growing

problem of unmitigated individuals in the colony with mental disabilities. The petition read as follows:

To the honorable House of Representatives of the Province of Pennsylvania,
The Petition of sundry Inhabitants of the said Province, Humbly showeth, THAT
with the Numbers of People, the number of Lunaticks or Persons distempered
in Mind and deprived of their rational Faculties, hath greatly encreased in this
Province. That some of them going at large are a Terror to their Neighbours,
who are daily apprehensive of the Violences they may commit; And others are
continually wasting their Substance, to the great Injury of themselves and
Families, ill disposed Persons wickedly taking Advantage of their unhappy
Condition, and drawing them into unreasonable Bargains, & That few or none
of them are so sensible of their Condition, as to submit voluntarily to the
Treatment their respective Cases require, and therefore continue in the same
deplorable State during their Lives; whereas it has been found, by the
Experience of many Years, that above two Thirds of the Mad People received
into Bethlehem Hospital, and there treated properly have been perfectly cured.
Your Petitioners beg Leave farther to represent, that tho' the good Laws of this
Province have made many compassionate and charitable Provisions for the
Relief of the Poor, yet something farther seems wanting in Favour of such,
whose Poverty is made more miserable by the additional Weight of a grievous
Disease, from which they might easily be relieved, if they were not situated at
too great a Distance from regular Advice and Assistance; whereby many
languish out their Lives tortur'd perhaps with the Stone, devour'd by the
Cancer, deprived of Sight by Cataracts, or gradually decaying by loathsome

Distempers; who, if the Expense in the present manner of Nursing and Attending them separately when they come to Town were not so discouraging, might again, by the judicious Assistance of Physic and Surgery, be enabled to taste the Blessings of Health, and be made in a few Weeks, useful Members of the Community, able to provide for themselves and Families. The kind Care our Assemblies have heretofore taken for the Relief of sick and distempered Strangers, by providing a Place for their Reception and Accommodation, leaves us no Room to doubt their showing an equal tender Concern for the Inhabitants. And we hope they will be of Opinion with us, that a small Provincial Hospital, erected and put under proper Regulations, in the Care of Persons to be appointed by this House, or otherwise, as they shall think meet, with Power to receive and apply the charitable Benefactions of good People towards enlarging and supporting the same, and some other Provisions in a Law for the Purposes above mentioned, will be a good Word, acceptable to God and to all the good People they represent. (Morton, 1897, p. 8)

The petition for segregation and experimentation used language and ideologies which defined people with disabilities as inferior, powerless and contaminating. This construction of disability continues to prevail in modern Western understandings of disability such that bodies which cannot be controlled or reformed are seen as failures (Shuttleworth, 2000). Following this construction of disability people with impairments became the problem and not the societies from which they came. As such, interventions aimed to provide individuals with disabilities the skills to rehabilitate. In this way, people with disabilities were expected to learn how to deal with their impairment(s) in order to behave in ways that were more congruent with typical bodies and minds.

Facilitating equality through education. The introduction of education systems for people with disabilities in the 17th century by the Spanish and the Turks in Europe marked the beginning of efforts to integrate people with disabilities into societies which were largely inaccessible to them (Miles, 2000). For example, some of the first institutions for people with hearing impairments began in the Turkish Ottoman court (Miles, 2000). In Miles' (2000) explorations of "deaf" culture and communication in Turkish history he found that people with hearing impairments had been employed in the Turkish Ottoman court. From as early as the 15th century these workers had trained one another to use hand signs to communicate. This form of sign language became a popular form of communication for the hearing impaired and is the basis for many modern forms of sign language (Miles, 2000). Miles noted that the Turkish signing system was thought to be so efficient that by the 18th century typical aristocratic people, like Sultans and diplomats, began using the system in order to maintain discretion during meetings and public gatherings. Miles also observed that the use and teaching of sign language for people with hearing impairments by people with hearing impairments created a sense of a deaf community/culture and dispelled the common misconception that people with disabilities could not be taught or integrated into common society.

By the 1700s, the use of simple hand signs and sequenced gestures within common society changed the perception that people with hearing impairments were of no use to society (Clapton & Fitzgerald, 1997). For instance, Jacob Rodriguez Pereire (1715-1780) in Portugal instructed "deaf mutes" and taught them to hear and speak by touch and vibration through muscles. Scientists of the time seemed amazed that students could imitate speech and dialects perfectly. In the 1780s, Valentin Haüy developed embossed print and claimed that people with visual impairments could be taught to read. These successful efforts to

educate people with visual and/or hearing impairments encouraged an interest in educating people with other disabilities. Through the consolidation of a social community based on common experiences individuals with disabilities may have felt encouraged to participate in social and physical activities with one another. In doing so, people with disabilities may attain support from people who they trust due to feelings of equality and common experiences. As such, efforts to adapt and to integrate difference were crucial in building relationships and communities. However, the majority of people who learned or taught sign language were often affiliated with aristocracy and therefore affiliated with wealth.

Much of the educational services for people with disabilities in Spain began with the children of wealthy families who had been hidden away in monasteries or convents in the 15th century. As such, the education and instruction of people with disabilities were undertaken by monks and/or nuns (Plann, 1997). The wealthy families who deposited their children at monasteries for care and education donated large sums as recompense (Braddock & Parish, 2001). Thus, education for common children with hearing impairments was limited for many families, well into the 18th century, who did not have the means to pay for the services provided by convents and monasteries. However, as children with hearing impairments in monasteries demonstrated that learning communication techniques was integral to life skills governments reinforced the importance of acknowledging the importance of facilitating adaptation for people with disabilities (Wright, 1969). From these beginnings many societies began implementing the protection, education and integration of people with disabilities.

Late Modern Period

Characterized by the industrial revolution of the 1800s the Late Modern Period was accompanied by a surge in productivity (Smelser, 2006). Also the dramatic advancements in science, education and commercialism made the Late Modern Period a revolutionary and innovative time (Mokyr, 2007). For people with disabilities the Late Modern Period was also a time for better understandings of impairment as a scientific and social issue (Borsay, 2005). However, many of these understanding came at the cost of the respect, safety and dignity of people with disabilities (Rushton, 2009). Due to the institutionalization and segregation of people with disabilities during the Early Modern Period impairment in the Late Modern Period was constructed as an issue that should be dealt with outside the parameters of common society (Asch et al., 2008). In this way, people with disabilities were subsequently refused social integration and social equality. Considering these issues the following section discusses constructions of disability and their implications for expressions of sexuality during the Late Modern Period in relation to developments in education for people with disabilities, the effect of institutional overcrowding and finally the movement towards the eradication of impairment all together.

Educational developments.

In order to accommodate the high number of children with physical disabilities who were being deposited at hospitals for people with mental illnesses and disabilities residential schools grew rapidly during the 19th century (Asch et al., 2007). The first school designed exclusively for children with physical disabilities was opened in 1832 in Bavaria (Braddock & Parish, 2001). Subsequently, residential schools opened in Germany, France, England, Switzerland, and Italy. In order to encourage children with disabilities to be

productive schools like that in Denmark had industrial training programs for their pupils with physical disabilities (Manzo & Peters, 2008).

Training programs and industrial training. As these programs were thought to be useful many European schools endorsed segregated curricula for students with disabilities well into the 20th century (Obermann, 1968). In this way, institutionalization, as the most popular solution to financial hardship or unwanted social stigma for families with children with disabilities, encouraged the separation of people with disabilities from typical society (Colker, 2009). The segregation of students with disabilities however, was not necessarily a negative thing. In this regard, people with disabilities, although constructed as abnormal, inferior, incompetent or burdensome, were given the opportunity to forge social support systems. In doing so people with disabilities within institutions often created communities in which they knew they belonged. In this way, people with disabilities had the opportunity to forge relationships with individuals who were like or understood them.

Through this experience people with disabilities may have enjoyed the opportunity to forge intimate relationships without fear of rejection due to impairment. This creation of a “disabled” community may have provided a sense of much needed social acceptance during a time when individuals had been abandoned by their families and communities. Furthermore, having people with disabilities in one place meant that many scientists, physicians and philosophers who were interested in the etiology of various impairments and deciphering the most effective treatment options for students with disabilities could provide and evaluate revolutionary treatment and education programs.

Educating people with visual impairments. In the 1820s Louis Braille published his revolutionary embossed dot code which allowed students with visual impairment to read through touch (French, 1932; Roberts, 1986). While the Braille system was formally adopted

by both the British and American Committees for the Blind in 1932 several competing systems of communication for people with visual impairments are evidentiary of the effort and attention paid in order to educate students with disabilities (Roberts, 1986). As the educational merit of the Braille system became noticeable the American Printing House for the Blind of Louisville, Kentucky became the premier printer of materials for people with visual impairments in the United States by 1858. In addition, to support the demand for high quality educational material for people with visual impairments in 1879, American Congress legislated that \$10,000 per annum be appropriated for the printing of educational materials (Allen, 1914; American Printing House for the Blind, 1999). Great strides were also made in the development of education programs during the 19th century for children with hearing and intellectual disabilities.

Educating students with hearing and mental impairments. As the difference between mental and physical disability was poorly understood healthcare practitioners during the Late Modern period continued to diagnose atypical community members as “idiots” (Kelly, 2008). Jean Itard (1775 – 1850) however, believed that the label “idiot” was superficial as some individuals who had external impairments or behavioural issues were in fact cognitively typical. Much like medieval times some healthcare providers during the Late Modern Period misdiagnosed people with hearing impairments who could not speak as having a cognitive impairment. This confusion continues in contemporary contexts as some people with physical disabilities are perceived to be cognitively impaired due to irregularities in their speech or the lack of speech altogether.

To reduce the incidence of misdiagnosis, Itard suggested techniques which would help health professionals distinguish intellectual disability from physical or sensory disabilities (Carrey, 1995). When Itard joined the medical staff at Sicard's National

Institution for Deaf Mutes in Paris, which focused on the education, research and treatment of children, he elaborated upon the complex relationship between psychology and impairment.

In order to facilitate learning Itard emphasized that successful education for children with a hearing impairment who did not speak needed to focus on five major areas; 1) sensory stimulation, 2) speech, 3) socialization, 4) concept development, and 5) transfer of learning (Itard, 1802). Through a multidimensional approach to teaching atypical students Itard demonstrated that: A) not only do people with disabilities need to make an effort to adapt to a world which does not always accommodate difference but also, B) typical frameworks for dealing with atypical populations need to adapt in order to cater to the needs and experiences of atypical individuals.

As students learnt and interacted with one another French scientists began to realize the importance of psycho-social development amongst people with disabilities. Through the establishment of a sense of community and belonging they were able to learn more successfully (Quartararo, 1995). Thus, prosocial behavioural techniques were included in education programs. For instance, Itard elaborated upon his teaching techniques with the use of behavior modification with children with disabilities, and the use of specialized education programs for those with mental and physical disabilities (Itard, 1821a, 1821b).

Seguin expanded Itard's techniques and included a psychological component to create a holistic education program which emphasized the importance of sensory-motor training, intellectual training (including academics and speech), and moral training or socialization (Simpson, 1999; Talbot, 1967). In 1844 Seguin's educational techniques for the hearing impaired were widely accepted and became the standard worldwide (Simpson, 1999; Talbot, 1967). In this regard, educators of the hearing impaired confirmed that people

with impairments could learn if they were taught using strategies which suited their skills and needs.

Digressions in education for people with disabilities. While strides towards the education of people with hearing impairment were being made some health practitioners continued to believe that people with disabilities were defective and unintelligent. In Spain for example, Tiburcio Hernandez, an educator for the hearing impaired at the Royal School, decreed a return to oralism (the education of people with hearing impairment through lip-reading) in 1814 (Plann, 1997). Hernandez who believed it was pointless to try and educate children with hearing impairments encouraged student to learn manual trades so they could be sold to factories.

In this way, the positivity, solidarity, community and support people with hearing impairments experienced in the creation of a “deaf” culture was refuted and rejected (Johnson, 2009). Following the rejection of deaf culture and community there was a marked rejection of teachers with hearing impairment (Slegers, 2010). Subsequently, the education of students with hearing impairments became dominated by “experts” with typical hearing for the remainder of the 19th century. In this way, students with disabilities were denied role models from whom they could learn. The removal of teachers who had similar experiences with impairment as their students may have also meant that students were not provided with representations of how people with disabilities adapted and/or reintegrated into society.

As negativity about disability increased within communities people presumed to be “defective” were admitted to institutions in staggering numbers (Braddock & Parish, 2001). Due to the infiltration of negativity about disability and impairment which had seemed to only exist outside institutional walls prior to the mid-1800s people with impairments began

to experience inequality and abuse, a reduction in successful treatment interventions and were ultimately denied their dignity.

Overcrowding and immoral treatment.

With the increase of institutionalization of atypical people during the Late Modern period access to resources for the provision of adequate education, training or intervention strategies for people with disabilities suffered (Kelly, 2008; Kelly, 2010). As there was not enough staff to cater to the number of patients staff members began cutting corners in order to maintain efficiency (Scull, 1991). For instance, in previous centuries more time may have been taken to escort patients to therapeutic appointments or to get through daily tasks. During the Late Modern period patients were herded, much like cattle, from one area to the next (Kanter, 2007). Those patients who were perceived as difficult were often dragged to and from locations and beaten or abused if they did not do as they were told in a timely fashion (Frieden, Bassett, Thorpe & Fraley, 2008; Neugebauer, 1979).

This dehumanization of people with disabilities reinforced perceptions that people with disabilities were not truly adults or even human and therefore did not require dignified treatment. Subsequently, staff at health care institutions seemed to believe that people with disabilities, particularly mental impairments, were in fact children who required forceful interventions and corporal punishment in order to acquire their compliance (Haag, 2007). Ultimately, patients began to revolt against the reduction in respectful and humane treatment they expected from those who were charged with their safety (Edwards, 1970; Renvoize & Beveridge, 1989). While the issue of overcrowding and mistreatment came to a head during the 19th century it had begun during the time of the Poor Law in the 1600s.

Overcrowding. Beginning almost immediately after institutions for people with mental disabilities and illness were constructed severe overcrowding was an issue

(Swarbrick, 2009). People were moved off the street and correctional facilities sought to release their most dangerous and disturbed inmates to the newly available facilities (Grob, 1966). As more patients and inmates were forced into institutions overcrowding and the need for expansion made staff attempts at moral treatment very difficult. By the late 1800s psychiatrists and physicians could not provide each patient with the treatments they required due to shortages in staffing and the sheer number of people they were expected to rehabilitate (Smark & Bowrey, 2010).

In Grob's (1966) analysis of institutions for people with mental impairment in America he argued that superintendents gave way to the inevitability of poor conditions, given severe overcrowding and limited contact with patients. In Rothman (1990) and Scull's (1991) evaluations of institutions for people with disabilities they contended that superintendents capitalized on the need for accommodation for people with disabilities. In this way, superintendants overcrowded the space they had in order to legitimize their own existence and revenue to the detriment of therapeutic interventions. By the beginning of the 1900s the optimism of earlier decades of rehabilitating patients with cognitive impairments and returning them to their families and communities was replaced by pessimism about the treatability and/or curability of their conditions.

The abandonment of reintegration activities within institutions for people with mental impairments meant that impairment was treated as a lost cause. While this was the case people with impairments were still not released and permitted to return to their families or communities. Efforts towards treatment and rehabilitation gave way to confinement and custodial care (Fakhoury & Priebe, 2007) and many institutions demanded that patients be kept in custody for the duration of their lives (Earle, 1877; Grob, 1966; Rothman, 1990). With the inability to provide adequate and timely care health practitioners

reported that mental illness and disability was largely incurable (Earle, 1877; Grob, 1966; Rothman, 1990; Scull, 1991).

Reinforcing inequality. In Szasz's (1973) attack on the abuse of people with mental illness, he argued that the institutionalization of people with mental impairments during the Modern period created a relationship between doctor and patient akin to that of master and slave. Early on however this relationship did not demonstrate its most horrific qualities until overcrowding in mental institutions became pronounced during the latter half of the 19th century in the United States. As such, medical practitioners were constructed as the arbiters of health and illness. In diagnosing someone as healthy or sick, atypical or typical, impaired or not doctors have been given power over how people with disabilities experience their lives. People who were diagnosed with impairment simultaneously lost their autonomy and social equality.

In this way, people with disabilities encountered the medical profession as a paternalistic entity. As people with disabilities continue to experience paternalistic treatment from within health care and other community settings Szasz argued that this relationship between doctor and patient continues to exist in contemporary Western societies. The "doctor-knows-best" ideology is passed onto patients with disabilities. As such, patients may forfeit their agency in attempts to follow the doctor's orders. As will be discussed later this paternalistic approach to rehabilitating people with disabilities may undermine or ignores important socio-sexual experiences and their contributions to a holistic sense of health. These significant changes to the way in which patients had been or expected to be treated did not go unnoticed.

Documented accounts of abuse. Elizabeth Packard (1868) documented her experience of being physically abused at the Illinois State Insane Asylum in Jacksonville.

Based on her experiences Packard campaigned for the civil rights of patients with mental illnesses in America upon her release. In Lydia Button's (1878) autobiography she recounted the abuse she and other "inmates" experienced while institutionalized at the State Asylum in Kalamazoo, Michigan. It can also be noted that Packard and Button were not formally documented as having any mental or cognitive impairment but were victimized by a legal system which permitted men to commit their wives to institutions during the 19th century (Peterson, 1982). Peterson's (1982) reportage of patients who experienced abuse also included a patient at the New York Asylum at Utica who wrote of his experiences of incarceration. Peterson states that this patient with mental illness recounted incidences of extraordinary abuse, severe overcrowding, and disgusting conditions at the facility during the mid-19th century. While these are individual accounts they are representative of the inhumane treatment many institutionalized people with disabilities experienced during the 19th century in North America and Europe.

The situation in British institutions for people with mental impairments was equally problematic. Those who visited the institutions relayed stories of people with mental illness who were confined in rooms without heat or clothing and had been chained and physically abused (Browne, 1837). While it was clear that people who had been institutionalized were not being treated with dignity and respect little was being done in order to change the conditions in which they lived. However, as issues of overcrowding and the dignified treatment of people with disabilities declined some health practitioners advocated for better treatment of patients.

Advocating for humane treatment. Psychiatrist Phillippe Pinel became a major figure in the respectful and effective care of people with mental impairments at the end of the 1700s. He is most popularly known for unchaining 50 patients in a Paris hospital in 1792.

In doing so, Pinel encouraged the need for liberty, equality, and fraternity amongst people with mental illness in order to attain the treatment which they deserved (Rousseau, 1762). Pinel's (1801) work had international influence on the fields of psychology and psychiatry (Braddock & Parish, 2001). Half a century later the editors of the *American Journal of Insanity* noted that "we know not of any work on insanity superior to this ... none more worthy of our daily study" (Seguin, 1846, p. 4). In Belgium, psychiatrist Joseph Guislain also unchained patients at an asylum in Ghent (Browne, 1864). In Italy Vincenzo Chiarugi gained notoriety by publicizing the amoral treatment of institutionalized people with disabilities (Alexander & Selesnick, 1964). These attempts to change institutional procedures marked the formal beginnings of advocacy groups for the rights, safety and emancipation of people with disabilities. In this way, people with disabilities were recognized as equals who deserved the same accommodations as their typical peers. This acknowledgement of people with disabilities as a disadvantaged group supported movements to reintegrate and rehabilitate.

In response to the abuses people with disabilities experienced within institutional setting due to overcrowding family care was introduced during the mid-1800s in North America and Europe (Pollock, 1945). Families who took in individuals with a disability were provided with government funding in order to support their care needs (Pollock, 1945). Although the family care setting proved beneficial it did not receive adequate support as it was thought to be inefficient and expensive (William, Gabe & Calnin, 2000). While the community based care system for people with disabilities did not catch on during the Late Modern period it would subsequently be revisited during the 20th and 21st centuries as viable and effective ways to reintegrate and rehabilitate members with disabilities (Grob, 1994; Mulvany, Barron & McConkey, 2006). In the meantime the increased stigma and fear

associated with disability prompted governments to identify and enumerate those presumed to be impaired.

Enumeration of disability. In the United States the growing concern about the number of people with disabilities resulted in their enumeration by census. From the 1830s people who had visual or hearing impairments were counted. By the 1840s the census began enumerating people diagnosed as “idiots” or “insane” (Gorwitz, 1974). As mentioned, those who were diagnosed as “idiots” were often removed from the societies in which they lived and institutionalized. As racism flourished in the United States black residents were often classified as insane by census enumerators and were subsequently institutionalized (Gorwitz, 1974). This systematic categorization and classification of people who did not look, act or experience life in the same way as typical white Americans of the time perpetuated the conception that difference was dangerous.

Furthermore, from 1870 to 1880 the number of people classified as insane rose from 97 to 183 per 100,000 people. Similarly, the proportion of the population diagnosed with an intellectual disability rose from 64 to 153 per 100,000 (Gorwitz, 1974). While it may be possible that advances in science and medical methodology increased the incidence of diagnoses of insanity this dramatic increase is partially attributed to the extra compensation census enumerators in 1880 received for each person they recorded as having a mental disability or illness (Gorwitz, 1974). While extra compensation may have filled their own bellies the steep increase of people who had disabilities, according to the census, was used as evidence to support the push for drastic measures to eradicate disability during the late 19th century (Knight, 1895).

Eradicating disability.

The eugenics movement in the early 20th century made a significant contribution to contemporary public and interactional constructions of disability and sexuality. In the US, during the late 1800s to the mid-1900s, people with disabilities were regarded as “problems” which needed to be addressed. As Ellis (1927) wrote, “They are ‘an evil that is unmitigated’, a ‘poison to the race’, and their ‘very existence is itself an impediment’ to civilization” (p. 43). During this time people who were classified as “mentally defective,” “idiot,” “feeble-minded,” “imbecile,” “habitual criminal,” “common drunkard” and “medically defective” could be subject to social, cultural and medical efforts to reduce the incidence of their “afflictions.” These labels and their negative connotations constructed disability as an infectious disease perpetuated simply by the existence of people with impairments.

Definitions. Eugenics as defined by Galton (1909) was considered the scientific study of the biological and social factors which improve or impair the inborn qualities of human beings and of future generations. Shakespeare (1998) however defined eugenics not as a form of study to improve or impair inborn qualities but referred to it in more action-based terms as “the science of improving the population by control of inherited qualities” (p. 668). Improving the population in this sense meant that people who were classified as defective would undergo sterilization via castration by removal of ovaries or testicles as that was the only method available before 1900 to prevent them from procreating. Pfeiffer (1994) noted that once the vasectomy procedure for men and the salpingectomy procedure for women was developed around 1900 “sterilization on a large scale was then begun even though there was no legal basis for it” (p. 482). In many cases sterilization was involuntary:

The defence of involuntary sterilizations is based upon the doctrine of *parens patriae* which means, in a loose way, “father power”. That is, fathers-both biological and legal know what is in the best interest of the ‘child’ and can force the ‘child’ to comply even if the ‘child’ is an adult who happens to have a disability. (Pfeiffer, 1994 p. 484)

Following these definitions being diagnosed or classified as defective meant that people with disabilities were denied their autonomy. In this way, intolerant societies and governments became arbiters of sexuality and sexual freedom.

Functions. The eugenics movement went about “improving” society by eliminating the possibility for “defectives” to procreate in the event that they did mate. To insure that people with disabilities were not able to engage in sexual activities they often became wards of the state and were institutionalized in order to limit their presence in general population and for their activities and interactions to be supervised. In addition, individuals who were committed to institutions or classified as defective were also denied sexuality by being denied the right to marriage. Massachusetts, like others American states from the mid-1900s, prohibited marriage for people with disabilities (General Laws 207, section 5):

An insane person, an idiot, or a feeble-minded person under commitment to an institution for the feeble-minded, to the custody or supervision of the department of mental health, or to an institution for medical defectives, shall be incapable of contracting marriage.

As marriage was seen as the basis for procreation during the 1900s individuals who were defective were thus prohibited from “tainting” American blood by perpetuating their afflictions through further generations. Hence, many steps were taken to exclude people with physical or mental differences as they were deemed unworthy of participating in

common society, were prevented from breeding and refused intimacy and sexuality through the prohibition of marriage amongst themselves or with others.

Although people with disabilities are not sanctioned from marriage or sexual relations in the same way as they were during the early 1900s they continue to experience segregation and exclusion which denies them access to social and sexual participation. Furthermore, some people with severe mental impairments are castrated to prevent the incidence of pregnancy. Although pregnancy/the ability to conceive in these situations are not seen as threats to the purity of the human race, they signify a complete absolving of sexual autonomy.

Educating exclusion. During the eugenics movement, disability was not simply an issue to be addressed by medical institutions and the law. Through town fairs and school curricula, up until the mid-1900s, US citizens were warned against fraternizing or mating with “defectives” and “inferiors” (Stoskopf, 1999). Typical others were led to believe that people with disabilities were ill and could infect the “fit” with their “afflictions.” This resulted in the exclusion of atypical people from society. During the fervour of the eugenics movement advocacy groups against the extreme medical and institutional interventions used to eradicate disability were formed. Disability advocacy groups during the early 20th century proposed that perhaps it was not physical or mental impairments that were the “problem” but instead the lack of accommodations for atypical populations which caused disability. Through discourse about disability as a social, cultural, medical and structural construction people with mental and physical impairments were given more social and environmental access (Shakespeare, 2000). However, by the time these positive and inclusive changes were being considered and being acted upon the effects of the eugenics

movement had propagated stereotypes about disability that have been difficult to erase (Stoskepf, 1999).

Ideologies reminiscent of the eugenics movement appear to prevail. Although disability is not generally handled in such extreme terms today, the eugenics movement was not wholly unsuccessful as the history of paternalism and infantilism towards people with disabilities continues (Björnsdóttir & Traustadóttir, 2010; Meekosha, 2006; Shakespeare, 2007). As such, people with disabilities continue to be addressed as though they have a severe mental impairment and (erroneously) are consequently incapable of hearing when spoken to, doing things for themselves or asking for help when they require it. Depending on the specific impairment others may also believe that people with disabilities are not interested in sex or able to engage in sexual activities (Milligan & Neufeldt, 2001). The perpetuation and internalization of archaic attitudes about people with disabilities and their experiences of sexuality have largely served to quiet discourse about sexuality and disability.

Issues to be Addressed

While historical constructions and perspectives on disability inform modern conceptualizations of disability as a bio-physiological and psycho-social phenomenon gaps remain within historical understandings of disability. For example, historical perspectives and constructions of disability exclude explicit discussions on the impact of scientific, social and religious movements on sexuality for people with disabilities. Although unmentioned, the impact of historical progressions and digressions in regards to disability and sexuality is/was implied. In this thesis historical perceptions and constructions of disability will be explicitly addressed in order to create a better understanding of the influence historical constructions of disability play in individual constructions of sexuality for people with Cerebral Palsy.

In addition, the lack of discussion, within historical contexts, about how to normalize sexuality for people with disabilities is concerning. As many programs or reforms were installed to normalize people with disabilities, in an effort towards integration, it seemed as though little was done to address the integration of their sexuality. As such, this thesis will explore, within the lives and experiences of people with Cerebral Palsy, the extent to which the efforts towards social, physiological and structural normalization have influence their experiences and therefore constructions of sexuality.

Summary and Conclusion

Historical constructions of disability played an important role in the formulation of contemporary constructions of disability and expressions of sexuality for people with disabilities (see Table 2.1). From antiquity through to the present day socio-cultural factors such as religion, scientific/medical advances and legislation have influenced constructions of disability and sexuality. In this way, religious doctrines informed conceptualization of disability which vilified its existence. In doing so, expressions of sexuality for and with individuals with disabilities were considered to be unclean. The increased medicalization and institutionalization of disability facilitated advances in the etiology and treatment for people with impairments. In addition, these experiences of medicalization people with disabilities developed a group identity. Simultaneously however, the medicalization and institutionalization of disability has served (and in some contemporary contexts continues) to segregate people with disabilities from common society and reinforced the stigma of disability by typical others (Hayes & Hannold, 2007).

Politically, perceptions of disability have evolved from an opportunity for wealthy individuals to provide charity to that of economic burden as expectations of integration acted as barriers due to a world which was largely constructed for and by typical others. In

order to deal with this issue, people with disabilities who had been afforded more financial and social freedom to pursue employment and social interaction were removed from their families and communities and institutionalized. While history has facilitated greater scientific and social understandings of disability it has left contemporary understandings of impairment marred by ideologies of difference as unwelcome and burdensome.

Chapter 3: Public Influences - A Review of Contemporary Constructions of Disability and Sexuality

Constructions of sexuality by people with Cerebral Palsy (within contemporary contexts) are informed, in part, by historical constructions of impairment and sexual behavior. For instance, prior to the 20th century sexual activity for pleasure had been ignored, vilified and undermined through segregation, institutionalization and eugenics (Ross & Rapp, 1981). As such, the acceptance and representation of sexuality for people with disabilities was largely absent. Constructing sexuality and disability in this exclusionary fashion continues within contemporary settings.

In the early 21st century past constructions of sexuality were often defined by healthcare institutions and providers, educational institutions, religious organizations, parents, families and peers' adoption of an "ignorance is bliss" attitude to discussing, educating or advocating sexual activity for wellbeing for people with disabilities (Tepper, 2000). This lack of discussion concerning sexual expression and disability often stemmed from restrictions on the accessibility of comprehensive sexual information.

Open discourse about the public factors which influence constructions of sexuality for people with disabilities brings awareness of the barriers which may inhibit sexual participation and prompt awareness and understanding. In doing so, sexual expression, pleasure, intimacy and ultimately satisfaction are acknowledged as essential to the formation of inclusive public constructions of disability. This chapter discusses public factors which may influence contemporary constructions of sexuality and disability for people with Cerebral Palsy and other physical disabilities.

Public Influences

For people with disabilities the relationship between impairment and the construction of their own sexuality is mediated by socio-cultural attitudes about disability and expectations of sexual activity. For example, the myth that people with disabilities are asexual or incapable of sexual expression is a widespread myth which disables socio-sexual access and opportunities for people in this group (i.e., Brown, 1988; Chance, 2002; Dune & Shuttleworth, 2009; Earle, 1999; Joseph, 1991; Sanders, 2007; Stevens et al., 1996; Taleporos & McCabe, 2005; Wiwanitkit, 2008; Xenakis & Goldberg, 2010). Many of the misconceptions about sexuality and disability can be attributed to a lack of clarity, representation and education about people with disabilities and their sexualities. Based on contemporary literature (see above) which explored disability and sexuality the following themes have been indicated as important to constructions of sexuality in people with disability and will therefore be discussed here:

- the myth of disability and asexuality
- contemporary media
- normative movement and functioning
- lack of accessibility and
- lack of privacy

The Myth of Disability and Asexuality

While alternate constructions of disability and sexuality exist, the erroneous construction of people with disabilities as asexual is increasingly recognized as an important influence in how sexuality within this population is constructed (i.e., Majiet, 1996; McCabe & Taleporos, 2003; Milligan & Neufeldt, 2001; Shakespeare, 2000; Shuttleworth, 2000). This public misperception of disability and sexuality is what Milligan and Neufeldt (2001), among

others, call the “Myth of Asexuality” which encompasses two lines of thinking depending on whether the person’s impairments are physical or intellectual;

First, for people with physical disabilities, because of actual or presumed sexual dysfunction, gratification opportunities are considered so limited that sexual needs are either deemed to be absent or subjugated. Second, although their sexual function is typically intact, individuals with intellectual disabilities and/or psychiatric disorders are thought to have limited social judgment, and therefore, lack the capacity to engage in responsible sexual relationships. (p. 92)

Here mental disability is defined as "any disability or disorder of the mind or brain whether permanent or temporary which results in a disturbance or impairment of mental functioning" (Law Commission, 1995, p. 36). Whereas physical disability is defined as a condition where a person experiences significant deviation or loss in their body function or structure that results in limitations in the physical activity (World Health Organization, 2011). The eugenics movement in North America, for example, was particularly aimed at eliminating such disabilities. However, little differentiation was made between mental and physical disability and the social privileges and human rights these individuals were entitled to. This lack of differentiation between mental and physical disability is maintained in contemporary contexts through condescending and paternalistic behaviour exhibited towards people with disabilities.

The historical literature discussed in this chapter implies that many misunderstandings about disability and sexuality could be perpetuated through socio-cultural institutions like religion, political systems and the law. In addition, influential contemporary socio-cultural factors include the media and popular culture, family,

educational institutions, health care professionals and institutions as well as urban infrastructure. While there are many public factors that influence socio-sexual development, sexual constructions and sexual experiences; perhaps popular culture and media are the most influential in post-modern society. As such, a discussion of modern media as discussed in contemporary research literature may be an appropriate starting point to understanding how sexuality and disability have been constructed in contemporary societies.

Contemporary Media

The media acts as a public influence on the expression of sexuality. In the past few decades, particularly with the advent of the World Wide Web, media have penetrated almost every aspect of social life, particularly in developed societies. At school young children discuss the most recent adventure of their favorite superhero(ine) and act out the script from the last episode when they play with their peers. Adolescents talk about the newest and hottest pop singer whose concert was aired the night before and as they leave school they sing and dance (in unison) their favorite tune. Adults congregate around the proverbial water cooler and chat about the “pod-cast” of their favorite sit-com or soap opera. Baudrillard (1983) argued that one of the consequences of the extent of media infiltration in contemporary life has to do with hyperreality. Hyperreality is experienced when media consumers cannot distinguish between reality and the simulated images used in advertizing, movies, television shows or pornography. Therefore, a considerable part of how disability (and sexuality) is conceptualised has to do with “the ubiquitous presence of the media in our everyday lives [which] has contributed to its potency as an important influence on attitude formation” (Milligan & Neufeldt, 2001, p. 37).

Representation of disability and sexuality in the media.

The use of sexuality in contemporary media is exemplified through many of its forms. For example, in a 1998 study of internet use and sexuality, sex was the most frequently searched topic online and the top 8 word searches on the internet all involved porn (Freeman-Longo & Blanchard, 1998). In the top 20 shows among teens, 8 in 10 include some sexual content and 1 in 10 depicts intercourse (Brown, Halpern & L'Engle, 2005). The presence of scripted sexual content is not only concentrated in television and the internet but also in magazines and books. Most magazines for girls aged 12-15 are extensively sexualized. In the United States up to three quarters of this age group read "YM," "Teen" and "Seventeen" magazines which focus on instructing girls how to be attractive in order to catch and hold onto the attention of boys (Brown et al., 2005).

Selling sex. Western media has exploited images or representations of sexual pleasure for profit. The target audiences for major consumer-based organizations are young, heterosexual, Caucasians with dispensable income. As such, sexual activity in popular media is portrayed as a privilege only enjoyed by Caucasians, heterosexuals, young people, single people and people who do not live with visible disabilities who buy their product. Sexual pleasure is used as an incentive in popular culture such that it becomes a reward for purchasing the right product at the right price. In this way, sexual activity as a means for pleasure, sexual expression and intimacy is rarely recognized (particularly in product advertisements) for marginalized populations in society. In his personal account of acquired physical disability, Tepper (2000) noted that "sexual portrayals of people who are older, who are larger, who are darker, who are gayer, who are mentally or physically disabled, or who just do not fit the targeted market profile have been conspicuously absent in mainstream media" (p. 285).

Within popular Western media, for example, satisfying sexual encounters, desirable sexual partners, appropriate expressions of sexuality and constructions of sexuality are portrayed as biologically, physically and economically determined (i.e., *Hung*, 2010). By excluding representations of people who do not fulfill the media's target population demographics sex as an act of pleasure and reproduction is reserved for the "best" human specimens. Subsequently, people with disabilities are viewed as unacceptable candidates for reproduction or even capable of engaging in sexual activity for their own pleasure as well as that of potential partners.

The sexual scripts portrayed in the media as "normal" and "appropriate" minimise the actual spectrum of human experience and instead focuses on ideals of perfection. As such, the media has a great influence on the representation of people with disabilities (Goggin & Newell, 2002). Media portrayals of what is sexy or desirable have seen significant changes since the 1950s (i.e., *Glee*, 2010; *Jersey Shore*, 2010; *Pumpkin*, 2002; *Transformers*; 2007). However, contemporary popular culture continues to represent people with various illnesses or impairments who are sexually marginalized as undesirables, deviants or excluded from portrayals of sexuality altogether (i.e., *Jersey Shore*, 2010; Tepper, 1999; 2000; *The Hard Times of RJ Berger*, 2010).

Movies and television. The presentation of people with physical disabilities in mass media under-represents the actual number of people who live with visible disabilities (Goggin & Newell, 2002) which accounts for 12-18% of the population in the US (Brault, 2005), 12.4% in Canada (Statistics Canada, 2001) and 20% in Australia (Australian Bureau of Statistics, 2003). As such, some filmmakers continue to reinforce constructions of disability which act as barriers to integration, accessibility and acceptance. For example, Raynor and Hayward (2009) explored the availability of acting positions for actors with a disability. Their

research indicated that not only are visual media opportunities for actors with disabilities limited, the roles of characters with disabilities are scarce. Focus group participants commented that many characters with disabilities were played in media by those without (i.e., *Boardwalk Empire*, 2010; *House*, 2004; *The West Wing*, 2004).

Disability in movies. The portrayal of individuals with disabilities in media contributes to societal perceptions of disability (Nelson, 1994; Susman, 1994). Research by Black and Pretes (2007) explored the representation of disability in 18 films, produced between 1975 and 2004, that had a main character with a physical disability. Their analysis included themes such as the character's (a) overall personality, (b) community integration, and (c) interpersonal relationships. The stereotypes Black and Pretes examined included (a) pitiable and pathetic; (b) supercrip; (c) sinister, evil, and criminal; (d) better-off dead; (e) maladjusted-own worst enemy; (f) burden to family/society; and (g) unable to live a successful life (see also Biklen & Bogdan, 1977; Nelson, 1994). They found that the majority of the films sufficiently developed the character with a disability's personality and some films portrayed healthy and realistic representations of interpersonal relationships. However, Black and Pretes noted that steady and mutually satisfying intimate relationships were rarely portrayed.

Although many of the movies included representations of disability as integrated in community life, portrayals of education and employment integration were noticeably lacking. The researchers found that the most common stereotype portrayed in the films was of maladjusted/being one's own worst enemy. The least common stereotypes portrayed within the films were pitiable and pathetic, sinister, evil and criminal. These stereotypes however are often used to personify the repulsive or amoral qualities (Raynor & Hayward,

2009) and portray disability as sexually undesirable. Stereotyped constructions of disability and sexuality are also evident in audio-visual media aimed at children.

Representations of disability in movies for children. The animated film *The Hunch-Back of Notre Dame* (1996) produced by Disney portrays difference and people with physical disabilities as objects of pity and shame. The Hunch-Back in this movie was relegated to the heights of the Notre Dame cathedral bell tower because of the constant negativity he experienced from typical others. Upon meeting the heroine in the movie it seemed as though his sexuality and thoughts of intimacy were awakened - as though he had been asexual before her arrival. Alas, she made it clear she was not attracted to him and could not be with him so he should find joy in the bells and the birds who lived with him in the bell tower while she courted the prince of France. The evil scientist's slave, Igor, has historically been a medieval hunch-backed social outcast whose life is devoted to the biddings of a powerful super-villain. This well-known fairytale character portrays disability as ugly, shameful, and certainly not sexy. Only in the recent popular Pixar animated movie *Igor* (2008), is the character of Igor presented as smart, funny, balanced and a possible candidate for love and intimacy. In the movie, Igor becomes the creator of a "monster" and subsequently falls in love with her. The monster who is much bigger, stronger, and made of various mismatched parts from different living and non-living things also falls in love with her creator. Here physical difference is shown to be sexy and desirable.

In this regard filmmakers have made and initiated progress to dispel common myths and stereotypes about people with disabilities (i.e., pitiable victim or dangerous monster). While some media successfully incorporate representations of disability into their scripts (i.e., *Glee*, 2010; *Pumpkin*, 2002) Goggin and Newell (2002) express that screenwriters of popular television and movie media fail to create non-parody characters that have physical

impairments (i.e., *The Hard Times of RJ Berger*, 2010). Hartnett (2000) indicates that when people with physical disabilities are portrayed in popular media they are often characterized as the villain, the charity case (see also Safran, 1998), the sexual deviant (see also Norden, 1994) or fetish (Norden, 2007), the evil scientist's slave (i.e., *Igor*, 2008) or the village idiot (see also Halliwell, 2004). Although these portrayals are damaging to positive and realistic constructions of disability they continue to infiltrate popular media. As with those concerned about violence, homophobia or anti-feminism in media the impact of misrepresenting minority groups may be most significant amongst young adults. Considering the marked increase in the amount of media young people consume weekly media magnates have focused heavily on youth.

Representations of disability in print media. Graphic novels aimed at young adults, for example, have increased in their popularity. As such, research by Irwin and Moeller (2010) on representations of disability in graphic novels indicated that the need to provide all students with literature that depicts people with disabilities has never been greater. Upon the examination of thirty graphic novels which were aimed at young adults Irwin and Moeller found that less than 50% of the novels portrayed an individual with a disability. Of these, the majority of the portrayals were of negative stereotypical images of disability.

The authors concluded that the writers, illustrators, and publishers of graphic novels recommended for teens have not provided a realistic representation of people with disabilities. The exclusion of characters with disabilities in graphic novels restricts understandings and awareness of disability. In doing so, young people may conceptualize people with impairments as weak, unintelligent and/or incapable. This however may not be the case for non-Western media markets.

Non-Western representations of disability in media. Research by Ciot and Van Hove (2010) in Romania has also indicated a move towards more integrative representations of disability in the media. Through their research the authors found that media representations function as social norms as well as biases among people with disabilities themselves. In their research Ciot and Van Hove (2010) investigated; differences between Western and Romanian representations of disability, whether culture influenced the construction of these images and what political, social, and cultural factors or positive and negative elements characterized the Romanian media models of disability. Ciot and Van Hove (2010) specifically focused on print media during 1989, 1990 and 2003. They found that over the course of the last two decades media, as a public influence on the social construction of people with disabilities, succeeded in fulfilling its role of constructing a better attitude toward people in this group. They noted that there is a wide range of media representations of disability, not only that of societal stigma. Their research indicated that the existence of different categories of representations of disability in Romania revealed the evolution of society, which switched from a culture of paternalism and protection to a culture of advocacy and promotion for people with disabilities.

As such, print media served as a medium of advocacy for people with disabilities, with a major contribution toward enlarging knowledge about disability and a real understanding of this minority group. Ciot and Van Hove (2003) believed that Romanian print media indicated that disability is natural and 'usual' therefore assisting the elimination of social ignorance and exclusion toward those who are socially marginalized. In this regard, print media is represented as a viable medium to advocate and integrate changes to the ways in which disability is presented and interpreted. As print media is often cheaper to produce than television or film media people with disabilities and other minority groups

have made good use of newspapers and newsletters in order to create a sense of community and awareness within the societies in which they live.

Ciot and Van Hove concluded that there were social representations of disability in the media which specifically reflected Romanian culture and constituted a specific Romanian model of disability. They did however note that Western models of disability in the media have had a significant impact on how people with disabilities are constructed, interpreted and ultimately, treated in Romania. While these findings indicate inclusive representations of disability in Romanian print media the research did not investigate visual media or constructions of sexuality for people with disabilities. As such, representations of disability in various media may differ from representations of disability in visual media; particularly in terms of sexuality.

Radio and audio media. While visual media monopolizes consumers' time and money, radio and audio media has an influence on how disability and social participants are conceptualized. Research conducted in Ireland by O'Malley (2008) examined how people with communication disabilities were dealt with in the talk radio programme *For and about People with Disability*. Through an analysis of 15 episodes of the radio programme three frames of discourse were identified: radio programme frame; presenter frame; and interview frame. O'Malley found that while the individual's communication impairment did not appear as a topic in the radio programme there was an overemphasis on the medical aspects of disability and discussions of disability as primarily a physical phenomenon. Although the programme often focused on medical or factual questions, interviewees managed to include rich accounts of their experiences of disability. O'Malley's research indicated that portrayals of disability which empower and give voice to people with disabilities certainly do exist. As such, media which deemphasizes the expectation that all

bodies act and look the same embraces difference promotes positive constructions of disability.

Normative Movement and Functioning

When dealing with a disability, whether congenital or acquired, likely barriers to the negotiation of sexual relationships are social restrictions caused by public, interactional and private expectations of normative movement and functioning. These social restrictions not only impede the ability of some people with physical disabilities to get to and from places easily. They may also significantly impact their ability to engage in normative sexual activities with sexual partners. In fact, research by Taleporos and McCabe (2001) which investigated the impact of physical disability on sexual feelings, sexual experiences, and sexual esteem, observed that some people with disabilities find themselves at a great sexual disadvantage versus their typical peers due to the influence physical impairment had on their lives. While this may be the case for some people with physical impairments others may interpret the impact physical disability has on their lives differently.

Expectations of normative movement and functioning.

Expectations of normative bodily functioning affect both people with disabilities and typical others. A participant in Taleporos and McCabe's (2001) study jokingly explained; "Yeah, it's really hard because guys expect you to be able to get into 101 different positions and I'm lucky if I can get into three!" (p. 137). Due to physical restrictions some people with physical disabilities deal with they may find it difficult to move their limbs, may have issues with trunk control, issues with spasticity or moving without pain; "I cannot lie comfortably and my movements are limited because of the types of disabilities that I have, so you can't enjoy that part of life—I am really angry and frustrated about it" (p. 137). Also, there are many individuals who use devices to assist them in activities of daily life, which can become

barriers to sexual negotiation; “When dealing with sexual expression there is only so much you can do in a wheelchair” (p. 137).

Shuttleworth (2000) explained that “in a culture that emphasizes sex acts and performance, men and women [with disabilities] are often portrayed as axiomatically prohibited from participation in satisfying sexual relationships and destined to emotionally empty lives” (p. 95). Shuttleworth (2000) explored the accounts of the search for sexual intimacy for 14 men with Cerebral Palsy which revealed a range of impediments, issues “and a complex intersubjective process(es) in their search for a lover” (p. 263). He discussed the social expectations of normative functioning and control which the majority of the men in his study expressed as a cause for frustration in their efforts to negotiate sexual relationships. Some of the men in the study felt that the impairment often physically disqualified them from social and sexual interactions. Shuttleworth explained that “those who used wheelchairs often put it in terms of women being turned off by the fact that they were in a wheelchair” (p. 267).

The physical barrier of not being able to move in a way that society expects the body to move may affect how a person with Cerebral Palsy or other physical impairment relates to others and themselves based on their body. Thus, expectations of normative movement and functioning are factors in the disablement of a person’s chances to be considered as a sexual partner. In addition, there are structural barriers to the access of built environments that deprive people with disabilities of the same number of opportunities to interact with others as their peers, and can thus restrict access to sexual relationships.

Bodily acceptance.

While some people with disabilities may feel that physical impairment has affected the way they experience their sexuality many also feel positively about their ability to

negotiate and participate in mutually satisfying sexual relationships. Esmail et al. (2010) investigated the impact of Multiple Sclerosis (MS) on existing sexual relationships in Canada. Participants reported that while having MS did have a negative affect on their ability to participate in mutually satisfying sexual activities with their partner being provided with useful information, counselling and engaging in open communication about sexual issues promoted sexual satisfaction for themselves and their partners. The authors stressed that clinicians can provide programs to facilitate open communication. Through the use of a problem-focused approach to identifying each partner's needs healthcare professionals can provide education and resources to alleviate duress caused by the disability. Esmail and colleagues further recommend that interventions which are focused on both partners may help to assist in the process of adjustment to disability. In this way imbalances caused by learning to cope with disability and the effect it has on sexual relationships may be neutralized. The key to the success of sexual intervention and/or education programs is the availability and accessibility to healthcare (or sexuality) professionals and programs.

Lack of Accessibility

Access has an important socio-structural influence on sexual participation (Barnes & Mercer, 2010; Corker & French 1999; Corker & Shakespeare 2002; Oliver 1996). Socio-structural access is characterized by the relationship between environmental infrastructure and social opportunities and ultimately mediates access to social opportunities and sexual information.

Definitions and implications of access (or the lack there of).

Environmental infrastructure includes a community's buildings, roadways, sidewalks and other areas meant for human access. However some of these structures are not constructed to provide access to people whose bodies do not function in the same way as

typical others (Kagan & LeBlanc, 2002). Social opportunities are characterized by the presence of opportunities to interact with others. Social opportunities are further mediated by an individual's perception of social peers and their worthiness as potential social peers and vice versa. Access to social opportunities may be limited for some people with disabilities due to infrastructure which does not facilitate easy access to built structures such as social venues (Corker & French 1999; Corker & Shakespeare 2002). Limited socio-structural access may thus exacerbate the social expectation of normative movement and functioning which some people with disabilities encounter daily (Schillmeier, 2007).

For example, appropriate ramps, wide walkways, large enough bathroom facilities that can accommodate wheelchairs or Hoyer lifts, appropriate elevators, automatic doors and accessible buttons with which people can operate these devices continue to be absent or difficult to operate in modern environments (Pendo, 2010). In addition, many of the places people commonly frequent to meet new people, and therefore negotiate sexual relationships, are not accessible, people with disabilities who rely on wheelchairs or who find it especially difficult to go up a flight of stairs are at a distinct disadvantage.

However, accessibility has become an important consideration in contemporary urban planning and architecture. In Australia for example, developers are strongly encouraged to procure information about accessibility from building consultants. According to the Disabled Access Consultancy Group in Melbourne:

Using the expert assistance and advice of an accredited access consultant can be useful for practitioners to help interpret Australian standards and the Building Code of Australia, and to ensure that its Deemed to Satisfy performance based requirements are met.

Whilst the requirements of relevant Australian standards are not mandatory in themselves, where building regulations and the Disability Discrimination Act invoke them, they or parts of them become mandatory. The use of enhanced standards is encouraged. (Disabled Access Consultancy Pty Ltd, 2010)

The provision of infrastructure which provides access to people with physical disabilities facilitates inclusion and integration. With unrestricted access to the physical environments in which people live comes access to more social opportunities.

Access to social opportunities.

As mentioned, social opportunities are characterized by the presence of opportunities to interact with others and are mediated by subjective peer dynamics. Social opportunities encompass several aspects; the accessibility of environmental infrastructure and its influence on opportunities for social inclusion and integration. As discussed above environmental infrastructure plays a key role in the provision of social opportunities for people with physical disabilities. For instance, in Yoshida's (1994) chapter on the teaching of disability studies in Canada and the US, he explained that for people with physical disabilities the planning of (social) excursions can often be a tedious adventure through the bureaucracy of organizing accessible public transit and travel concessions, procuring wheelchair accessible taxis, enduring the spectacle of being lifted up a flight of stairs and/or being carried into a room full of one's peers;

There is a lot more problems, things don't move quite as smoothly...And that can be anywhere from going to functions somewhere where there may be problems with steps. There may be problems with elevators. Getting to where you want to go. It's more of a hassle. Um...the whole thing you have to deal and think ahead

and deal with more problems. And everything doesn't go as smooth as two able-bodied persons going somewhere. Like you always have to think about barriers and the whole deal. (Yoshida, 1994 pg. 185)

Many people with moderate to severe Cerebral Palsy, as an example, use a wheelchair. In some settings, the lack of ramps and curb cuts is a significant drawback to not only physical but also social access. The lack of accessible taxis and buses further restricts the individual from venturing out to cafés, malls and night clubs. For instance, Marn and Koch (1999) explored the challenges that youths with Cerebral Palsy encounter as they attempt to accomplish the developmental tasks of adolescence. They reported that adolescents with Cerebral Palsy experienced transport barriers which subsequently reduced opportunities for social integration. Lack of accessibility may be a symptom of a bigger social problem in which people with disabilities are excluded from opportunities for social and sexual interaction. As the provision of social opportunities is often a precursor for sexual opportunities the lack of resources to include and integrate disability may very well be the most restrictive barrier to sexual inclusion. Social and sexual integration however, can be supported through unrestricted access to education and information about disability.

Access to sexual information.

Often the barriers to sexual activity and relationships that people with physical disabilities experience are the result of ignorance caused by a collective lack of education and information. For example, Anderson and Kitchin (2000) examined access to family planning clinics for people with disabilities and reported that facilities for sexual health education and relationship information were not adequately informative or accessible. Accessible and relevant information and education for young people and adults with disabilities promotes their right to intimacy and relationships and can facilitate a more

accepting and inclusive social environment (i.e., Esibill, 1980; Rousso, 1993; Berman, Harris, Enright, Gilpin, Cathers & Bukovy, 1999; Earle, 1999; Murphy, Molnar & Lankasky, 2000). However, research on what people with disabilities formally know about or have been formally educated about sex, sexual activities, sexual health, contraceptives, sexual intimacy and relationships, their sexual rights and sexual agency is meager. Information designed to foster sexual knowledge, positive sexual identity and sexual agency is vital for people with disabilities in order to promote self-respect, pleasure, and safety.

“The Ignorance is Bliss” attitude.

Often, however, information about sexuality is treated as dangerous in itself and a potential cause of sexual victimization (Cole & Cole, 1993). For example, people with disabilities who were raised in overprotective families may have been discouraged from being involved in activities where they could learn social skills, learn about sex or engage in sexual activities (Nosek et al., 2001). Nelson (1995) who explored sexuality in childhood disability found that parents of children with disabilities were reluctant to provide sex education for fear it would cause a premature interest in sex and sexual activity. Guardians to children with disabilities may feel that exposing their child to social and sexual situations with typical peers could make their child more prone to sexual coercion, socio-sexual disappointment.

For example, Goodman, Budner, and Lesh (1971) qualitatively explored how parents addressed sexual issues with their child(ren) with a disability. They found that although guardians of children with disabilities may teach them facts of reproduction, they were often hesitant to discuss other socio-sexual aspects. Goodman et al. noted that parents seemed afraid that their child would never be able to attain a mutually satisfying sexual relationship and would therefore be hurt if they became involved with someone. However,

limiting sexual information endangers young people with disabilities as they may not have learnt, practiced or know how to utilize social and sexual agency with others.

Implications of lack of access to sexual information.

Without sexual education the socio-sexual powerlessness experienced by people who are sexually marginalized receives little attention. However, efforts have been made to include disability and sexuality education into tertiary curricula for those aspiring to be health care professionals (Esibill, 1980). While this may be the case, there are indications that those who provide health care services do not address sexuality with their clients or their clients' carers and parents (i.e., Earle, 1999; Murphy, Molnar & Lankasky, 2000; Wiwanitkit, 2008; Wazakili, Mpofu & Devlieger, 2009; Xenakis, & Goldberg, 2010). This lack of sexual openness and discussion reinforces the misconception that sexuality is not important for people with impairments (i.e., Brown, 1988; Blum, Resnick, Nelson & St Germaine, 1991; Neufeld, Klingbeil, Bryen, Silverman & Thomas, 2002). For example, women from Nosek et al.'s (2001) study expressed numerous frustrations in their quest for information about sexuality and reproductive health. Those who did receive sexual information felt that because they had a disability the information received did not apply to them. As such, many of the women in the study had no idea about how their disability would affect their ability to have sex or children. To be considered perhaps is the way in which sexual health information is presented, by whom and through what methods.

For many young people sexual education is provided through educational institutions often by teachers or medical practitioners. In addition, disseminators of sexual information often do not have a visible disability themselves. Structured information provided to students through handouts or instructional manuals may be hetero-normative and focus on (perceived) typical experiences of sexuality. While school sexual education

curricula may not be inclusive to all students, comprehensive or provide life skills information (Silva, 2002) they are often the formal basis for which students become aware of safe-sex and contraceptives.

During my time as a personal care attendant for the Attendant Services Program at Carleton University in Ottawa, Ontario, Canada some clients told me that some schools separated students with disabilities from the class during sexual education and were given a recess. In their theoretical paper on sexuality and disability, Shakespeare and Watson (1998) argued that school systems which exclude students with disabilities from sexual education confirm the myth that people with disabilities are not the same as everyone else. In effect, students with disabilities and their typical peers received messages that people with disabilities did not need to know the same things about sex. It may have been presumed that they would be less likely to find themselves in sexual situations and therefore would find the sexual information less useful.

Cole and Cole (1993) stated; “to be imperfect is to be asexual and anonymous or overlooked in the sexual spectrum of adult life. The continuing emphasis on the healthy and physically fit adult (who must also achieve a perfect body) is a concrete message learned repeatedly from early childhood through media and advertising” (p. 196). Deficits in the sexual health curriculum in some educational institutions emphasize the importance of programs tailored to address difference and accommodate alternative expressions of sexuality. The lack of inclusive sexual education provided to students thus acts as a barrier to the construction of a positive sense of one’s sexuality. The provision of alternative frameworks of sexuality may provide young people with disabilities a foundation on which to build positive constructions of their sexuality.

Lack of Privacy

Personal care is often a part of life for people with moderate to severe disabilities (Winkler, Sloan & Callaway, 2007). According to ParaQuad (2010), paraplegic and quadriplegic association of New South Wales, Australia, personal or attendant care is defined as home-based support and plays a vital role in the lives of people with high level physical disabilities by supporting them to maintain active lifestyles, achieve independence and dignity and have control over their lives. ParaQuad's personal carers can help with:

- Bathing
- Toileting
- Dressing
- Transfers in and out of bed
- Meal preparation
- Eating
- Light household tasks
- Respite care so that your carer can have a break
- Access to recreational activities
- Access to community services

Due to personal care requirements that can often be quite intimate (bowel and urine voiding regimens) it can be difficult to maintain privacy which can be necessary to express one's sexuality. Crewe (1979), who discussed the psychologist's role in sexual rehabilitations for people with disabilities, emphasised that there are many people with physical disabilities that require daily, and some even hourly personal care so being able to find time and space for privacy is difficult. In my time working as a personal care assistant for students (most of whom had Cerebral Palsy) who attended university in Ottawa, Ontario, Canada, clients told

me that in certain other facilities in which they lived, the residents were not permitted to lock their doors and in some cases even to close them. Although it seems that these types of rules are enforced so that personal care attendants or emergency services can reach the client in the event that they were in trouble this lack of privacy makes sexual expression particularly difficult. Thus, rules against something as simple as door-closing or locking can inadvertently reinforce the myth that people with physical disabilities do not have a need for privacy and sexual expression (Crewe, 1979).

Restrictions to client privacy and sexuality.

For care programs which cater to many clients, bedtimes, wake-ups, meal times and bathroom visits are often scheduled and if missed, for whatever reason, can be hard to reschedule. In such cases, some personal care providers can become irate with changes to the schedule and may inquire as to why the daily routine had been changed (St. Kitts, personal communication March 2nd, 2010). Clients however, may not feel comfortable explaining to care staff that they would like to masturbate or engage in sexual behaviours as a reason for the change of their schedule (Sage, personal communication June 12th 2010). Browne and Russell (2005) investigated the sexual well being needs of people with physical disabilities in Australia and found that respondents described the need for privacy as crucial. They argued that “the data indicated that professional carers needed to be more aware of clients’ need for privacy... It is inevitable that carers will encounter situations that may be embarrassing for both clients and themselves. Professional carers require training to ensure that clients’ sexual lives do not create uncomfortable working environments” (p. 386).

In the provision of care staff members may become quite familiar with their clients. Considering the intimate relationship that some care staff may have with clients, the client may then be inclined to ask for assistance with masturbation, sexual positioning, the

application and/or removal of a condom or the insertion or administration of other contraceptives. In Tepper's (1999) personal story and professional perspective on the impact of disability on male sexuality he explored how acquiring a disability may affect sexuality. He discussed the difficulties he encountered in attempts to express his sexuality while spending time in rehabilitative care. One day he decided to ask a staff member if she could be of some assistance; "Having no success with masturbation, I attempted to convince my private duty nurse to help me out. We were about the same age and got along very well. She seemed sympathetic and potentially willing to give me a hand, but ultimately she was too nervous about her professional boundaries to help" (p. 39).

Unfortunately, however, policy and/or a lack of information about sexuality and disability within certain care facilities may prohibit care staff from being able to provide this type of intimate assistance (Sanders, 2007). Certainly, some staff may find it personally difficult to give this type of assistance. In a review of literature Earle (2001) explored the role nurses can play in acknowledging and facilitating the sexual needs of patients with disabilities within a holistic framework of nursing care. She attests that "in spite of the importance of sexuality and sexual expression to the psychosocial welfare of patients, sexuality is often excluded from nursing practice" (p. 1). This statement implies health care institutions and providers are lacking in the provision of adequate opportunities for people with disabilities to construct their sexuality based on inclusive sexual education and/or rehabilitation. Ultimately, how interactional authority figures (i.e., teachers, parents and health care professionals) address sexuality has an effect on how people with disabilities interact with their own sexuality as well as that of others.

Issues to be Addressed

While contemporary literature has confronted many issues in regards to education and acceptance towards dispelling myths about sexuality for people with disabilities some discussions remain incomplete. Although contemporary media has made efforts to integrate difference or atypical populations within their scripts people with disabilities continue to be portrayed as asexual. While contemporary literature has explored the impact of media on constructions of disability it has not thoroughly addressed media and sexuality for people with disabilities (or Cerebral Palsy for that matter). As such, this thesis aims to explore what impact the continuation of misrepresentation has on constructions of sexuality for people with Cerebral Palsy.

In addition, this thesis will look to further expound the role that a lack of accessibility to public places and services plays in the construction of sexuality for people with Cerebral Palsy. In doing so, this project may be able to provide a better understanding of the interplay between structural, social and educational access for individuals who may be perceived as mentally impaired due to the severity of a physical impairment.

Although the literature indicates that efforts have been made to allow/ensure clients of attendant care programs dignity some continue to confound that right by invading client's privacy. In response to the lack of hermeneutic phenomenological discussion about the impact of being denied privacy and implicitly sexual agency this thesis will explore the impact that a denial of privacy has on constructions of sexuality for people with Cerebral Palsy. Through this process this thesis ultimately aims to instigate thought, discussion and ideas for the integration of socially and therefore sexually marginalized populations.

Summary and Conclusion

People with disabilities construct their own sexuality under the influence of socio-cultural attitudes about disability and expectations of sexual activity. As such, some public attitudes and expectations myths which imply that people with disabilities are asexual create barriers which prevent people with impairments from interacting with others and their environment (Dune & Shuttleworth, 2009; Wiwanitkit, 2008; Xenakis & Goldberg, 2010). As discussed in this chapter, the majority of the misunderstandings about sexuality and disability can be attributed to a lack of representation and lack of education about people with disabilities and their sexualities.

Through the analysis of public influences on contemporary constructions of disability myths about disability and asexuality as portrayed and perpetuated by contemporary media were found to be undergoing a transformation. While there may be a long way to go for some mediums media as a whole has become more inclusive of difference. In doing so, contemporary media portrays public scripts of tolerance and acceptance. With the insistence of structural modifications to public areas communities and governments encourage businesses and educational institutions to participate in an effort to reduce exclusion and segregation of people with disabilities. In this way, accessibility to many public and ultimately interactional and private activities and arenas can be achieved. Through the provision of accessible spaces the literature indicates that people with disabilities are facilitated with opportunities to live independently thereby having control over who comes in and out of their home and when. In doing so people with disabilities are afforded the dignity and privacy that many others take for granted.

These advances in the level of public understanding and inclusion of disability (and ultimately sexuality) come mainly through open discourse about the factors which influence

constructions of disability and sexuality for people in this group. In doing so, contemporary societies can increase their awareness of the barriers which inhibit sexual participation, expression, pleasure, intimacy and satisfaction. Through awareness and acknowledgment people with Cerebral Palsy (and other physical disabilities) are encouraged to create a positive and healthy construction of themselves and their sexuality.

Chapter 4: Interactional Influences - A Review of Contemporary Constructions of Disability and Sexuality

As per Simon and Gagnon (1986, 1987, 2003) interactional constructions of sexuality are influenced and reinforced by public attitudes and interpretations. As such, people may be encouraged to engage in sexual activity only with those who are publically prescribed as appropriate (Simon & Gagnon, 1986). The public construction of who is an appropriate sexual partner often excludes individuals with disabilities and their experiences of sexuality (Guildin, 2000). If people with disabilities are publically (i.e., mass media) excluded from portrayals of sexuality they may not be considered as viable sexual partners and thus experience reduced sexual opportunities (Overstreet, 2008). As such, the influence that inclusive, versus exclusive, constructions of sexuality has on interactional sexual experiences for people with Cerebral Palsy requires investigation.

Interactional Influences

Interactional experiences of sexuality may significantly influence how people with Cerebral Palsy construct their sexuality (Dune & Shuttleworth, 2009; Earle, 1999; Taleporos & McCabe, 2005; Xenakis & Goldberg, 2010). Although there are many interactional relationship configurations, people with Cerebral Palsy most often engage in three. As such, the following sections will discuss the influence of healthcare providers, parents, and peers in the promotion of positive interactional representations and constructions of sexuality.

Healthcare Institutions and Providers

People with moderate to severe impairments are more likely to seek medical help than typical others. Health care providers examine their patients' medical history closely and do their best to help them with their medical needs. As such, it is logical that the healthcare environment should be a setting for the patient and the medical personnel to

address questions about how the disability or impairment might factor into their sexuality (Dune, 2011). Although sexual education and counselling services can be made available for people receiving rehabilitative care it is particularly important for those with chronic health issues. Through rehabilitative programs people with chronic health issues are provided with information which may help them to adapt to their condition and the effect it has on their body.

As such, people with chronic health issues would be made aware of how to prevent or manage health crises related to their condition. Once the most pressing matters in relation to their condition are dealt with the patient's attention may turn to how to incorporate their health condition and its management requirements into other aspects of their lives. While sexuality may not be imperative to the outcome of the patient's health condition, sexuality and sexual expression are associated with psychological well-being (Dune & Shuttleworth, 2009). Considering that chronic health issues and disabilities affect many aspects of a patient's life, addressing the impact a patient's condition has on their sexuality is important within rehabilitation and healthcare contexts.

Barriers to effective sexual counselling for people with disabilities.

Most problematic though is the case where a health care provider may simply dismiss questions or concerns about sex initiated by their patient (Ricciardi, Szabo & Poulos, 2007). The health care provider may be under the impression that discussions about sexual development and expressions of sexuality are not pertinent or too intimate in relation to the service they are providing and may therefore refrain from opening the dialogue themselves (Cole, 1975). This behaviour may reinforce the perception that sexuality is not something that people with disabilities should think or talk about (Milligan & Neufeldt, 2001).

Practices in medical contexts. While medical personnel may shy away from discussing sex with people with disabilities clients may also do the same. For instance, in their qualitative exploration of people with disabilities and their quest in negotiating sexual health needs from care providers, Browne and Russell (2005) reported that; “It was not only carers who were ‘too embarrassed,’ participants also described being ‘too shy to ask’” (p. 381). When care professionals did address issues of sexuality for their patients, they unknowingly reinforced the misconception that the sexuality that their client did experience was not adequate and/or completely fulfilling. In these situations, medical practitioners may then suggest that clients with disabilities try medications or prostheses that will make them more sexually “functional.” A participant in Guldin’s (2000) qualitative research conceptualizations of sexual self in people with disabilities talked about the medical suggestion that he have a penile implant:”

They strip all of the innards out of your penis—everything that works is taken out and replaced with their plastic things, their pumps, all this kind of mess . . . besides, to me there’s something very erotic about the amount of hard-on I get—even though it may not get as long or as hard as a lot of other guys, it’s still my erection. It’s caused by my stimulation or my feelings or my emotions. It’s me, it’s all me. (p. 235)

As can be seen from this quote, the medical perspective may dismiss the person’s own experience of a holistic and personal sexual experience.

For some people with disabilities the message seems to be that sex can be possible or better if one did not have a disability. As the field of medicine has historically been cure/goal oriented and experimentally focused, separating sexuality from the stereotypical performance model can be difficult to do. However, this separation is necessary in order to

fully address sexual issues and experiences for people with disabilities. While the goal of conventional medicine is often to minimise the symptoms of impairment in order to normalize people's lives medicine can also encourage holistic and/or alternative experiences of sexuality and functioning (Guldin, 2000).

Multidisciplinary approaches. Although there is room for improved integration of sexuality counselling in the rehabilitative environment many changes have taken place in order to provide patients with opportunities to discuss their sexual issues and concerns. Modern frameworks (see Table 4.1.) of sexuality counselling have taken on a multidisciplinary approach to discussing sexual issues as well as providing treatment or interventions where necessary (i.e., PLISSIT, Kaplan & ALLOW). The PLISSIT model can be used to assess and treat a patient's sexual concerns within a rehabilitation context. PLISSIT stands for Permission to discuss sexuality, Limited Information regarding sexuality, Specific Suggestions regarding the person's sexual issues, and Intensive Therapy with an expert when needed (Annon, 1976). PLISSIT is distinctively aimed at providing patients with suggestions specific to their sexual concerns versus generalized information about sexuality and its effect on people with their disability or illness. In light of limits to the level of practitioner knowledge about particular sexual concerns or issues patients would be referred to specialists who could further assess needs.

The Kaplan model focuses on the chief complaint, sexual status, psychiatric status, family and psychosocial history, relationship assessment, summary and the provision of recommendations. The Kaplan model emphasizes that healthcare providers take the initiative to discuss sexuality with their patients while maintaining approachability. In consideration of clinical limitations the Kaplan model outlines the importance of referring patients to sexual health specialists when necessary (Kaplan, 1983). Using the Kaplan model, healthcare professionals can introduce the topic of sexuality health during follow-up visits. The maintenance of an accepting

and calm disposition while approaching sexual issues may help the health care provider demonstrate the willingness to help and non-judgmental nature.

ALLOW stands for Ask the patient about sexual activity and function, Legitimize the patient's concerns by acknowledging them as relevant within their rehabilitative program, addressing Limitations presented by lack of knowledge and comfort, Open discussions about sexual issues for assessment and the provision of referrals to a specialist, and Work collectively in or to develop a treatment plan (Hatzichristou et al., 2004). Unlike the PLISSIT and Kaplan models for sexual counselling the ALLOW model places more emphasis on the collaboration of healthcare provider and patient to facilitate sexual rehabilitation. Finally, in the event that a rehabilitative health care provider needed to refer their patient to a sexual health specialist they would still participate in the development of the treatment plan.

Table 4.1 Multidisciplinary Approach to Sexuality Counselling Summary

Approach	Key Features	Summary of Approach
PLISSIT	PLISSIT stands for <u>P</u> ermission to discuss sexuality, provision of <u>L</u> imited <u>I</u> nformation regarding sexuality, <u>S</u> pecific <u>S</u> uggestions regarding the person’s sexual issues, and <u>I</u> ntensive <u>T</u> herapy with an expert when needed.	PLISSIT is distinctively aimed at providing patients with suggestions specific to their sexual concerns versus generalized information about sexuality and its effect on people with their disability or illness. In light of limits to the level of practitioner knowledge about particular sexual concerns or issues patients would be referred to specialists who could further assess needs.
Kaplan	The Kaplan model focuses on the chief complaint, sexual status, psychiatric status, family and psychosocial history, relationship assessment, summary and the provision of recommendations. The Kaplan model emphasizes that healthcare providers take the initiative to discuss sexuality with their patients while maintaining approachability. In consideration of clinical limitations the Kaplan model outlines the importance of referring patients to sexual health specialists when necessary.	Using the Kaplan model, healthcare professionals can introduce the topic of sexuality health during follow-up visits. The maintenance of an accepting and calm disposition while approaching sexual issues may help the health care provider demonstrate the willingness to help and non-judgmental nature.
ALLOW	ALLOW stands for <u>A</u> sk the patient about sexual activity and function, <u>L</u> egitimize the patient’s concerns by acknowledging them as relevant within their rehabilitative program, addressing <u>L</u> imitations presented by lack of knowledge and comfort, <u>O</u> pen discussions about sexual issues for assessment and the provision of referrals to a specialist, and <u>W</u> ork collectively in or to develop a treatment plan	Unlike the PLISSIT and Kaplan models for sexual counselling the ALLOW model places more emphasis on the collaboration of healthcare provider and patient to facilitate sexual rehabilitation. Finally, in the event that a rehabilitative health care provider needed to refer their patient to a sexual health specialist they would still participate in the development of the treatment plan.

While the general population may experience instances of sexual difficulties or concerns, people with chronic disabilities or medical illnesses are likely to be further impacted by the effects of the actual injury/illness/impairments and any treatment programs they are participating in. Common sexual counselling practices in rehabilitative care involve a mixture of sporadic sexuality counselling sessions, questions about how patients are coping with intimacy, subtle questions or hints about sexual concerns and jokes made by patients in attempts to manage their sexual concerns, organized sexual counselling sessions and referrals to sexual health professionals.

The future of effective sexuality counselling programs in rehabilitative care rests on comprehensive training for health care professionals about how to address sexual concerns, provide information, treatment interventions as well as deal with comfortability issues and attitudes about sexuality, illness and disability. As such, institutions must be ready and willing to provide sexual education, counselling and treatment as the timing of this service in relation to the onset of the illness or injury can be crucial to future psychosexual wellbeing. Healthcare professionals must make the effort to address sexual concerns and broach difficult sexual issues with their patients in order to facilitate a holistic and successful rehabilitation program.

Healthcare provider education about disability and sexuality.

Education for healthcare practitioners can make a significant difference in the provision of adequate and informative sexual education for patients with disabilities. Often, the lack of a holistic understanding of sexuality by some members of the medical profession is due to a lack of professional education about alternative expressions of sexuality (Dune, 2010; Earle, 2001). Although the PLISSIT, Kaplan, and ALLOW models have been indicated for the provision of sexual counselling in rehabilitative care their use by staff may be infrequent due to unfamiliarity with how to approach sexual issues with their patients. Considering the lack of comprehensive and easy-to-administer sexual counselling programs,

Bitzer and his team of researchers created a sexual counselling framework specifically for staff who facilitate rehabilitative programs (Bitzer, Platano, Tschudin, & Alder, 2007). Bitzer and colleagues created a full sexual counselling program using 3 dimensions of sexuality: person-related preexisting factors, disease-specific factors and patient's and partner's response (see Table 4.2).

Table 4.2 Bitzer, Platano, Tschudin and Alder (2007) Model: Three Dimensions of Sexuality Summary

Dimension	Activity and Example Questions
<p>Person-related Preexisting Factors</p>	<p><i>Ask actively about the actual sexual experience by giving a general introduction:</i></p> <ul style="list-style-type: none"> • In many patients the disease or the treatment you are having impacts on their sexuality. • How is your experience? <p><i>Help the patient to describe the sexual problem in terms of desire, arousal, orgasm, pain, and general satisfaction.</i></p> <ul style="list-style-type: none"> • Did or do you observe any change in your sexual desire or interest, in sexual fantasies or activities? • Do you have difficulties in getting sexually aroused? • Does the vagina not feel wet enough? • Do you have difficulties to experience an orgasm? • Do you feel pain during intercourse or masturbation? <p><i>Ask questions regarding the specific disease and its impact on the patient's sexuality:</i></p> <ul style="list-style-type: none"> • Do you have difficulties with continence? • Do you have difficulties moving into a position for intercourse? • Do you have difficulties stimulating yourself or your partner due to your arthritis (for example)? • Do you have difficulties now with breast stimulations since your surgery/radiation (for example)? <p><i>Assess the preexisting characteristics of the patient's sexual experience and behavior and body image with the following questions:</i></p> <ul style="list-style-type: none"> • How would you rate the importance of sexuality in your life before the onset of the disease? • How would you rate your enjoyment of sexuality at that time?

	<ul style="list-style-type: none"> • Did you experience any of the following sexual difficulties (loss of interest, difficulty to reach orgasm, arousal difficulty, etc.)? <p><i>Assess the preexisting level of physical and psychological well-being:</i></p> <ul style="list-style-type: none"> • What diseases did you suffer from before the onset of the actual illness? • How would you rate your physical and psychological well-being before?
Disease-specific Factors	<p><i>Assess the disease-specific impact on sexuality following the 8D anemogram:</i></p> <p>Danger (Threat):</p> <ul style="list-style-type: none"> • How does the patient experience the threat of the disease to her or his life? <p>Destruction:</p> <ul style="list-style-type: none"> • Does the disease or treatment have a direct impact on the integrity of sexual organs? <p>Disfigurement:</p> <ul style="list-style-type: none"> • Does the disease lead to a change in the body's outer appearance with a possible negative emotional impact? <p>Disability and pain:</p> <ul style="list-style-type: none"> • Is the disease causing chronic pain and motor disability which may impact on the patient's capacity to enjoy the bodily expression of her sexuality?

	<p>Dysfunction:</p> <ul style="list-style-type: none"> • Does the disease lead to an impairment of the sensomotor and sensovegetative innervation of the physiological processes involved in the human sexual response? <p>Dysregulation:</p> <ul style="list-style-type: none"> • Does the pathophysiology of the disease have an impact on the neurobiological and neuroendocrine processes involved in the central or peripheral regulation of the sexual response cycle? <p>Disease load:</p> <ul style="list-style-type: none"> • Is the disease accompanied by an impairment of intimate physical mechanisms like micturition and defecation? <p>Drugs:</p> <ul style="list-style-type: none"> • What is the impact of the drugs used for the treatment of the disease?
<p>Patient's and Partner's Response</p>	<p><i>Assess the patient's and partner's response to the disease:</i></p> <ul style="list-style-type: none"> • How would you describe your actual state of mind (mood)? • What are the greatest difficulties you encounter in living with the disease? • How do you cope and what are the things that help you in confronting the disease? • What was and is your partner's reaction to the disease? • Have you observed a change with respect to your sexual needs? • What about your partner? Have you observed a change in your partner's sexual needs? • Have you observed a change with respect to your self-image? • Have your feelings for your partner currently changed?

The three dimensions used in the Bitzer model address patient sexual functioning and dysfunction, the impact and influence of illness or disability on the patient's sexual experiences and finally the psychosexual and sociosexual state of both the patient and their partner. The Bitzer sexual counselling framework is not only for the benefit of patients but was created to promote healthcare provider knowledge, competence and comfortability. In this way, healthcare practitioners can provide patients as well as their loved ones with advice and strategies to adapt and communicate openly about sex.

Influence of Parents

Interactional constructions of sexuality often begin in the home. From infancy children are exposed to schemas of acceptable gender and social roles. In this way parents indicate to their children what may be expected of them in interactional settings. Educating children about interactional expectations also involves demonstrations of what behaviour, roles and partners are sexually appropriate. For instance, some parents may demonstrate heteronormative sex roles and sexual behaviour which children observe, interpret and (often) internalize (Lamb, Bigler, Liben & Green, 2009). In addition, parents may discourage children from engaging in sexual exploration with their peers of the same sex, from a different socioeconomic level or racial/ethnic group. When children ask why they should or should not express their sexuality in a particular way some parents may dismiss the discussion or provide a fictitious answer (Davies & Robinson, 2010).

As such, the openness of parents or caregivers to discuss sex with children may dictate their child's ability to analyse and/or challenge exclusive interactional sexual scripts throughout life. However, some parents may find it difficult and even awkward to talk to children about sex and/or answer questions about sex (Davies & Robinson, 2010). Some parents fear that discussions about sex and sexuality would open the proverbial can of

worms and expose their child to opportunities of unprotected sex, early onset of sexual activity, promiscuity, unplanned pregnancy and sexually transmitted infections (Bleakley, Hennessy & Fishbein, 2006). Negative sexual encounters can very well be part of a young person's sexual experiences. However, parents who deal with these realities and speak to their children can provide them with valuable information about sexual safety and awareness.

Reinforcing perceptions of vulnerability.

In the case of parents who are caring for a child with a disability this natural protectiveness is compounded and may be exacerbated by the physical impairment which they may perceive as a point of vulnerability (Cole & Cole, 1993; Goodman, Budner & Lesh, 1971; Nelson, 1995; Nosek et al., 2001). Hallum's (1995) research indicated that parents may be worried about possibly negative outcomes of their child engaging in sexual activity. For instance, parents of children with disabilities may be concerned that their child will engage in sexual experiences against their will or knowledge. In her theoretical paper on effect disability had on transitions to adulthood Hallum stated that "fears of their children being abused [were] a repeating theme heard from parents of adult-age children" (p. 16).

In addition, some parents were seriously concerned that talking to their child about sex and sexuality would peak their child's interest in sexual activities. These parents may believe that sexual interest may lead children with disabilities to actively pursue sexual experiences and make themselves a target for sexual abuse. Parents were particularly worried about this possibility as they felt that their child may not be able to defend themselves if the situation went further than they had expected. Sobsey and Doe (1991) investigated 162 reports of sexual abuse and assault involving victims with disabilities. From

their analyses they made suggestions about strategies to prevent the abuse of children with disabilities:

Most sexual child abuse prevention programs focus on the child's ability to resist abuse. This strategy has wisely been criticized as simplistic and inadequate, but some intervention may be valuable at this level when combined with other prevention methods. People with disabilities should be taught to discriminate appropriate occasions for compliance and for assertiveness, not taught generalized compliance with everyone for all things. Of course, as with non-disabled victims, saying "NO!" is not always adequate. Appropriate sex education is also essential. The belief that keeping sex a secret from people with disabilities somehow protects them is as unrealistic as it is distasteful. (p. 255)

Most parents of children with disabilities are aware of the social negativity which creates social and possibly sexual barriers for their child (Blum, 1983). However, parental support and approval of intimate relationships is beneficial to the stability and quality of their child's future intimate relationships (Sprecher & Felmlee, 1992). Sobsey and Doe (1991) noted that those parents who do not speak to their child about sexuality for fear of unwanted sexual advances, but still want them to experience satisfying intimate relationships may be reinforcing the myth that people with disabilities are not sexual agents who are in control of themselves and their sexual experiences.

Consistent with Sobsey and Doe (1991), Hallum (1995) noted that some parents of children with a disability may be less willing to talk about sex and sexuality because they felt that they were protecting their child from sexual and intimate rejection, embarrassment and humiliation from their peers. In this case parents are acknowledging the myth that

people with disabilities are non-desirable and that they would be rejected by others based on their impairment. As such, children with disabilities may be discouraged from engaging in developmentally appropriate social activities as they approach adolescence such as dating and extra-curricular social activities (Rintala et al., 1997). A participant from Howland and Rintala's research said:

My parents trained me to be asexual, to not think about sex...I seriously don't think that they expected me, or still don't expect me, to be a person who has a sexuality. I don't think they even really worried about me. I think they were all concerned about my sisters, because I had four other sisters. I really don't think that they took me into consideration when they were concerned about sexuality or girls doing the wrong thing. (p. 48)

As such, some parents choose to filter sexual information and simply skip or skim over open discussions of sexuality and instead encourage their child to focus on other more meaningful preoccupations (Hallum, 1995) - implying that sex, although important, is not important for them. Malawi, Kvam and Braathen (2008) examined 23 stories of sexual assault or abuse towards women with disabilities. Many of the women claimed that they allowed men to engage in intercourse with them because they felt it may have been their one and only chance to be sexually intimate and/or to be mothers. Once they were pregnant their sexual partners left them. These women felt that they were not provided with adequate information about their sexual and social rights from parents or social authorities: "the informants stressed that adapted education for women with disabilities would allow them...to be better able to refuse the advances of unserious suitors" (p. 5).

Regardless of the provision (or lack there of) of sexual education from parents young people often turn to their peers in attempts to learn about and explore their sexuality.

The Influence of Peers

It is one's peers that often have the greatest influence on socio-sexual development (Paek, 2009; Potard, Courtois & Rusch, 2008). Seminal works on peers include a theoretical paper by Sullivan (1953) on childhood friendships as the prelude to adult intimate relationships, explains that preadolescents begin to develop intimacy in the context of same-sex "chumships" as a prelude to romantic relationships. In his theory, chumships help teach preadolescents how to disclose and receive private information and to build a close and mutual friendship based on honesty, loyalty, and trust. Sullivan asserted that "those who have been unable to negotiate successful chumships, or who are too insecure to expand their worlds to include a meaningful partner, arrive at late adolescence not having successfully negotiated one of the most important interpersonal tasks" (p. 6).

To ease the discomfort of making friends and forging chumships, humans tend to gravitate towards people that are the most like themselves. However, this way of relating to others may exclude people with disabilities from sports, games and common social events as they may not look or be able to engage in the same activities as some of their typical peers. Following this ideology Clarke, Kitzinger and Potter (2004) noted that "kids are just cruel anyway" (p. 531). Thus, in young people's attempts to sort out their social and sexual identities they may often exclude those that are not like them in order to define the parameters of their own identities. By delineating their social group as different from another young people foster a sense of belonging and purpose (Clarke et al., 2004). Other social conceptions may include sexual scripts about what is sexy, how to engage in sexual behaviours and who is an appropriate sexual partner.

Public, social and sexual scripts that young people hold may mirror what is advocated as appropriate socio-sexual behaviour amongst their peers and within their peer group (Neemann, Hubbard & Masten, 1995). For instance, Lawlor et al.'s (2006) qualitative research on families of children with Cerebral Palsy indicated that "reported barriers to participation were the attitudes of individuals and the ingrained attitudes of institutions...The attitudes of strangers towards the child and family which altered the choice of activity for some families" (p. 225). As such, it is the task of typical others as well as people with disabilities to advocate change, acceptance and recognition for more inclusive societies. In this regard, the dissemination of disability issues is seminal to the integration of people with disabilities as equal members of the communities in which they live. However, some of the people who experience the most stigmatization and exclusion are those whose impairments restrict their ability to easily participate in oral communication with others.

Communication issues.

According to Blakar and Nafstad (2006), communication is a broad construct defined as the ways in which people share information, thoughts and feelings and encompasses several mediums. Some of the mediums used for interactional communication include tone of voice, facial expressions, hand gestures and body language. When children are young they communicate with their caregivers through the ways they behave. For instance when babies cry, they may be hungry, thirsty, lonely, scared or in need of toileting. As typically developing children age then may learn to express themselves and their needs through gestures like pointing, facial expressions, body language and simple sounds. Soon after, typically developing children learn to use the words that they have been exposed to by the people around them. They learn that words, tone of voice, gestures and facial expressions

are all part of how they communicate with others and how others communicate with them. However, some children with disabilities (i.e., Cerebral Palsy) may not develop speech as easily or in the same way as their typical peers.

In a theoretical paper by Gould (2009) on communication from a speech pathology perspective “typically speech pathologists identify communication as effective when both the speaker and the listener have executed their roles to an age expected level within the biological capabilities of the individual” (p. 59). McCormack, McLeod, McAllister and Harrison (2010) aimed to understand the experience of speech impairment as described by children with speech impairment and their communication partners. McCormack et al. interviewed thirteen preschool children with mild to severe speech impairments and twenty one of their significant others. Their data revealed the following issues: a) the child’s inability to “speak properly,” b) the communication partner’s failure to “listen properly” and c) frustration caused by the speaking and listening problems. Their data also presented solution-focused themes. Solutions included: a) strategies to improve the child’s speech accuracy (e.g., home practice, speech-language pathology), and b) strategies to improve the listener’s understanding (e.g., using gestures, repetition). McCormack et al. concluded that intervention for children with speech impairment should support the speaker as well as the listener and address the frustration they both experience.

Children with speech impairments may be stigmatized, excluded or may not be able to participate in educational and/or peer activities (Gould, 2009; Jemta, Fugl-Meyer & Oberg, 2008). For example, Jemta, Fugl-Meyer and Oberg (2008) aimed to describe experiences of intimacy and sexual activity and exposure to sexual abuse among children and adolescents with mobility impairment, and to relate these experiences to socio-demographic data, disability characteristics and well-being. Through semi-structured

interviews with 141 children with mobility impairment they found that children with severe speech impediments played “house” and “doctor/patient” less than the other children in the sample. It may have been that some children were not asked to participate in the games while others chose not to participate. As such, some children with speech impairments may shy away from utilizing their communication skills with others as it may be physically tiring or emotionally traumatizing (Faulkman, Sandburg & Hjelmquist, 2005).

Implication of communication issues for people with disabilities. The social implications of communication or speech skills which manifest themselves differently than in typical populations are numerous. For example, people with speech impairments may experience social exclusion, delays in educational milestones, restrictions to access and psychological disturbance due to societal stigmatization. McCormack et al.’s (2010) Australian study explored the applicability of the Activities and Participation component of the International Classification of Functioning, Disability and Health – Children and Youth (ICF-CY, World Health Organization) as a framework for investigating the perceived impact of speech impairment in childhood. They surveyed 205 speech pathologists and 86 parents of children who had been identified as having speech impairment. Speech pathologists and parents indicated that speech impairment impacted six aspects of children’s lives; verbal communication (i.e., conversation, speaking), advanced learning (i.e., learning to read/write), interpersonal interactions (i.e. relating with strangers, Informal social relationships), basic learning (i.e., copying, rehearsing), applied learning and general tasks (i.e., focusing attention, handling stress), and non-verbal communication. In addition both of the sample groups rated verbal communication and interpersonal interactions as the most difficult activities for children with speech impairment. While these results are interesting

they may not fully encompass the views of children with speech impairment as they had been derived from parents and speech pathologists.

For example, Gould (2009) suggested that communication is conceptualized within the profession of speech pathology as being primarily biological. Gould contests that communication, however, is not only a biological phenomenon and that defining communication in this narrow way may not capture the many variations in communication styles. While speech may be largely biologically determined, conceptualizing communication in this way may problematize social interactions and/or create stigmatization for people with disabilities.

The risk of social unpreparedness. Faulkman, Sandburg and Hjelmquist (2005) of Sweden conducted a longitudinal study with six children with Cerebral Palsy who had severe speech impairments. Their study aimed to explore the development of Theory of Mind within children in this group. Faulkman et al. argued that due to the lack of mutual conversation children with severe speech and physical impairment experience they may not be able to attribute thoughts, beliefs and feelings to themselves or to other people as well as understand that their actions are governed by these thoughts, beliefs and feelings. This may be because children with severe speech and physical impairment may not have been given the opportunity to express themselves and/or engage in meaningful communication with others (McCormack et al., 2010). Faulkman et al. explained that when people speak to children with severe speech and physical impairment it may be specifically focused on feeding, toileting and the provision of care. Indeed, due to the lack of vocalizations children in this group often experience less self-initiated and spontaneous social contact with their environment than their typical peers (McCormack et al., 2010).

Lower incidences of social contact through one's lifetime may impact the incidence of sexual contact (Jemta, Fugl-Meyer & Oberg, 2008). For people with speech impairments (like some people with Cerebral Palsy) the added variable of limited communication may change how people in this group construct their sexuality. Public scripts via television and other audio media create sexual scripts in which people engage in what their societies define as normalized forms of courting. Often these courting procedures involve talking to one's potential partner as publically prescribed. Interactional sexual scripts dictate what an individual should say in order to increase their potential for a sexual encounter or relationship. While there are positive representations of sexuality and speech impairment within contemporary media (i.e. *Pumpkin*, 2002) many normalized public and interactional scripts demonstrated through audio-visual media rarely depict people with speech impairments within sexual situations. Private sexual scripts may then be created which do not account for variance in communication styles. Without a framework which allows people with speech impairment to express their thoughts, feelings and desires their socio-sexual experience(s) may not be acknowledged (Blakar & Nafstad, 2006; Gould, 2009; Faulkman et al., 2005; McCormack et al., 2010).

Issues to be Addressed

Although contemporary literature has identified some of the major barriers to experiences of sexuality for people with disabilities some issues still need to be addressed. For example, while healthcare institutions and providers are taking a more inclusive approach to their practices and communication techniques to accommodate people with disabilities there is still room to identify the effect their practices have on constructions of sexuality for this group. This thesis aims to provide a better understanding of the role that

disability, as a biophysical phenomenon, and how it is dealt with by medical practitioners and institutions in the constructions of sexuality for people with Cerebral Palsy.

Other important factors to the construction and implementation of interactional sexual scripts are parents and parenting. While contemporary literature aptly discusses the important role that parents play in facilitating healthy and positive constructions of the self within their children discussions about how healthy and positive constructions of sexuality can be fostered are limited. As such, this project hopes to expound some of the main influences in the construction of sexuality and sexual self. In doing so the level of importance parents play in the construction of sexuality for people with Cerebral Palsy can be understood.

Finally, this thesis will discuss the level to which peers influence constructions of sexuality for people with Cerebral Palsy. As the literature suggests peers may, in fact, be the most influential source of sexual information, interactional socio-sexual scripts and opportunities for socio-sexual participation. As such, this thesis will analyze the importance people with Cerebral Palsy attribute to peers in the construction of their own sexuality.

Summary and Conclusion

The above discussions of interactional constructions of sexuality within contemporary literature confirms Simon and Gagnon's (1986, 1987, 2003) sexual script theory. Primarily, interactional constructions of sexuality implore people to engage in sexual activity with those prescribed as appropriate partners and only engage in sexual activities that meet public and interactional expectations (Simon & Gagnon, 1986). Contemporary literature confirms that while individuals with disabilities may have satisfactory and positive sexual experiences and feelings, if their experiences and feelings do not conform to prescribed sexual behaviour they may be excluded from common experiences of sexual

activity and relationships with others (L'Engle, Brown & Kenneavy, 2006). Thus, the sexuality that people with disabilities experience may be constructed as inadequate or abnormal. As such, considering the effect constructions of interactional sexuality may provide a better understanding of how healthcare practitioners, parents and peers can approach sexuality with people with Cerebral Palsy.

Chapter 5: Private Influences - A Review of Contemporary Constructions of Disability and Sexuality

Constructions of sexuality can be created through private mental processes which involve inner dialogue (Emerson, 1983). These private mental processes can influence the way individuals internalize sexual scripts and consolidate perceptions and constructions of sexuality. Simon and Gagnon (1986) noted that private sexual scripts are “the symbolic reorganization of reality in ways that makes it complicit in realizing more fully the actor’s many-layered and sometimes multicoated wishes” (p. 99).

Privatizations of sexual expectations, behaviour and constructions are bound to public and interpersonal social scripts (Kant, 1958). In this regard, the ways in which people think about disability is linked to how it is publically represented (i.e., mass media) and how people with disabilities experience in interactional encounters (i.e., intimate relationships). As such, this section begins with a brief discussion of the role private influences play in the construction of sexuality for people with disabilities. This will be followed by an analysis of the following private influences and their salience to private constructions of sexuality:

- disability and sexual identity,
- human and sexual agency,
- constructions of sexual self
 - body image and body esteem,
 - sexual esteem and,
 - sexual desirability.

Private Influences

There have been positive public and interactional efforts made towards the socio-cultural inclusion of people with disabilities (Olkin, 2002). For example, renovations in

infrastructure and including people with disabilities in discussions about the issues that affect them (Shakespeare, 2000, 2007). However, public and interactional reconstructions of sexuality and disability may not have been fully privatized by those involved in the process. For instance, while individuals working for funding agencies may appreciate that people with disabilities experience barriers to sexual expression they may remain reluctant about providing funding for sexual surrogacy.

As such, some private constructions of disability and sexuality may be based on misunderstanding about how atypical others experience or want to experience their sexuality. Subsequently typical and atypical others may privatize misleading information or attitudes about sexuality in people with disabilities. The privatization of exclusionist public and interactional scripts of sexuality has played a significant role in how people with disabilities construct their (sexual) identity (Guildin, 2000).

Disability and Identity

According to seminal work by Erikson (1968a, 1968b, 1994) identity is defined as the distinct personality of an individual, regarded as a persisting entity, or the individual characteristics by which a thing or person is recognized or known. In addition, identity formation is an important psychological and social function which is created through the interplay of several identities (i.e., social/cultural and personal) acting within one individual (Erikson, 1968a, 1968b, 1994). External factors, such as nurturance, may impact the construction of their identity (Bronson, 2001). As such, identity can be charted along a series of developmental stages in which identity is formed in response to increasingly sophisticated challenges (Erikson, 1968a). According to Erikson, the development of a strong identity was dependant on proper integration into a stable society and culture. Accordingly,

a deficiency in either of these factors may increase the chance of confusion which can lead to an identity crisis (Ostrander, 2008).

Constructions of identity.

People with disabilities may construct their identity through the experiences they have had with impairment and the experiences others have had with disability (see Shakespeare, 1996). It has been suggested however, that this view of identity may lack holistic elements. Giddens (1991) for example, explains that “self-identity is not a distinctive trait, or even a collection of traits, possessed by the individual. A person's identity is not to be found in behaviour nor - important though this is - in the reaction of others, but in the capacity to keep a particular narrative going” (p. 53). In this way identity is created through the complex interplay between the heterogeneous influence of the public, the interactional and the private to create a homogeneous self. For instance, through the context of GLBTQ (Gay Lesbian Bisexual Transgender Queer) advocacy Weeks (1977) suggested that the concept of identity is akin to finding a map to explore a new country. These understandings of identity attract attention to positive identity narratives about disability which are created by the individual themselves. As such, disability as part of one’s identity may not be intrinsically negative. The experience of disability as a negative identity arises out of a process of socialization.

Shakespeare (1996) discussed the social contention experienced due to assumptions made about what he called “disabled identity.” Shakespeare uses a quote by Morris (1991) to explain that the identity of the person with a disability in relation to those around them influences how they will interact with others:

One of the most important features of our experience of prejudice is that we generally experience it as isolated individuals. Many of us spend most of our

lives in the company of non-disabled people, whether in our families, with friends, in the workplace, at school and so on. Most of the people we have dealings with, including our most intimate relationships, are not like us. It is therefore very difficult for us to recognize and challenge the values and judgments that are applied to us and our lives. Our ideas about disability and about ourselves are generally formed by those who are not disabled.’ (p. 37)

In this way negative constructions of the “disabled identity” may reinforce the stigmatization of people with disabilities. According to Shakespeare the disabled identity does not need to be constructed negatively if societies are given opportunities to discuss, listen and understand experiences of disability or impairment. In doing so, people with disabilities can actively participate in discourse which they are directly and indirectly involved. In doing so impairment and disability can be discussed openly thereby addresses myths, misconceptions, and barriers as well as acknowledge similarities between people with and without disabilities and the facilitators which improve social and sexual acceptance and integration.

Disability and sexual identity. Public, interactional and private representations (or the lack thereof) of how people with physical disability experience their sexuality has a multitude of implications for the private formulation of their sexual identity (Cheng & Udry, 2002; Murphy, Molnar & Lankasky, 2000; Rurangirwa, Braun, Schendel & Yeargin-Allsopp, 2006). While contemporary societies work through the process of socio-sexual acclimatization to difference, some people with disabilities may feel inclined to downplay or separate the effect of impairment from their construction of their sexual identity. Overstreet (2008) analysed the disability/sexuality split exhibited by Texas Rose, a female porn-star with a physical disability and whose primary form of movement was her

wheelchair. Overstreet investigated the presence of visible markers of disability and sexual imagery on Texas Rose's website. In the majority of the photos analyzed there was no sign of Texas Rose's wheelchair. In addition Overstreet classified the types of sexual activities depicted when Texas Rose was in her wheelchair as tame which consisted of her posing, undressing, and blowing kisses.

When the wheelchair was partially or fully pictured but she is not sitting in it her actions consisted of applying sunscreen, blowing kisses, and holding her thong down to show her genitals. However, when her wheelchair was not pictured her actions were more sexual. These pictures showed her touching her breast, touching her hair and shoulder, mutual petting/she and another woman touching each others' arms, another woman using a tasseled whip to tickle Texas Rose's leg and holding her knee tied with a stocking, and Texas Rose holding and licking another woman's nipple. Portraying sexual activity as separate from disability is problematic. This research implies that sexual activity may be perceived by some viewers of pornography as unsexy when paired with disability or indicators of physical impairment. Consequently, people may privatize conditional portrayals of sexual activity, expression, pleasure and satisfaction. The conditionality of normalized constructions of sexuality may mean that someone with a disability may be perceived as sexier if they separate the indicators of difference from their sexual identity. However this type of restriction on individual constructions of sexual identity may impair one's ability to exercise choice and control over sexual experiences (McCormack et al, 2010).

Human Agency

Current understandings of human agency are epitomized by Bandura (1986, 1997, 2006). While investigating the role of self-efficacy in patients with phobic disorders in the

1960's, Bandura found that self-efficacy helped to mediate changes in behavior and fear. Following his findings he continued to pursue research which examined the influential role of self-referent thought in human psychological functioning (Bandura, 2006). Bandura (1986, 1997, 2006) offered a social cognitive theory of human functioning that accords a central role to cognitive, vicarious, self-regulatory and self-reflective processes in human adaptation and change. This social cognitive theory has its roots in an agentic perspective that views people as self-organizing, proactive, self-reflecting and self-regulating, not just as reactive organisms shaped by environmental forces or driven by inner impulses. According to Bandura (1997), human agency is the capacity for human beings to make choices and to impose those choices on the world. Bandura believed that human agency is based on the premise that humans do in fact make decisions based on a multitude of factors and enact them on the world (Bandura, 2006). The capacity of an individual to act as an agent is a subjective construction. Understanding of human agency as outlined by Bandura provides the basis for conceptualizing the creation and enforcement of sexual agency.

Sexual agency.

As defined by the World Health Organization (2011) sexual agency is a basic sexual right and includes “the right to have one’s bodily integrity respected and the right to choose—to choose whether or not to be sexually active, to choose one’s sexual partners, to choose to enter into consensual sexual relationships, and to decide whether or not, and when, to have children” (Parker, 2007, p. 973). Froyum (2009) suggests that sexual agency as not only the right to choose but also to seek knowledge and assert sexual desires. In addition, Wilkerson (2002) argues that sexual agency is not merely the capacity to choose, engage in, or refuse sex acts, but is a more profound good which involves a larger social dimension in which others recognize and respect one’s identity. Wilkerson’s

conceptualization of sexual agency expresses the interdependence of public, interactional and private experiences of sexual expression and behaviour. In this way, Wilkerson demonstrates the importance of sexual agency, a key component of the liberation struggles of all disenfranchised groups, rather than a luxury for those who are categorized as typical or something that can be addressed after achieving goals that might be perceived as more basic. This is particularly important in rehabilitative contexts for people with physical disabilities.

Sexual agency and disability. Wilkerson (2002) described many instances in which medical discourse, often in the very literal form of a doctor's words, denied the sexuality of people with disabilities. Three instances she reports include: A man and a woman who had spent years living in an institution for people with epilepsy wanted to marry, and requested permission of a doctor at the institution. They were told "that they could get married, but they were not allowed to have sex" (p. 48). She also reports an instance in which a paraplegic woman was denied her oral contraceptives by her doctor: "about four days after I broke my back I asked my surgeon, 'I don't have my birth control pills with me. Is there something I can do about that?' He said 'Well, you don't need those anymore,' and walked out of my room" (p. 34). Wilkerson also tells of the abuse of a young boy with an intellectual disability: a young man living in an institution masturbated in the presence of others "by rubbing his thighs together when sitting down. So the staff at the institution attached sandpaper to the insides of his thighs" (p. 34). In each of these instances the relationship between disability and sexual identity and agency, are determined and controlled by healthcare providers. Considering the influence of public and interactional factors on sexual agency people with disabilities may experience a sense of powerlessness. Particularly, interference with the sexual agency of an individual caused by unnecessary or

unfair restrictions, penalties, and coercion, denies people with disabilities access to important information about their sexual rights and the discovery and exploration of their sexuality.

Portrayals of positive sexual identity, agency and disability are being represented. Abbott (2010) drew on theory, literature and art to explore representations of embodiment that are produced at the intersections of queer studies and disability studies. According to Abbott the acknowledgement of different manifestations of the human body as sexual is being realized through the Arts. For example, performance artist Flanagan and performance collective Sins Invalid create theatrical representations of the intersection of disability and sexuality. In their performances, these artists assert the experiences of “queer” and “disabled bodies” as sites of knowledge, agency, exploration, respect and pleasure. Abbott (2010) notes that by “embracing vulnerability and interdependence, by imbuing the individual with the agency to re-imagine the socially produced body, and by rooting these struggles in community, the work of these artists fiercely locate liberatory struggle in the body” (p. 12). This is to say that people with physical disabilities may have to struggle to integrate experiences of disability into their experiences of sexuality and experiences of sexuality into their experiences of disability. In doing so these individuals can create a sexuality which holistically reflects their thoughts, feelings, choices, desires and actions.

Constructions of Sexual Self

The consolidation of sexual identity and its place in relation to the sexual identity of others is mediated by public, interactional and private influences. It may be however that people with disabilities may construct their sexual selves (and perhaps their sexuality) differently than prescribed or expected. In this way sexuality for atypical populations may not exist as a script in which one must play a role but as an individual creation which is

asserted, experienced, developed and negotiated through oneself and, potentially, others. However, due to the prevalence of hegemonic sexual schemas people with disabilities may experience barriers when attempting to privatize their experiences of sexuality in relation to others. The contention some people with disabilities may experience due to the differences between popular constructions of sexuality and their own may have a detrimental effect on their ability to privatize a positive sense of sexual self.

Barriers to constructions of a positive sense of sexual self.

According to Nosek et al. (1996) people with physical disabilities face pervasive, persistence and significant barriers to expressing their sexuality. Some of these barriers include; the built environment, societal attitudes, and the way in which people with disabilities are treated by their parents, families, peers and other social figures. As mentioned above, how one's identity is consolidated depends on their experiences with their environment. According to Daniluk (1998) the sexual self is characterized by ones individual identity along with socio-cultural variables:

The sexual self is a fluid, complex entity consisting of various forms of self-relevant knowledge...beliefs and perceptions that a [person] holds about the sexual aspects of [themselves]...it involves physical and biological capacities, cognitive and emotional development, and evolving needs and desires. It is a product of the public, the person and the political, the individual and [their] context. (p. 15)

Conceptualizations, or one's sense of, sexual self as per Gagnon and Simon (1973) are found in the intrapsychic (or private) level of sexual scripts. As mentioned, private sexual script involve mental rehearsals of sexual(ized) scenarios, by drawing on fantasies, memories, desires and arousal as well as preferred methods of engaging in ones sexuality. In his

theoretical chapter on the modern constructions of sexual self Kimmel (2010) stated that “fashioning a sexual-self is based on drawing on others’ sexual stories in order to tell one’s own” (p. 12). Kimmel further discussed reality TV and internet dating as methods through which one’s sense of sexual self in contemporary societies was created, measured and presented. However, the representations of socio-sexual scripts within these media often do not encompass portrayals of disability or obvious difference. In essence privatizations of sexuality which include or exclude conceptualizations of disability influence how people with disabilities perceive themselves as sexual beings.

For instance, McCabe and Taleporos (2003) investigated the association between the severity and duration of physical disability and sexual esteem, sexual depression, sexual satisfaction, and the frequency of sexual behavior. Their quantitative study included 748 participants who had a physical disability and 448 people who did not. They found that people with more severe physical impairments experienced significantly lower levels of sexual esteem and sexual satisfaction and significantly higher levels of sexual depression than people who had mild impairments or who did not report having a physical impairment. McCabe and Taleporos believed that the socio-sexual barriers people with severe physical disabilities experienced were often detrimental to their ability to attribute positive thoughts about themselves and their sexuality. Hence, the relationship that a person with a physical impairment has with his or her body can substantially influence how he or she relate to their sexuality and ability to negotiate intimacy with potential sexual partners (McCabe & Taleporos, 2003). In Comfort’s (1978) discussions on the sexual consequences of disability he summed up the situation as follows:

Besides the pressures of folklore, individuals whose mobility is limited or whose deformity is evident are exposed to other forms of attack upon

their sense of worth and desirability. Cultural constructs, such as a wholly unrealistic emphasis on physical beauty or strength as an index of being desirable, and the practical barriers of finding a partner, all combine to make the aim of sexual self-validation seem better given up; the relief of hospital staff and relatives with this renunciation becomes evident and may contribute to it, even though they do nothing to remedy the frustration and loss of self-value which may accompany it. (p. 3)

As the body is perhaps the most apparent basis upon which humans interpret and judge another the privatization of conceptualizations of one's body is important to constructions of one's sexual self.

Body image.

Body image is an important factor in how humans conceive of themselves physically and is an integral part in the conception of sexual self (Grogan, 2008). Taleporos and McCabe (2002) defined body image "as the combination of an individual's psychological experiences, feelings and attitudes that relate to the form, function, appearance and desirability of one's own body which is influenced by individual and environmental factors" (p. 971). Body image is of significant importance to people with physical disabilities as their bodies may not function or look the same as typical bodies. As such, the influence that physical impairment has on perceptions of body image may affect how people with disabilities relate to themselves and others sexually (Hong, Nam, Lee & Jeong, 2006) and the formation of body esteem. Body esteem is connected to the value one places on his or her body image and refers to the "overall positive or negative evaluation of the body" (Lease, Cohen & Dahlbeck, 2007 p. 399).

Although issues surrounding body image and body esteem are central to the formation of sexual identity for people with (physical) disabilities minimal research has specifically been conducted in this area. Of note however is the body of research conducted by Taleporos and McCabe, which specifically explored the effect physical disability had on ones sense of sexual self, is exemplified in their publications related to body image and body esteem such as; 1) which aspects of body image were most likely to cause concern for people with physical disability (Taleporos & McCabe, 2002a); 2) how people with physical disabilities experience and respond to social attitudes towards physical difference and how this affects their body image (Taleporos & McCabe, 2002b); and 3) the relationship between sexuality and psychological well-being among people with physical disabilities compared to typical others (Taleporos & McCabe, 2002c). The results of these canonical studies will be explained within the discussions to which they best contribute below.

Body esteem.

According to Taleporos and McCabe (2002c) body esteem refers to the perceptions an individual has about their own body. Moreover, these perceptions are linked to and influenced by an individual's identity, body image and experiences. Moin, Duvdevany and Mazor (2009) explored the association between sexual identity, body image and life satisfaction among women with and without physical disabilities. Their quantitative research included 70 women with disabilities and 64 without in Israel. Data was collected via the Sexuality Scale, Body Image Scale and Quality of Life Questionnaire. Moin et al. found that although women with physical disabilities had the same sexual needs and desires as women without disabilities, the way women with disabilities perceived their bodies was more negative. Specifically, some of the women with physical disability felt that their bodies were physically and sexually unattractive.

As such, some people with physical disabilities perceived disability as the antithesis of attractiveness. These findings reinforce data which implies that people with physical disabilities generally perceived bodies without physical impairments as more attractive and desirable (Cheng, 2009; Hahn, 1988; Potgeiter & Khan, 2005). However, some women with disabilities felt the same way about their bodies and sexual selves as the women without disabilities. Moin et al. (2009) found that experiences of a lowered sense of sexual self due to negative perceptions of one's body was stronger among the younger participant's with disabilities than among the more mature women with and without disabilities. It was also found that sexual satisfaction was a major factor in explaining the variance in life satisfaction in both groups, and the relationships between sexual satisfaction and life satisfaction were bidirectional. At the same time, different patterns of congruency and inconsistency between sexual satisfaction and life satisfaction were exposed in both groups. In addition, the research demonstrated a moderating effect of family status on links between sexual and life satisfaction.

The results from this study imply then that perceptions of one's body act as important mediators in the development of a positive sense of sexual self. While the focus of this study was on women some understandings of the factors which influence constructions of sexual self can be useful for other populations. For many people with physical impairments factors which are external to individual impairment are implicated in the constructions and perceptions of body image and body esteem.

Although the physical impairment may be an obvious external characteristic for some people with physical disabilities, a theme of increasing acceptance of their body is noted (Ferreira & Fox, 2008). As such, people with physical disabilities who perceive their body positively often accept features that they thought were less attractive and focused on

the positive aspects of their body. The acceptance of less positive features is enhanced by the recognition that even typical others are not perfect and could not achieve so-called physical perfection (Grixti, 2008). Many of the participants in Taleporos and McCabe's (2002a) mixed methods study expressed that they were comfortable with their body and were not especially concerned with attempts to disguise or hide their physical impairments or disabilities. In addition, their data showed that people with physical disabilities did not necessarily believe that bodies with disabilities were wholly unattractive.

Here an important distinction was made by a participant from Taleporos and McCabe's research between feeling sexy and looking sexy. Feeling sexy related to feelings of confidence within oneself as a sexual being, who was sexually interested, active and responsive. Feeling like one looks sexy relates to feelings about how other people perceived their body. Hence, the body may be perceived as unattractive or attractive in relation to the context in which it is being interpreted. However, Taleporos and McCabe maintain that "it is important to recognise that bodily dissatisfaction in people with disabilities may be more likely to stem from the limitations or even pain that their disability causes rather than from the altered appearance that their disability creates" (p. 307).

Influences on perceptions of body image. The perceptions people with disabilities have about their bodies may be built on previous experiences and opportunities to develop or participate in intimate relationships. As such, feedback from the social environment is a powerful mediator of body esteem among people with physical disabilities (Palombi & Mundt, 2006). Quantitative research by Lease et al. (2007) investigated whether body and sexual esteem mediated the associations between sexual satisfaction, perceived severity of the disability, and social perceptions of the disability and interpersonal competencies. The data from 326 web-based questionnaires indicated that sexual satisfaction, social

perceptions of the disability, and perceived severity of the disability significantly predicted competence with relationship initiation for the male participants. For men, higher levels of sexual satisfaction and social perceptions of their disability predicted competence with negative assertion (i.e., disagreeing with ones partner). Social perceptions of disability predicted both interpersonal competencies, and sexual satisfaction for the female participants. Lease et al. explained that these results demonstrated that participants' perceptions of their disability were mediated by their perception of their sexual attractiveness to others. As such, negative social attitudes about disability or physical impairment were unlikely to nurture the development of positive perceptions of one's body. Alternatively, Lease et al. indicated that positive social and sexual feedback can provide the basis for adjustment and acceptance of one's body and supports the formation of positive body image (see also Piotrowski & Snell, 2007).

Previous experiences of positive feedback may temper negative feedback for people with physical impairments. Moos and Holahan's (2007), for instance, discuss the effect of positive feedback for adaptation and coping in people with chronic illness and disability were discussed. The authors explained that while chronic illness and disability may be traumatising people often utilize coping skills, build closer relationships with family and friends, have broader priorities and richer experiences of life. The positive feedback experienced in these cases is from the experience of successful coping strategies. Moos and Holohan also emphasizes the importance of positive feedback from peers, family and healthcare providers as an important step in physical, social and mental rehabilitation. In terms of body image, people with disabilities can learn to integrate positive perceptions of their bodies with the help of friends, family and healthcare practitioners in order to promote the development of a healthy sense of sexual self.

Implications of perceptions of body image. The implications of a positive or negative sense of one's body can be expansive. Considering that sexual expectations, like physical perfection, may complicate perceptions of body image and esteem, people with (physical) disabilities may experience problems with depression and self-esteem related to concerns about their bodies, their sexual selves and their sexual lives (Esmail, Darry, Walter & Knupp, 2010; Moin, Duvdevany & Mazor, 2009; Sheilds, Murdoch, Loy, Dodds & Taylor, 2006). In fact, body esteem and sexual well-being are more closely associated with overall psychological well-being for people with a physical disability than for typical others (Taleporos & McCabe, 2002c; Taylor & Davis, 2007).

Physical impairment may have an impact upon the psychological experiences, feelings and attitudes people with physical disabilities have towards their own bodies. For example, Taleporos and McCabe (2002c) quantitatively examined the relationship between sexuality and psychological well-being among people with physical disabilities compared to typical others. Taleporos and McCabe found that sexual esteem, body esteem, and sexual satisfaction were strong predictors of self-esteem and depression among people with physical disability. In addition, this relationship was stronger for people with physical impairment than amongst their typical peers. Specifically the authors indicated that negative attitudes towards disability and physical difference made it difficult for people with disabilities to think of themselves positively. These results imply that at some point in the lives of participants with a disability, body image had been a serious struggle as negative social attitudes towards physical difference were privatized (see also Shuttleworth, 2000). They also found that body esteem was more closely associated with self-esteem for women with disabilities, while sexual esteem was more closely associated with self-esteem in men with disabilities. Taleporos and McCabe concluded that researchers and healthcare

practitioners concerned with the psychological well-being of people with physical impairments should consider strategies to improve the body esteem and sexual well-being of people within this group. If feelings of physical or sexual inadequacy are left to fester some people with disabilities may become more prone to abuse or assault than their peers who have been provided with readily accessible resources to cope with the psychological impact of disability.

Sexual and body esteem. Hassouneh-Phillips and McNeff (2005) examined the link between low sexual and body esteem and intimate partner abuse in women with physical disabilities based on findings obtained from 72 in-depth interviews. The authors found that women with high degrees of physical impairment were more likely to perceive themselves as sexually inadequate and unattractive than women with mild impairment. Hassouneh-Phillips and McNeff found that when women with a physical impairment were in fear of losing an intimate partner or not being able to negotiate/access a sexual relationship they were prone to lower their standards and make relationship choices which caused them to enter into an abusive relationship, stay in an abusive relationship or resolve to lowered sexual satisfaction. Poor levels of sexual esteem influenced women with disabilities to “settle” for partners who they felt/knew were incompatible. In this regard perceiving oneself positively may help people cope with feelings of loneliness or depression through the creation of an agential sense of sexual self. Taleporos and McCabe’s (2002c) qualitative study which investigated the social interaction between people with physical disabilities and typical others demonstrated that if people with disabilities feel good about their sexuality, their body and are sexually satisfied they are less likely to feel depressed and more likely to have high levels of self-esteem. However, the ability to create a positive sense of sexual self is mediated by many public, interactional and private factors.

Taleporos and McCabe (2002c) argue that this is a complex interaction that is mediated by, among other things, the nature of the person's disability and the degree to which their body deviates from the social ideal. This interaction, and the resulting social feedback, has a powerful impact on body image, which itself appears to be mediated by a number of factors including the amount of time since the onset of disability, social support and positive feedback. Ultimately, the perception a person with a physical disability has about his or her body has varying levels of impact upon the development of their sexual identity (and sense of sexual self) and subsequently their ability to create a positive construction of their sexuality.

Sexual esteem.

Another facet of the sexual self is sexual esteem. According to Hassouneh-Phillips and McNeff (2005) sexual esteem "refers to one's sense of self as a sexual being, ranging from sexually appealing to unappealing and sexually competent to incompetent" (p. 228). As sexual esteem is a factor which is influenced by perceptions of sexual identity Hassouneh-Phillips and McNeff suggest that perceiving oneself as a sexual being who is deserving of sexual attention can make a difference in regards to feelings about one's sexual worth. For example, Sakellariou (2006) explored the barriers that may compromise the sexuality of men with spinal cord injury in Greece. Through in-depth interviewing of the six men in the study Sakellariou found that several barriers inhibited the participants from exercising their right to a satisfying sexual life. These barriers included social beliefs and attitudes (e.g. social disapproval and exclusive notion of sexuality), lack of employment, inappropriate personal assistance and inaccessibility among others.

In regards to social disapproval, Sakellariou (2006) noted that the ability for someone with a physical disability to see themselves as sexually appealing and competent positively

influences their satisfaction with sexual activities/encounters and increases willingness to initiate and engage in sexual negotiations. As such, Impairment in itself was not viewed as a barrier, but instead the way in which impairment was socially constructed was the issue. While functionality and pain issues (amongst other factors) caused by physical impairment(s) are a significant problem for people with physical disabilities, they also have to endure environmental and social barriers which can exclude them from socializing with potential sexual/intimate partners. Sakellariou concludes that education in conjunction with the removal of environmental barriers may affect changes in public attitudes thereby increasing accessibility to sexuality for people with disabilities. In order to do so education about disability and their sexual rights is necessary.

Jemtå, Fugl-Meyer and Öberg (2008) investigated experiences of intimacy and sexual activity and exposure to sexual abuse among children and adolescents with mobility impairment. They examined these experiences of sexuality alongside socio-demographic data, disability characteristics and measures of well-being. Their data was collected through semi-structured interviews with 141 children with mobility impairments from 7-18 years in Sweden. They found that 50% of the participants had experienced a boyfriend/girlfriend type relationship and one fifth was involved in an ongoing intimate relationship. Of the adolescents, 15% had had at least one sexual relationship and another 15% were concerned about how their impairment would affect future sexual activities. Some youngsters with physical disabilities felt that it was harder to find a sexual partner due to their impairment(s). The authors noted that 7% of the students aged 13-18 reported a history of sexual abuse. However, the socio-demographic and impairment related factors had minimal influence on the experiences of intimacy and sexual activities as well as incidence of abuse. Jemtå et al. concluded that a lack of adequate and/or comprehensive sexual health

knowledge may reduce understanding of sexual rights for children with mobility impairments.

As mentioned, the lack of sexual or relationship information provided to children with disabilities may be due to the assumption that their chances at mutually satisfying sexual relationships are non-existent or they are not interested in sexual activity. While opportunities for sexual interactions may be reduced due to social and environmental barriers, there is no evidence to suggest that people with physical impairments experience lower levels of sexual need or experience less enjoyment in their sexual or romantic lives than their typical peers (Fraley, Mona & Theodore, 2007). Perhaps it is the case that research on experiences of sexuality and disability tend to focus on the kinds of sexual activities characterized by typical populations. People with disabilities may construct sexual activity differently thereby conceptualizing/perceiving themselves and their sexuality outside the parameters of hegemonic sexual scripts.

Perceptions of oneself as a sexual being. As mentioned previously, the perceived impact impairment has on the sexuality of a person with a disability varies subjectively. While some people with disabilities feel as though impairment and their sexuality are not necessarily linked (Jemtå et al., 2008) others feel that impairment interferes with their substantive ability to perform sexually and subsequently provide sexual pleasure to themselves and their partner(s) (Kolotkin, Binks, Crosby, Østbye, Gress & Adams, 2006). Guldin (2000) asserts that as so much of our sexual value is based on what we can do for our partner(s) and how well we can satisfy them, sexual esteem increases when we can show our partner(s) a “good time”. Guldin’s research is important to the discussion on sexual esteem as it explored how people with mobility impairments “self-interpret and self-claim their sexuality in light of cultural assumptions which largely desexualize them” (p. 233). In

her study of 7 participants, Guldin reported on one of her participants' experiences of sexual satisfaction through pleasuring his partner:

[Marv] believes that the tongue can elicit more pleasure from a woman than the penis and he considers his tongue to be more finely tuned than the tongues of non-disabled men who, according to Marv, only perform oral sex so the act will be reciprocated. (p. 236)

Guldin's data indicates that sexual satisfaction can be experienced in many and different ways. Her research reinforces that there are plenty of activities that people can engage in that are sexually arousing and satisfying without necessarily including penetrative sex.

Moreover, this group experienced high levels of sexual esteem and believed their creativity provided their sexual partners with a different and more sensual type of sexual satisfaction. Guldin explains that some of the participants in her research took more time with their partners and felt that this made them more thorough lovers which they viewed as more sexually rewarding in relation than experiences of sexuality characterized by sexual scripts based on typical others. Guldin suggests that:

This inversion of ability/disability, physically non-disabled men become sexually disabled by their lack of sexual skill and sexual introspection. This "sexual disabling" of bodies that are—according to cultural definitions—functional, challenges notions not only of the "sexual body" and "sexuality" but also of what it means to be "disabled." (p. 236)

Although there is variability in regards to how positive people feel about their sexuality, many people with physical disabilities feel that having a disability does not necessarily make them any less "sexy" than their typical peers (Guildan, 2000; Quinlan & Bates, 2008).

Influences on perceptions of sexual self. Several factors influence how people with disabilities perceive their sexuality. For instance, meeting normative sexual expectations, like that of sexual spontaneity, may play an important role in how people with disabilities feel about their experiences and constructions of sexuality. Meeting sexual expectations is often determined by an individual's ability to conform to public, interactional and private sexual scripts such as physical aesthetics and lifestyle (Metz & McCarthy, 2007). Considering that some public and interactional scripts may be unattainable for the typical population, people with disabilities may find conforming to some of the physical expectations within these scripts difficult to fulfil. Although the body (and its appearance) plays an integral part in conceptions of sexual identity and sexual esteem, how others perceive one's lifestyle is also important to the formation of sexual identity. For example, Mobius and Rosenblat (2006) found that individuals who are perceived to live an independent lifestyle and are self-reliant are assumed to be in control of themselves, their environments and their relationships. In their research Mobius and Rosenblat experimentally explored the effect of prospective employee "beauty" on employers' perceptions of the employees' ability to perform a maze-solving task and the remuneration they would receive for the task. The authors noted that the maze-solving task required genuine skill which is not affected by perceived attractiveness. They found that employee attractiveness influenced potential wages in three ways; (a) physically attractive workers were more confident and higher confidence increased wages, (b) for a given level of confidence, physically attractive workers were (erroneously) considered more able by employers, (c) controlling for worker confidence, physically attractive workers had communication/social skills which raised their wages when they interacted with employers. Mobius and Rosenblat noted that people who are attractive may receive higher wages regardless of their actual ability to complete tasks.

Receiving more money then translated into financial independence and social confidence. As such being perceived as independent was associated with confidence, success and therefore may make an individual seem more sexually attractive over people who are perceived as dependant. Many people with a disability, however, may require assistance with daily living, from assistive devices or from others which may characterize them as dependant (Reid & Knight, 2006).

People with disabilities who require daily care or utilize assistive devices, like those with moderate to severe Cerebral Palsy, may be perceived as lacking financial, social and sexual independence when compared to the socio-economic standards of the societies in which they live. However, restrictions on the ability to secure financial independence may be due to restrictive employment frameworks and the lack of inclusive employment opportunities or environments for people with disabilities. Barriers to social and sexual independence for people with disabilities may stem from the perception that they may not be a viable sexual option for others. As such, perceptions of one's sexual self may be tainted by feelings that they cannot live up to the expectations of an "independent" lifestyle (Lassmann, Garibay, Melchionni, Pasquariello & Snyder, 2007).

Hence, the image of the independent man or woman as sexy and desirable may have serious consequences on how people with physical disabilities think of their sexuality. In fact, qualitative research by Lassmann et al. (2007) indicated that people with physical disabilities often felt as though they are being treated like children by family, friends, peers and care attendants (see also Reid & Knight, 2006). As mentioned earlier, infantilizing and paternalistic behaviour towards people with physical disabilities sends the message that people with disabilities are not capable of making life/sexual choices, doing things for themselves or others/partners or being sexual agents. Consequently, the internalization of

these misconceptions may result in the person with a disability perceiving their sexuality as nonexistent or unimportant (Tepper, Whipple, Richards & Komisaruk, 2001).

Implications of perceptions of sexual self on sexual esteem. Social and environmental barriers that people with disabilities experience influence experiences of sexual satisfaction and sexual frustration. Laursen et al. (2005) assessed the importance of an active sex life, the ability to feel sexual desire, and the frequency of sexual intercourses in 40 females suffering from chronic pain syndromes and 41 healthy females. Data collected from 3 questionnaires revealed that an active sex life was more important to women in the control group than it was for those with pain syndromes. Of the women with pain disorders 53% reported that they were not able to feel sexual desire and had significantly lower incidence of sexual intercourse. These findings were linked to feelings of frustration for women with pain syndromes resulting in low levels of sexual esteem and negativity about oneself as a sexual being. The authors concluded that impairment had a significant influence on the perceived importance of an active sex life, the ability to feel sexual desire and sexually desirable, and the frequency of sexual intercourse for women with pain syndromes. However, Taleporos and McCabe (2002b) noted that for people with physical disabilities that the frequency of sexual intercourse was not a predictor of sexual satisfaction in women or men. This challenges the emphasis placed by some research, popular media, peers and healthcare institutions on the achievement of penetrative intercourse.

Guildin (2000) asserted that as it may be difficult to change physical characteristics /functionality of one's body it may be within an individual's control to dictate how they will behave while negotiating and/or engaging in sexual activities. As such, people with physical impairments may begin to experience and express their sexuality in ways that are more congruent with their abilities and learn various creative techniques in order to help them

enjoy their sexuality (Guildin, 2000). In this way, people with disabilities are encouraged to focus on how their sexual needs and desires can be met instead of trying to fulfil hegemonic expectations of sexuality perpetuated by the societies in which they live. As such, private acceptance of one's own disability as well as the acceptance of difference within others may improve feelings of sexual worth and positivity. This suggests that perhaps people with physical disabilities can experience high levels of sexual satisfaction from other types of sexual activities. By using their impairment(s) in sexually creative ways, people with physical disability may encourage feelings of sexual desirability and view themselves as an intimate option for others.

Sense of sexual desirability.

Sexual desirability is defined here as being considered physically and socially attractive by others which evokes sexual interest from others and results in being considered as a potential sexual partner. As such, it should be noted that although there may be a considerable portion of sexual desirability that is influenced by perceptions of physical attractiveness more subjective interactional factors are also involved (Kaufman, Kozbelt, Bromley & Miller, 2008). For example, Kaufman and colleague's (2008) theoretical paper indicated that people who are perceived by others as having a good sense of humour are likely to have more friends and social opportunities than their peers. More friends and social opportunities could possibly lead to more sexual opportunities and perceived desirability (Kaufman et al., 2008). Individual sexual desirability is also influenced by how one presents themselves (i.e. clothing and accessories), their level of confidence and positivity. Public sexual schemas further reinforce the perceived desirability of these traits and are advocated through popular culture as particularly attractive and sexy (i.e., *Cosmopolitan*, *Men's Health*).

Perceptions of ones attractiveness to others. Popular constructions of disability and sexuality which represent people with disabilities as sexually desirable mates are scarce. In their theoretical paper Glass and Padrone (1978) explain that “illness and disability remove the patient from accustomed personal, social, and sexual interactions, changing the entire life pattern . . . Feelings of self-worth and attractiveness are threatened at a time when need for intimacy and belonging is greatest, causing a sense of loneliness and isolation” (p. 42). Glass and Padrone acknowledged that positive experiences of sexuality and perceptions of sexual self were undermined by attitudes and assumptions which resulted from a lack of information experienced by people with disabilities as well as the various disciplines that serve them (i.e. medical, psychological and palliative). Participants in Murray and Harrison’s (2004) qualitative research, which explored the meaning and experience of being a stroke survivor, reported multiple disruptions in social interactions and believed themselves to be sexually undesirable and less likely to be chosen as a romantic partner than someone who did not have a visible disability. This is often due to the barriers to inclusion they experience when trying to fulfill the requirements of normative sex roles and hegemonic sexual expectations (Kaufman et al., 2008; Murray & Harrison, 2004).

Rintala et al. (1997) found that women with physical disabilities had self-defeating attitudes about their disabilities and ultimately themselves. Rintala and colleagues’ (1997) quantitative research explored the dating issues women with physical disabilities face. They found that external discouragement of sexual activity and behaviour lowered the women’s sense of sexual desirability. Participants of the Rintala et al. study expressed that when negotiating intimacy mutual attraction and flirting proceed normally until the potential partner realized they had a disability and suddenly changed their behaviour and they appeared to have lost interest. As such, some woman in their research devalued anyone

who chose to date them and had internalized the societal belief that in choosing them, the other individual must have something wrong with them and are 'damaged goods' as well (see also Phillips, 1990). As some people with physical disabilities feel that their disability is what restricts them from being thought of as a potential sexual partner some begin to socially invert. Due (1995) explains that "many people with disabilities fear they'll be screened out before they can even say hello. Some figure they'll not even try - and not trying can become a lifestyle" (p. 50). The mixture of how people with disabilities perceive themselves and how they are perceived by others has a definitive effect on their ability to negotiate and access satisfying sexual relationships.

Influences on ones sense of sexual desirability. As with body image and sexual esteem, ones sense of sexual desirability is influenced by the interplay of public, interactional and private sexual scripts. For example, negative perceptions (perpetuated through family, peers, media and the structural environment) held by typical others as well as people with physical disabilities act as barriers to intimacy and discourage opportunities for sexual interaction (Nosek et al., 1994; Ray & West, 1984). Howland and Rintala's (2001) qualitative research demonstrated that efforts to maintain a positive sense of self-worth, positive body image and feelings of attractiveness were threatened by pervasive social myths of disability and asexuality. Research indicates that when people with physical disabilities internalize and fulfill negative societal expectations their sense of sexual desirability is significantly impacted (Rintala et al., 1997).

Sense of sexual desirability for people with disabilities was also influenced by how others perceived the womens' choice of sexual partner(s). Women in Howland and Rintala's (2001) study explained that their partner's friends looked down on people who dated someone with a physical disability. Notably some of the women believed that if others saw

them with a partner with a disability it would increase their own stigmatization, and that they deserved better. One respondent explained:

I was involved with a man 25 years older than I was. He was disabled, I hate to say, because I don't like to date disabled people. I feel like it alienates me from the mainstream of society. I'm trying to break out of my disability. My attitude is, if I'm disabled, why would I want to link myself with another disabled person? I've never found any attraction to a disabled man. I couldn't pull someone else out of the black hole of disability. (p. 54)

In addition, friends and family may discourage people with physical disabilities from starting intimate relationships with someone without a disability as they believed "there must be something wrong with anyone who would date someone with a disability, that they must have some serious flaw that makes them unattractive to other able-bodied people" (p. 52).

Alternatively, some people resolve to lowered standards and are non-selective of potential mates (Hassouneh-Phillips & McNeff, 2005). Howland and Rintala (2001) indicated that the non-selective women in their study "felt pressured to go out with anyone who asked for fear of being left with no one, or to disprove their fear that they would never again be worthy of love" (p. 53). On the other hand, some people with physical disabilities became very selective and would only date someone who has a disability which they perceived as complimentary to their own or would not date someone who had a disability at all (Hassouneh-Phillips & McNeff, 2005; Howland & Rintala, 2001). Howland and Rintala explained that some of the more selective heterosexual women in their study may perceive a man with a disability as unable to fulfill their image of masculinity and husbandry therefore making men with disabilities less sexually desirable.

The effect that sexual expectations and sexual stigmatization impose on feelings of self-worth and attractiveness (sense of sexual desirability) is detrimental to how people with physical disabilities choose their partners. As such, Howland and Rintala expound a pervasive societal assumption about disability and sexual negotiation:

Since they are lucky to get anyone to ask them out on a date, the societal view is that they should be grateful for the attention of any[one], even if [they are] abusive and contributes little or nothing positive to their relationship. In other words, they should take what they can get or go through life without a partner. (p. 41)

What is apparently missing for people with disabilities is the provision of adequate and accessible education, relationship information, counselling and social support. The provision of these services would help to facilitate improvements in understandings and acknowledgements of the sexual rights and social entitlements for people with disabilities. In doing so, the reconfiguration of private sexual scripts for people with and without disabilities about disability can be executed.

Issues to be Addressed

The literature indicates that disability and impairment have a distinctive effect on the formation of sexual identity and the implementation of sexual agency. In this regard, recent literature is in line with the goals of this thesis which will explore how people with disabilities construct their own sexuality through an inquiry of their sexual identity and sexual experiences. The main difference between previous academic explorations of the factors which influence private constructions of sexuality in people with disabilities is that this thesis is particularly focused on people with Cerebral Palsy who (as mentioned) are an understudied group.

In addition, contemporary literature which analyzed the effect private influences (i.e. perceptions of body image and body esteem, sexual esteem and perceptions of sexual desirability) have on disability reflects to goals of this study. Through the collection and analysis of data about the effect personal and private factors have on individual constructions of sexuality this thesis aims to contribute to contemporary understandings of sexuality for people with Cerebral Palsy and ultimately people with disabilities.

Summary and Conclusion

Constructions of sexuality are partly created through private mental processes which involve inner dialogue (Emerson, 1983). Through these private mental processes individuals may internalize sexual scripts which consolidate perceptions and constructions of their sexuality. However, it seems as though the private sphere of sexuality and disability has yet to fully reap the benefits of societal change towards issues of inclusion, acceptance and education about disability.

Through open discourse about the public, interactional and private factors which influence constructions of sexuality for people with disabilities comes awareness of the barriers which may inhibit sexual participation and prompt awareness and understanding (Kazukauskas & Lam, 2010). In doing so, sexual expression, pleasure, intimacy and ultimately satisfaction are acknowledged as essential to the formation of inclusive constructions of sexuality and disability.

Chapter 6: Method

This chapter focuses on the research methods used within this study. As such, this chapter will present the research design used within this study and its importance to the research objectives. This chapter will also discuss the utility and results of the pilot study used to test the trustworthiness of the study protocol. Finally, the main study design will be presented and discussed.

Research Design

Qualitative methodology was used for this investigation in order to compliment the hermeneutic phenomenological framework upon which this study was based. Hermeneutic phenomenology aims to answer questions about the meaning of being, the self and self-identity (van Manen, 2002). According to McCarthy (2010) in order to better understand psycho-social experiences of impairment and disability researchers should effort to explore the lived experiences of their participants.

Qualitative research employs a naturalistic approach which seeks to comprehend phenomena in specific settings, such as "real world settings [where] the researcher does not attempt to manipulate the phenomenon of interest" (Patton, 2001, p. 39). In this regard, qualitative methodology is broadly defined as "any kind of research that produces findings not arrived at by means of statistical procedures or other means of quantification" (Strauss & Corbin, 1990, p. 17) (see also Creswell, 2007, 2009) and instead, the kind of research that produces findings arrived from "real-world" settings where the "phenomenon of interest unfold naturally" (Patton, 2001, p. 39).

Ajjawi and Higgs (2007) stated that in the context of hermeneutic phenomenological inquiry, qualitative methodology "enabled access to a phenomenon that is often subconscious and provided a means of interpreting participants' experiences of personal

learning journeys” (p. 612). A qualitative methodology aims to explore phenomena in its nuanced richness was appropriate for this study whose goal was to understand insider perspectives of constructions of sexuality by people with Cerebral Palsy.

Insider Perspectives

Insider perspectives refer to individual participant interpretations of a construct or phenomena (Liamputtong, 2010; Silverman, 2009). An insider perspective allows for the exploration of concepts from the participants own perspective(s). Rich descriptions result from qualitative exploration of insider perspectives. In turn rich descriptions allow for interpretative conceptualizations important for comprehensive understandings (Mayoux, 2006). This thesis explored insider perspectives of Cerebral Palsy; how they construct their sexuality and the factors that influence that process. Descriptive data acquired from in-depth interviews contributed to an understanding of the ways in which people with Cerebral Palsy construct their own sexuality in light of normative cultural sexual expectations.

Qualitative Interviews

Qualitative interviews allow narratives or stories of people’s experiences, local histories, and shared knowledge important to how they construct meanings (Patton, 2001; Silverman, 2009). Interpretive sexual scripts capture how people understand personal sexual experiences in relation to others (Jackson & Scott, 2010; Simon & Gagnon, 1986). Qualitative interviews enable an understanding of how people explain and communicate meanings people give to their lives. The in-depth interview techniques used in this study were interactive conversations between the investigator and participants to explore contextual, interactive and personal sexual scripts. In order to do so successfully this project and its procedures were assessed for trustworthiness.

Issues of Trustworthiness within a Qualitative Study

Almost two decades ago, Lincoln and Guba (1985) posed the question: "How can an inquirer persuade his or her audiences that the research findings of an inquiry are worth paying attention to?" (p. 290). This question highlights the importance of a trustworthy account of human experiences and their utility. According to Patton (2001) trustworthiness is a factors which every qualitative researcher should concern themselves with while designing a study, analyzing results and judging the quality of the study. In qualitative paradigms the term "trustworthiness" encompasses "credibility," "transferability," "dependability," and "confirmability" (Tipping, Scholes & Cox, 2010). Credibility is the evaluation of how well the study's findings represent a sound conceptual interpretation of the data which comes from participant data (Hoffman, 2010). Transferability is the potential of the study's findings to transfer to other settings. Dependability is the assessment of the quality of the collective processes which include data collection, analysis, and theory production. Finally, confirmability is a gauge of the level to which the study's findings are supported by the collected data (Tipping, Scholes & Cox, 2010). These qualities are important in qualitative inquiry as they affirm the value and utility of one's research findings (Patton, 2001).

Sampling Frame

The sampling frame comprised adults living with moderate to severe Cerebral Palsy within Australia and Canada. In this study moderate Cerebral Palsy was defined according to levels three, four and five of the Gross Motor Function Classification System (Palisano, Rosenbaum, Walter, Russell, Wood & Galuppi, 1997, see Appendix B). In addition, adults with Cerebral Palsy who were subscribers of disability newsletters, magazines and/or who

were members of Cerebral Palsy groups and associations in Australia and Canada were specifically recruited.

The sampling frame for this study was inclusive a variety of living arrangements. For instance, individuals who lived with their families, with their friends, within residential institutionalizations, those who required daily assistance from others and those who did not require daily assistance from others were included. Individuals under 18 years of age, with mild symptoms of Cerebral Palsy or those with intellectual impairment(s) were not included in the sampling frame. This study sought out participants with moderate to severe Cerebral Palsy regardless of habitation, with whom they lived, ethnic or cultural background, religious affiliation, sexual orientation or nationality.

Considering the many configurations and the continuum of severity of Cerebral Palsy (see Chapter 1) each participant will possess different physical and mental capacities. In this regard, it was important to ensure that individuals included in the sampling frame could be accommodated by the study. In order to ensure that the study was viable a pilot study was conducted.

Pilot Study

A pilot study was conducted to pretest the study protocol; including the establishment of networks, assessing accessibility, assessing trustworthiness and the amendment of issues identified. According to van Teijlingen, Rennie, Hundley and Graham (2001) “advantages of conducting a pilot study is that it might give advance warning about where the main research project could fail, where research protocols may not be followed, or whether proposed methods or instruments are inappropriate or too complicated” (p. 1). As such, the goals of the pilot study were to:

1. Establish the networks in which to locate possible participants with Cerebral Palsy who fulfilled the inclusion criteria (see Table 6.2).
2. Assess the cognitive and procedural accessibility of the interview guide (see Figure 6.1).
3. Assess the trustworthiness of the interview guide (see Appendix C) as a tool for understanding constructions of sexuality as created and experienced by people with Cerebral Palsy.
 - a. Assess whether people with Cerebral Palsy discuss their sexuality in ways that mirror public, interactional and private sexual constructs (credibility).
 - b. Assess whether the data collected through the interview guide can be found in similar populations of people with Cerebral Palsy (transferability).
 - c. Assess whether the data collection, data analysis and theory generation processes of the study were consistent and repeatable (dependability).
 - d. Assess the influence of the researcher and/or their bias on the study's findings in relation to the data collected (confirmability).
4. Anticipate and amend any logistical and procedural issues or limitations related to the study.

Participants

In selecting participants for the pilot study, consideration was given to demographics, levels of mobility and acquired assistance, socio-economic status, medical interventions, living arrangements and sexual profile (also see Table 6.1 for a summary of participant profiles). These factors were important to study as they provided contextual

information about participants and their perspectives. Data on these variables would allow a comprehensive analysis of participant's experiences of disability and sexuality.

Demographics.

A convenience sample of three adults with Cerebral Palsy (23 to 36 years of age) and living in New South Wales, Australia participated in the pilot study. Of these three participants one was female and the remaining two were male. The female participant had Spastic Paraplegic Cerebral Palsy (SPCP), one male had Spastic Quadriplegic Cerebral Palsy (SQCP) and the other male participant had Ataxic Quadriplegic Cerebral Palsy (AQCP). SPCP is characterized by the lower extremities being affected with little to no upper-body spasticity. People with SQCP are least likely to be able to walk due to impairment of all four limbs. If people with SQCP can or want to walk their muscles are too tight making it too much effort to do so. AQCP is characterized by difficulty with dexterity and precise use of all limbs and appendages. For all participants mobility was moderately or severely affected by impairment. It was important to understand how participant demographics would likely influence how participant's harmonized their experiences with impairment and disability with their sexuality.

Mobility and assistance.

The two male participants required the use of a mechanized wheelchair to assist in mobility and the female participant often used crutches to assist in mobility. One of the male participants had a noticeable oral/facial muscle impairment which affected eating (mastication), speaking (annunciating words and expressing thoughts and opinions), breathing and drinking (sucking and swallowing). The male participants had severe Cerebral Palsy which required significant daily assistance in order to complete quotidian tasks. As such, they enlisted the help of their parents (most often their mothers), paid personal care

attendants and on the occasion friends and other family members to complete daily activities. The quality of paid care they received was also facilitated by their ability to access funding from social services. In relation to Cerebral Palsy, the behavioural profile of the participants can be characterized as typical. Being aware of participant's behavioural profiles facilitates understanding of the influence disability has on how people with Cerebral Palsy construct their sexuality.

Socio-economic status.

All participants for the pilot study were Caucasian Australians and of middle to upper-middle class background. The three participants had received tertiary education in Australia and pursued activities within their fields of study. The male participants were actively involved in sporting clubs, community groups and leisure activities while the female participant had full-time employment in addition to community, sport and leisure activities. In this regard participants had access to social involvement. However, due to restrictions in mobility due to infrastructure and impairment all participants had experienced medical interventions to facilitate mobility. Although participants of the pilot study could be classified as privileged they may share some of the same socio-cultural experiences as individuals from lower (or higher) socio-economic status (i.e., ethnicity, access to basic health services, citizens of a developed country and access to similar educational opportunities).

Medical intervention.

All participants had experienced significant medical intervention through major surgeries during childhood and early adolescence. A history of medical health care meant participants would likely be reliably retained. The medical interventions they experienced required all of the participants to endure a number of long recovery periods, extended stays

in medical institutions and life-long rehabilitative commitments. These experiences and commitments meant that some of the participants felt that rehabilitative activities were necessary before and after sexual encounters to facilitate ease of movement during sexual activities or to prevent stiffness or pain afterwards. Due to differing levels of physical mobility each participant's living arrangements complimented their abilities and facilitated independence.

Living arrangements.

In terms of living arrangements the youngest male participant lived in an independent living facility at the time of their interview. The female participant lived with her partner at the time of the interview. The eldest male participant reported that he lived at home with his mother and had lived with his parents for the most of his life. Each participant had engaged in different sexual activities prior to the time of the interview. While privacy may be limited for people with moderate to severe Cerebral Palsy due to the daily and consistent involvement of caregivers projections about the correlation between living arrangements and sexual activity cannot be made.

Sexual profile.

All participants identified as heterosexual. One of the male participants indicated that he had had engaged in sexual activities with men. Of the three participants interviewed only the female participant was in a steady sexually intimate relationship. She described her partner as physically and mentally typical. The male participant with Spastic Quadriplegic Cerebral Palsy had engaged in sexual activities and intimacy with himself and others but had not yet been involved in a steady sexually intimate relationship. Prior to the interview the male participant with Ataxic Quadriplegic Cerebral Palsy had been in a steady sexually intimate relationship for four years. As per the pilot study participants, people with Cerebral

Palsy do not experience sexuality in the same way(s). The heterogeneous nature of sexual experiences for this group suggests that the pilot study will capture information which mirrors experiences of sexuality of potential main study respondents.

Table 6.1 Pilot Study Participant Summary

Participant	Sex	Type of Cerebral Palsy	Assistive Devices or Services	Socio-economic Status, education and ethnicity	Medical Interventions	Living Arrangements	Sexual Profile
Participant 1	Female	Spastic Paraplegic Cerebral Palsy (moderate)	Crutches	Upper-middle class, tertiary education, Caucasian Australian	Major musculoskeletal surgery during childhood and adolescence. Rehabilitative maintenance.	Lived with her partner independently	Heterosexual, in a long term sexual relationship at time of interview
Participant 2	Male	Spastic Quadriplegic Cerebral Palsy (severe)	Mechanized wheelchair, daily personal assistance from others	Middle class, tertiary education, Caucasian Australian	Major musculoskeletal surgery during childhood and adolescence. Rehabilitative maintenance.	Lived with his mother in his family's home	Heterosexual, sexually active, no history of sexually intimate relationships
Participant 3	Male	Ataxic Quadriplegic Cerebral Palsy (severe)	Mechanized wheelchair, daily personal assistance from others	Middle class, tertiary education, Caucasian Australian	Major musculoskeletal surgery during childhood and adolescence. Rehabilitative maintenance.	Lived in an independent living facility	Heterosexual, history of long term sexually intimate relationship

Establishing Networks for Participant Recruitment

To establish networks for the recruitment of eligible participants four sources were: 1) requesting participation from major Cerebral Palsy organizations in Australia, 2) disability/Cerebral Palsy newsletter or magazines, 3) Sydney-based community centres or advocacy groups and, 4) snowballing (see Table 6.2). A multipronged recruitment strategy was piloted to allow members of different communities the opportunity to participate in the study. In doing so, the study could capture the experiences and perspectives of sexuality from a variety of individuals.

People with Cerebral Palsy are a hidden population in that it may be difficult to gain access to members without being a part of the community (Rhodes, Bowie & Hergenrather, 2003). As such, diverse but complementary approaches to participant recruitment, such as those used in this study, are recommended for recruiting hard to reach or hidden populations (Ompad et al., 2008).

Major Cerebral Palsy organizations.

First, major Cerebral Palsy organizations in Australia were identified through a Google search. Of the many results displayed only those which only focused on Cerebral Palsy in Australia were of interest. The researcher then telephoned the major Cerebral Palsy foundations, associations and organizations (i.e., Cerebral Palsy Foundation, Spastic Centre, Cerebral Palsy Australia, The Centre for Cerebral Palsy and Cerebral Palsy League) in Australia and requested their participation in the project (see telephone script in Appendix D). Of the five organizations contacted in Australia the Cerebral Palsy Foundation and the Spastic Centre agreed to participate in the promotion of the study to their members/subscribers.

Disability newsletters and magazines.

I carried out a search through Google in Australia for major disability newsletter or magazines which catered to people with Cerebral Palsy. Those which were based in New South Wales, Australia were shortlisted. The researcher then telephoned each newsletter and requested their participation in the project (see telephone script in Appendix D). Of the four newsletters contacted; 1) The Scene Newsletter, 2) SX News, 3) Warringah Disability Newsletter and 4) IDEAS Newsletter, The Scene and the Warringah Disability Newsletter were the only two who agreed to facilitate this study and ran the study advertisement (Appendix E) for one year and six months respectively.

Community and advocacy groups/centres.

Google community and advocacy groups/centers which catered specifically to people with Cerebral Palsy were searched. As there was a large number of results only those organizations in Sydney, New South Wales, Australia which had had programs specifically designed for or which catered to people with Cerebral Palsy were contacted (Disability Services City of Sydney, Mary McDonald Activity Centre, Harry Jensen Activity Centre, St. Helen's Community Centre, Cliff Noble Activity Centre and Ron Williams Activity Centre). The researcher subsequently sent each facility a letter (see letter in Appendix F) requesting if the researcher could present the project to their constituents with Cerebral Palsy. The letter was also followed up by a telephone call and/or email to ensure the letter had been received and considered. Of the six community centers contacted all indicated that they no longer had active disability programs/gatherings and were therefore unable to participate.

Snowballing.

The snowballing technique was utilized at the end of each participant's interview, to identify others they knew who met the eligibility criteria, and if so, whether she or he would be willing to give that person a copy of the participant information sheet (Appendix G). The investigator did not know the identity of this person, and the interviewee did not know if that person agreed to participate in the project or not.

Table 6.2 Establishing Cerebral Palsy Networks Summary

	Strategy			
Steps	<u>Cerebral Palsy Organizations in Australia</u>	<u>Disability Newsletters and Magazines in Australia</u>	<u>Community Centres and Advocacy groups catering to people with Cerebral Palsy</u>	<u>Snowballing</u>
1	Google search and telephone calls	Google search and telephone calls	Google search and telephone calls	Asking participants if they knew someone who could be included in the sampling frame (x = 3)
2	Refined to major organizations which cater exclusively to people with Cerebral Palsy and their families in Australia (x = 5)	Refined to newsletters which catered to people with Cerebral Palsy particularly in New South Wales (x = 4)	Refined to community centres in Sydney, New South Wales, Australia that had (had) disability programs/events for people with Cerebral Palsy (x = 6)	Giving the participant a copy of the Snowball Participant Information Sheet
3	Telephoned all 5 organizations	Telephoned all 4 organizations	Letter sent to all 6 organizations. Email or phone call used to follow-up	The participant gives the Snowball Participant Information Sheet to someone they know
4	Posted advertisement for the study on organization website or within their newsletter(s) (x = 2)	Posted advertisement for the study on within hardcopy newsletter(s) and newsletter webpages (x = 2)	None of the community centre had the resources or participation in the disability programs to participate	The individual the participant gives the Snowball Participant Information Sheet to contacts the researcher
Resultant Participants	1	2	0	0

Assessment of the Cognitive and Procedural Accessibility of the Interview Guide

To ensure that the interview guide was accessible to all potential participants Fry's readability analysis was applied to assess cognitive accessibility. Procedural accessibility was assessed through the provision of different methods for people with Cerebral Palsy to participate.

Readability analysis.

The interview guide was assessed using Fry's (1968) readability graph (Figure 6.1) which includes reading/grade levels from early childhood to adulthood. To gauge the readability of a text one must calculate the number of syllables and sentences for three 100-words passages to compute a result in school years. Considering that the interview guide is organized as a series of questions, to create 100-word passages several questions were calculated together and each question was treated as an individual sentence. Of the 261 words assessed, 26 sentences/questions and approximately 500 syllables the pilot study interview guide lies between a grade 5 and grade 7 level of reading. Considering that all the participants successfully completed tertiary studies their reading level would exceed that of a 5th, 6th, or 7th grade pupil. As such, cognitive accessibility could reasonably be assumed.

Fry Graph for estimating Reading Ages (grade level)

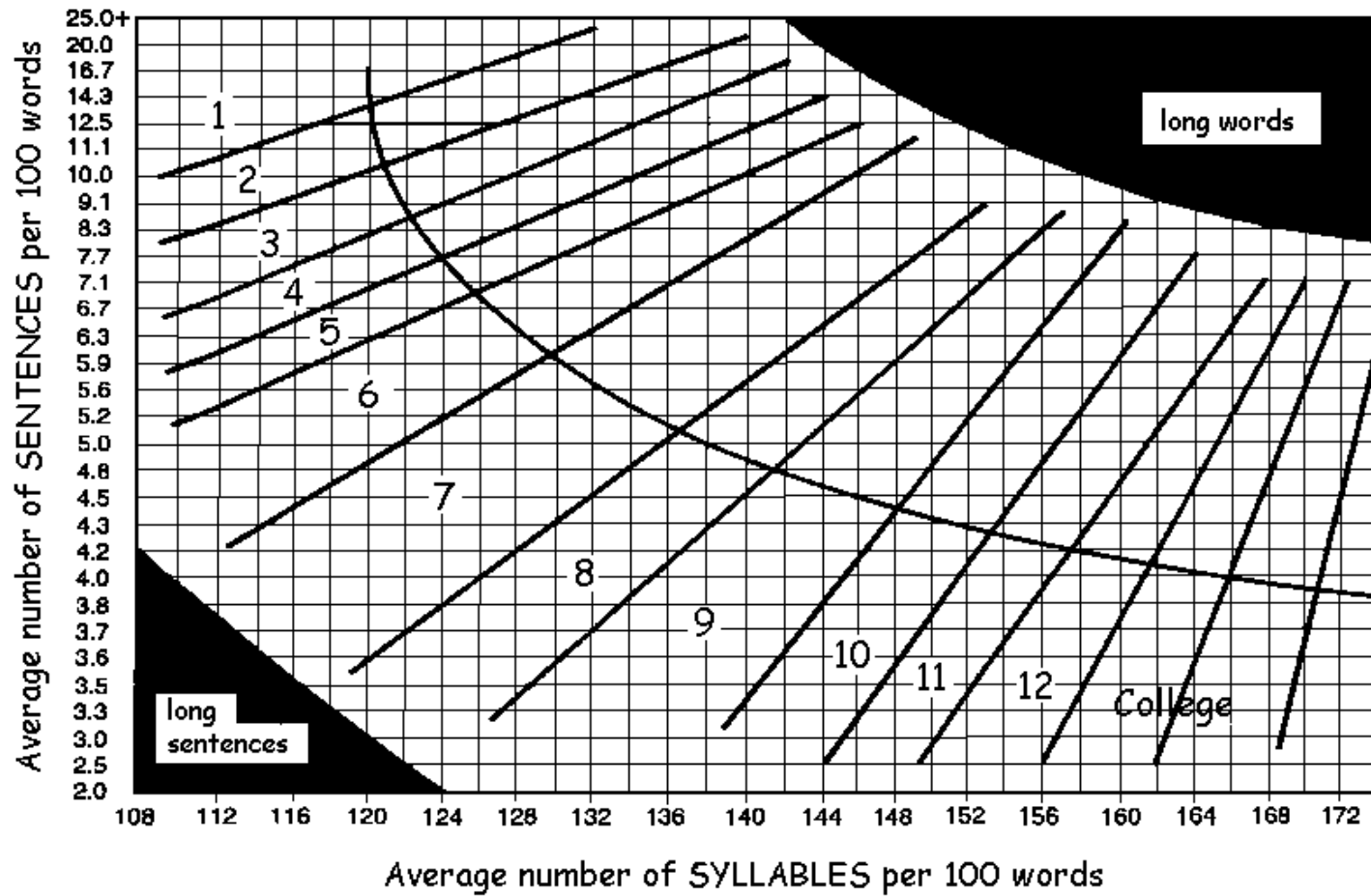


Figure 6.1. Fry's Readability Chart (Adapted from school.discoveryeducation.com)

Procedural accessibility.

Procedural accessibility within this study refers to the availability of data collection techniques which could accommodate the needs of potential participants. The procedural accessibility was assessed through the provision of different social mediums for participation in the study: face-to-face, via telephone or Skype, via email or any combination. All the pilot study participants reviewed the options for participation (within the Participant Information Sheet (see Appendix F)) and decided independently which one suited them best. For instance, some people with moderate to severe Cerebral Palsy may have difficulty with oral communication and an interview guide sent via e-mail to be would be more appropriate. Participants were also offered a telephone interview if transportation was difficult to arrange or if they preferred to stay at home. One of the participants chose this method and felt it provided him with access to participation and accommodated his schedule. It can be projected then, that the participants of the main study will understand and be able to make a choice best suited to their preferences.

The provision of accessible options for participation allowed individuals to be involved in whatever setting(s) they felt suited them best. In addition, participants who felt fatigued or distressed and who wanted to continue participating in the study were provided the option of being interviewed over two sessions or more sessions. Two of the pilot study participants completed the interview in one face-to-face sitting while the third participant chose to do the interview over the phone in two portions due to fatigue. Participants were also advised that they were welcome to enlist the aid of communication devices, translators or other aids if they felt that they wanted or needed to. Ultimately, procedural access to the interview had been achieved as participants were provided with a multitude of ways to be part of the study.

Assessing Trustworthiness of the Interview Guide

Four issues which contribute to trustworthiness were piloted: credibility, transferability, dependability, and confirmability. The procedures are discussed below.

Assessing credibility.

The study was premised upon the assumption that people with Cerebral Palsy, in their general understanding of sexuality, would describe it in terms that parallel or mirror private, interactional and public sexual constructs. As such, a goal of the pilot study was to determine the credibility of these constructs. To tackle the issue of credibility “member checking” (Lincoln & Guba, 1985) with all three of the pilot study participants was conducted. In the process of member checking, each of the research participants was asked questions via telephone (see Table 6.3 for member checking telephone script) to ascertain whether or not the use of private, interactional and public conceptualizations of sexuality were credible constructs for this study. The following script (Table 6.3) which included questions and probes was used to gauge the presence of public, interactional and private constructs in participants’ conceptualizations of sexuality.

Table 6.3 Credibility of Public, Interactional and Private Constructs Member Checking Script

	Questions/Discussion:
Introduction:	<ul style="list-style-type: none"> • Some people would say that a person’s sexuality is made up of a variety of different things. I’d like to ask you a few questions about some of the ways that people think about sex.
Grand Tour:	<ul style="list-style-type: none"> • Tell me about your views about sexuality. • Tell me what comes to mind. • There is no importance to what comes first. <ul style="list-style-type: none"> a) If participant generates concepts, probe concepts b) If they feel differently ask them why.
Private:	<ul style="list-style-type: none"> • Generally sexuality and sexual activities are considered private things. What do you think about that? <ul style="list-style-type: none"> a. If participant generates concepts, probe concepts b. If they feel differently ask them why.
Interactional:	<ul style="list-style-type: none"> • When people think about sex they may often think about having sexual experiences with another person or people. What do you think that means? <ul style="list-style-type: none"> a. If participant generates concepts, probe concepts b. If they feel differently ask them why.
Public:	<ul style="list-style-type: none"> • The media presents a lot of information about sex. How do you think that could influence sexuality? <ul style="list-style-type: none"> a. If participant generates concepts, probe concepts b. If they feel differently ask them why.

Member checking results. All participants surveyed felt that sexuality was made up of many different factors (see Table 6.4). They further confirmed that while spaces for experiences of sexuality are commonly considered “private” (i.e., in the privacy of one’s home or “behind closed doors”) the initiation of sexual encounters was personal. In addition, participants felt that part of a satisfactory sex life included being able to share one’s sexuality with others. This included exploring sexual options and activities with different people and settings in order to discover what they really wanted from intimate relationships.

Finally, all the participants mentioned that they had fantasized about a celebrity or a friend who resembled a media personality when they engaged in sexual activities with themselves and sometimes with others. The participants explained that the media tells people how to deal with sex as well as who and what is sexy. In addition, all three participants made comments that directly connected private, interactional and public sexual constructs to one or more personal experiences they had in the past. This feedback suggests that private, public and interactional sexual constructs may be natural to the discourse of people with Cerebral Palsy in understanding their sexuality.

Table 6.4 Credibility of Public, Interactional and Private Constructs Member Checking Results Summary

Participant	Private Construct of Sexuality	Interactional Construct of Sexuality	Public Construct of Sexuality
Participant 1	<p>"...sex, like intercourse, isn't something that I'd do with anybody, anywhere...I mean, like I'd do it at home. Like, it doesn't have to be in the bedroom or in the bed for that matter but in my own space...I'd feel more comfortable".</p>	<p>"Sex is intimate, like not just with yourself, I mean it is in that respect, but I mean like it is connecting...connective...with someone else...Not that having 'sex' with yourself isn't fun or satisfying but doing it with someone else is even better. Like, it reinforces that you are sexy, deserve sex or like you are what or who someone thinks is worthy of 'gettin' jiggy with'".</p>	<p>"I mean who doesn't like a good looking body or person. I mean there are so many good looking people, like sometimes it doesn't have anything to do with disability or anything but when they have the features you know? Those things that make someone sexy...I mean it's hard I'm sure for anyone to resist that."</p>
Participant 2	<p>"I mean look, I don't necessarily 'get it on' on a daily basis, physically I mean, but I don't need that either...Look, sometimes it's nice just to think about it, fantasize without anything physical happening. It gets you going, you know?"</p>	<p>"Part of me, my sexuality I mean, is made up of trying, the ability, the desire you know, to try out different things and different people. Like you don't have to have 'sex-sex' but being with different people sensually kind of is like exploring my sexual side...figuring it out you know?"</p>	<p>"Jennifer Hawkins, that's right everybody knows who she is...But I guess I'm a red-blooded male. Any pretty face that smiles at you...Particularly if they're long legged and absolutely gorgeous. You know Donald Trump even seems to think that the sunlight shines out of her every orifice, which it does. And look, to add to the mix, with someone like that, it's really the first time you fall in love although you don't really know it".</p>
Participant 3	<p>"I feel like, when I'm having fun, like having sexual type fun with myself or someone else it's just more fun when you think of something or the other person as everything you want...why not right? I mean it's my head, I can think of whatever I want".</p>	<p>"The best part of sex, or doing sexy stuff, with other people is the look on their face. I mean like, you know that look when you know someone is having a good time? Like for me, I suspect for everyone that is like the goal, like to please, satisfy the person you're doing sexy stuff with".</p>	<p>"I mean if you have experiences that aren't what people think is right then that can put a damper on things a bit...I mean it's ruined by what other people think is supposed to happen for men or women or whatever...I mean in that respect things can get confusing because you not doing what 'you're supposed to' even though it makes you happy."</p>

Assessing transferability.

Transferability pertains to the potential for this study's finding to transfer to other settings and/or populations. Transferability was achieved as the findings from the pilot study mirror those of similar nature in other studies (i.e., Taleporos & McCabe, 2001, 2002, 2003, 2005) which explored constructions of sexuality (i.e., sexual esteem, sexual satisfaction, sexual ideation(s)) by and within people with Cerebral Palsy and other physical disabilities. In this regard, public, interactional and private constructions of sexuality and disability have been indicated both in this pilot study and relevant research (i.e., Shakespeare, 1996, 2000, 2007; Tepper, 1999, 2000) as salient to experiences of sexuality and the self for people with physical disabilities. As such, it can be expected that the findings from the pilot study can be transferred to the participants of the main study as they share many of the same developmental experiences and/or qualities.

In addition, a number of the data analyses done through NVivo 9 software and line-by-line analysis, were used to help answer the research questions and formulate a new *Model for the Construction of Individual Sexuality in People with Cerebral Palsy*.

Transferability of this study's protocol was also achieved through making these documents available upon request. Providing evidence of the analytic process allows other researchers to repeat, as closely as possible the procedures of this project. In addition, other researchers can utilize the study procedures to analyze data from research which explores similar concepts. In this way transferability can be accessed and assessed by other research and researchers.

Assessing dependability and confirmability.

As mentioned, reviewing the dependability of one's research is an assessment of the quality of data collection, analysis, and theory production. Confirmability is a measure of the level to which the study's findings are supported by the collected data (Tipping, Scholes & Cox, 2010). To enhance the dependability and confirmability of the study, an independent audit of my research methods by a competent peer (Lincoln & Guba, 1985; Patton, 2001) was sought. As such, the independent auditor must review all documents in order to make an assessment of on whether or not the study and its conclusions followed a logical progression through the chain of evidence (Smith, 2003).

Yin (2010) suggested that one way of checking the trustworthiness of one's research report is to file all the data in such a way that allows others to follow the chain of evidence that has led to the final report. Part of this chain may include initial notes on the research question(s), interview schedule, digital audio files, annotated transcripts, codings and initial categorizations, draft reports and final reports. Subsequently, the file of material is given to an associate researcher who played no part in the study.

The auditor of this project, Nicole Hartman (not real name), is a practicing occupational therapist in the field of disability and sexuality whose "hands-on" experience with disability parallels some of those of the researcher. At the time this study was being conducted she was also in the process of finishing her own Ph.D. in the Faculty of Health Sciences, Sexual Health Unit and is quite familiar with qualitative research methodologies.

Upon completion of the data analysis for this project and the majority of writing for the Results and Discussion chapters, Ms. Hartman examined the audit trail which included; initial notes on the research question, original transcripts, data analysis documents, line-by-line coding, comments from the member checking process, and the text of the thesis itself.

In doing so the auditor assessed both the dependability and confirmability of the study, as well as the completeness and availability of auditable documents. She further assessed the degree and significance of researcher influence through the examination of verbatim transcripts. See Appendix H for her full attestation letter.

Ethics

This project was approved by the University of Sydney Human Research Ethics Committee and the Spastic Centre Ethics Committee in March 2009. In terms of the approved ethics procedure, participants were informed that their involvement in this study was completely voluntary and that there were not under any obligation to consent. In addition, participants could choose not to answer any particular question.

Participants were further informed in writing and verbally that they could withdraw at any time without prejudice or penalty, and without giving any reason for withdrawing and that withdrawing from the study would not affect their relationships with their disability service provider(s). Participants were assured that if they did choose to withdraw any information provided to the researchers would be destroyed. Full and thorough attempts had been made to insure that no individual participant, any other person, or organization, could be identified in any reports, presentation or documents produced from this project.

Data Analysis

After all interviews were transcribed verbatim the pilot study data were analyzed using a line by line analysis (Luborsky, 1994). According to Luborsky (1994), "line-by-line analysis" includes the careful reading of transcripts followed by a division of the data into meaningful analytical units (segmenting the data). Once meaningful segments (based on meaningful themes in this case) are identified the researcher then codes them. For the

purposes of the pilot study this was sufficient to ascertain topical responses, direct and emotional statements and discourse markers.

Key Lessons from the Pilot Study

Consistent with the aims of the pilot study networks were established which facilitated recruitment of individuals within the sampling frame and also provided participants for the main study. However, relatively few participants were projected by agencies to as likely to participate in the study in Australia. While participation in the pilot study may have been limited it was still accessible. The interview guide's readability (grade 5 to 7) level meant that all participants were likely to understand the questions. All participants found that the majority of the interview guide was easy to understand and answer. Further, the pilot study confirmed that the interview guide could be accessed by many people in the sampling frame as it was adaptable to different media and social formats. It also met common standards for cognitive and procedural accessibility.

The trustworthiness of the study was confirmed through an assessment of the credibility, transferability, dependability and confirmability of the interview guide. Credibility was achieved during the member checking process as participants of the pilot study spontaneously and naturally used terms consistent with private, interactional and public sexual constructs included in the interview guide.

Transferability was achieved through the provision of evidence of the analytic process which may allow other researchers to repeat, as closely as possible the procedures of this project. Alternatively other researcher may utilize the procedures indicated within this study to analyze data from research which explores similar concepts

Dependability and confirmability of the data collection, analysis, theory production and the level to which the study's findings are supported by the collected data were

ensured through the employment of an independent audit of the research methods by a competent peer.

Through the process of conducting the pilot study only minor changes to the interview guide or analytic process were made. For example, an international sample was sought for the main study (through the Attendant Care Program in Ottawa, Ontario, Canada) in order to boost the level of participation. In this respect future recruitment efforts may be more successful if the researcher was a trusted member of the communities in which people with Cerebral Palsy (or disabilities in general) exist.

In addition, minor additions and modifications to some of the interview guide questions were made (see main study interview guide in Appendix C) in order to increase clarity and reduce confusion about questions which the researcher and her peers felt may have been complicated concepts. From these results the main study design was adapted (see Figure 6.2).

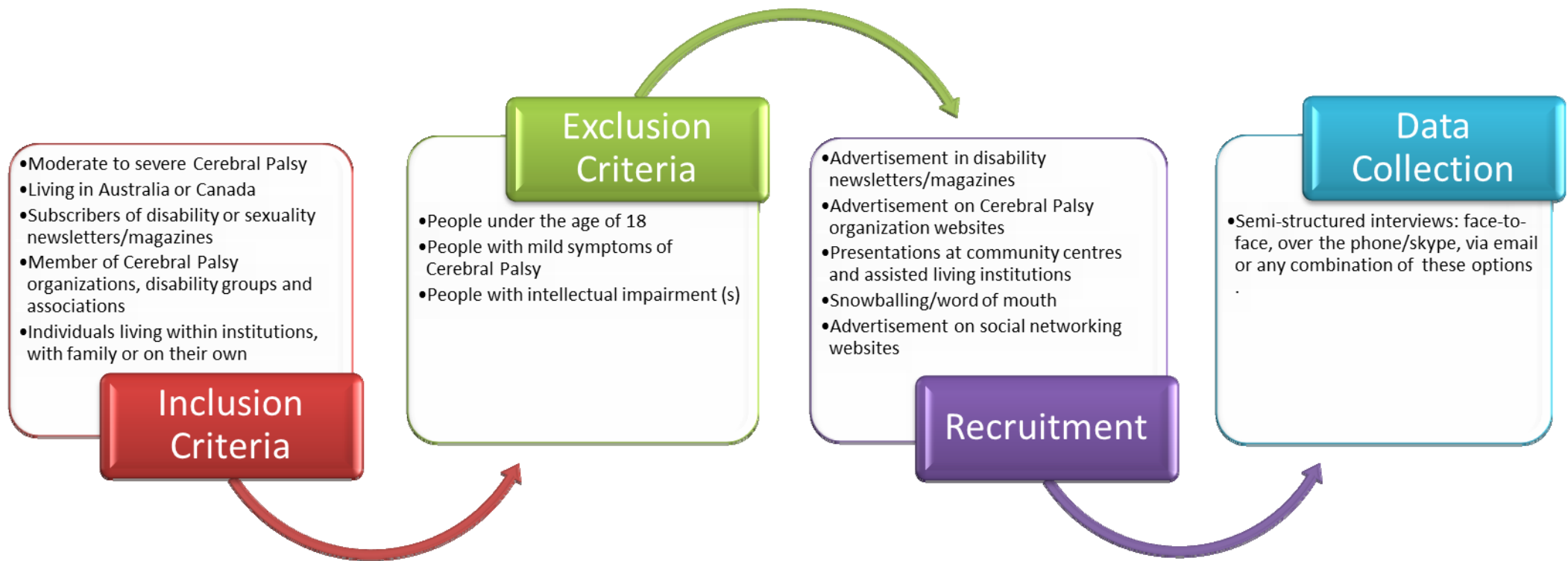


Figure 6.2. Main Study Design Flowchart

Main Study

Participants

Based on the limited enrollment (likely due to the hidden nature of the population) during the pilot study the main study used a rolling enrollment framework (McPhee, 2006) in order to admit participants throughout the duration of the project. In doing so, participants were interviewed throughout the entire research period (2009 – 2011). This enabled an iterative approach to data analysis. From this process of including international and rolling participation, this project was able to attract a total of 7 people with Cerebral Palsy from Canada and Australia, all of whom were included in the study. Four of the participants were recruited from advertisements posted in disability newsletters in Australia. The other three respondents were recruited through the Attendant Care program at Carleton University in Canada.

Demographics.

Two participants were female and the remaining five were male (see Table 6.5). The resultant distribution of sex within the sample is reflective of the higher incidence of Cerebral Palsy in males (Johnston & Hagberg, 2007). The majority of participants (5) had Spastic Cerebral Palsy (SCP), three of whom (male) lived with Spastic Quadriplegic Cerebral Palsy (SQCP) and two (female) with Spastic Paraplegic Cerebral Palsy (SPCP). The high incidence of SCP amongst participants reflects the dominance of SCP amongst people with Cerebral Palsy (The Spastic Centre, Australia). The remaining two male participants had Ataxic Quadriplegic Cerebral Palsy (AQCP). As mentioned, people with SQCP are least likely to be able to walk due to impairment of all four limbs. If people with SQCP can or want to walk their muscles are too tight making it too much effort to do so. SPCP is characterized by the lower extremities being affected with little to no upper-body spasticity. AQCP is

characterized by difficulty with dexterity and precise use of all limbs and appendages. All participants experienced moderate or severe impairment to mobility due to Cerebral Palsy.

Mobility and assistance.

All but one of the participants required the use of a mechanized wheelchair to assist in mobility. The female participant who did not use a wheelchair of any type occasionally used crutches to assist in mobility. One of the male participants had a noticeable oral/facial muscle impairment which affected eating (mastication), speaking (annunciating words and expressing thoughts and opinions), breathing and drinking (sucking and swallowing). All of the male participants lived with severe Cerebral Palsy for which they required a high level of daily assistance in order to complete everyday tasks. These participants most often enlisted the help of paid personal care attendants and on the occasion friends and other family members to complete daily activities. The quality of paid care they received was also facilitated by their ability to access government or institutional funding. Both female participants lived with moderate Cerebral Palsy. They did not require daily assistance from paid care personnel and completed many of their daily tasks on their own. The diversity of mobility and behaviour amongst participants can be characterized as typical (Dobson, Morris, Baker & Graham, 2007).

Socio-economic status.

All participants were Caucasian and of lower-middle (2), middle (2) or upper-middle (3) class background. All participants had received tertiary education in Australia or Canada. All participants also pursued activities within their fields of study and/or interest. Some of the male participants were actively involved in sporting clubs, while others were more actively involved in community groups and leisure activities. Both of the female participants were employed (Mary full-time and Leah part-time) in addition to involvement in

community and leisure activities. As such, all participants had access to social, and potentially sexual, participation. However, for participants whose main form of mobility was their wheelchair they experienced restrictions to access due to infrastructure. All participants had experienced medical interventions to facilitate mobility. As all participants could be classified as privileged they may have had access to socio-cultural experiences which individuals of lower socio-economic status may not.

Medical intervention.

All of the study participants have been through major surgeries during childhood and early adolescence. The medical interventions participants required involved several lengthy recovery periods, long stays in medical institutions and life-long rehabilitative commitments. For instance, all participants visited or were visited by a physiotherapist to assist in mobility and flexibility as often as once per week to once per month. All participants did exercises and/or stretches in order to maintain strength, reduce soreness and tightness and encourage relaxation of the muscles. These experiences and commitments meant that some of the participants felt that rehabilitative activities were necessary before and after sexual encounters to facilitate ease of movement during sexual activities or to prevent stiffness or pain afterwards. Due to differing levels of physical mobility each participants living arrangements complimented their abilities and facilitated independence.

Living arrangements.

Two of the participants lived in non-subsidized accommodation with their partners in Australia. One participant lived with his mother at their home in Australia. The last Australian participant used subsidized community-living accommodation which catered to people with disabilities. The three Canadian participants lived in residence rooms equipped

to facilitate independent living at Carleton University (2) and the University of Nottingham (1). Each participant had engaged in a variety of sexual activities prior to the interview. While privacy may have been limited for some participants due to the daily and consistent involvement of caregivers living arrangements did not seem to adversely impact experiences of sexual activity.

Sexual profile.

Six participants identified as heterosexual and one identified as homosexual. The two female and one male participant were in steady sexually intimate relationships with physically and mentally typical partners. The other four participants had engaged in sexual activities and intimacy with themselves and others but had not yet been involved in a long term sexually intimate relationship. Overall participants reported a variety of sexual experiences with the same sex and opposite sex. In this regard, the study may have captured an essence of sexuality for people with Cerebral Palsy.

Table 6.5 Main Study Participant Summary

Participant (Pseudonym)	Sex	Type of Cerebral Palsy	Assistive Devices or Services	Socio-economic Status, education and ethnicity	Medical Interventions	Living Arrangements	Sexual Profile
John	Male	Spastic Quadriplegic Cerebral Palsy (severe)	Mechanized wheelchair, daily personal assistance from others	Upper-middle class, tertiary education, Caucasian Australian	Major musculoskeletal surgery during childhood and adolescence. Rehabilitative maintenance.	Lived with his mother in his family's home	Heterosexual, sexually active, no history of long term sexually intimate relationships
Mary	Female	Spastic Paraplegic Cerebral Palsy (moderate)	Occasional use of crutches	Middle class, tertiary education, Caucasian Australian	Major musculoskeletal surgery during childhood and adolescence. Rehabilitative maintenance.	Lived independently in an apartment with her partner	Heterosexual, in a long term sexual relationship at time of interview
Brian	Male	Ataxic Quadriplegic Cerebral Palsy (severe)	Mechanized wheelchair, daily personal assistance from others	Middle class, tertiary education, Caucasian Australian	Major musculoskeletal surgery during childhood and adolescence. Rehabilitative maintenance.	Lived in an independent living facility	Heterosexual, sexually active, no history of long term sexually intimate relationships

Leah	Female	Spastic Paraplegic Cerebral Palsy (moderate)	Mechanized wheelchair, daily personal assistance from others	Lower-middle class, tertiary education, Caucasian Australian	Major musculoskeletal surgery during childhood and adolescence. Rehabilitative maintenance.	Lived in an apartment with her boyfriend.	Heterosexual, in a long term sexual relationship at time of interview
Ian	Male	Ataxic Quadriplegic Cerebral Palsy (severe)	Mechanized wheelchair, daily personal assistance from others	Lower-middle class, tertiary education, Caucasian Canadian	Major musculoskeletal surgery during childhood and adolescence. Rehabilitative maintenance.	Lived in an independent living facility.	Heterosexual, sexually active, no history of long term sexually intimate relationships
Trevor	Male	Spastic Quadriplegic Cerebral Palsy (severe)	Mechanized wheelchair, daily personal assistance from others	Upper-middle class, tertiary education, Caucasian Canadian	Major musculoskeletal surgery during childhood and adolescence. Rehabilitative maintenance.	Lived in an independent living facility	Heterosexual, in a long term sexually intimate relationship at time of the interview
Alex	Male	Spastic Quadriplegic Cerebral Palsy (severe)	Mechanized wheelchair, daily personal assistance from others	Upper-middle class, tertiary education, Caucasian Canadian	Major musculoskeletal surgery during childhood and adolescence. Rehabilitative maintenance.	Lived in an independent living facility	Homosexual, high frequency of casual sexual encounters, no history of long term sexually intimate relationships

Instruments

The interview guide (see Appendix C) was used for data collection and comprised of the following sections: demographics and severity of disability, private sexual scripts, interactional sexual scripts, public sexual scripts and reflective summary. Technical terms such as “script” or “scripts” were not used with participants during interviews in order to reduce the opportunity for convolution or confusion.

Demographics and severity of disability.

The interview began with questions which provided demographic information about the participant’s age and the severity of their disability. This section of the interview included preliminary questions about the participant’s sexual orientation/identity as well as the level of assisted care they may need due to Cerebral Palsy. For example, participants were asked: “How do you sexually identify?” and “What is your form of Cerebral Palsy?” Some people with Cerebral Palsy may require daily care needs which may restrict their ability to express their sexuality as they would like to due to a lack of privacy and/or freedom particularly for persons residing, with family, in institutional or group home settings (Nosek et al., 1996).

As such, understanding how potential care requirements coexist with sexual expression may shed some light on how people with Cerebral Palsy construct their sexuality. While this section of the interview was also used to build rapport with the interviewee its main goal was to collect information which would provide a contextual framework for the intimate and in-depth questions about the participant’s sexuality which followed. In doing so, the interviewer and interviewee were primed to discuss sexual scripts.

Sexual scripts.

Three sexual constructs were included within the main study interview guide: private, interactional and public sexual scripts. Questions about these scripts were used in order to explicitly access information from participants about the factors which influence their construction of their sexuality.

Private. In order to gain information about the influence of private sexual scripts on constructions of sexuality for people with Cerebral Palsy this section was aimed at allowing participants to express private sexual feelings, thoughts and fantasies. The questions in this portion of the main study interview guide aimed to allow participants to express any private sexual schemas which act as a significant factor in personal mental processes and inner dialogues. Questions asked examined early sexual thoughts (i.e., “Can you please describe your early sexual thoughts or feelings to me?”), how participants would describe themselves and what they thought made them sexual and/or desirable (i.e., “What do you find sexy about yourself?”). These questions precluded the interactional section of the interview as they provided information about individual internalizations of sexuality.

Interactional. In this portion of the interview participants were asked questions to ascertain if any interactional constructions of sexuality influenced the way in which they expressed and negotiated their sexuality. Questions about sexual relations were included in order to identify how people with Cerebral Palsy describe and measure mutually satisfying sexual activity. For example, “Please explain your romantic and/or sexual history” was intended to allow participants to express their experiences with sexuality. The question “Can you describe to me the best sexual experience(s) you have had?” was used to ascertain how participants conceptualized sexual experiences. Through the data collected the

researcher aimed to identify instances in which interactional sexual schemas affected how participants experienced their sexual relationships, intimacy and sexual desires.

Public. The questions in this section of the interview aimed to gather information about the affect public sexual scripts had on constructions of sexuality as experienced by people with Cerebral Palsy. To understand how people with Cerebral Palsy were taught to construct (their) sexuality they were asked: “Where did you learn about sex? What did you learn about sex?” Further, participants were asked to reflect on their conceptualization and opinion about the term sexual spontaneity in order to ascertain whether people with Cerebral Palsy described their sexuality as inclusive of popular constructions of sexual spontaneity; “How would you define or explain the term sexual spontaneity?” and “How does your explanation of sexual spontaneity fit into your sexuality?” In addition, participants were asked to describe their perception of romance (“What is your idea of romance?”) and satisfying sexual experiences (“What factors have influenced how you experience your sexuality?”). These questions were used to identify any aspects of sexual spontaneity within individual experiences of sexuality as well as gain information about the participant’s perception of what their sexual partner would be like and/or look like.

Reflective summary.

To conclude the interview participants were asked if their opinion of their own sexuality had changed since they first became aware of themselves as sexual beings. These questions allowed participants to reflect on the interplay of private, interactional and public sexual scripts on the development of their sexuality over time: “Since your first sexual feelings has anything changed your view of your sexuality? If yes, how so?”). Finally participants were prompted to include any further information that may not have been addressed or clarified during the earlier sections of the interview.

Recruitment Procedures

Similar to the methods by which data was collected for the pilot study, a purposeful sampling strategy was employed to recruit participants for the main study (see Table 6.6). As the pilot study revealed, participants were widely distributed and relatively inaccessible. Hence, the main study recruited from Canada and Australia in order to enhance the possibility of finding members of the target population to participate.

Australian sample.

In Australia, participants were recruited through advertisements published in community newspapers, bulletins, through advocacy group and sexuality and/or disability focused newsletters and webpages. In addition, the snowballing technique was carried out at the end of participant interviews and required asking each participant if they knew someone who met the eligibility criteria and, if so, whether s/he would be willing to give that person a copy of the participant information sheet. The researcher did not know the identity of this person, and the interviewee did not know if that person agreed to participate in the project or not. Recruitment in Australia yielded four participants.

Canadian sample.

In Canada, participants were sought through the Attendant Care Program in Ottawa, Ontario, Canada (see Table 6.6). The Attendant Care Program services two of the major educational institutions in the city with round-the-clock provision of personal care for tertiary students with disabilities who live in the university residence buildings. The program which has been running for over 20 years services approximately 50 – 60 students per year with numbers increasing every year. Due to the client-directed style of the program clients are provided with the resources they need to live independently through the provision of dignity-focused care and accessible living arrangements. As the researcher was formerly

employed by the service she forwarded the coordinator of the program the details of this project and was informally given permission to ask clients (the majority of whom had Cerebral Palsy) of the Attendant Care Program if they would like to participate. Recruitment in Canada yielded three participants.

My prior connection and continued involvement with the Attendant Care Program, its employees and clients, in Ottawa, Ontario, Canada made the process of participant recruitment easier than that in Australia. Considering that the researcher had worked as an attendant with the Attendant Care Program from 2004 – 2007 she had been able to build intimate relationships with clients and staff thereby establishing a level of trust and comfortability that may not have been experienced in Australia. While both contexts produced participants the researcher's lack of established networks in Australia meant that identification and recruitment of participants in Australia required more time and effort to ascertain. As such, recruitment in Australia was relatively slow and laborious.

Table 6.6 Main Study Recruitment Procedures

	Strategy in Australia			Strategy in Canada
Steps	<u>Cerebral Palsy Organizations in Australia</u>	<u>Disability Newsletters and Magazines in Australia</u>	<u>Snowballing</u>	<u>Attendant Care Program, Ottawa, Ontario, Canada</u>
1	Google search and telephone calls	Google search and telephone calls	Asking participants if they knew someone who could be included in the sampling frame (x = 3)	Forwarded the coordinator of the program the details of this project
2	Refined to major organizations which cater exclusively to people with Cerebral Palsy and their families in Australia (x = 5)	Refined to newsletters which catered to people with Cerebral Palsy particularly in New South Wales (x = 4)	Giving the participant a copy of the Snowball Participant Information Sheet	Received informal permission to ask clients who fulfilled the inclusion criteria to participate
3	Telephoned all 5 organizations	Telephoned all 4 organizations	The participant gives the Snowball Participant Information Sheet to someone they know	Researcher asked clients who fulfilled the inclusion criteria to participate
4	Posted advertisement for the study on organization website or within their newsletter(s) (x = 2)	Posted advertisement for the study on within hardcopy newsletter(s) and newsletter webpages (x = 2)	The individual the participant gives the Snowball Participant Information Sheet to contacts the researcher	Researcher distributed the Participant Information Sheet to potential participants
Resultant Participants	1	2	1	3

Data Collection and Transcription

The interviews were (for the most part) conducted within two or three interactive sessions (see Table 6.7). The interviews were conducted at a time, place and format (i.e., face-to-face, telephone, email) of the participant's choosing. Each interview lasted approximately 1 to 1½ hours. For some participants who had communication difficulties or became stressed or fatigued the interviews were extended over more than two sessions. Participants who responded via email participated in two or more sessions in order to allow the researcher to seek (via email or telephone) clarification if needed. All oral interviews were audio-recorded digitally and then transcribed in full. The first two were transcribed by the researcher and subsequent audio-recorded interviews were transcribed verbatim by RapidType Transcriptions Services (rapidtype.com.au).

Table 6.7 Data Collection Procedures

Participant	Social Format	No. of Sessions	Approx. Running Time	Country
John	Telephone	2	1 hr	Australia
Mary	Face-to-face	1	1.5 hrs	Australia
Brian	Face-to-face	2	1.5 hrs	Australia
Leah	Face-to-face	1	1.5 hrs	Australia
Ian	Email	3	2 hrs	Canada
Trevor	Email	2	2 hrs	Canada
Alex	Email	2	2.5 hr	Canada

Data Analysis

The data were analyzed for the content by identifying topics and substantive categories within participants' accounts in relation to the study's objectives. Via content analysis this study aimed to achieve, as best as possible, understanding -- what Creswell (2007, 2009) describes as a deep knowledge of some social setting or phenomenon. According to Creswell (2007) the use of content analyses for the generation of theory compliments the hermeneutic phenomenological approach used within this study as

they both aim to understand how phenomena manifest and what they mean to those that experience them.

NVivo 9 was used to ascertain topical responses and emergent substantive categories, coding particularly for word repetition, direct and emotional statements and discourse markers including intensifiers, connectives and evaluative clauses. From these analyses of individual transcripts, a preliminary index of each participant's transcript was produced. NVivo 9 allows the researcher to interrogate participant data efficiently and improve the rigor of the analysis process by validating (or not) some of the researcher's own impressions of the data.

While this may be the case Welsh (2002) noted that "the software is less useful in terms of addressing issues of trustworthiness in the thematic ideas that emerge during the data analysis process and this is due to the fluid and creative way in which these themes emerge" (p. 12). Welsh (2002) further stated that "it is important that researchers recognize the value of both manual and electronic tools in qualitative data analysis and management and do not reify one over the other but instead remain open to, and make use of, the advantages of each" (p. 12). As such, I also carried out a manual line-by-line analysis of the data. In doing so, I was able to compare and contrast topical responses and emergent substantive categories between participants' transcripts in order to identify higher level conceptual categories and core themes which recurred across participants' accounts.

Summary and Conclusion

The use of qualitative methodology within this study facilitated a hermeneutic phenomenological approach to understanding how the people within this project constructed their sexuality. This was initially indicated by the results of the pilot study. As mentioned previously, the results from the pilot study confirm that the conceptual

framework, procedures and data collection techniques for this project fulfill standard expectations of credibility, transferability, dependability and confirmability (trustworthiness). Based on the pilot study the main project was adapted to include amendments to the interview guide for the sake of clarity and the expansion to an international sampling frame in order to increase access to people with Cerebral Palsy.

The main study included seven participants. The majority of participants were male, had severe Spastic Cerebral Palsy, had all been through major musculoskeletal surgery during childhood and adolescence and continually participated in rehabilitative exercises and used a motorized wheelchair for mobility. In addition, all the participants were lower-middle to upper-middle class Caucasians who had completed tertiary studies. The majority of participants reported that they lived independently and all participants had engaged in sexual experiences with themselves and others. Using the main study interview guide with participants provided solicited rich descriptions of how some people with Cerebral Palsy experience, conceptualize and construct their sexuality.

Chapter 7: Results

The study applied a hermeneutic phenomenological approach to understand the factors influences on people with Cerebral Palsy in constructing their sexuality; public, interactional or private sexual schema. This chapter presents the findings in three parts; 1) the relative salience of public, interactional and private sexual schema in the construction of sexuality for people with Cerebral Palsy, 2) how people with Cerebral Palsy construct sexual participation, and in particular sexual spontaneity and, 3) how people with Cerebral Palsy describe their sexuality. Several of the themes and subthemes characterizing a schema overlap. These points of overlap are noted and discussed. Participants perceived that interactional sexual schema are the most influential in the construction of participant sexuality, followed by public sexual schema and finally, private sexual schema (see Table 7.1).

Table 7.1 Relative Salience of Public, Interactional and Private Sexual Schema Major Themes and Sub-themes

Sexual Schema	Major Theme	Major Theme Ranking	Sub-Themes	Frequency of Nomination	Sub-theme Ranking
Interactional (Mean Rank = 1)	Perception of Sexual Experiences with Others	1	• Peer Acceptance of Impairment and Disability	23	1
			• Feeling Worthy of Sexual Experiences with Others	19	2
			• The Importance of Communication	16	3
			• The Role of Sexual Intimacy	12	4
			• The Importance of Socio-Sexual Compatibility	10	5
Public (Mean Rank = 5.25)	Contemporary Media and Popular Culture	2	• Media as a Source for Sexual Information	7	6
	The Myth of Disability and Asexuality	5	• The Impact of Public Sexual Scripts	7	7
			• Constructions of Masculinity and/or Femininity	6	8
	Expectations of Normative Movement and Functioning	6	• Perceptions of How Others Perceive Disability and Sexuality	7	14
Issues of Accessibility	7	• Internalization of the Myth of Disability and Asexuality	7	15	
		• Impact of Expectations of Normative Movement and Functioning on Socio-Sexual Development	5	16	
		• The Ideal Partner	4	17	
Private (Mean Rank = 6.8)	The Intersection between Disability and Sexual Identity	3	• Perceptions of What is and is Not Physical Disability	1	18
			• Structural Access Issues	5	19
			• Access to Sexual Opportunities	3	20
	Perceptions of Sexual Desirability	4	• Access to Resources which Support Sexually Intimate Relationships	2	21
• Reconciling Disability and Sexuality			7	9	
Body Esteem	8	• Harmonizing Care Needs and Sexual Needs	4	10	
		• Accepting Oneself	3	11	
		• Perception of Sexually Desirable Traits	7	12	
Sexual Agency	9	• Privatization of Others' Perceptions	7	13	
		• Positive Body Esteem	3	22	
		• Negative Body Esteem	3	23	
Sexual Esteem	10	• Reflections on the Influence the Body has on Experiences and Constructions of Sexuality	2	24	
		• Feeling Apprehensive	3	25	
		• Fostering Agency	3	26	
			• Resignation	2	27
			• Counting Oneself Out	3	28

Relative Salience of Sexual Schema

Table 7.1 presents the relative salience of interactional, public and private sexual schema based on respondent nominations. In regards to the relative salience of sexual schema in the construction of sexuality, participants perceived interactional schema as the most influential (nominations = 80). Public schema (nominations = 54) were the second most important influence in the construction of their sexuality. Private influences were cumulatively (nominations = 50) described by participants as relatively less influential factor in the construction of their sexuality. The following sections present and discuss the influence interactional, public and private sexual schema have on constructions of sexuality by people with Cerebral Palsy.

Interactional Sexual Schema

Participant constructions of their own sexuality related most significantly to interactional sexual experiences with others (or the lack thereof). For instance, participants relied on feeling accepted by others, in order to construct a sense of sexual worthiness. They observed that communication with others fostered acceptance and intimacy. Socio-sexual compatibility was described as important to positive experiences and thereby constructions of participant's sexuality.

Perceptions of Sexual Experiences with Others.

Five sub-themes characterized the perceived influence of others on sexuality: Peer Acceptance of Impairment and Disability, Feeling Worthy of Sexual Experiences with Others, The Importance of Communication, The Role of Sexual Intimacy and The Importance of Socio-Sexual Compatibility.

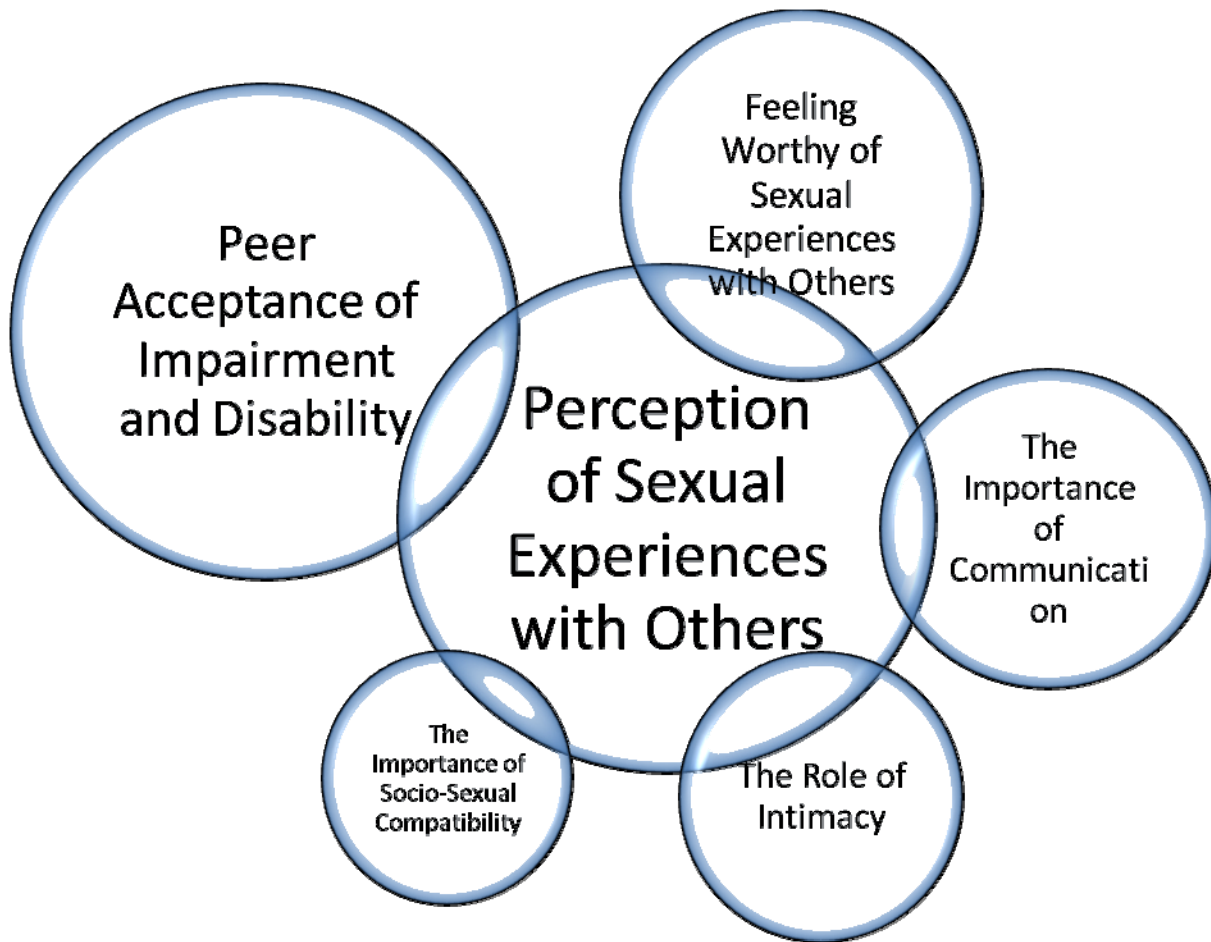


Figure 7.1. Perception of Sexual Experiences with Others Theme and Sub-themes (Note: The size of the spheres is a visual representation of the relative salience of sub-themes within the theme).

Peer Acceptance of Impairment and Disability. Peer acceptance of impairment and/or disability was a significant influence on participants. Informants articulated three concepts associated with peer acceptance of impairment and/or disability: 1) acceptance based on understanding of impairment and disability (Wu & Mok, 2006), 2) acceptance as an unusual trait (Howland & Rintala, 2001) and, 3) tolerating difference (Milligan & Neufeldt, 2001). For instance, Alex articulated interpersonal qualities that a potential partner must have in order to be in a sexually intimate relationship with him. He notably

highlighted the importance of being with an individual who was accepting of impairment and disability based on understanding and experience:

Alex: My ideal partner would be extremely open-minded. It would be helpful if they have had some experience with the disabled community, but I realize how rare that is. I tend to think that I would date someone older only because they have more life experience. My lack of physical ability means that I am relying on my partner to accept that they need to facilitate much of the movement.

Trevor also indicated that finding a partner who understood and could accept someone with severe physical impairment. He observed:

Trevor: My care needs do influence my sexuality. I think this is a result of how much physical assistance I require. It tends to make my sexual partners very apprehensive and unsure of how to handle the situation. I need help with all of my daily functioning, and it is not often that I found someone who is truly comfortable with my level of disability. So, yes, my disability does influence my sexuality.

While informants indicated that they would like to be with someone who understood and accepted impairment and disability they also articulated that it was a rare: *"It would be helpful if they have had some experience with the disabled community, but I realize how rare that is"* (Alex) or a difficult combination of traits to find in others: *"I need help with all of my daily functioning, and it is not often that I found someone who is truly comfortable with my level of disability"* (Trevor). Furthermore, all the participants explained that someone who exemplified such a level of understanding and acceptance was a rare find. Brian explained:

Brian: The one couple that I know. It seems odd. I can't imagine how they dealt with it. One thing I can tell is that the wife [physically and mentally typical] is one of the most serene and unflappable people I have ever met. And that may be at the heart of it. And

they also had a very successful, very well-balanced kid. I often wonder, at the core, about her [the wife's] emotional stability.

Participants also considered acceptance of impairment and disability an unusual character trait or improbable in others. For instance, Ian discussed how potential sexual opportunities would transpire with an individual who had no prior experience with disability.

Ian: It takes someone with an unusual character, I mean an unusual gal to come up and speak to someone [with a disability]. I mean if you're talking about someone who's had no experience with disability and you think what are they going to do are they necessarily going to come up and say "hello" or strike a conversation for absolutely no reason at all or are they not. It would take an unusual girl indeed.

Furthermore, John explained that acceptance from one's peers is not simply a matter of accepting atypical sexual circumstances but accepting the realities of severe physical disability. He observed:

John: In my mind they'd have to be accepting of some very faulty equipment. And this isn't the sexual, it's a lot of medical needs, I'm all those things. I know of one fellow who has obviously deliberately married a woman [with a disability] and he must have known that she had polio. I mean he must have known, I mean you don't just get polio, and I know she had polio earlier in her life. And you know it was rather difficult for her, so look, I mean, I don't know how they came to their arrangements or understandings.

John has emphasized the idea that for people with severe physical disabilities it may be difficult to interactionally negotiate the terms of engagement: *"I don't know how they came to their arrangements or understandings,"* as he perceived others to be unaccepting and intolerant.

All the male participants felt that someone who would accept issues related to impairment and disability was rare and with considerable emotional resources. Similarly, the female informants, both of whom were in steady long term relationships, expressed that they too were skeptical of finding such an individual. For instance, Mary observed that while her boyfriend was accepting of impairment and disability others in his extended circle would not be:

Mary: Yes, he [her boyfriend] does accept me and my disability and that's a nice thing. Especially when I do think sometimes that there are people in his extended circle who would probably say, you know, "What does he see in her?"

The view that prospective or actual partners could be influenced by social network supports the salience of interactional schema. Leah also alluded to the idea that others were generally unaccepting of impairment and disability. However she acknowledged incidences in which she met someone who was tolerant:

Leah: Sometimes you meet great people. I've been so surprised, which is nice to be, when you realize how jaded you are when you meet someone who's great and doesn't give a shit and you're thinking in your head all kinds of things and you think, "hang on a minute. I'm pretty awesome."

Interactional experiences of intolerance from others were perceived to influence socio-sexual development and one's construction of their sexuality. For instance, Mary explained:

Mary: For all their good attributes, kids are naturally mean. By the time I started secondary school I was just pretty nervous and I ended up with a problem with the school structure. A large group of girls who were friends from the junior school managed to come through into the same Year 7 class, when they should have been broken up. So, for whatever reason, they chose me as the person they were going to make fun of. Yeah,

I don't think my social skills were brilliant earlier in school because I was so uncomfortable.

Mary's experiences of social ostracism and exclusion due to peer intolerance in elementary and high school may not have been directly linked to her sexuality. However, experiences of intolerance in youth may impede socio-sexual development (Wiegerink, Roebroek, Donkervoort, Stam & Cohen-Kettenis, 2006). Ian and Alex, acknowledged experiences of intolerance from others that influenced construction of sex.

Ian: Since my first sexual experience, I have become much more jaded about sex.

Alex: I am kind of jaded when it comes to romance. In my experience, every time I have tried to enter into a romantic relationship – or every time I have had those feelings for a guy I have been rebuffed and hurt.

Experiences of intolerance from others as indicated by all the participants influenced their sense of sexual worthiness and the construction of themselves as potential sexual partners.

Feeling Worthy of Sexual Experiences with Others. Feelings of sexual worthiness (or the lack thereof) were significant to participants' constructions of their sexual worth. Sexual worthiness overlaps both interactional and private sexual schema. On the one hand, feeling worthy of sexual experiences with others is mediated by sexual experiences with others. On the other hand, feeling worthy of sexual experiences with others is consolidated through private processes. While this duality exists feelings of sexual worthiness are primarily dictated by one's socio-sexual experiences with others (Esmail et al., 2010). As such, informants describe feeling worthy of sexual experiences with others as a result of: 1) sexual validation from others (Esmail et al., 2010), 2) being sexually pleased by one's partner (Howland & Rintala, 2001), 3) pleasuring one's partner (Taleporos & McCabe, 2002) and 4) the impact of negative sexual experiences on perceptions of sexual worth (Esmail et al.,

2010). Alex, for example, explained that feeling sexually worthy was the result of validation from sexual partners:

Alex: The best sex I ever had was with a popular television personality in the summer of 2008. I think it was mostly because I didn't have to try and convince him that I was worthy of him. He actively sought me out and that made the sex feel more authentic. It was passionate and wild – kind of like what you would see in the movies – or at least that's how I remember it. I also think the best sexual encounters are humorous ones. It makes it less “scripted” and natural.

Alex's experience of socio-sexual validation made him feel worthy of sexual experiences with others. John also noted that feeling worthy of sexual attention was out of the ordinary.

John: I mean again, I guess, the only reference point I'd have there is the rather sudden response of this former carer. I don't know, but under any other circumstances either one of us could have complained about being assaulted and neither of us did [LAUGHS].

In this respect John jokingly alluded to the idea that he was not worthy as a sexual candidate as the sexual activities that he and his former carer engaged in may have been construed as sexual abuse: *“one of us could have complained about being assaulted,”* even though both parties unambiguously consented to the behaviour.

For Leah and Mary feeling worthy of sexual attention and sexual experiences with others was reinforced by their partners wanting to pleasure them and therefore taking the initiative to start sexual activity or reinforce intimacy. Leah's experience with her boyfriend exemplifies this sentiment:

Leah: I probably ... some of the best sex, I think, is probably when we've started mucking around doing something and neither one of us really wanted sex and for whatever reason we've ended up doing it but I think at the times I've probably talked about are

the times when he's initiated it. Sometimes I feel a little bit pressured when I go to initiate it because I think, you know, oh we shouldn't do that now.

In addition, Trevor and Brian felt that their sexual worth was proven by pleasuring their partners. Their thoughts imply that doting on one's partner made them sexually worthy of their partners.

Trevor: I am an old-fashioned romantic and enjoy the art of dating. I thoroughly enjoy getting to take care of my partner, and treating them like the Queen of the world. I am the kind of guy who still believes that chivalry has its place.

Brian: Dinner and a spa with candles. Good wine. Good timing is important. Kissing, feeling their hair. Heading towards the breasts and caressing their breasts.

Based on responses from Trevor and Brian pleasing one's partner involves both physical and emotional pleasure through sexual activity: *"Kissing, feeling their hair. Heading towards the breasts and caressing their breasts"* (Brian), chivalry: *"...treating them like the Queen of the world. I am the kind of guy who still believes that chivalry has its place"* (Trevor) and, the creation of an intimate atmosphere: *"Dinner and a spa with candles. Good wine. Good timing is important"* (Brian). Leah however, was concerned that what she perceived as a lack of confidence stopped her from believing she could please her partner or initiate sexual activity.

Leah: Yeah, just having a bit more confidence. There are times where I worry that I haven't pleased him and, you know, he's very reassuring. But yeah, I haven't been encouraged in any kind of physical pursuit let alone having sex with somebody.

Leah's partner was reassuring, but other participants explained that they had not had many (if any) experiences of reassurance or validation of their sexual worth from others. For example, Alex, John and Ian explained that negative sexual experiences with

others have made them feel as though potential sexual partners would not see them as sexually worthy.

Alex: The first guy that I slept with told me that I was a “pity fuck.” This is an experience that has shaped my sense of sexual encounters ever since, because I often wonder if the majority of my encounters are on that premise.

John: In all honesty, I don’t feel as though I am sexually desirable. I think this stems from me, like my disability makes me an outsider.

Ian: With my first couple sexual encounters, I was much more naïve. I would think they would want to come back for more (I still do), and when they didn’t I would become depressed because I would automatically relate it back to my disability. I still secretly hope they want to come back for more. They often don’t.

Feelings of sexual unworthiness influenced participants’ constructions of their own sexuality in that it reinforced negative perceptions of themselves. In order to alleviate or avoid the potential of negative sexual experiences with others participants indicated that communication was integral to fostering satisfactory sexual encounters and relationships.

The Importance of Communication. Communication was also of significant importance to how people with Cerebral Palsy experienced their sexuality. Respondents noted the importance of: 1) constructing a sexual dialogue to use with potential partners (Kralik & Bostock, 2008), 2) communicating the role that disability and impairment play in intimate relationships (Kralik & Bostock, 2008), 3) Communicating the impact of impairment and disability with potential sexual partners (Papile, 2009) and, 4) communication to reconstruct normative expectations of sexuality (Esmail, Esmail & Munro, 2001). In terms of constructing an effective sexual dialogue Trevor, John and Brian, for instance, noted that

being light-hearted, honest and open about their abilities was a staple of their sexual dialogue with potential partners.

Trevor: I feel that communication especially when situating disability and sexuality is important. I try to put [my partners] at ease through humor and honesty about my abilities.

Ian: Openness with my partner is the key in this regard. I cannot afford to be shy about my needs, as these are discussions that need to happen before physical intimacy.

Brian: For me, it's all about engaging with my partner to determine their comfort level as well as mine, and working to combine those two. There is no sense in hiding anything, because my physical needs are very apparent, so I have never openly denied MY [participant's emphasis] need for care.

John, too, felt that discussing the impact of disability on intimate relationships was important; however, he acknowledged that this dialogue was not only restricted to sexual activity but was necessary in order to make the dynamics of an intimate relationship with him clear to a potential partner.

John: Oh yes. Look in my view it would be unfair to present yourself to someone and not engage in these conversations that says "well look, I cannot guarantee that I can support you. But what I can say is that you may end up doing a lot of the work. And what I can say it that not only will you have to do all the work, but you may end up doing a lot of the house work, the child rearing work, you may end up doing a lot of everything." And look, under those circumstances I would expect 99% of people to be out the door so quickly.

Alex also iterated the importance of communicating the role that disability and impairment plays in intimate relationships. Communicating the role of disability and impairment in his sexuality helped partners to accept different sexual circumstances. To Alex however, these discussions were indicative of a sexual script which influenced his construction of sexuality.

Alex: I've learned what it was "supposed" to be like. When you constantly have one-night stands with "randoms", a certain protocol is formed. I learned that sex follows certain scripts. Having a disability and having sex follows a very specific script. One key element of that script is to put my partner at ease regarding the disability during and before the sex.

Communicating the impact of impairment and disability seemed to be an important feature in what Alex described as a component of the "*script of having a disability and having sex.*" Part of communicating the impact of impairment and disability on sexuality included encouraging the reconstruction of sexual expectations (Papile, 2009).

Reconstructing sexual expectations involved approaching sexual encounters without distinctive expectations or preconceptions and allowing communication to navigate the course of the encounter. For instance, Ian explained that communicating the impact of impairment, disability and his sexuality with potential sexual partners was imperative to reconstructing sexual expectations in order to ensure satisfactory sexual encounters.

Ian: I also try to prepare my partners for how a sexual encounter with me would be different than with an able-bodied individual... It just means that a partner has to communicate and reconstruct what sex can be when they are with me.

Through this dialogue Ian indicated that he could direct the course of sexual encounters and experience his sexuality in a way which satisfied him. Leah described some of what she and her partner did in order to reconstruct the expectation of normative sexual expectations during sexual encounters.

Leah: I mean we still try to do the normal stuff. But if my leg goes spastic I just go “hip, hip” whichever one it is. “Move it, move it, move it, no I can’t go there!” It’s not always painful, sometimes it is, but sometimes that helps so you just stay with the pain because you get a pay-out. There are a few positions we tried because they’re meant to be easy on your hips but you don’t get a lot from them.

Leah’s experience of directing her partner through communication allowed the two of them to be flexible and open about what did and did not work for them as intimate partners. As such, participants indicated that communicating with sexual partners about disability and sexuality was a multidimensional process which involved honesty, openness and a receptive partner. In this way, communication fostered an atmosphere for satisfactory sexual encounters and intimacy.

The Role of Sexual Intimacy. Intimacy was described as integral to satisfactory sexual relationships. Participant data reveals intimacy as: 1) a sense of closeness and experiences of affection (Jemtå, Fugl-Meyer & Öberg, 2008), 2) reciprocity and a sense of relationship satisfaction (McCabe, Cummins & Deeks, 2000) and, 3) the result of friendship, respect and familiarity (Papile, 2009). These interactional experiences with sexual partners positively influenced constructions of individual sexuality. For instance, Mary provided an example of how intimacy, characterized by a sense of closeness and experiences of affection, influenced her relationship with her partner and her experiences of sexuality with him:

Mary: We like to light some candles because sometimes—I find when I’m wanting to relax you need that sensory deprivation, you’ve got to have the TV off and no music and I like to have nice light and quiet. So we’ll put some candles on, sometimes we’ll have a bath together. I just like sitting in the bath and talking in the bath. We don’t always fool

around one side or the other but sometimes we have a shower together, you know, wash each other's backs, that kind of thing. I like that kind of intimacy and that kind of intimacy is a big part of sexual attraction for me as well. Whereas I think sometimes guys have two very separate things – there's intimacy and then there is sex. I get that - I think. I mean given I didn't have sex until a couple of years ago, you don't get intimacy from anything else. You don't get that moment of—and for me because it's so physical, the moment where you're not thinking about anything else except doing something physical and it's just quite a connection to someone. And you know, when you don't do it [have sex] for a little bit it changes the dynamic and I think you get some harmony back from doing that [having sex]. I just like that connection.

For Mary, the process of fostering a sense of closeness and affection with her partner through physical activities: *"we wash each other's backs... when you don't do it [have sex] for a little bit it changes the dynamic and I think you get some harmony back from doing that [having sex],"* was important to her construction of intimacy. These activities denote nurturance and love reinforced by the emotional and mental connection she has with her partner: *"You don't get that moment of—and for me because it's so physical, the moment where you're not thinking about anything else except doing something physical and it's just quite a connection to someone,"* and the sense that she is accepted and loved. Brian also felt that a sense of closeness and affection via certain activities encouraged intimacy.

Brian: I think that foreplay is the key to good sex because it creates intimacy. Without intimacy on some level, I think you cannot have good or even satisfactory sex.

Intimacy, for Brian and Mary, was further emphasized by reciprocity: *"...but sometimes we have a shower together, you know, wash each other's backs"* (Mary) and a sense of satisfaction: *"Without intimacy on some level, I think you cannot have good or even*

satisfactory sex” (Brian), with both their partners and sexual activities. Five of the participants also alluded to intimacy as important to positive constructions of their sexuality. John’s experience with a former carer of many years highlighted that intimacy is an iterative process which involved friendship, respect, affection and familiarity.

John: I was somewhat aware that I might not have had first claim on her, let’s put it that way. So when I realized that “oh she’s actually kissing me” my response was “oh yes I’m going to encourage this”. So I mean I remember quite deliberately putting my arms around her waist and locking them in a sense that “you’re not going to go anywhere for sometime” and then it came to the point of kissing her and holding her for as long as humanly possible and she seemed quite happy to play along as well. So we were both very much involved. And I mean for me it’s probably the first and the last time that I’ve been involved so intimately in probably 10 years and probably a bit more. I mean look, we honestly didn’t negotiate it, I mean, I just kinda happened. It was after she dressed me and bathed me and she was almost ready to go. And as far as I remember she came over to say goodbye and I was not aware and was not necessarily planning for anything to happen. To be absolutely frank, I don’t remember how it happened. I remember where I was sitting, I remember that suddenly she was sitting on my lap. I mean I don’t even remember us necessarily looking at each other and saying anything. I guess it was quite, I think, quite comfortable for me, and quite easy for me. Obviously I mean I don’t know how we would have negotiated it. I don’t know if it was something that she had planned to do and she was just going to see what I did in response. I can’t say whether she was the initiator just certainly that I was aware she was sitting on my lap and then we started kissing and I mean, well I knew then I had a choice so I decided to make it

very clear, I put my arms around her and we continued. And look nothing was said but it was quite clear that both of us were quite happy to let it happen.

For John the long standing relationship he had with his former carer fostered friendship, respect, affection and familiarity due to the intimate nature of their relationship; *“It was after she dressed me and bathed me and she was almost ready to go.”* In doing so, both John and his former carer felt comfortable crossing the parameters of friendship and share a highly sexualized moment with one another: *“I guess it was quite, I think, quite comfortable for me, and quite easy for me...So when I realized that ‘oh she’s actually kissing me’ my response was ‘oh yes I’m going to encourage this.’”* It can be seen that feeling comfortable with one’s partner facilitates an interactional atmosphere in which participants can engage in mutually satisfying experiences of sexuality: *“I knew then I had a choice so I decided to make it very clear, I put my arms around her and we continued. And look nothing was said but it was quite clear that both of us were quite happy to let it happen.”* In this regard, an ideal sexual partner could be identified in an individual who was socially and sexually compatible.

The Importance of Socio-Sexual Compatibility. Three participants indicated that socio-sexual compatibility was of least importance to how they perceived their sexual experiences with others. In contrast, another three participants described instances in which socio-sexual compatibility supported their constructions of satisfying sexual relationships. In particular, participant data highlighted: 1) the role that socio-sexual compatibility plays in intimate relationships, 2) socio-sexual compatibility as a conglomerate of awareness, receptiveness and attentiveness to one’s partner and their socio-sexual needs (Phillips, 2008) and, 3) perceived emotional, mental, social and physical compatibility (Dune

& Shuttleworth, 2009). Mary's experiences with her boyfriend exemplify the role that socio-sexual compatibility played in her relationship.

Mary: And I think we're very real with each other. We talk about almost anything with each other. It might not be the exact moment that something happens but I think some of what he likes is probably with a lot of people would say: "Well stick it up you" but at the same time I'm more bendable for people than he would be. I see a lot of grey and he would be a black and white person. But that's what I like about him. When I feel I give people too much and be a bit too flexible or too forgiving he kind of goes—he's able to function with a lot less people than I am. He doesn't care too much about a whole lot of social interaction, needs very few people, which I like as well.

For Mary socio-sexual compatibility was highlighted by the complimentary nature of her and her partner's personality and character traits. In doing so, socio-sexual compatibility facilitated a communicative process between them which exemplified their acceptance and appreciation of one another: *"I think we're very real with each other. We talk about almost anything with each other."* Leah's sexual experiences with her boyfriend highlight socio-sexual compatibility as a mixture of her boyfriend's awareness, receptiveness and attentiveness to her socio-sexual needs.

Leah: Yeah, my boyfriend helps me [during sexual intercourse] if I get in a certain position and I go "Left hip, left hip, left hip," he knows to do something—he's got a fairly good sense of it now. So he'll say "I don't want to hurt you more!" I've only slept with him. I've done other things with other people but I just did not, I could not fathom that kind of physical intimacy when it might have just been a whole lot of different things other people wanted from me. I'm not quite sure what went into it but I didn't hesitate with him. And I think that's important too.

For Leah, socio-sexual compatibility was characterized by her partner's awareness: *"he'll say 'I don't want to hurt you more!'"*, receptiveness: *"if I get in a certain position and I go 'Left hip, left hip, left hip,' he knows to do something"*, and attentiveness: *"my boyfriend helps*

me,” to her physical needs. In doing so she felt as though physical intimacy with her boyfriend did not drain her through mental and physical exertion: *“I’ve only slept with him. I’ve done other things with other people but I just did not, I could not fathom that kind of physical intimacy when it might have just been a whole lot of different things other people wanted from me.”* Similarly John’s experience with his former carer indicated that upon further reflection the sexual experience he shared with her was facilitated by emotional, mental, social and physical compatibility.

John: I mean now that I think about it Emily [not real name] and I had quite unwittingly become closer than carer and caree should have been. We were both very comfortable with each other and I guess part of that was because we were happy to talk to each other. I mean we must have had, you know a mutual interest. And I guess we had to a certain extent similar senses of humour. I mean there must have been trigger points even though neither of us really thought about it deliberately. We were very very comfortable with each other. And again, home care is a very tactile, touching profession, well I mean it has to be because of the care involved and I mean probably, she and I, although we probably weren’t aware of it or did it deliberately we probably encouraged each other to become, well you know, just sort of open and tactile with each other where with other people I probably hadn’t or wouldn’t have.

In summary, the participants of this study appeared to feel that, in addition to peer acceptance of impairment and disability, feeling worthy of sexual experiences with others, the importance of communication and the role of intimacy and finding someone who was socially and sexually compatible helped to facilitate positive perceptions of their sexual experiences with others. However, interactional sexual activities, behaviours or emotions do not exist independently but eventuate from the influence of public sexual scripts.

Public Sexual Schema

Public sexual schema was the second most salient factor in the construction of sexuality in people with Cerebral Palsy. Four major themes were identified within participant data in regards to public sexual schema: 1) Contemporary Media and Popular Culture, 2) The Myth of Disability and Asexuality, 3) Expectations of Normative Movement and Functioning and, 4) Issues of Accessibility.

Contemporary Media and Popular Culture.

Participant responses indicated that the public influence of contemporary media and popular culture was of relatively moderate importance (compared to the influence of their perceptions of sexual experiences with others). Primarily, participants expressed that media (although skewed) was a source for sexual information. Of equal importance was the impact of public sexual scripts. Of these scripts respondents noted that normative gender role expectations influenced how they constructed their sexuality. As such, Contemporary Media and Popular Culture (see Figure 7.2) included three sub-themes: Media as a Source for Sexual Information, The Impact of Public Sexual Scripts and Constructions of Masculinity

and/or Femininity.

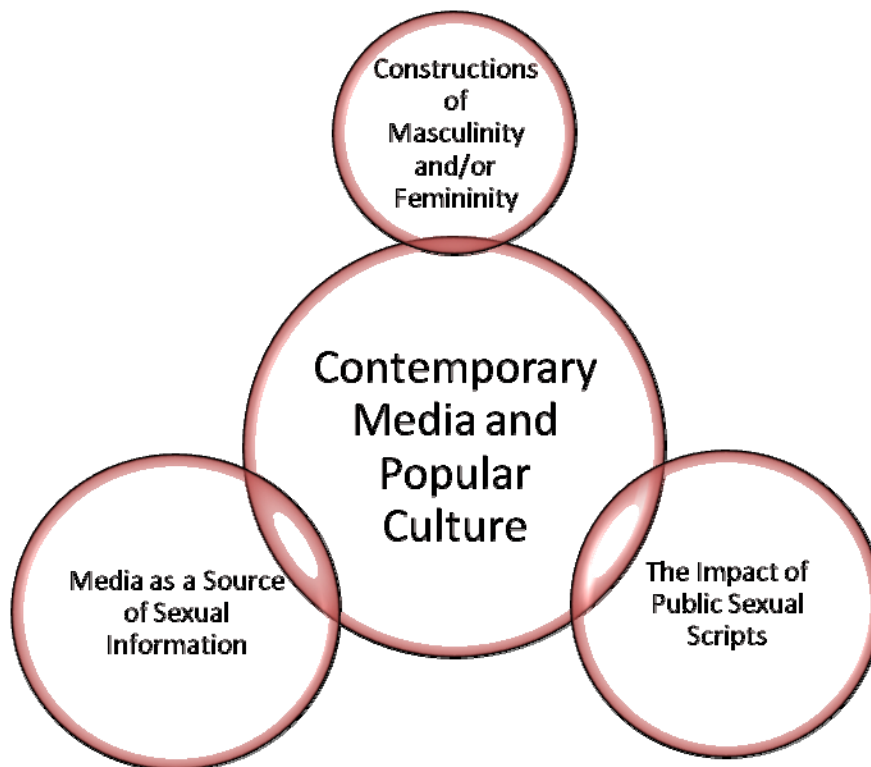


Figure 7.2. Contemporary Media and Popular Culture Theme and Sub-themes

Media as a Source for Sexual Information. Participant responses indicated that contemporary media served as a source for sexual information. The data indicate two conceptualizations which participants acquired from the media: 1) how to experience, conceptualize and construct sexual behaviour (Sanders, 2008) and, 2) sexual information from media as skewed and/or unrealistic (Brown, Halpern & L'Engle, 2005). Responses from Alex, Ian and Trevor indicated that contemporary media has informed how they experience, conceptualize and construct sexual behaviour.

Alex: I learned about sex and what to do from the media. I was watching pornography from when I was 12.

Ian: From TV, movies, from media I learnt what to do? How to do it? From pornography I thought "oh ya that's how it's done."

Trevor: I learned that sexuality and sex was an expression of intimacy between two (or more) partners for the purposes of enjoyment. I learned the mechanics of sex, through sex education classes in school. I learned some of my own sexual barriers and desires, as well as what excites me. As a consumer of media, I learned a lot from television, although I recognized from an early age that a lot of it was a skewed reality.

Although all participants indicated that contemporary media and popular culture were sources of information, Trevor and John notably described the information as skewed or unrealistic: *“As a consumer of media, I learned a lot from television, although I recognized from an early age that a lot of it was a skewed reality”* (Trevor). For John the process of learning about sexual experiences from the media was implicit but he ultimately thought of it as inaccurate.

John: You learn it by osmosis if the truth be told and you don't have to go far to find, it's all over the newspapers, all over the internet. And I'm sort of matter a fact about it now that it doesn't even raise an eyebrow. It doesn't matter anymore. I mean particularly with the internet. Everyone knows everything and everybody's seen just about everything. And you know, you can go back to the media, a lot of stars became very famous simply because they had some sort of extra, sexual exploit recorded on tape. And that tape ended up somewhere and somebody publicized it or gave it to a media outlet or put it online. I guess with my interest in media, current affairs and popular culture sexual information is always there whether in a polite or, most often, blunt way...Equally though, I know it's not accurate either.

Through the intake (whether active or passive) of sexualized messages (accurate or otherwise) from contemporary media and popular culture, participants perceived public sexual scripts to have impressed upon them idealized portrayals of sexuality and disability.

The Impact of Public Sexual Scripts. The impact of contemporary media and popular culture can be seen in participants' reiteration of popular public scripts about people with disabilities and their experiences of sexuality. Several types of impact described by participants included: 1) the impact categorizations of disability in the media and popular culture have on socio-sexual inclusion (Hartnett, 2000), 2) the impact of representations of sexuality which lack inclusion of disability (Raynor & Hayward, 2009), 3) portrayals of disability which deny social and sexual agency (Duncan, Goggin & Newell, 2010) and, 4) public sexual scripts as the instigator of upward and downward social comparison (Hammer, Ozolins, Idvall, & Rudebeck, 2009). For instance, Brian and Alex explained that the ways in which disability is constructed and categorized by media made it difficult to be noticed.

Brian: One of my annoyances about the media is that disability tends to be constructed in two extremes. One is that we're terribly vulnerable or needy and totally reliable on a carer (which holds a kernel of truth) or we exist as mountain climbers or paralympians conquering the world. And there is no middle ground but 99.99% of us live in this gray-area-middle-ground and you just don't see us.

Alex: I guess my idea [of romance] comes from media depictions and what I see played out at bars, but I have no real life experience to draw from. I honestly feel that romance is only in the movies and that because I am "different", I will not find it conventionally or long term.

According to Brian and Alex representations of sexuality and disability in the media may lack inclusivity. As such, participants felt that exclusive representations of sexuality and disability in the media restricted access to sexual opportunities. For instance, Leah and Mary felt that exclusive constructions of sexuality implied that they were socially and sexually inadequate.

Leah: And then when you've got someone who—the messages they are getting is that you're not sexually attractive, you're not going to get anyone to do that [have sex with you]. You're not going to have someone who is going to love you outside of your family. Because I think that's what a lot of people get because then it's going to affect your social development.

Mary: Yeah... because part of me, I am a bit of a romantic and I think I like the idea of just that one person, but it's not always true or realistic. But thank goodness considering the amount of things I was willing to change in myself to try and make friends with people but doing that was not one of them. Because I could have [had sex] and I came close a couple of times.

Leah and Mary made an effort to conceptualize the salience of public sexual scripts within the construction of their sexuality: *"...the messages they are getting is that you're not sexually attractive... I think that's what a lot of people get because then it's going to affect your social development"* (Leah), *"I am a bit of a romantic... but it's not always true or realistic... thank goodness considering the amount of things I was willing to change in myself to try and make friends"* (Mary). John however, felt that media portrayals and discourse about impairment denied people with disabilities the right to sexuality. For instance, John explains that portrayals of disability within the media and disability advocacy groups exclude people with disabilities from experiences of sexuality and agency:

John: I suggest for example you look at some of the debates; it pops up everyday in the media, as to what you do with a severely mentally handicapped person or someone who has significant damage to the frontal lobe and had a disability or a range of disability. And they are getting to the age that they'll have a period or something like that so it's probably best, to remove the sexual organs or turn them off in such a way so that a

person won't have those "difficulties" because they won't understand what's going on. For my own part I take the view that it's actually quite a reasonable step to take when you are dealing with a person who is that disabled. And they can't deal with those sorts of problems. But there's a disability lobby that says "how dare you?" And again, I'm not necessarily any type of friend of the disability lobby, as I told you I went to a seminar a while ago and it took me a while to figure out what they were talking about. They talked in acronyms and it was like going to a meeting for the Masons.

Based on John's thoughts discussions of sexuality in the media and advocacy groups seem exclusionary: *"They talked in acronyms and it was like going to a meeting for the Masons."* However, Ian felt that public sexual scripts had a more balanced (neither wholly positive nor wholly negative) impact on the construction of his sexuality. As such, the construction of his sexuality involved both upward and downward social comparison. Ian explained:

Ian: Mass media and the sexually charged culture that we live in have also played a role in influencing my sexuality, both in the positive and negative. Positive because it has allowed me to place my sexuality in the context of the larger world, and has slowly helped me build up my sexual confidence. In the negative, because it has at times, made it seem as though I need to look a certain way, or perform a certain act in order to be sexually desirable.

In this regard, Ian highlights the difficulty some people with Cerebral Palsy may have in the effort to feel positive about their sexuality while conforming to a variety of public sexual scripts. In particular, the implication of public ideals of masculinity or femininity as presented by contemporary media and popular culture was difficult to incorporate into the construction of participant's sexuality.

Constructions of Masculinity and/or Femininity. Contemporary media and popular culture produce many public sexual scripts which influence human sexuality (Brown, Halpern & L'Engle, 2005). The participants believed that conforming to normative constructions of masculinity and femininity, as portrayed by the media, influenced the construction of their sexuality. Two issues were of relevance: 1) the traits a perfect male or female would have (Lemish, 2010) and, 2) acceptable and attractive female and male attributes and behaviours (Jackson, 2005; Shuttleworth 2000, 2006). Mary and Alex's description of "the" sexually attractive woman and man exemplifies this sentiment.

Mary: When you think of attractive people—you know those people where you can't imagine anyone would dislike them. They're the woman most women would hate, because they're perfect. The type of people who are good-looking, confident and self-assured. They would just be able to put everybody at ease and there's something indefinably sexy about them. That's what I find sexy. Whether it's a man or a woman you think they've got that X factor that people talk about.

Alex: I always knew that I was "different" from other kids my age. I always found myself attracted to men. I had crushes on masculine TV characters (John Stamos aka Uncle Jesse from Full House). I liked how masculine he was in that role. I found myself attracted to that type even when I was young.

Although Mary indicated that the ideal of the "perfect man or woman" was sexy she could comprehensively define why: *"Whether it's a man or a woman you think they've got that X factor that people talk about."* From a young age Alex internalized portrayals of masculinity from popular television shows which influenced the "type" of man he presently finds attractive: *"I had crushes on masculine TV characters... I found myself attracted to that type even when I was young."* Leah however, perceived the normative construction of the

perfect man as more difficult for males to deal with than the normative construction of the perfect woman for females.

Leah: I often wonder what it would be like to be a guy with CP because as a girl who is meant to be dainty and delicate and, you know, somewhat helpless for men, there's some ability for people to reconcile that with your physical weakness because you're a girl anyway. Whereas I wonder what it's like for guys when they're physically weak and how that affects their concept of their masculinity and their sexual confidence and what a relevant issue it is?

On the one hand, Leah explained that her perception of the hegemonic construction of femininity involved women as dainty, delicate and helpless: *"...because as a girl who is meant to be dainty and delicate and, you know, somewhat helpless for men, there's some ability for people to reconcile that with your physical weakness because you're a girl anyway."* On the other hand, the men in this study indicated that part of their attempts to fulfill hegemonic constructions of masculinity involved conforming to what they were, or who they were supposed to find attractive. John's attraction to a popular female television personality exemplifies his acceptance of hegemonic constructions of femininity.

John: I think as a male you always maintain a certain amount of whatever the hormones are, the testosterone that goes through the body, which means you should respond positively when people or certain sights appear. Like, Jennifer Hawkins, that's right everybody knows who she is. I mean she wouldn't look at me in a million years but I guess I'm the same sort of red-blooded male that everyone else is for any pretty face that smiles at you, particularly if they're long legged and absolutely gorgeous. Even Donald Trump seems to think the light shines out of her every orifice, which it does I

suppose. To add to the mixer being hot for someone like that is really the first time you fall in love although you don't really know it.

Being attracted to the type of women that contemporary media validates as attractive contributed to how John constructed his idea of the ideal sexual partner. However, his thoughts imply, through upward social comparison (Hammer, Ozolins, Idvall, & Rudebeck, 2009), that he would never be considered in return. Brian explained that proving oneself as a sexual contender is compromised by having a disability while at the same time trying to conform to hegemonic constructions of masculinity.

Brian: Men have to do it and initiate. They can't get in there if they don't perform and ask the lady out and get things going. How are dudes expected to be negotiating sexual relationships when they have CP? Women [with CP] may not have to deal with that.

Brian's sentiments raise the important issue of incorporating one's sexuality with experiences of disability in an effort to consolidate one's identity: *"How are dudes expected to be negotiating sexual relationships when they have CP?"* However, five participants indicated that positive constructions of sexuality, while living with Cerebral Palsy, were often undermined by the myth of disability and asexuality.

The Myth of Disability and Asexuality

The data suggest that all the participants' constructions of their own sexuality were influenced by the pervasive myth that people with disabilities are not sexual beings. In this regard, five participants were concerned about the erroneous nature of the myth and how it affected the way that others perceived them. Four participants seemed to have internalized elements of the myth of disability and asexuality. In addition they implied that asexuality was inevitable due to the pervasive nature of the myth. As such, participant data fell into

two sub-themes (see figure 7.3): Perceptions of How Others Perceive Disability and Sexuality and Internalization of the Myth of Disability and Asexuality.



Figure 7.3. The Myth of Disability and Asexuality Theme and Sub-themes

Perceptions of How Others Perceive Disability and Sexuality. Respondents indicated that they had several concerns about how others perceived disability and sexuality. Notably participants articulated that public schema reinforced: 1) the erroneous perception that people with disabilities were inherently asexual (Milligan & Neufeldt, 2001), 2) people with disabilities are destined to sexual dissatisfaction (McCabe & Taleporos, 2003), 3) others' perceptions of disability and sexuality as detrimental to socio-sexual development (Shuttleworth, 2000), 4) the presumption that people with physical disabilities also have mental disabilities (Milligan & Neufeldt, 2001) and 5) the salience of a lack of public knowledge about sexuality and disability (Cole & Cole, 1993; Shakespeare, 2000). Trevor and Ian for example, explained how the erroneous perception from others that people with disabilities were inherently asexual manifested in their lives:

Trevor: I think that I am overlooked and not necessarily considered as a sexual partner.

Ian: As I say, I do not think that most able-bodied people will necessarily see disabled people as sexual. I think most people will remain to be quite disturbed with that concept.

The myth of disability and asexuality in this context implies that people with disabilities are destined to sexual dissatisfaction; destined to a life of celibacy, unsatisfactory sexual experiences and negative constructions of their own sexuality due to social ignorance. Leah's response synthesized what she perceived the myth of disability and asexuality to imply.

Leah: The messages we are getting is that you're not sexually attractive; you're not going to get anyone to do that [have sex with you]. You're not going to have someone who is going to love you outside of your family. I think that's what a lot of the message we get. It's going to affect your social development.

Leah's description of the myth also indicated that these types of messages have an impact on how people with disabilities develop as social and sexual beings: *"It's going to affect your social development."* As such, others' perceptions of disability and sexuality were detrimental to participant's socio-sexual development. Of particular concern for Mary was how the myth of disability and asexuality seemed to stem from the misconception that people with physical disability are also intellectually challenged. For example, Mary explained how her transition from a wheelchair and onto crutches after major surgery made the public misunderstanding about disability quite clear.

Mary: I think that people can communicate with someone in a wheelchair generally by speaking to them as if they are a small child. I'm quite obviously going to be able to discuss something with someone without any difficulty and I think that made people

uncomfortable. Before my big surgery a lot of people would speak to me or to people around me as though they assumed I was intellectually retarded and when you're able enough to understand what's going on, you know, that's part of my issue when I went to school and trying to socialize because you're reticent to put much out there because you know that there's going to be people who are thinking those kind of things.

All of the participants experienced the impact of the myth of disability and asexuality in some form. Notably, a lack of societal (public) knowledge about disability was cited as the cause of these experiences.

Leah: No one wants to talk about it because "people who are disabled don't have sex." They don't want to address it.

Alex: I think that people should know that being disabled doesn't stop any sexual urge; it doesn't mean that I am asexual. It just means that a partner has to communicate and reconstruct what sex can be when they are with me.

In addition, Brian, explained that typical others did not "get it" and the impact that societal ignorance had on being considered by others as a sexual partner.

Brian: Just little things too, like, just trying to think. Sometimes what other people think. They just don't get it. In general really. Like they um, it's really a taboo subject, disability and having sex. People with disabilities think that there is no chance for sexual contact with them [typical others]. They [typical others] would think that I'm just not sexually active. If they think I'm not sexy or sexual it makes it difficult to have a relationship with people like that. It's hard, hey? I think it's because they don't think of me in a sexual way.

As can be seen there are a multitude of messages integral to the myth of disability and asexuality. All participant responses indicated that although they may have wanted to

construct their sexuality via other scripts they had internalized the myth in some way, shape or form.

Internalization of the Myth of Disability and Asexuality. The internalization of the myth of disability and asexuality was supported by the evidence. The data suggest participants internalized the perception that people with disabilities were and would always be socially and sexually deprived (Howland & Rintala, 2001). For instance, participants explained that satisfying sexual experiences were not going to be a part of the life of someone with a disability because of how sexuality and disability is publically conceptualized. Mary explained how she has observed the myth impact her twin sister who has a more severe form of Cerebral Palsy than herself.

Mary: When you look at someone like my sister, we're both about to turn 25, and the biggest thing in her head is that she will never live independently, she'll never partner, and she'll never be able to have sex or children. But no one talks about that with her. And I'm just saying I'm pretty sure that's what she thinks about - trying to find a partner.

While Mary highlighted the impact of the myth of disability and asexuality she has distanced herself from it by highlighting its effects on others. Similarly, Ian also implied (in reference to his friend who also used a wheelchair) that people with disabilities are privy to fewer sexual options or consideration as sexual partners.

Ian: I mean thank god he was in a wheelchair, because if he wasn't he'd be running after anybody in a skirt, or not in a skirt.

John seemed to agree that sexual opportunities were limited and his chances slim as he was never formally spoken to about sex or sexuality.

John: There was no great sitting down and telling me the facts of life because it wasn't really necessary. I mean when am I going to end up in a situation where I need to be told? Well look, it has always put me along the lines of being asexual.

For Alex the myth of disability and asexuality made him feel as though he must settle for unsatisfactory sexual encounters if he wanted to experience sexuality with others at all.

Alex: I now don't often equate sex with romance. As much as I have tried to do that in the past, and sometimes currently, I feel that it is not realistic... so now, I take what I can get. I am not happy this way, but I understand it to be the reality of my sexuality.

For these four participants being considered asexual was integral to how they perceived and experienced sexuality with others. Furthermore, participant responses also indicated that having a physical disability went against what was publically expected in order to be perceived as a sexual option for others.

Expectations of Normative Movement and Functioning.

Expectations of normative movement and functioning seemed to influence how all the participants' perceived themselves as potential sexual partners for others. Expectations of normative movement and functioning referred to the expectation that the body should, move, function and behave like that of typical bodies. Participants indicated that expectations of normative movement and functioning influenced who they would most be attracted to. As such, participant data fell into the following three sub-themes (see figure 7.4): Impact of Expectations of Normative Movement and Functioning on Socio-Sexual Development, The Ideal Partner and Perceptions of What is and is Not Physical Disability.

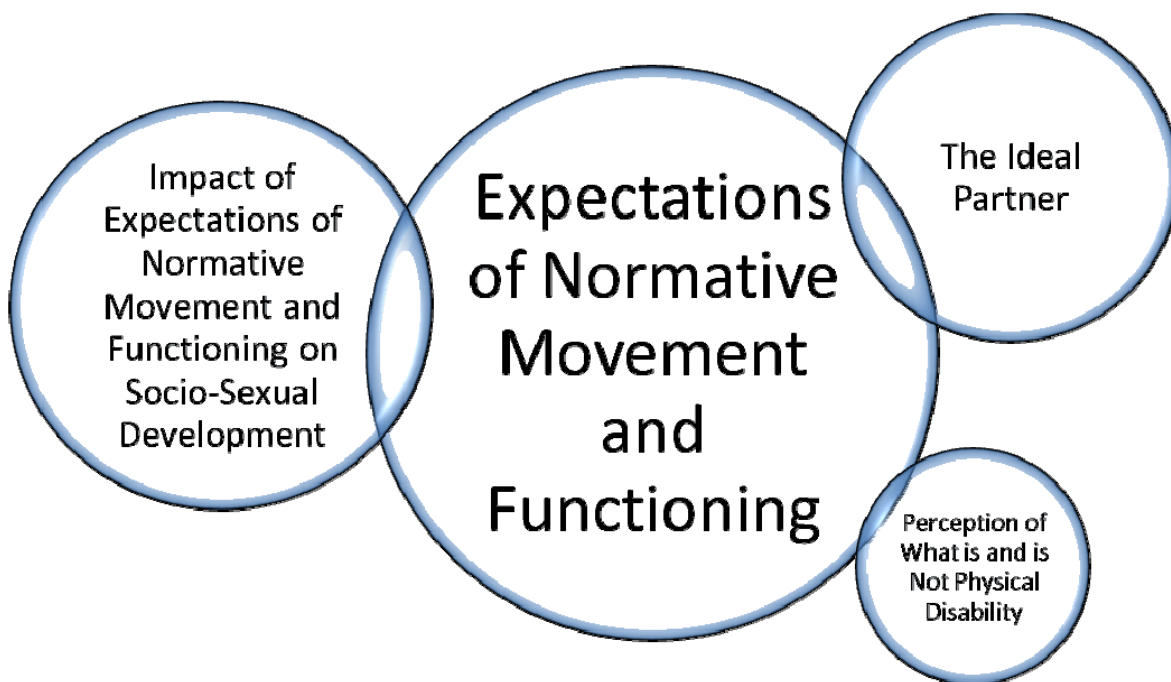


Figure 7.4. Expectations of Normative Movement and Functioning Theme and Sub-themes

Impact of Expectations of Normative Movement and Functioning on Socio-Sexual Development. Participants were of the view that being expected to physically move and function in the same ways as a typical individual created tension within the construction of their sexuality. Participants noted that expectations of normative movement and functioning: 1) affected participation (Shuttleworth, 2006), 2) socio-sexual equality (Dovidio, Pagotto & Hebl, 2011) and, 3) implied that physical difference was a socio-sexual “turn-off” to others (Dune & Shuttleworth, 2009). For instance, Alex and Trevor both indicated that living with a physical disability restricted their ability to participate in socio-sexual activities and development.

Alex: My level of mobility also influences my sexuality because I can’t perform all of the same functions as an able-bodied person so I often feel inadequate. I think the fact that I have had mostly one night stands also influences how I experience sexuality, because I feel like I won’t find anything long term due to my disability.

Trevor: As I grew older, sexual thoughts developed from “playing house” into more sexual, or sexually charged, in nature. But, due to my physical limitations, I was not able to fully explore those feelings as early as some people might.

Brian explained the impact of having to use a wheelchair for mobility on socio-sexual development. Primarily, he indicated that being in a wheelchair meant that he would not be considered as a social or sexual equal because he could not be at eye level with his peers.

Brian: Males are competitive so I mean if I’m after one female and there are three other able-bodied males where is she going to go? I was talking to this girl and there were other guys who walked in and they didn’t say “hello” or anything but they could stand and face her. I was in the room but I might as well not have been there.

The expectation that everyone can or should stand when conversing, particularly in the context of public social venues, made Brian feel that he could not be a social or sexual contender when physically typical men were in the room: *“Males are competitive so I mean if I’m after one female and there are three other able-bodied males where is she going to go?...I was in the room but I might as well not have been there.”* John also articulated similar implications of the public expectation to move and function typically:

John: Even around professional colleagues, particularly when you go to a seminar and everybody breaks for morning tea, and usually how that works is everybody stands around a coffee table or a drinks table or whatever and has their cakes and biscuits and coffee. Because they’re standing and you’re sitting it is pretty hard to make it known that you’re still there. I had a recent experience of this, in that I was at a seminar and we were at the State Palms House and the theatre was fine but the space outside was very cramped with 200 people and it gets very hot. That’s where they were serving tea and

coffee and the only reason that I got any of either is that there were a couple people that I knew because I was on the committee and they had to arrange it for me. But again the problem is, and people don't do it deliberately, everybody has to stand up for conversation and you are immediately on the wrong level to get any tea, coffee, biscuits or a chance.

While John engaged in social activities in order to negotiate relationships not being at eye level made him feel as though he were not and could not build relationships with his peers: *"But again the problem is, and people don't do it deliberately, everybody has to stand up for conversation and you are immediately on the wrong level to get any tea, coffee, biscuits or a chance"* (John). Living with a physical disability made it difficult for participants to find opportunities to engage in conversation let alone court. Ultimately, some participants felt that living with a disability would be a complete "turn-off" to a potential partner. Ian and John described what they experienced as the realities of living with disability and the effect it would have on a potential partner and sexually intimate relationship.

Ian: Well I mean I'd like that in any context it doesn't have to be about sexuality or anything like that. But that's in nirvana or at the end of the yellow-brick road. That would be in a world where we finally got over all our hang ups and we actually do the research and we actually make sure that we're not condemning people to disability just so someone can say that we can have a diverse society.

John: I mean the issue really is if you really claim that you really love someone and that you want to spend your life with them under what terms is that mediated. I mean, again, I think I said to you last time, the standard marriage vows go in sickness and in health and that's fine. But it doesn't go in sickness and in constant disease and in constant doctor's appointments and in constant co-morbidities.

The sentiment that impairment was unacceptable or unattractive to potential sexual partners was influenced to how expectations of normative movement and functioning were conceptualized: *“The standard marriage vows go in sickness and in health and that’s fine. But it doesn’t go in sickness and in constant disease and in constant doctor’s appointments and in constant co-morbidities”* (John). As such, Ian and John constructed the possibility of finding a suitable partner: *“But that’s in nirvana or at the end of the yellow-brick road. That would be in a world where we finally got over all our hang ups”* (Ian). As mentioned in the interactional theme Perception of Sexual Experiences with Others, participant’s responses indicate that finding an individual to share in the realities of disability with them through understanding and openness was necessary. As such, finding a partner who accepted physical difference was both an interpersonal and public issue. Participants seemed to allude to their ideal partner as a physically typical individual, who did not necessarily understand or have experience with impairment.

The Ideal Partner. Interestingly, all of the participants in this study discussed potential partners and previous partners as individuals who were physically typical. As such, participant’s ideal partner would: 1) meet public expectations of normative movement and functioning (Moin, Duvedevany & Mazor, 2009) and, 2) be necessary to fulfill care needs and family sustainability (Wilder, 2006). For instance, Alex and Brian made it clear that a physically typical partner would be imperative.

Alex: My ideal partner would be able-bodied because I think that having sex with a disabled person is too much work. My ideal partner would be masculine, but extremely open-minded.

Alex blatantly indicated that being with someone who had a disability would not conform to his idea of the perfect partner as they would be *“too much work.”*

For John, a physically typical individual was indicated as necessary in order to fulfill care needs and family sustainability.

John: Well, I mean, generally in my mind it would need to be a non-disabled person. Now I don't rule out the other but my concern would be that you're just mounting up the problems for yourselves. Now with respect to my friends that I mentioned earlier, they are both disabled, but they both could walk. And they have done quite well and I've seen them quite recently and now only one of them can walk [the wife] and he's very you know, his age has caught up with him [the husband]. He's in his 60's and he can't walk and it's very hard to understand him because he's always had a speech problem and it seems a lot worse. He's had a lot of medical problems over the past few years which is again a worry for me because I look at him and I look at me and I think 20 or 30 years down the track I'm going to be just as sick and just as disabled and just as cranky about all the things I can't do. And then you know somebody else is going to be doing even more.

Based on participant responses the construction of the ideal sexual partner for an individual living with a severe physical disability conformed to expectations of normative movement and functioning: *"...generally in my mind it would need to be a non-disabled person. Now I don't rule out the other but my concern would be that you're just mounting up the problems for yourselves"* (John). In particular participants indicated that it would be difficult to navigate a satisfying sexual relationship with someone who also had a disability: *"My ideal partner would be able-bodied because I think that having sex with a disabled person is too much work"* (Alex). Although Alex, Brian and John indicated that their ideal partner would be physically typical, their choice may not have been founded on superficial reasons. An

individual who was physically typical or did not have a moderate to severe impairment could serve as a sort of assistive medium for sexual expression and daily living requirements.

Perceptions of What is and is Not Physical Disability. Of the seven participants included in this study Mary (whose twin sister has a severe form of Cerebral Palsy) was the only one who did not use a wheelchair for mobility (after major corrective surgery) but instead relied on crutches some of the time. Mary's experience with physical disability is of interest as she described that in certain situations others perceived her as physically typical. For Mary, this process of being what she perceived as partially typical was consolidated by both public perceptions about disability and interactional encounters with others. As such, Mary explained that living on both sides of the fence (physically typical and atypical) simultaneously proved to be challenging.

Mary: Yeah so, I mean, I had a fairly decent group of friends in school. At break I'd just go from my Home Group to my Twins. We called them my Twins because she [her sister] was kind of allocated a group of friends and I think because she's in a wheelchair and can be so child-like, they find it more ... comfortable.

Investigator: Do you reckon it's like they want to, say, if you have a physical impairment, it either—like you're saying, it has to be obvious, and therefore we can put you in a little box or it's either you don't and therefore we can put you in this box, but if you're in the middle we don't know where to put you –

Mary: -- yeah, absolutely! Because that's what I think I get all the time. I've got a disabled parking permit. But I always get people who shout at me for parking in the parks.

Investigator: Really?!

Mary: Yep. Old people in particular are bad at that!

Investigator: What do you say?

Mary: I just ignore them. I say I've got a sticker and then, you know, sometimes I drag my leg a bit more. Because they look at you! Old people are shocking for it. Like, I haven't been able to walk my entire life, these people end up on a stick at 70, get a parking permit. Get screwed! But they're the worst offenders for it. You get that, where people give you dirty looks for parking in a disabled bay or you get people gorking at you down the street. Or people who go to take things away from you because they think I'm embellishing my impairments. Before my big surgery a lot of people would speak to me or to people around me as though they assumed I was intellectually retarded even when you're able enough to understand what's going on. That was part of my issue when I went to school and tried to socialize. I couldn't because I was reticent to put much out there because you know that there's going to be people who are thinking those kinds of things.

For Mary, being identified as both an individual with a mild and moderate impairment highlighted the confounding aspects the public scripts about physical impairment and public scripts about physical typicality: *"Before my big surgery a lot of people would speak to me or to people around me as though they assumed I was intellectually retarded even when you're able enough to understand what's going on."* Mary's experience with disability brings to attention the many barriers that people with mild to moderate Cerebral Palsy face daily: *"You get that, where people give you dirty looks for parking in a disabled bay or you get people gorking at you down the street."* Mary's dichotomous relationship with disability highlights public misunderstandings about atypicality which limits access and therefore restricts social and sexual integration and inclusion. Limited accessibility was also indicated

by the other six participants as a factor which restricted them from socio-sexual opportunities and relationships.

Issues of Accessibility.

Participants believed that access to services, resources, sexual opportunities and the environment in which participants lived also influenced their construction of their sexuality. In this regard, four participants were concerned about the tedious and frustrating experience of trying to navigate structural environments in order to access socio-sexual opportunities. However, three participants indicated that with the help of modern technology they were able to simulate courting and dating online. Finally, one participant indicated that without resources sexually intimate relationships with others were difficult to support for both parties. Participant view fell within three sub-themes (see figure 7.5): Structural Access Issues, Access to Sexual Opportunities and Access to Resources which Support Sexually Intimate Relationships.

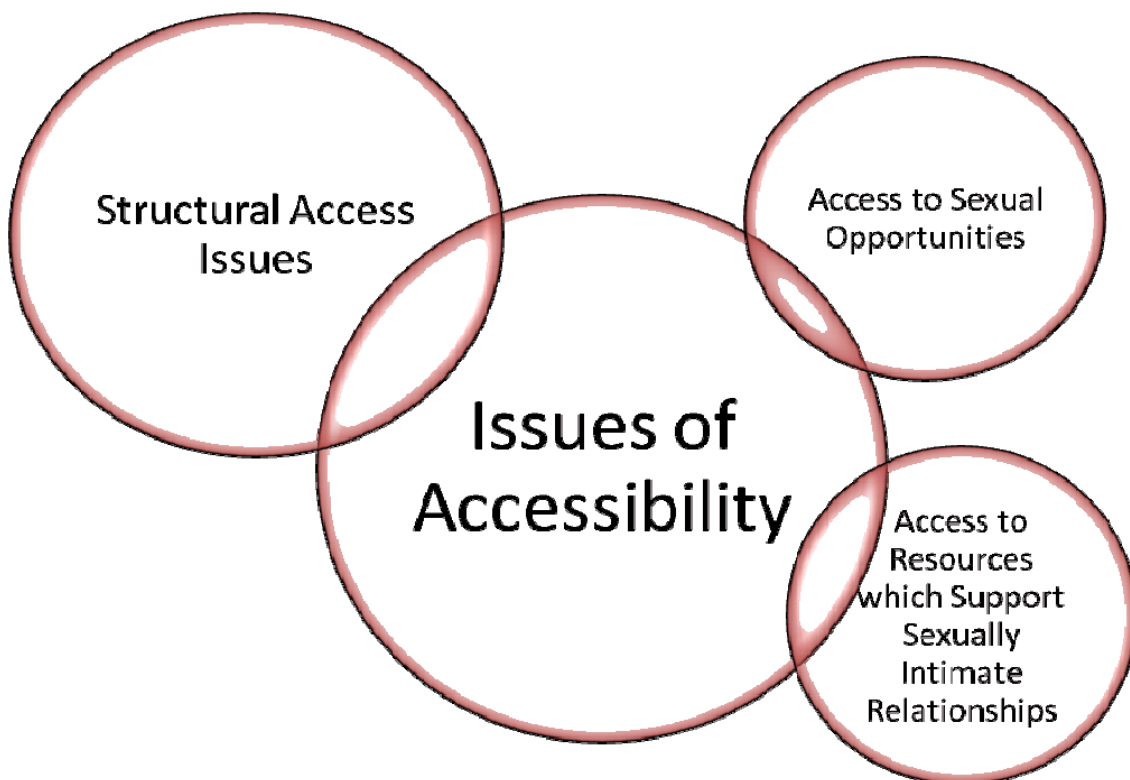


Figure 7.5. Issues of Accessibility Theme and Sub-themes

Structural Access Issues. Participants perceived that accessibility to infrastructure restricted sexual opportunities. Notably, participants perceived that; 1) they spent more time than typical others in the preparation or negotiation of a social outing (Yoshida, 1994), 2) infrastructure was generally as accessible as it was inaccessible (Rummel, 2009) and, 3) there were ways to bypass structural access issues (Jang, Choi & Lee, 2010). For example, Brian perceived that he had to spend extra time and money when arranging social outings. For him this meant that he had to make more of an effort to access sexual opportunities than his peers:

Brian: It's really frustrating because like I said no one gets it. I think they don't understand what its like to want to do things like everyone else but I can't and I try but there are limits. Wow!! Just stuff like accessibility. I can't go were all the cute girls are going because I can't get in. The extra money I have to spend to do things. It's just difficult so I don't go to those places.

According to John the "extra time" and thought involved in order to organize a date reduced the opportunity to go out spontaneously with friends or a potential sexual partner.

John: Equally, I guess there's the practical point of view. How could I ask someone out? How can we go anywhere every time I go to a lunch? When I went to a lunch or dinner with the office I had to arrange taxis or get mum involved to get me there or to get me back or something like that. So there was always sort of an infrastructure or arrangements that had to be made, unmade or remade to make my attendance somewhere possible. The other factor, it has to be wheelchair accessible doesn't it? So there are immediate questions of, particularly about something being spontaneous, going through all those check points there is nothing spontaneous.

Brian and John considered many social gathering places as difficult to access: *"I can't go were all the cute girls are going because I can't get in"* (Brian). However the women acknowledged that there were places that did accommodate people with disabilities. For instance, while Leah felt that negotiating infrastructure (i.e., clubs, pubs, bars, restaurants, etc.) was difficult it could be managed.

Leah: Where do people meet, in bars, restaurants, in cinemas? Again a lot of those places are now accessible but equally a lot of them aren't.

For five of respondents, feeling excluded from sexual opportunities was characterized by limited access to public spaces. Alex, however, indicated that one does not necessarily need to "go out" to find a sexual partner.

Alex: My sexual history is mostly comprised of casual sexual encounters. I meet the men usually online, because it is difficult for me to get into bars. Most of the men I meet online aren't looking for anything serious though.

Although Alex felt that he may not get a chance to foster a long term relationship from his interactions on the internet he highlights an innovative portal for access to sexual opportunities.

Access to Sexual Opportunities. For some participants going online was a viable alternative to trying to navigate infrastructure which was not guaranteed to be accessible. This was primarily exemplified through being virtually available via the internet and being physically present at social venues and outings (Holden, 2006). Sexual opportunities were also accessed through the employment of sex workers (Sanders, 2007). For Mary a conjunction of physically "getting out there" and using the internet helped increase her chances when she met her boyfriend.

Mary: I think probably getting out there and going out to places and being seen and doing stuff. Maybe also the internet. Seeing what's out there you know.

Brian also felt that navigating the virtual world of internet dating proved to be less frustrating and more liberating than being out in the real world.

Brian: You just go online really. And I have several girls on my list and the virtual world gives me the chance to act out ideas or fantasies that I would like to experience. It's a lot of fun but it's frustrating... if someone doesn't like that. But I stay hopeful, like anyone else and just keep going.

For Ian, the opportunity to be with someone sexually was all he really wanted.

Ian: In my experience it's probably just the opportunity to have sex which makes it good. When I get an erection from someone touching my penis. Being able to experience my sexuality is the best part.

All participants suggested that it was difficult to access sexual opportunities due to structural restrictions: *"I meet the men usually online, because it is difficult for me to get into bars"* (Alex) or low levels of peer-receptiveness: *"It's a lot of fun but it's frustrating... if someone doesn't like that"* (Brian). To alleviate some of the social and structural issues Brian, for instance, employed the services of a sex worker:

Investigator: Which was your best experience?

Brian: The one in Melbourne. It's called the "Gentleman's Club"

Investigator: So it's actually called the "Gentlemen's Club." Why was that your best experience?

Brian: Well I got there and went to the room and it was a proper place. There was several rooms. And I had time with a dancer.

Investigator: So you got your own private dance? Anything else happen?

Brian: Oh yeah. I went to touch her and I thought I couldn't touch her. I spent quite a bit of money on her.

Investigator: Was it just dancing?

Brian: I spent a bit of money on her. So you can imagine.

Investigator: Have you been to any brothels?

Brian: No, no yet.

Investigator: Do you want to go?

Brian: At some stage yeah.

Investigator: So your best sexual experience was someone who talked with you, danced for you and kinda just played with you and was cheeky.

Brian: Yeah.

Investigator: So there wasn't anything overtly sexual in terms of touching or anything...

Brian: Well you know...

Investigator: That's cool.

Brian: YEAH! IT WAS! [participant's emphasis]

Facilitation of sexual services (as provided by a sex worker in Australia) helped Brian bridge access to sexual encounters. In doing so, he may be privy to experiencing and constructing his own sexuality without the social or structural restrictions some of the other participants indicated. While Canadian participants could not legally have explored their sexuality through the employment of a sex worker they did indicate that public access to resources which can support sexually intimate relationships were necessary.

Access to Resources which Support Sexually Intimate Relationships. The lack of resources which allow people with disabilities to enjoy long-term sexually intimate relationships appeared to affect participants' construction of themselves as potential sexual

partners (Kitchin, 2002). For instance, Ian felt by others not wanting to facilitate sexual activity between people with disabilities restricted his sexual expression.

Ian: I would have liked to [have sex] yeah but we just went to the bedroom and tried to get in there but we just ended up having a bit of a pash [“making out”] and a cuddle. I would have liked to [have sex] because at that time there was an attendant around they could have helped us but thought it was weird.

For John, the practicalities of life with a disability made him feel skeptical about opportunities to access a long-term sexually intimate partner.

John: Let’s just theorize for a moment. That other partner or person would end up with a great deal of the economic responsibility purely for the reason that. Employers will look at somebody with a disability and say “well yes we could tick a diversity box but we don’t want all the red tape that goes along with it” and you know, that’s a half reasonable economical decision to make. Particularly if you believe you are going to have to file a lot of forms, get a lot of approvals, and it’s going to cost you to adjust the workplace, and if you’re a small or even a medium or even sometimes a big business you wonder whether that is an appropriate use of your resources.

For all participants accessibility proved to be an issue when trying to negotiate sexual opportunities. Not being able to engage in sexual activities or express one’s sexuality had an impact on how people within the study constructed themselves and their bodies as sexual. In this regard, the consolidation of interactional and public sexual schema by the informants of this study was reinforced by private constructions of themselves and their sexuality.

Private Sexual Schema

Private sexual schema was the least influential factor in the construction of sexuality by people with Cerebral Palsy. Five major themes were identified within participant data in

regards to private sexual schema which will be presented and discussed as follows: 1) The Intersection between Disability and Sexual Identity, 2) Perceptions of Sexual Desirability, 3) Body Esteem, 4) Sexual Agency and, 5) Sexual Esteem.

The Intersection between Disability and Sexual Identity.

Personal experiences of disability and perceptions of sexual identity was of relatively moderate importance to participants overall construction of their sexuality. Participants also expressed that harmonizing their personal care needs with their sexual needs was imperative to satisfactory experiences of their sexuality. Finally, respondents mentioned that being comfortable with themselves and their sexuality was important to cultivating a positive construction of their sexuality.

The theme Intersection between Disability and Sexual Identity yielded three sub-themes (see Figure 7.6): Reconciling Disability and Sexuality, Harmonizing Care Needs and Sexual Needs and The Importance of Accepting Oneself.

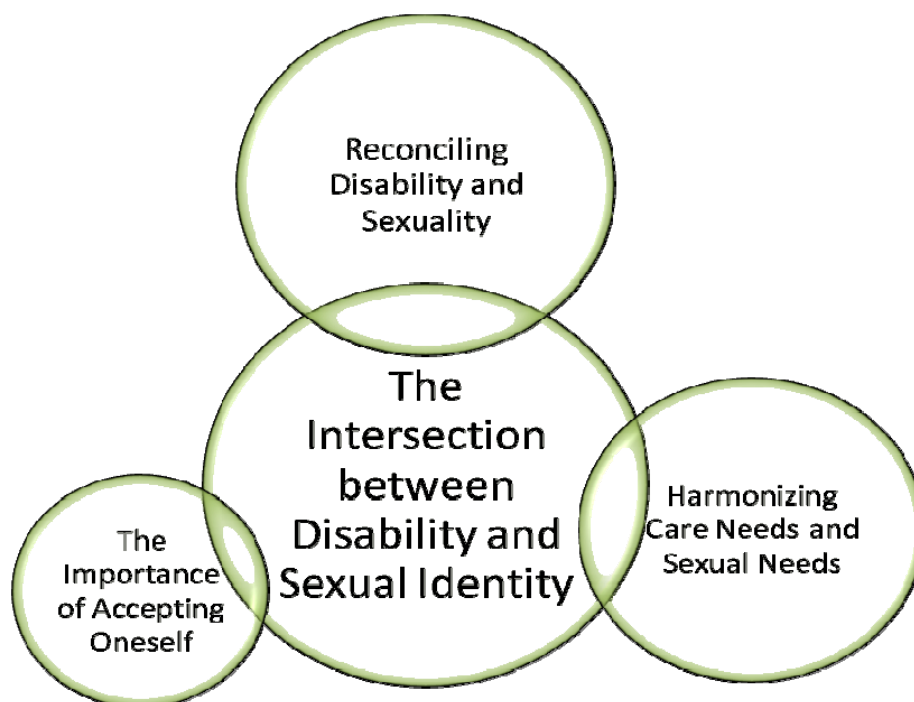


Figure 7.6. The Intersection between Disability and Sexual Identity Theme and Sub-themes

Reconciling Disability and Sexuality. Participants believed that a concerted effort needed to be made in order to privately reconcile their identity as an individual living with a disability and their sexual identity (Kaufman, 2010). However, they also believed that sexuality and disability were best dealt with separately (Cheng & Udry, 2002). For example, Alex explained that some of the most important transitions in his life revolved around consolidating his sexual and “disabled” identity.

Alex: Obviously my coming out of the closet was a very important transition in my life. However, I also think that I had to come out twice: as gay and disabled. That happened when I starting meeting sexual partners. It was at that point that I truly understood the impact of my disability.

Brian felt that the most obvious influence on the way he privatized his sexuality was living with a severe physical disability.

Brian: The most obvious one that jumps out at me is my disability. Being limited to the use of two fingers on my left hand and limited vocal ability has definitely influenced the way that I perceive my sexuality and the way my sexuality is perceived by others. My personality is another key factor, as I have never been one to hide my disability and have always been very strong on my identity as an individual with a physical disability.

Brian indicated that disability is an integral factor in the way they he perceives his sexuality and his identity: *“Being limited... definitely influenced the way that I perceive my sexuality and the way my sexuality is perceived by others.”* Living with a moderate to severe disability was indicated by all participants as a factor they needed to negotiate privately in order to satisfactorily experience their sexuality: *“I have never been one to hide my disability and have always been very strong on my identity as an individual with a physical disability”*

(Brian). Ian and Trevor, however, explained that they made the effort to keep their daily care needs and sexual intimacy separate.

Ian: I think that, with a disability as severe as mine, it is impossible for my care needs not to influence that part of my life in some way. I have always tried to keep the two separate, and will continue to endeavor to do so, but they both involve a physical intimacy that is reflected in one another.

Trevor: My care needs do not in any way dominate my sexuality, but they do influence. While sexuality and disability were separate entities for some participants: "I have always tried to keep the two separate, and will continue to endeavor to do so" (Ian), others felt differently: "...when I starting meeting sexual partners. It was at that point that I truly understood the impact of my disability" (Alex). Ultimately all participants found strategies in order to harmonize their care needs with their sexual needs.

Harmonizing Care Needs and Sexual Needs. As indicated by participant data the intersection between disability and sexuality involved privately managing the need for sexual intimacy with the need for daily care. Participant's highlighted; 1) the difficulty they faced in the process of harmonizing their care needs and sexual needs (Overstreet, 2008) and 2) the importance of physically preparing oneself for sexual activities (Tepper, 2000). For example, Brian's experiences with sexuality and living with a disability exemplify the difficulty some participants faced in the process of harmonizing their care needs and sexual needs.

Brian: I feel like my care needs make it a little difficult to organize for people to come over and if they were to come over I would feel nervous about asking them to help me with personal care needs. It's not really negative but it is a factor.

Brian indicated that he found it confronting to ask a potential sexual partner to help him with his care needs: *"I would feel nervous about asking them to help me with personal care needs."* Alex, Trevor and John found that dealing with their care needs prior to or exterior of sexual activities was beneficial.

Alex: I try as much as I can to keep my major needs (toileting, redressing, eating) separate from my sexual encounters.

Trevor: I am incontinent and therefore require assistance with toileting before any sexual act is to take place.

John: I always make sure that my attendant has thoroughly cleaned me, and that all of my care needs are taken care of prior to any act.

Harmonizing one's perceived care needs and sexual needs was important to participants.

For instance, Mary and Leah's experiences with their boyfriend's exemplify the importance of being physically prepared for sexual intimacy.

Mary: Most of the time we stick to a routine because I worry about being too tired to do what I need to do in any given week so I'm probably not spontaneous enough but I do try to be more spontaneous and then there is the matter of always meeting each other at the right moment. Because sometimes when I'm ready he'll look at me and go "not now". I end up saying "are you kidding me?"

Leah: I normally try and actually do every hip stretch I know before I—otherwise I just get him to massage my hips while I'm there and as long as I don't end up crouching backwards. Sometimes I go to get off and I can't because one hip locks up. So it's like "tip me that way" [LAUGHS].

Through preparation participants were able to dichotomize the realities of impairment and the experiences of sexuality. In doing so, participants used planned: *"I always make sure*

that my attendant has thoroughly cleaned me, and that all of my care needs are taken care of prior to any act" (John), *"I normally try and actually do every hip stretch I know before"* (Leah), in order to experience their sexuality satisfactorily. In addition to the private reconciliation of disability and sexuality and harmonizing one's care needs and sexual needs respondents explained that being accepting of oneself was a key component of their experiences with disability and sexual identity.

The Importance of Accepting Oneself. In describing the relationship between disability and sexuality participants explained that being accepting of oneself was important to constructing a positive perception of their sexuality (Murphy, Molnar & Lankasky, 2000).

Alex: I always knew that I was "different" from other kids my age. And hey, that's fine.

John: That's the only part [his penis] of that region that works consistently. The legs don't work. Off and on I don't feel the feet properly. So I make the best use of it as I can.

Mary: Well that's actually advice that my German friend gave me. "You need to walk around naked more." So, okay, I started to do that and I felt, "this feels strange," but you know, if you don't actually look at your body enough you're going to be more uncomfortable with it or showing it to anybody else.

In the process of accepting oneself participants appeared to feel more comfortable and positive about the role disability played in the formation of their sexual identity (Esmail et al., 2010). In doing so, participants created perceptions about how they as potential sexual partners were perceived by others.

Perceptions of Sexual Desirability.

Participants' perception of their own sexual desirability was influenced by what they thought were sexually desirable traits in conjunction with what they perceived others

thought of them. Two sub-themes were apparent: Perceptions of Sexually Desirable Traits and Privatizations of Others' Perceptions (see Figure 7.7).

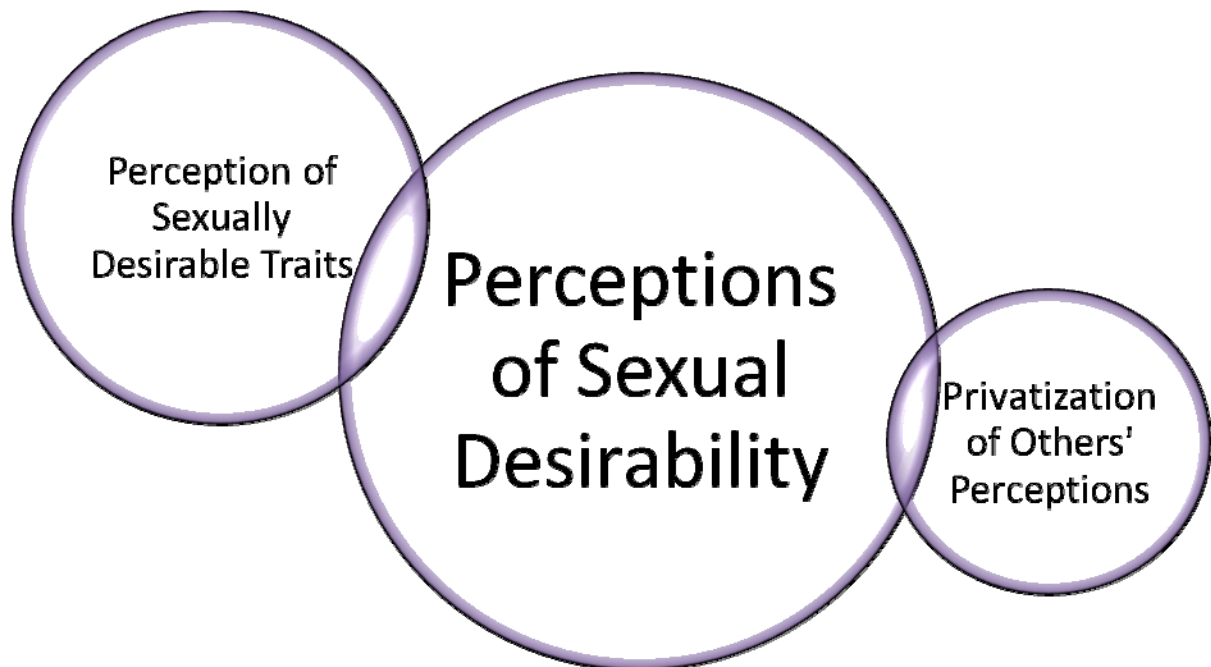


Figure 7.7. Perceptions of Sexual Desirability Theme and Sub-themes

Perceptions of Sexually Desirable Traits. Participants' private perceptions of sexually desirable traits within themselves and others influenced the private construction of their sexuality. Private perceptions of sexuality are characterized by individual thought processes about their sexuality and sexual concepts (Simon & Gagnon, 2003). Private perceptions of sexual desirability overlap with both interactional and public conceptualizations of sexual desirability. In this regard, participants explained that personality traits (i.e., confidence, humor and intelligence) were what made them (and others) sexually desirable (Kaufman, Kozbelt, Bromley & Miller, 2008). They also believed that engaging in sexual activity reinforced private perceptions of one's sexual desirability (Glass & Padrone, 1978). In terms

of personality traits, participants described sexually desirable traits they perceived within themselves and others.

Alex: I think confidence is extremely attractive, which is funny because I don't feel like I exhibit enough confidence. I think that a sense of humour is also very important to sexual attractiveness. I think that my crass, bold, honest sense of humour has the potential to make me sexually attractive.

Leah: I think I can be funny, you know, in a sarcastic kind of way.

Trevor: In my opinion, my sexiest attribute is my sense of humor and intelligence. I am a firm believer that the brain is the sexiest organ in the body, which works out well for me.

Mary: I also think that my intelligence and openness lend themselves to my sexual desirability. My sense of humor also helps in this regard.

Ian: The most obvious sexually desirable quality to me is confidence. If someone can own their body, be comfortable in it and be comfortable in expressing it - that leads to sexual desirability. I do not think that there is one physical or social quality that is universally sexually desirable. But all of these qualities, if encased in social and physical confidence, become a lot more attractive.

Alex, Leah and Trevor and Ian indicated that character and personality traits are of particular importance to the perception of sexual desirability. For instance confidence was described as an expression of comfortability with oneself and was therefore attractive: *"The most obvious sexually desirable quality to me is confidence. If someone can own their body, be comfortable in it and be comfortable in expressing it - that leads to sexual desirability"* (Ian). Participants perceived humour as a sexually desirable, perhaps as a derivative of intellectualism: *"In my opinion, my sexiest attribute is my sense of humor and intelligence"*

(Trevor). Participants also described intelligence as an important character trait: *“I also think that my intelligence and openness lend themselves to my sexual desirability”* (Mary), *“I am a firm believer that the brain is the sexiest organ in the body, which works out well for me”*

(Trevor). For Brian he felt sexually desirable when he was engaged in sexual activity.

Brian: My body is sexy when I do cum...my abdominals when I cum, they tense. Can't think of anything else. I dunno. My eyes.

Participants generally believed that they had personality, character and some physical traits which they perceived as sexually desirable. Privatizations about how people with Cerebral Palsy thought was sexually desirable traits was further mediated by what they thought other thought of them

Privatizations of Others' Perceptions. On the one hand, participants indicated that they mostly felt that they were sexually attractive. On the other hand, they explained that privatizations of others perceptions of their sexual desirability: 1) created tension within the private construction of their sexuality (Murray, 2004) and, 2) made them feel that others did not or could not find them sexually attractive (Rintala et al., 1997). For instance, Alex described the contention between privately feeling sexually desirable and privatizing the idea that others view him as sexually desirable:

Alex: Perhaps, my sense of humour and my sense of self and masculinity make me sexy.

Partners have told me I have great eyes, and I am a good kisser. In all honesty, I don't feel as though I am sexually desirable. I think this stems from me feeling like my disability makes me an outsider.

For Brian, being perceived by others as a sexual being let alone a potential sexual partner was difficult to consolidate.

Brian: I don't think they see me like that [as sexual].

Investigator: How about the people in your sexual history?

Brian: They might have felt alright, that I was sexual I guess.

Investigator: What do you think they thought about your sexuality?

Brian: I think that they felt I was a sexual person and that I gave them sexual pleasure.

Investigator: Do you think they think about you as a sexual being.

Brian: For sure yeah.

Investigator: Do you think strangers would think of you as a sexual person?

Brian: No, I don't think so. No.

Alex, Ian and Leah's responses also seem to reiterate that others perceptions of their sexuality has an impact on their private sense of sexual desirability.

Alex: Most of the time I don't feel desirable in this manner. This may also be a result of social ostracism due to my disability – and the projection of attitudes surrounding disability back on to me.

Ian: Well to be perfectly honest I would be surprised if anybody does.

Leah: I think it's a social thing. Because if you went around saying to everyone "of course I'm sexy, why wouldn't I be?" I think some of it is that you would get some negative feedback so if part of me thinks I'm sexy it's the part of me I'm going to keep to myself because you don't let people at everything that feeds your soul.

Participants' responses seemed to indicate a struggle to reconcile how they thought about

themselves: *"My sense of humour and my sense of self and masculinity make me sexy"*

(Alex) and how they believed other perceived them: *"In all honesty, I don't feel as though I am sexually desirable"* (Alex). John's experience with his former carer is an example of what he thought versus what actually happened.

John: It didn't occur to me, I mean I knew we were close. But there again, you're making me realize I constructed this purely as a carer relationship. And to be honest I was quite thrilled when suddenly I had her on my lap and here I was and here she was and suddenly there was a kiss. And OH DEAR [participant's emphasis], it was wonderful!

John further observed that the likelihood of experiencing his sexuality in the way he did with his former carer was rare because he had privatized the idea that disability excluded him as a viable sexual option for others.

John: I'm realistic enough to know that nobody who's anything like that will probably take one look at me and think...I mean the reality I think is that, a high proportion of people with disabilities will probably not get married because I mean again people who have had no experience of disability will find it very confronting. Equally I expect that these people will find the question of marriage with someone like me or even co-habitation very confronting. Because I mean there are some confronting things that I have to have done of a very personal nature, and that's just care issues.

As mentioned under both interactional and public sexual schema perceptions by others may encourage feelings of sexual undesirability within people with physical disabilities (Murray, 2004): *"I'm realistic enough to know that nobody who's anything like that will probably take one look at me"* (John). As such, participants believed that others did not find them attractive which was also consistent with the internalization of the public myth of disability and asexuality: *"I mean the reality I think is that, a high proportion of people with disabilities will probably not get married because I mean again people who have had no experience of disability will find it very confronting"* (John). While several private, interactional and public sexual schema influence constructions of participant sexuality many of these scripts were tied to their private construction of their body.

Body Esteem.

Participants had some negative perceptions of their body image, but this did not necessarily have a significant impact on the construction of their sexuality. Four participants felt positively about their body image, two felt negatively and one was concerned mostly about how their body and their perception of it influenced how they experienced and constructed their sexuality. Body Esteem then, was divided into three sub-themes (see Figure 7.8); Positive Body Esteem, Negative Body Esteem and Bodily Experiences.

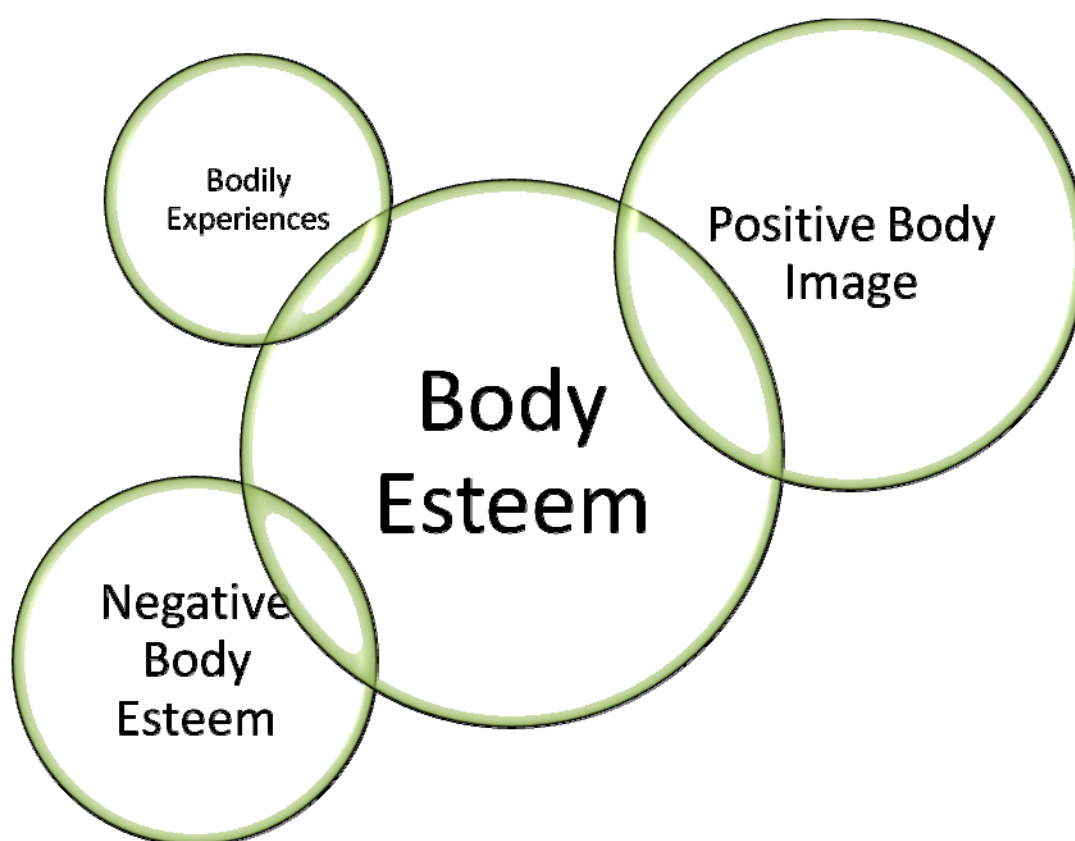


Figure 7.8. Body Esteem Theme and Sub-Themes

Positive Body Esteem. Body esteem (one's perception of their body image: Taylor & Davis, 2007) had an impact on how participants conceptualized themselves as potential sexual partners. Notably, participants experienced positive body esteem through: 1) the

private consolidation of positive sexual experiences with others (Palombi & Mundt, 2006), 2) the process of downward social comparison (Varsamis & Agalotis, 2011) and 3), exploring one's sexuality (Mona, Cameron, Goldwaser, Miller, Syme & Fraley, 2009). Leah, for instance, described how positive body esteem was privately consolidated through positive sexual experiences with her boyfriend.

Leah: I just ... I didn't think it hurt and hurt and I wasn't concerned at all about being naked in front of him or what my legs may or may not do. I think it did cross my mind afterwards. But I thought "Oh he'd tell me if things weren't going to work."

For Leah, sexual activity with her boyfriend reinforced that she wasn't worried about her body: *"I wasn't concerned at all about being naked in front of him or what my legs may or may not do,"* and did not have to be unless her boyfriend indicated that there was a problem; *"I thought 'Oh he'd tell me if things weren't going to work.'"* For Ian, positive body esteem was also reinforced by engaging in sexual activities with others.

Ian: Good really. I think I'm sexy in those times [sexual activity with others]. I like how it [his body] moves and reacts when I'm having sex.

Positive body esteem was also validated by the process of downward social comparison. Brian articulated that he felt good about his body because it could do more than other bodies with impairments could do.

Investigator: How do you feel about your body?

Brian: Alright really. Yeah!

Investigator: Good or bad – alright.

Brian: On the good side! I could be doing better but I'm doing okay.

Investigator: Why do you feel you have a good body?

Brian: Well I can transfer and like for instance May [not real name] she can't even stand without help.

Investigator: You do archery and other sports as well. Does that make you feel like you have a good body?

Brian: Yeah and I go to the gym twice a week and do weights.

Investigator: Do you feel that doing things with your body, I mean being able to do things with your body makes you feel good?

Brian: Yes definitely. I can do more than most people in my position. So my body is good.

Exploring one's sexuality was also described as a means by which people with Cerebral Palsy could foster positive body esteem. Trevor described that being able to explore his sexuality instigated a positive change in his privatizations about his body.

Trevor: I have never really seen my body as sexy, but I've recently began to explore that side of my sexuality more. I am not there yet, but I'm definitely starting to change my view.

Trevor's experience with sexual exploration highlights the contention between feelings of negativity towards one's body and positive ideations of one's body.

Negative Body Esteem. Two of the participants suggested that negative body esteem in people with Cerebral Palsy is linked to privatizations of the socio-sexual implications of physical impairment (Taleporos & McCabe, 2005). For instance, Alex indicated that negative body esteem influenced the way he privatized interactional sexual relationships.

Alex: I enjoy casual sex because I hate labels, or perhaps because I fear that I will never meet someone who wants to have a long-lasting relationship because of how my disability makes me look, so I hide behind casual sex to protect myself from getting hurt.

For Alex, negative body esteem reinforced privatizations that he was not an eligible candidate for long term sexual relationships with others: *“I will never meet someone who wants to have a long-lasting relationship because of how my disability makes me look.”*

John’s thoughts, however, indicated that physical impairment on a more medicalized level reduced his ability to perceive his body positively.

John: My vulnerabilities to illness, my inability to take care of myself in some very intimate ways and rolling on from that the necessity for me to rely on others to do some rather intimate and rather messy things for me. Which most people don’t have to ask another to do unless they are very elderly or very frail or very aged. Probably not wonderful, let me put it this way, what I would like to see in terms of public policy and medical policy is a greater emphasis on the actual sort of medical things that actually cure and replace and restore. Some will say that makes me akin to a eugenicist and if some people want to make that argument. Go ahead! If you are going to find a legitimate one of these people like Bono who want to end hunger, who want to end AIDS and make it history. Why don’t you add one more to the list?

All participants were of the view that people with moderate to severe Cerebral Palsy are often defined by what their bodies can or cannot do. For instance, John observed: *“My vulnerabilities to illness, my inability to take care of myself in some very intimate ways and rolling on from that the necessity for me to rely on others to do some rather intimate and rather messy things for me.”* The privatization of this sentiment is influenced by both interactional (i.e., peer acceptance of impairment and/or disability) and public schema (i.e.,

expectations of normative movement and functioning). As such, how people with moderate to severe Cerebral Palsy experience their sexuality invariably involves how they relate to their bodies.

Bodily Experiences. Body esteem in individuals with moderate to severe Cerebral Palsy is often influenced by how much control they feel they have over their bodies (Wiegerink, Roebroek, Donkervoort, Cohen-Kettenis & Stam, 2008). Mary, for example, explained how her experience with impairment and her body influenced her body esteem.

Mary: I think part of—for me, with having CP is you don't always feel at one with your body because you feel like it's running its own race and you're not quite in control of it so that's one of the important things for me. I was having this conversation with my masseur this week, I go once a month, and he fixes quite a lot and I said to him 'I have this great few days, sometimes even a week after I've had a massage where I just feel totally in myself'. It's a feeling I don't get much. Like yesterday I got up and I knew I was really tired this week. I slept about 12 hours on Friday night and I thought yesterday, should I go for a walk in the morning, and I didn't feel my legs were quite with me and I ended up going for a walk at about 4 o'clock in the afternoon and I felt much better. But sometimes it's not doing what I want.

As described above Mary sometimes felt that her body was its own entity which she could not control: *"sometimes it's not doing what I want."* In this respect, people with moderate to severe Cerebral Palsy (versus physically typical individuals) have a unique relationship with their bodies based on their developmental history (i.e., the medicalization of their bodies). As such, sexual agency for people with Cerebral Palsy may be affected due to the privatization that they are not agents of their own bodies and therefore may not feel like agents of their own sexuality.

Sexual Agency.

Three participants indicated that their ability to be sexually agential was impeded by feelings of apprehension. While this may have been the case some of the participants made a concerted effort to foster sexual agency within their lives through practice and positive thinking. Although five of the seven participants knew how they could initiate sexual relationships, two participants felt that there was no point investing energy into sexual pursuits as they felt that misconceptions (held by others) about disability and sexuality made it too difficult. Participant descriptions of their sense of sexual agency fell into three sub-themes (see figure 7.9): Feeling Apprehensive, Fostering Agency and Resignation.

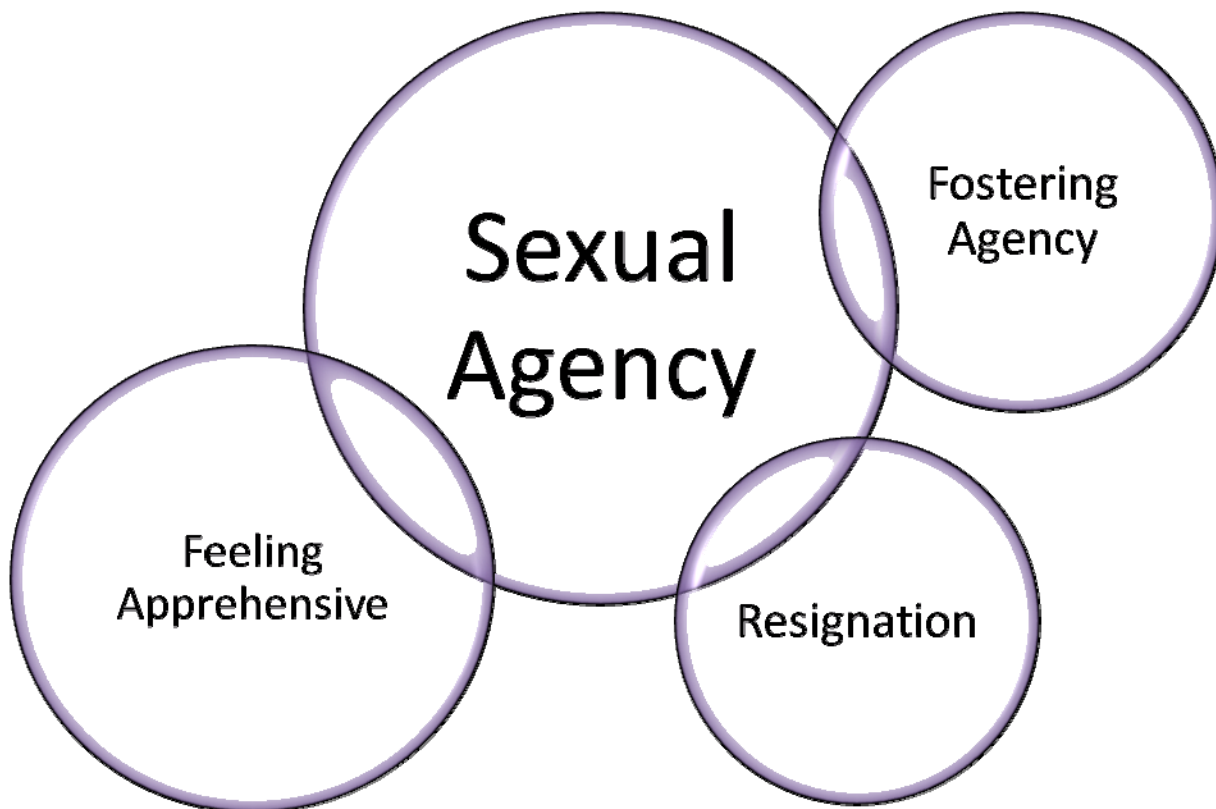


Figure 7.9. Sexual Agency Theme and Sub-themes

Feeling Apprehensive. Participants were unsure about negotiating sexual relationships. They were about: 1) initiating sexual intimacy due to privatizations of public

perceptions about people with physical disabilities and sexuality and, 2) expressing one's sexual needs (Hassouneh-Phillips & McNeff, 2005).

In regards to privatizations about initiating sexual intimacy Brian stated:

Brian: It's hard to initiate sexual relationships. I think that I am overlooked and not necessarily considered as a sexual partner.

According to Leah and Mary their ability to be sexually agential with their boyfriends was restricted by the privatization that they could not express their sexual needs.

Leah: I was getting a lot of negative messages [from others] I think I didn't embrace it [her sexual needs]. So I think I sometimes have trouble expressing that kind of interest and then I do have trouble with my hips, which doesn't affect me most of the time, but you know, if you want to have sex it's going to become an issue.

Mary: Most of the time it is my boyfriend [who initiates sexual activity] because I'm not—I think that comes back to I'm not having, you know—because that issue about when you acknowledge your sexuality and let yourself do things. Because I didn't do that. I think I stunted myself in some ways.

Here Leah and Mary explain that although they wanted to express their sexual needs to others they were apprehensive due to negative messages from others. For instance, Leah: *"I was getting a lot of negative messages I think I didn't embrace it [her sexual needs]"* and not having had the opportunity to acknowledge their own sexuality: *"that issue about when you acknowledge your sexuality and let yourself do things"* (Mary). Although Leah did not always feel confident about enforcing her sexual agency she indicated that she needed to release some of her inhibitions in order to assert her agency.

Leah: Probably just being less inhibited though I don't realize at the time that I was being inhibited or goodness knows what I'm thinking about but ... yeah, just having a bit more confidence.

Some participants appeared to struggle with allowing themselves to practice their sexual agency due to pressures to conform to interpersonal or public sexual expectations. In contrast, others made a concerted effort to do so.

Fostering Agency. While some participants were apprehensive about enforcing their sexual agency they also made an effort to privately reject those fears. Notably, participants fostered their sense of sexual agency through practice (Wilkerson, 2002). Mary expressed that she had been apprehensive about refusing suitors who she thought were socially and sexually incompatible; although, she was glad she had not given in to her desire to conform.

Mary: Yeah, because the stigma was there already because I lived on the campus for the first couple of years I was here so even in college all the people there, they start to talk about the people who don't fit in and don't do things. And there was a lot of talk and it did play on my mind a bit, but I always thought about it in terms of meeting someone, not 'picking up'. I ditched a couple of guys at my door a couple of times and that made the rumour-mill worse but I always thought to myself, "well, in the end I'm glad I did that."

Mary highlights the interactional and public sexual expectations which may make people with Cerebral Palsy apprehensive about enforcing their sexual agency in an effort to seem typical amongst their peers regardless of the private ramifications: *"Yeah, because the stigma was there already because I lived on the campus for the first couple of years I was here so even in college all the people there, they start to talk about the people who don't fit in and don't do things."* She also expressed a sense of relief and empowerment via her

refusal to conform to normative sexual expectations: *“I ditched a couple of guys at my door a couple of times and that made the rumour-mill worse but I always thought to myself, ‘well, in the end I’m glad I did that.’”*

For Trevor part of his journey of sexual development involved being more sexually agential in order to fulfill his desire to experience life in the way he wanted.

Trevor: I have always been willing to put myself out there, another reason that my sexuality has grown. My upbringing and surroundings also play a role, in that I was always taught to go for what I wanted, and to actively explore the world around me. Alex expressed that the only factor that limited his sexual agency was physical mobility.

Alex: I suppose I am sexually liberated. I am reserved only by what it is that I can do physically (mobility).

Four of the participants expressed that sexual agency (i.e., initiating sexual intimacy, refusing sexual intimacy and/or expressing sexual needs) although something that was difficult to enforce, could help them experience their sexuality in the ways they wanted to. A few participants, however, felt that there was nothing they could do to improve how they privately constructed or experienced their sexuality.

Resignation. Some participants expressed that their sexuality could not be improved and had privately resigned to experiencing their sexuality based on what others allowed them (Due, 1995). For instance, Alex and John described their sexuality as unsatisfying and dead-ended.

Alex: I now don’t often equate sex with romance. As much as I have tried to do that in the past, and sometimes currently, I feel that it is not realistic... so now, I take what I can get. I am not happy this way, but I understand it to be the reality of my sexuality.

John: I think it's the way people think about disability. So sometimes I reckon "why bother?" You know. And I don't always feel like we know what we're doing. It's hard to present myself because I don't match up. I feel exposed. I've laid out all my cards and I can't hide. I worry sometimes that the other person would react negatively.

For these participants resignation was a way to deal with negative perceptions about disability and sexuality.

Sexual Esteem.

The information from participant transcripts indicated that sexual esteem (one's sense of self as a sexual being or potential sexual partner) had relatively little influence on how they constructed their own sexuality. However, some participants indicated that overall they did not feel quite comfortable with the idea that they could be perceived as a potential sexual partner, sexual being or sexually desirable. As such, they appear to count themselves out (see Figure 7.10).

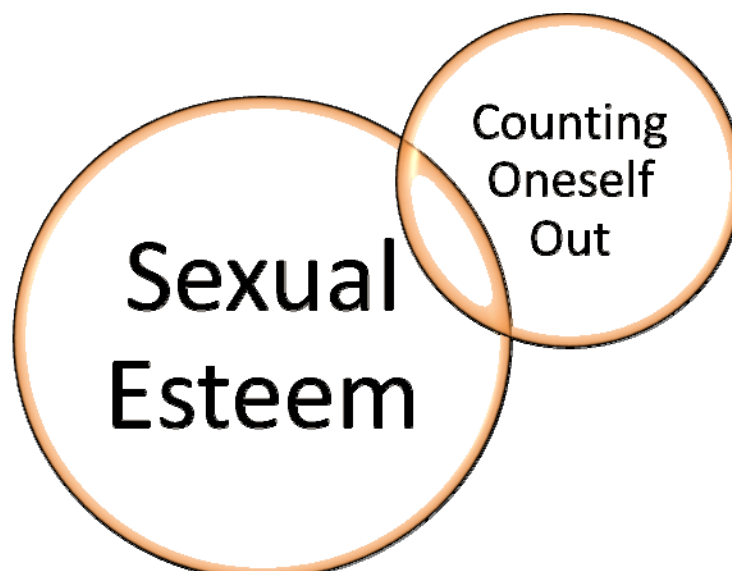


Figure 7.10. Sexual Esteem Theme and Sub-themes

Counting Oneself Out. “Counting oneself out” sexually was characterized within participants’ responses as the private conviction that others could not perceive them as suitable sexual partners (Esmail et al., 2010). Paradoxically, participant’s responses from earlier in the chapter indicated that they have positive ideations, experiences and constructions of their sexuality and yet their sexual esteem waned (Guildin, 2000). Leah, for instance indicated that she could not attribute the word “sexy” to herself:

Leah: Yeah, see sexy is not an adjective I would attribute to myself.

Ian felt that the possibility of a sexual relationship with someone was somewhat theoretical but was at best an impractical privatization:

Ian: Well I mean I guess you’re aware that it’s possible [finding a sexual partner]. But I mean the other issue is well, where and with whom would that be possible? I don’t know whether you repress it or ignore it.

For Ian, the idea of finding a sexual partner was something he implicitly repressed or ignored: *“I don’t know whether you repress it or ignore it.”* On the other hand, John actively created distance between himself and potential sexual partners.

John: I’ve pretty much always kept a very discreet distance as I think I said to you last time there have been the odd regret in that I spoke to this women on one or two occasions. Just a casual “hello” you know, passing of the day. I never really indicated the interest beyond that because I was too frightened to. The other part of it was that she appeared to have quite any number or reasonably of other suitors. To the effect that I didn’t see myself being, a contender in a “month of Sundays.” I mean, many people will be to a degree standoffish because they won’t know how to handle me. They won’t know whether to speak to me or not. Or they’ll just step around the issues like “it’s a bit too complex for me to work out.” For them they just don’t know what is going to

happen, what I'm going to say, whether I'm going to bite them or start foaming at the mouth.

In this respect, John provides an example of the implications of sexual esteem on privatizations of oneself as a potential sexual partner: *"To the effect that I didn't see myself being, a contender in a 'month of Sundays,'"* sexual equal: *"They won't know whether to speak to me or not,"* or sexually desirable: *"For them they just don't know what is going to happen, what I'm going to say, whether I'm going to bite them or start foaming at the mouth."* As indicated through participant responses, however, the sexuality that people with Cerebral Palsy experience (or want to experience) may not be validated or reinforced by interactional, public or private sexual schema. As such, opportunities to reconstruct normative sexual expectations and scripts are restricted. In this regard sexual schema like that of sexual spontaneity can serve as an example of the conflicting nature of hegemonic sexual schema and constructions of one's own sexuality.

Constructions of Participation: Effects on Sexual Spontaneity

In terms of sexual spontaneity, participant responses indicate that they had constructed it as a derivative of sexual exploration. Sexual spontaneity (as defined by respondents) included the spontaneous selection of a sexual partner or unscheduled sexual activity.

The Role of Sexual Exploration with Others

For several participants their perception of sexual experiences with others was influenced by their ability to explore their sexuality. Part of that process involved sexual spontaneity. Alex and Ian described what sexual spontaneity meant to them and how it influenced the construction of their sexuality.

Alex: Sexual spontaneity in my view means not to plan out the sexual activity—go with the flow. It means doing something without a lot of planning. So, I guess doing “randoms” is sexual spontaneity in some sense.

Ian: Sexual spontaneity is the act of becoming sexually charged without planning or forethought. To me, it is the ability to go with the flow and be in the moment with your partner. Sexual spontaneity also means letting go of your inhibitions and allowing yourself to sexual freedom.

Unlike the restrictive connotations discussed in previous chapters about the normative script of sexual spontaneity (Dune & Shuttleworth, 2009; Sanders & Cairns, 1987), this study’s participants described sexual spontaneity as liberating: *“Sexual spontaneity also means letting go of your inhibitions and allowing yourself to sexual freedom”* (Ian). As such, it seemed to allow them to experience their sexuality without the pressure of following predetermined sexual scripts. In fact, Trevor felt that experiencing sexual spontaneity based on unscheduled sexual activities was integral to how he constructed his sexuality.

Trevor: It all goes back to my openness, and my newfound confidence with regards to sexuality. Sexual spontaneity is a big part of any relationship. My expression of who I am as a sexual being relies on sexual spontaneity. I think it plays a major role in the way that I perceive myself, but also in others' perceptions of me. Sexual spontaneity is a crucial element of my sex life, and therefore of my sexuality.

Experiencing sexual spontaneity in this way also influenced Alex’s construction of sexual freedom.

Alex: I am spontaneous in who I meet to sleep with. I cannot be spontaneous physically (much of what I can do sexually needs to be planned), but I can be spontaneous in who I choose.

Through the process of exploring their sexuality through sexual encounters (i.e., the spontaneous choice of partner or behaviour) participants found that they had the chance to learn more about themselves. Brian for instance, stated that sexual experiences with others facilitated learning.

Brian: I also learned a lot about sex from having it too.

Ian also explained that exploring his sexuality helped him figure out what he liked and from whom.

Ian: Well he was my friend from up the road. We lived on a block of three acres and he was not next door but the house after. There was a lot of land. He came down one day and we were 16 and we spontaneously started to explore a bit. It was alright. We had fun the one time. It was alright. We were back to being friends after that.

Some participants described sexual exploration as key to feeling sexually connected to themselves and others. Trevor described his ideal partner as someone who would join him on his journey of discovering his sexuality.

Trevor: My ideal sexual partner would be open and willing to explore their sexuality, as well as my own. My ideal sexual partner would be fun, spontaneous, and would be interested, as I am, in the edgier side of sexuality, and would be open to allow me to take them to those places. My ideal sexual partner, as cliché as this sounds, is embodied in my current girlfriend.

As mentioned earlier, several participants felt that it was rare to find an individual who was willing to reconstruct typical sexual expectations with them. However, some (4) participants were able to explore their sexuality and that of others without the restrictions (perceived or otherwise) perpetuated by normative sexual scripts and expectations. Descriptions and conceptualizations of sexuality by people with Cerebral Palsy seems inextricably linked to

interactional sexual experiences (i.e., sexual activity) and participant's perceptions about them (i.e., levels of sexual satisfaction, sense of sexual worth and feelings about peer acceptance).

Sexuality and Cerebral Palsy: Personal and Contextual Settings

Overall, the results indicate that the way(s) in which people with Cerebral Palsy construct their sexuality was multilayered. While the interactional, public and private sexual schema discussed in this chapter feature in all participant's descriptions of their sexuality interactional sexual scripts dominated participant's construction of their sexuality. Trevor and Alex, for example, thoroughly explained how their perception of their sexual experiences with others has influenced the construction of their sexuality.

Trevor: There are three key sexual transitions in my life. The first was entering into my first romantic relationship as a teenager. Getting to actually go on dates, and to call someone my girlfriend, was a very liberating experience at the time. The second was my first physical sexual experience and the loss of my virginity. This was key, because I'd been waiting for it for so long, and when it happened, a large part of me regretted it. It was not, looking back, an enjoyable experience. The final transition occurred very recently, when I finally had a physical sexual experience that was purely enjoyable. I had become sexually aroused prior to this, but never fully enjoyed the act.

The best sexual experience I ever had was with my current girlfriend, and only occurred a month or so ago. It was the best because she took the time to physically explore my body, and not simply accepted that what is supposed to feel good, should feel good. The experience was accompanied by a very open and honest dialogue between the two of us, and allowed me to grow in sexual confidence. I was able to fully embrace the

limitations, but more importantly the abilities, of my body and use them to full effect. It was also the first time that I was able to let go of my need to pleasure my partner, and allow myself to be pleased without feeling obligated to reciprocate immediately.

Ultimately, good sex, to me, is all about sexual exploration. It is all about, a physical dialogue between the partners, where we find out what works for each other and for us as a couple. It is about not accepting that something feels good, because that is the way that it is typically done, but about creating your own version of typical. My desire to push the boundaries of my disability, and finding a partner who is willing to go on that journey with me is the hallmark of a positive and good sexual experience. The biggest detriment to sex for me is when we are just "going through the motions". Good sex is about pure and unrestricted physical expression.

Trevor highlights that each of the major sexual transitions in his life (all interactional) provided allowed personal and sexual growth: *"The first was entering into my first romantic relationship as a teenager...The second was my first physical sexual experience and the loss of my virginity...The final transition occurred very recently, when I finally had a physical sexual experience that was purely enjoyable."* Trevor's illustration of the best sexual encounter he had experienced included the several factors discussed earlier in the chapter. For instance good sexual experiences included several factors: 1) peer acceptance of impairment and atypical sexual experiences: *"My desire to push the boundaries of my disability, and finding a partner who is willing to go on that journey with me is the hallmark of a positive and good sexual experience,"* 2) the reconstruction of sexual expectations: *"It is about not accepting that something feels good, because that is the way that it is typically done, but about creating your own version of typical,"* 3) exploring one's sexuality:

“Ultimately, good sex, to me, is all about sexual exploration,” 4) accepting oneself: *“I was able to fully embrace the limitations, but more importantly the abilities, of my body and use them to full effect,”* 5) feeling worthy of sexual experiences with others: *“It was also the first time that I was able to let go of my need to pleasure my partner, and allow myself to be pleased without feeling obligated to reciprocate immediately,”* 6) communication and validation: *“The experience was accompanied by a very open and honest dialogue between the two of us, and allowed me to grow in sexual confidence”* and, 7) feeling sexually liberated: *“Good sex is about pure and unrestricted physical expression.”* Trevor’s description of his sexuality emphasizes the salience of positive interactional experiences with others in order to circumvent detrimental public sexual schema and consolidate positive private sexual schema.

Alex also speaks to the importance of interactional sexual experiences with others in his construction of his sexuality.

Alex: The main factors that have influenced how I experience sexuality are as follows: the reactions from potential partners to my disability. This is the key factor, followed closely by how I view myself. When I am having sex with someone, that is when I feel most vulnerable and disabled—if that makes any sense. My level of mobility also influences my sexuality because I can’t perform all of the same functions as an able-bodied person so I often feel inadequate. I think the fact that I have had mostly one night stands also influences how I experience sexuality, because I feel like I won’t find anything long term due to my disability. I mean I’m not trying to deliberately down-cast myself I think what I’m saying is simply an acknowledgement of the facts as I see them.

Alex illustrated that interactional sexual experiences with others was the main influence on his construction of sexuality. Notably, Alex reiterated several factors discussed earlier: 1)

peer acceptance of impairment and disability: *"...the reactions from potential partners to my disability,"* 2) private constructions of oneself: *"...followed closely by how I view myself."* 3) acceptance of oneself: *"When I am having sex with someone, that is when I feel most vulnerable and disabled,"* 4) expectations of normative movement and functioning: *"My level of mobility also influences my sexuality because I can't perform all of the same functions as an able-bodied person so I often feel inadequate,"* 5) myth of disability and asexuality: *"I think the fact that I have had mostly one night stands also influences how I experience sexuality, because I feel like I won't find anything long term due to my disability"* and 6) counting oneself out: *"I mean I'm not trying to deliberately down-cast myself I think what I'm saying is simply an acknowledgement of the facts as I see them."*

In this respect, participants' responses exemplify that interactional sexual experiences with others was of primary importance to their interactional, public and private construction of their sexuality. However, interactional, public and private schema may be of varying salience amongst people Cerebral Palsy due in part to individual circumstances.

The Effect of Individual Circumstances

Individual perceptions and experiences of disability and constructions of sexuality are mediated by circumstance (Shakespeare, 2000). Several circumstantial elements can be interpreted as influential to participant constructions of sexuality. These include medical interventions and severity of impairment, living arrangements, modes of communication, intersecting experiences of oppression, ethnicity, culture and socio-economic status and relationship history.

Medical interventions and severity of impairment.

Medical interventions and the severity of impairment may have a distinct effect on individual constructions of sexuality (Miller, Chen, Glover-Graf, & Kranz, 2009). Mary for

instance, whose medical interventions have facilitated mobility without the use of a wheelchair, may have a wider range of motion than some of the other participants in the study. In this regard, she may have more access to socio-sexual opportunities as she may not be similarly restricted by environmental infrastructure as other people with Cerebral Palsy whose main form of mobility is a motorized wheelchair.

Living arrangements.

Although restrictions to mobility may reduce socio-sexual opportunities living arrangements play a fundamental role (Maggs et al., 2010). For example, Leah, despite additional mobility barriers, may have increased access to socio-sexual opportunities as she does not reside in assisted housing. As such, she may have increased flexibility (i.e., unrestricted meal times, fewer privacy issues, and reduced regulations about visitors) thereby increasing autonomy and opportunities for socio-sexual development. This can be contrasted with John, who also lives outside of assisted housing. However, he lives with his mother (who acts as primary carer) in the family home. In this regard, John may not be privy to as many socio-sexual opportunities as stigma is often associated with adults who live with their parents.

Modes of communication.

Stigma may also be related to one's ability to communicate easily with others (Pakula, Van Naarden Braun, & Yeargin-Allsopp, 2009). Brian, for instance, has a noticeable oral/facial muscle impairment which reduces his ability to speak typically. Due to the difficulty he experiences in interactional communication he may encounter additional barriers to building socio-sexual relationships thereby reducing socio-sexual development. In this regard, severe impairment may exacerbate experiences of socio-sexual stigmatization.

Intersecting experiences of oppression.

Stigma can also be exacerbated by intersecting experiences of oppression (McRuer, 2006). Alex, who identifies as homosexual, found it difficult to negotiate sexual relationships and subsequently feel sexually desirability because he belonged to two publically marginalized populations. For Alex, his membership in both the gay community and the disabled community increased his experiences and perception of barriers to socio-sexual opportunities. In this regard some people with Cerebral Palsy may encounter more barriers than others.

Age, ethnicity, culture and socio-economic status.

Experiences of socio-sexual barriers are also mediated by age, ethnic, cultural or socio-economic advantage or disadvantage (Blanchett, Klingner & Harry, 2009). Trevor, for instance, is a tertiary educated Caucasian male in his early to mid-twenties (as with the majority of the participants), identified as heterosexual (in a long term intimate relationship) and upper-middle class. In this regard, Trevor's experiences of socio-sexual barriers due to disability may be reduced due to the increased perception by potential partners that he is young, independent (i.e., educated and employed with dispensable income), is of a privileged ethnic and cultural group and widely accepted sexual orientation. As Trevor was also in a long term intimate relationship, being perceived by others (and oneself) as socio-sexually desirable can also be increased via sexual interactions with others.

Relationship status.

Although the majority of the participants (4) had never been in a long term sexual relationship all had had sexual interactions with others. It may be however that those participants who had been in long term sexual relationships increased their socio-sexual development through practice (Xenakis & Goldberg, 2010). As such, people with Cerebral

Palsy like Ian, who have never been in a long term sexually intimate relationship, may seem or feel less socially and sexually attractive because their sexuality had not yet been validated or reinforced by another over an extended period of time.

Summary and Conclusion

Through the utilization of a hermeneutic phenomenological approach participant data was used to better understand what factors influenced how people with Cerebral Palsy constructed their sexuality. This chapter presented data which helps to answer questions related to the relative salience of public, interactional and private sexual schema in the construction of sexuality for people with Cerebral Palsy, how people with Cerebral Palsy construct the term sexual spontaneity and how people with Cerebral Palsy describe their sexuality.

The results indicate that how people with Cerebral Palsy perceive sexual experiences with others (interactional) is the most influential factor in the construction of their sexuality. Public influences were cumulatively the second most important factor in the construction of sexuality by people with Cerebral Palsy. Finally, private influences were cumulatively the least influential factor in the construction of their sexuality.

Sexual spontaneity primarily featured as a derivative of sexual exploration. Furthermore, participants defined sexual spontaneity as liberating and allowed them to experience their sexuality with others relatively independent of hegemonic sexual scripts. Participants also described their sexuality primarily in terms of major transitions and experiences which involved others. Participant's individual circumstances highlight the salience of demographics in understanding and contextualizing constructions of sexuality and perceptions of interactional sexual experiences with others. As such, sexual interactions

with others seem to be of primary importance to conceptualizations of interactional, public and private sexual schema in people with Cerebral Palsy.

Chapter 8: Discussion

The present study investigated the way(s) in which people with Cerebral Palsy construct their sexuality. The discussion of the findings considers: 1) how people with Cerebral Palsy construct sexual participation, in particular, the relative salience of public, interactional and private sexual schema in the construction of sexuality for people with Cerebral Palsy, and 2) how people with Cerebral Palsy describe their sexuality. Findings are discussed in the context of the *Modified Model for the Construction of Individual Sexuality in People with Cerebral Palsy* of the lived sex lives of people with Cerebral Palsy as proposed (see Figure 8.1). Avenues for future research are also explored.

Relative Salience of Sexual Schema

The results suggest that interactional sexual schema are of primary importance to how people with Cerebral Palsy construct their sexuality. Public and private sexual schema were of secondary and tertiary importance (respectively) to the construction of sexuality by people with Cerebral Palsy. The following section discusses the key findings on interactional, public and private sexual schema in people with Cerebral Palsy, highlighting pertinent theoretical constructs and in the context of extent research.

Interactional Sexual Schema

Perceptions of sexual experiences with others was influenced by peer acceptance of impairment and disability, feeling worthy of sexual experiences with others, communication, sexual intimacy and socio-sexual compatibility.

Peer Acceptance of Impairment and Disability.

The data suggest that people with Cerebral Palsy primarily construct their sexuality based on their acceptance by others. Participants conceptualized acceptance as an element of understanding impairment and disability and regarded this acceptance as an exceptional

quality. Being accepted by others for who one is was considered to be important.

Acceptance was important for satisfying sexual encounters and partnerships, in particular, were important for the women with disabilities.

Unconditional acceptance of impairment and disability by others was important to social and sexual development. It was linked to a sense of validation by others. It was suggested that acceptance of impairment and disability by a significant other validates the individual as an equal and desirable sexual being. People with Cerebral Palsy perceived unconditional acceptance to reduce barriers to satisfying social and sexual relationships. Conceivably, people with Cerebral Palsy may want a sexual partner who is accepting of their disability for the instrumental need for satisfying sexual relationships (Papile, 2009). Although the data from this study do not fully address this aspect, it is possible that egalitarianism in sexual relationships is mutually satisfying. Future studies could examine the functions served by unconditional acceptance in the sexual relationships of those with a significant disability.

Participants perceived that typical others who were accepting of impairment and disability were atypical or exceptional; typical others would not normally accept difference in others. By implication, acceptance by others could lead to self-devaluation and/or placing a lower value on social others seeking intimate relationships. This is consistent with Howland and Rintala's (2001) research which indicated that women with disabilities may devalue a partner who chose to date them from internalizing the societal belief that they are "damaged goods" from having a disability (see also Phillips, 1990).

People with Cerebral Palsy may perceive their typical peers to lack acceptance because they are not intimately familiar with impairment and disability. Where unconditional acceptance occurred, people with Cerebral Palsy believed it was atypical and

those who exhibited unconditional acceptance may possibly share a developmental history of exclusion. Data are needed on the underpinning reasons for different levels of acceptance in potential sexual partners.

Feeling Worthy of Sexual Experiences with Others.

People with Cerebral Palsy suggest that being worthy of sexual experiences was mediated by partner validation within sexual relationships. Validation as a sexual being enhanced the quality of sexual encounters. Taleporos and McCabe (2001) reported that feeling worthy of sexual experiences with others resulted in positive sexual experiences with sexual partner(s) and validated their sense of sexual being. Similarly, Esmail et al. (2010) observed that peer validation supported feeling worthy of sexual experiences and the initiation of sexual activity. Validation as a sexual being reinforced self-perceptions as a sexual agent (Milligan & Neufeldt, 2001). By implication, asexualizing representations of sexuality exclude disability reduced participants sense of agency as a sexual being. Therefore, interactional experiences with others in the context of public representations of disability influenced one's sense of sexual agency.

The Importance of Communication.

Constructing a sexual dialogue for use with potential partners was important to satisfying sexual experiences and relationships for people with Cerebral Palsy. Participant sexual dialogue included communicating the role and the impact of disability and impairment on intimate relationships. Subliminal communication (i.e., body language) was important to expressive sexuality in those with Cerebral Palsy; perhaps this is also the case for typically developing individuals. For people with Cerebral Palsy communicating sexual need included using body language to inform sexual partners of their feelings or thoughts. For instance, participants used eye contact, light touches and open body posture to express

their sexual interest in others. Participants perceived that the effectiveness with which they communicated their sexual needs led to satisfying relationships. Research by Kralik and Bostock (2008) suggests that effective communication was evidence of developed sexual skills, allowing for a fuller expression of sexuality.

By communicating their sexual desires, people with Cerebral Palsy can facilitate understanding of themselves and reconstruct normative sexual expectations with sexual partners (Esmail, Esmail & Munro, 2001; Papile, 2009). Communication about disability and sexuality facilitated understanding in that it allowed participants to think about and acknowledge their sexual needs, desires and expectations. Through communication participants were able to identify expectations of their own sexuality and that of the other. People with Cerebral Palsy believed that the use of a sexual dialogue (verbal communication and subliminal communication) with potential sexual partners was a means to exert their sexual agency. Future research should explore further the link between the use of sexual dialogue and sexual agency in those with significant disability.

The Role of Sexual Intimacy.

Participants suggested that sexual intimacy involved a sense of closeness, experiences of affection, reciprocity and a sense of relationship satisfaction. They perceived intimacy as an expression of friendship, respect and familiarity between sexual partners. Sexual intimacy was seen as being essential for positive constructions of themselves as accepted and worthy sexual beings. Experiences of intimacy appeared to enhance the socio-sexual development of people with Cerebral Palsy. Jemtå and colleagues (2008) found that experiences and ideations of sexual intimacy played an integral role in facilitating socio-sexual development in individuals with significant disability.

The findings of this study suggest that ideations about sexual intimacy increased one's likelihood of engaging in sexual encounters. For the participants, positive interactional reciprocity (i.e., responding to a positive action with another positive action) (Fehr & Gächter, 2000) was an important aspect of intimacy. McCabe, Cummins and Deeks' (2000) reported that a sense of positive interactional reciprocity encouraged sexual well-being in people with significant physical disability. Future research could seek to clarify the nature of different forms of intimacy and their salience in the sexual lives of people with Cerebral Palsy.

The Importance of Socio-Sexual Compatibility.

Socio-sexual compatibility with sexual partners was described as an important prerequisite to satisfying sexual relationships. The participants described socio-sexual compatibility (awareness, receptiveness and attentiveness) as important to sexual satisfaction (see also Pujols, Meston & Seal, 2010). Participants with Cerebral Palsy were of the view that these elements can be fostered and encouraged in self and others. The findings from this study suggest that socio-sexual compatibility was a precursor to sexual satisfaction and not an element of it. Notably, participants indicated that if they felt socially compatible with their partner it would be easier to negotiate sexual compatibility.

This concept of socio-sexual effortlessness (Phillips, 2008) posits that intimate relationships are easier with someone who is socially and sexually compatible. Sexual partner(s) socio-sexual compatibility facilitates emotional, mental, social and physical connections (Dune & Shuttleworth, 2009). Additional research could clarify the elements that are fundamental to socio-sexual compatibility; its antecedents, processes and outcomes for people with Cerebral Palsy and others with physical impairments.

Public Sexual Schema

Public sexual schema were the second most important factor in the construction of sexuality in people with Cerebral Palsy. Participants identified contemporary media and popular culture, the myth of disability and asexuality, expectations of normative movement and functioning and, issues of accessibility as important public influences on their constructions of sexuality.

Contemporary Media and Popular Culture.

Contemporary media and popular culture were perceived to be of moderate importance to constructions of sexuality for people with Cerebral Palsy. According to participants, contemporary media and popular culture provided information about how to perceive one's sexuality and conceptualize sexual behaviour. These findings suggest that media was a source of sexual information.

Media as a Source for Sexual Information. Participants identified sexual information from media as important to shaping the ways in which people construct their sexuality. For instance, participants indicated that they learnt from media idealized constructs of how to have sex such as with whom it was appropriate to have sex, and what sex was supposed to be like. However, it is unlikely that people with Cerebral Palsy only seek out individuals and encounters which fulfill or mirror media representations. The view by people with Cerebral Palsy that media disseminated information which was skewed or unrealistic would likely be shared by typical others (see also Brown, Halpern & L'Engle, 2005; Freeman-Longo & Blanchard, 1998; Goggin & Newell, 2002; Tepper, 2000). Consequently, their choice of sexual partner would be similar to that of typical others.

Disability advocacy or media awareness groups would also share the view that media representations of disability and sexuality were unrealistic (Goggin & Newell, 2002). Media

portrayals which do not represent people with disabilities as sexual, for example, tend to deny people with Cerebral Palsy their sense of sexual agency.

The Impact of Public Sexual Scripts. The results suggest that categorizations of disability in the media and popular culture inhibit people with Cerebral Palsy from being noticed as social or sexual beings. This may be because few, if any, public media expositions idealize sexuality with disability (Hartnett, 2000). People with significant disability may be depicted in non-complimentary terms such as “evil avenger” (irremediable villain) or “supercrip” (remarkable achievers – who triumph against all odds). In the words of Hartnett, people with disabilities are “exploited by screenwriters for dramatic effect, for emotional appeal or blatant symbolism” (p. 21).

The results from this study suggest that mass media lacks inclusivity thereby restricting access to sexual opportunities. Black and Pretes (2007) found that media sometimes portrayed people with disabilities as asexual or undesirable. Exclusive constructions of sexuality imply that people with Cerebral Palsy are not socially and sexually equal to their peers (Duncan, Goggin & Newell, 2010). Research should investigate which public sexual scripts people with disabilities perceive to be inclusive, acknowledging and empowering their sense of sexuality.

Finally, participants indicated that public sexual scripts instigated upward and downward social comparison (Hammer, Ozolins, Idvall, & Rudebeck, 2009). As Hammer and colleagues (2009) observed, comparing oneself (in this context) to those who are publically believed to be “better” than oneself (upward social comparison) and those who are perceived to be more “unfortunate” (downward social comparison) than oneself, spurs the individual to analyze and identify where she or he fits into the spectrum of what is and is not socially and sexually acceptable. In the process of social comparison however, participants

indicated that public ideals of masculinity and/or femininity as presented by contemporary media and popular culture were difficult to successfully incorporate into the construction of their sexuality.

Constructions of Masculinity and/or Femininity. Participants indicated that they felt required to be attracted to the type of women or men that contemporary media validated as desirable. Nevertheless, as previously noted, the participants were very discerning in that they seemed to be aware of the convoluted and abstract nature of the “perfect” man or woman alluded to in public media as attractive. Lemish (2010) regarded the idealism associated with the performance and embodiment of the perfect man or woman to be detrimental to the way people with disabilities (and typical others) conceptualize themselves and their peers. However, performance and embodiment of femininity were seen as less challenging to “live up” to for women with Cerebral Palsy than the performance and embodiment of masculinity for men with Cerebral Palsy.

Ideals of masculinity were therefore, perceived to be more oppressive than ideals of femininity for people with Cerebral Palsy. This may be because of the cultural bias to perceived women as dainty, delicate and helpless and men as aggressive and competitive. Shuttleworth (2000, 2006) was of the view that men with Cerebral Palsy may perceive themselves to not sufficiently perform or embody masculinity. Scripted normative gender roles create tension between how people with Cerebral Palsy perceive themselves (and others) and how they want to experience their sexuality (similar experiences are noted in typical populations (Zilbergeld, 1999). However, normative public constructions may seem more restrictive for people with Cerebral Palsy due to public constructions of sexuality which asexualize people with Cerebral Palsy.

The Myth of Disability and Asexuality.

The data indicated that constructions of one's own sexuality were influenced by the pervasive myth that people with disabilities are not sexual beings. In this regard, most participants were concerned about the erroneous nature of the myth and how it affected the way that others perceived them.

Perceptions of How Others Perceive Disability and Sexuality. Participants believed that typical others thought they were asexual. Milligan and Neufeld (2001) observed that the myth of asexuality stems from the misconception that people with physical disabilities are also intellectually challenged. In this regard, participants implied that typical others may not believe that people with Cerebral Palsy can understand sexuality or give consent – much in the way a child may not understand the complex psychological, social, physiological and emotional components of adult sexual relationships. A simple lack of knowledge about impairment and disability and its manifestation may be the reason why the myth exists and persists. People with Cerebral Palsy were of the view that others perceive them as destined to a life of celibacy, unsatisfactory sexual experiences and negative constructions of their own sexuality.

Cole and Cole (1993) stated: “to be imperfect is to be asexual and anonymous or overlooked in the sexual spectrum of adult life. The continuing emphasis on the healthy and physically fit adult (who must also achieve a perfect body) is a concrete message learned repeatedly from early childhood through media and advertising” (p. 196). This myth negatively impacts constructions of sexuality by people with Cerebral Palsy. While alternate constructions of disability and sexuality exist, the results suggest that the erroneous construction of people with disabilities as asexual is increasingly recognized as an important influence in how sexuality within this population is constructed (i.e., Dune & Pearce, 2010;

Majiet, 1996; McCabe & Taleporos, 2003; Milligan & Neufeldt, 2001; Shakespeare, 2000; Shuttleworth, 2000). Although people with Cerebral Palsy may want to construct their sexuality positively, some may have inadvertently internalized the myth of disability and asexuality.

Internalization of the Myth of Disability and Asexuality. Participants believed they had fewer sexual options than their typical peers. This effect may be the result of internalizing the myth of disability and asexuality. Rintala et al. (1997) reported that when people with physical disabilities internalized negative societal expectations their sense of sexual desirability is significantly impacted (similar experiences are noted in typical populations (Koert & Daniluk, 2010). Alternatively, people with Cerebral Palsy may be objectively appraising the discrimination directed at them. Research is needed in order to further explore idealized sexual attitudes by people with Cerebral Palsy so as to clarify the impact of those attitudes on sexual identity development in people with Cerebral Palsy.

Expectations of Normative Movement and Functioning.

The results suggest that expectations of normative movement and functioning influence how people with Cerebral Palsy perceived themselves as potential sexual partners. In addition, the results indicate that people with Cerebral Palsy idealized typicality in a sexual partner.

Normative Movement and Functioning on Socio-Sexual Development. Participants indicated that using a wheelchair may lead to not being considered as social or sexual equals because they are not often at eye level with their typical peers. Dovidio, Pagotto and Hebl (2011) observed that being in a wheelchair may literally mean being overlooked and therefore ignored by typical others. In the current study it was felt that use of a wheelchair excluded individuals from social opportunities (i.e., conversation or courting behaviours)

with their typical peers. As noted previously, typical others may overlook people with Cerebral Palsy who use a wheelchair as sexual partners because they may find it difficult to engage in conversation while maintaining eye contact with them. However, cases of others using wheelchairs in satisfying sexual relationships mean that people with Cerebral Palsy are not inevitably excluded (Papile, 2009).

Reconstructing sexual expectations. Sexual spontaneity was widely defined by participants to include sexual exploration. The results suggest that people with Cerebral Palsy may learn more about themselves and others in doing so. It was regarded key to being sexually connected to oneself and others. Esmail, Esmail and Munro (2001) observed that people with disabilities who explore their sexuality are more in tune with it. In doing so, people with Cerebral Palsy and their partners can reconnect and liberate themselves from normative expectations of sexual activity. Research in the forms of sexual exploration that work for people with Cerebral Palsy can provide information about sexual participation.

The Ideal Partner. The results suggest that some people with Cerebral Palsy preferred typical others for their ideal partner. This preference may speak to the pervasive effect of a world which is constructed primarily for and by typical others. Moin, Duvedevany and Mazor (2009) also reported that people with significant disability generally preferred typical others for partners. This may also be, at least partly, due the higher proportion of typical others in the general population. However, some people with Cerebral Palsy may prefer a typical partner for the provision of personal care, breadwinning, childrearing and family sustainability. This speaks to the many similarities, in terms of values and desires, between people with disabilities and typically developing others. For instance, both atypical and typical partners may value and desire long-term intimate companionship with someone they believe is socially and sexually compatible.

Wilder (2006) reported that some preferred a physically typical partner who could help around the house and supplement their abilities in order to sustain family life. For instance, some people with Cerebral Palsy may require assistance with daily living from assistive devices or from others which may characterize them as dependant (Reid & Knight, 2006). Nonetheless, people with Cerebral Palsy can also carry care functions of typical partners and ascribing them as only receivers of help is a stereotype.

Issues of Accessibility.

Participants perceived that access to services, resources, sexual opportunities and the environment to influence their understanding of their sexuality. For instance, participants considered the structural environment a barrier to accessing socio-sexual opportunities (see also Barnes & Mercer 2010; Corker & French 1999; Corker & Shakespeare 2002; Oliver 1996). The male participants of this study believed they spent more time and money than their typical counterparts in order to arrange social outings (i.e., accessible public transportation, researching accessible venues and organizing care needs while on an outing) (see also Yoshida, 1994). Typical others also invest time and resources to cultivate and sustain sexual relationships; however, participants with Cerebral Palsy may put in extra effort to organize accessible public transit and travel concessions and procuring wheelchair accessible taxis (see also Corker & French, 1999; Shuttleworth, 2000). Barriers to sexual participation resulting from inadequate or inaccessible infrastructure may cause people with Cerebral Palsy to problematize their own bodies rather than the societies in which they live.

Participants noted that there were social services and venues they could access. For instance, organizations like Disabled Access Consultancy Pty Ltd (2010) in Australia suggest that increased corporate and societal awareness about the need for accessible structures and services for people with disabilities is being encouraged and promoted. Rummel (2009)

reported that global transportation, accommodation and leisure activities are becoming increasingly accessible thereby inviting participation and integration of people with disabilities. Increased social participation via access to transportation and leisure thereby increases sexual participation.

Participants reported using the internet to gain access to sexual opportunities. The internet allows people with Cerebral Palsy access to virtual social and sexual environments (see also Jang, Choi & Lee, 2010). Going online is a viable solution to the perceived extra effort or psychological and emotional confrontation people with Cerebral Palsy may face when trying to navigate infrastructure which is not guaranteed to be accessible. Future research which explores the usefulness of virtual environments and access to sexual opportunities with disability is encouraged.

As noted previously, increased access to resources would help people with Cerebral Palsy access sexual networks. Participants suggested that care providers could also be more helpful in facilitating sexual activity (see also Earle, 1999). Primarily, assistance engaging in sexual activities with others was indicated. Ethical issues surrounding the facilitation of sexual activities by (health)care providers arise when people with disabilities are constrained in their choices regarding sexual partners. Literature about the facilitation of sexual expression with disability is limited but could prove informative. Future research could investigate the role of facilitated sexual services in sexual expression for people with physical disability.

Private Sexual Schema

Private sexual schema were least influential in the construction of sexuality for people with Cerebral Palsy. The process of reconciling disability with sexuality was primarily characterized by dealing with disability and sexuality separately. For example Tepper (2000),

who is an individual with a disability, considered sexuality and disability as very different concepts. Participants perceived the harmonizing of care needs with sexual needs as imperative to satisfactorily experiencing sexuality. Harmonizing care needs with sexual needs was characterized by attending to physical care needs (i.e., bath, toilet or eat) before sexual encounters (see also Murphy, Molnar & Lankasky, 2000).

Accepting oneself. Accepting oneself was important to people with Cerebral Palsy's sense of sexuality. Murphy, Molnar and Lankasky (2000) observed that adults with Cerebral Palsy who accepted themselves with a disability are more comfortable with their sexuality. By critically discounting exclusionary or negative sexual schema, people with Cerebral Palsy learn to be more accepting of their abilities and attribute positive conceptualizations to themselves and their sexual identity. Participants considered personal resources such as confidence, humour and intelligence to make them sexually desirable to others. This could be because engaging in intellectually stimulating interactional relationships added to one's sense of personal attractiveness. Kaufman et al. (2008) observed that people who are perceived by others as having a good sense of humour were likely to have more friends and social opportunities than their peers. Nonetheless, some people with Cerebral Palsy perceive their personality attributes to be overshadowed by physical attributes in how they are perceived by others.

Body esteem. Participants had mixed perceptions of body esteem as an aspect of their sexuality. Body esteem refers to the perceptions an individual has about their own body (Shavelson, Hubner & Stanton, 1976). Palombi and Mundt (2006) observed that interactional sexual experiences with others influenced body esteem. Body esteem is also influenced by the type of self-comparisons one engages (Varsamis & Agaliotis, 2011). Downward social comparisons were associated with positive body esteem. For instance,

participants believed that other people with severe physical disabilities (i.e., paralytic spinal cord injuries, or degenerative musculoskeletal conditions) may be more physically, socially and sexually restricted by their bodies than they were.

Negative body esteem could be an after effect of the lack of resources to support people with Cerebral Palsy in their sexual participation (i.e., sexual surrogates, workers, sexual facilitation from care providers, privacy or accessibility to transport) (see Earle 1999). By implication, people with Cerebral Palsy may perceive their bodies as socially and sexually contentious.

Sexual agency. Participants believed their sexual agency was constrained. For instance, they were apprehensive about explicitly asking for what they required from a sexual partner for fear that they may seem overly demanding, which could frustrate a sexual partner or end a relationship. This apprehension could decrease sexual satisfaction, sense of sexual empowerment or expose people with Cerebral Palsy to increased risk of abuse. For instance, Hassouneh-Phillips and McNeff (2005) reported that women with significant impairment could be less assertive with partners and make relationship choices which exposed them to abuse. The present study suggests that people with Cerebral Palsy do in fact recognize that being sexually agential would increase their sense of sexual satisfaction and empowerment.

Participants believed that sexual agency could be enhanced with personal effort. Guildin (2000) explained that while it may be difficult to change physical characteristics or levels of functionality it may be within an individual's control to dictate how they will behave while negotiating and/or engaging in sexual activities. Wilkerson's (2002) research indicated that people who are socially and sexually marginalized can bolster their sense of sexual agency through practice. For instance, some participants reported refusing suitors

who they did not perceive compatible. In doing so, they felt empowered and confident about their choices as sexual beings. Research should explore aspects in which sexual agency may be realized relatively more than others.

Modified Conceptual Model

On the basis of these findings, a modified model to illustrate sexual constructions with disability is proposed (see Figure 8.1). The preliminary model (presented in Chapter 1) illustrated public, interactional and private scripts and sub-scripts equally. The modified conceptual model indicates that interactional schema are primary to public and private schema at a group level. Specific elements of interactional, public, and private sexual schema which influence constructions of sexuality in people with Cerebral Palsy emerged from the thematic analysis. While both the preliminary model and modified conceptual model illustrated that sexual scripts are not directionally influential – but are relatively interdependent – the modified conceptual model shows that individual constructions of sexuality with Cerebral Palsy have a bidirectional relationship with both interactional and private sexual schema. This is to say that how people experience their sexuality with others and how they privately conceptualize their sexuality are interdependent processes. Public sexual schema however has a unidirectional influence on interactional sexual schema and individual constructions of sexuality with Cerebral Palsy. As such, contemporary media and popular culture, for example, influence how people with Cerebral Palsy participate in sexual relationships but not the other way around. Public sexual schema influence how people with Cerebral Palsy interact with others and how they perceive their own sexuality. By implication people with Cerebral Palsy are not recognized by society as part of popular culture.

This model proposes that participation in sexual activities with others is more important for constructions of sexuality than, for example, severity of one's disability, expectations to experience life like typical others, sexual self-concept(s) or media and popular culture. Although interactional scripts influence constructions of sexuality, individual factors imply heterogeneity between people with Cerebral Palsy and their resultant levels of social and/or sexual participation and preferred social and/or sexual activities (social and/or sexual negotiations). For instance, an individual with Cerebral Palsy who has completed tertiary education may prefer social activities which require critical thinking and intellectualism (i.e., mock parliament or GLBTQ support group). In doing so they may encounter fewer barriers to social and sexual opportunities when with people who share their views and values.

The influence of interactional, public and private sexual schema may have varying degrees of salience depending on context. Several circumstantial elements may influence individual constructions of sexuality with Cerebral Palsy. These may include: medical interventions and severity of impairment, living arrangements, modes of communication, intersecting experiences of oppression, gender, ethnicity, culture and socio-economic status and relationship history may have more influence on certain schema or sub-schema than others. Individual contexts and circumstances may alter the construction of one's sexuality, and perhaps the relative influence of interactional, public or private sexual schema. An individual with severe Cerebral Palsy may be influenced more by issues of accessibility (an aspect of public sexual schema) than another with moderate Cerebral Palsy. Nonetheless, sexuality for both individuals will primarily be influenced by the type and quality of sexual experiences they have with others.

Sexual interactions with others influences sexuality regardless of circumstance, or disability status (see also Hassouneh-Phillips & McNeff, 2005; Hoefinger, 2010; Mitchell, 2010). It would seem this conceptual model would explain sexual participation with Cerebral Palsy in many contexts. While the sub-schema may change, the relative salience of interactional, public and private schema could be universal (see also Anderson & Cyranowski, 1994; Anderson, Cyranowski & Espindle, 1999; Bancroft, 1997).

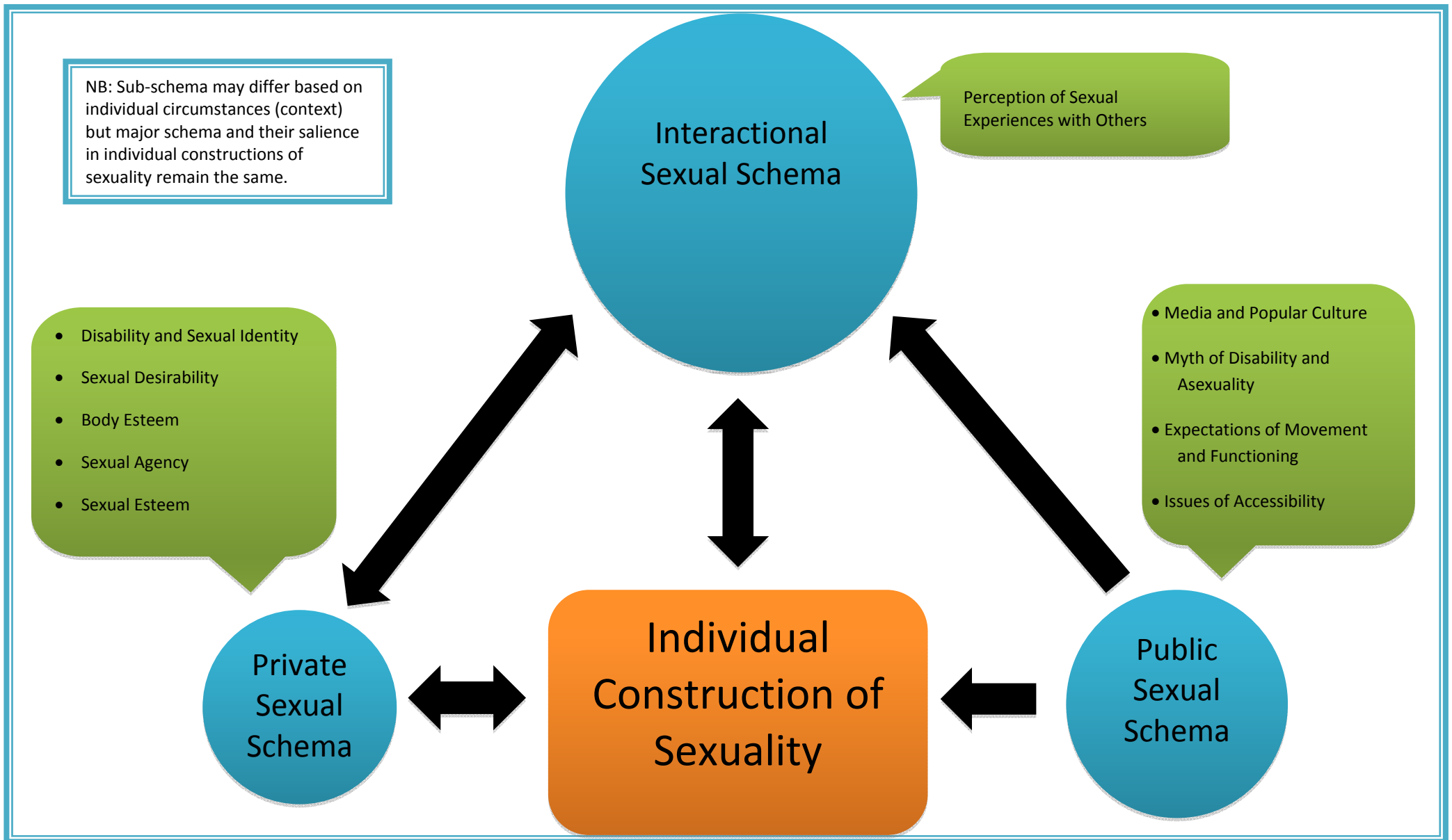


Figure 8.1. Modified Model for the Construction of Individual Sexuality in People with Cerebral Palsy

Implications for Constructing Sexuality with Significant Disability

The findings of this study have consequences for theory and practice in sexuality and disability. Firstly, sexual theory needs to be more cognizant of sexual agency as primary in the construction of sexuality with significant disability. In terms of practice, healthy sexual participation is likely when healthcare providers and people with significant disability work as partners in understanding sexuality. Finally, research which insider perspectives are indicated as supportive of participant agency.

Implications for Theory

People with Cerebral Palsy are believed to influence their sexual participation within communities biased towards typical others. The interdisciplinary field of disability and sexuality aims to represent people with disabilities as sexual beings and agents (Shakespeare, 1998, 2007). However, contemporary models of disability and models of sexuality identified within the field of disability and sexuality imply that people with disabilities and their experiences are the product of their bodies, environments and societies (Corker & Shakespeare, 2002). The findings of this study suggest that the biomedical model which posits that pathology is the issue and that disabilities are objective conditions that exist in and of themselves (Smart & Smart, 2007) misrepresent lived sexual experience with disability. The Biomedical model of disability, while useful in understanding etiology and epidemiology (Albrecht, 1992; Longmore, 1995), denies the role that agency plays in mediating and constructing disability or sexuality.

The functional and environmental models of disability have been described as interactional models as they posit that disability (within the individual) interacts with functionality and environment (Swain & French, 2010). Disability is defined as an interaction between the skills, abilities, achievements, individual circumstances and the environment

(Thomas, Burton & Hyatt, 1998). While biological/organic factors are recognized they are not the basis of these models. These models however maintain that the individual with a disability, her or his skills, abilities, circumstances, experiences and sexuality are primarily dictated by his or her interactions with the world as a person with a disability (Wolfensberger, 1972). While these models may acknowledge the individual with a disability as an element within the construction of their sexuality their conceptualizations and expressions of disability and sexuality are not specifically agentic in nature.

The findings of this study are more consistent with socio-political model of disability. This model proposes that prejudice and discrimination influence sexual participation of people with disabilities found in societies which act as barriers to agency with disability (Shakespeare & Watson, 2001). The processes by which prejudice and discrimination influence sexuality with disability include biased social and political frameworks which highlight instead of integrate experiences of impairment (Higgins, 1992). A limitation of the socio-political model is that it continues to highlight that how people with disabilities conceptualize their identity (and their sexuality) is primarily contingent upon how societies deal with and receive disability. The social model of sexuality, by emphasizing the salience of historical, cultural and political influences (Mottier, 2008), moves further away from acknowledging the salience of individual agency in the construction of their sexuality. Both the sociopolitical models of disability and the social model of sexuality, while useful in advocacy against social and political discrimination (based on historical and cultural prejudice) of people with disabilities, do not emphasize that people with disabilities are agents of their identities or sexualities.

Based on these models there may be a false consensus among sexuality and disability models that constructions of sexuality are impressed upon the individual who has

little to no agency in the process, in all cultures, across the life span, and in most domains of living. Similarly, sexual script theory which informed this study used was useful in identifying cultural, historical, political, social, environmental and functional sexual scripts and sub-scripts which influence sexual participation. However, as will be discussed below, it does not encompass sexual agency as a main factor in the construction of sexuality.

Considering the obvious influence of sexual agency in the construction of sexuality with disability this thesis calls for the development of a model of sexuality and/or disability which more explicitly identifies the individual as the creator and agent of her or his sexuality. This model would be formed on the assumption that the individual (atypical or otherwise) is the arbiter of her or his own sexuality and its manifestations. Its tenet would account for the influence of culture, history, politics, society, environment and function in a way that indemnifies the individual with a disability through the acknowledgement of their sexual agency.

Implications for Practice

The developmental history of people with Cerebral Palsy (i.e., skills in negotiating environments) makes them competent partners in their own sexuality with healthcare providers. The relationships built during these encounters can be the foundation for both parties to encourage positive constructions of sexuality and disability which empower and acknowledge individual agency. The findings of the present study suggest that healthcare providers and people with Cerebral Palsy will likely achieve preferred sexual participation goals by working collaboratively on opportunities for social and sexual participation. The results indicate that people with Cerebral Palsy are knowledgeable and educated about their own sexuality and experience of disability. Practices in person-oriented healthcare are pertinent to partnerships for sexual health with people with disabilities.

Person-oriented healthcare is usually associated with allowing or enabling people to make their own (autonomous) decisions about which health care interventions they will or will not receive (Entwistle, Carter, Cribb & McCaffery, 2010). Autonomous decisions are those made intentionally and with substantial understanding and freedom from controlling influences (Beauchamp & Childress, 2009). Autonomy within the partners in sexual health and disability framework would encourage, for example, clients to make informed decisions about a range of options to express sexuality.

Sexual healthcare providers and people with Cerebral Palsy as partners in learning can contribute to addressing the issue of inequality in the formulation of sexual health interventions. Partnerships in learning can be characterized as collaborative learning whose goal is the acquisition or construction of new knowledge (Brufee, 1993). The practice of collaborative learning used within the partners in sexual health and disability framework encourages a shift from the hierarchical provider-client relationship to a partnership in which both the client and healthcare provider teach one another in an effort to reconstruct understandings and conceptualizations about sexuality and disability (Saltiel, 1998). This shift from hierarchy to equality supports the agency of both the individual with a disability and the healthcare provider as equal contributors to understandings about sexuality and disability.

Implications for Research

This study relied on insider perspectives to gain a better understanding of constructions of sexuality with disability. As mentioned earlier, insider perspectives allow rich descriptions about phenomena from the participants own perspective(s). Through this process rich descriptions allow for interpretative conceptualizations important for comprehensive understandings (Mayoux, 2006). Insider perspectives are also used when

there is little or no literature extant on particular phenomena or concepts. Through the solicitation of insider perspectives people with disabilities, for example, can create the foundations upon which future studies are built (Hammel et al., 2008).

Insider perspectives are also indicated as useful in gathering knowledge from individuals in minority or hidden populations (White, 2006). The results indicated that insider perspectives are useful for generating information about sexual phenomena as they are understood by people with Cerebral Palsy. While other qualitative techniques (i.e., case studies or focus groups) may have generated similar data the findings further suggest that insider perspectives recognize the importance of participant agency and voice in the generation of knowledge (see also Ahlberg, Kamau, Maina & Kulane, 2010). However, the use of insider perspectives within this study was limited, as is discussed below, by the investigator's use of relatively short in-depth interviews.

Limitations

This study had some limitations: 1) cultural homogeneity, 2) restrictions of qualitative methodology, and 3) constraints of script theory and 4) the lack of member checking.

Clearly, the cultural frame of the sample was homogenous. All the participants in this study were Caucasian, from developed nations, with post-secondary education and of middle class socio-economic status. As such, the participants of this study may only represent a range and depth of socio-sexual development experienced by members of privileged ethnic groups and resourced nations. The findings may not accurately represent the experiences of those from culturally and linguistically diverse (CALD: Rao, Warburton & Bartlett, 2006) societies. For instance, CALD participants could identify sexual sub-schema not represented among the findings. However, without data from CALD respondents, the

findings may lack cross-cultural utility. Socioeconomic status may have been significant a confound. Presumably, people with significant disabilities from the middle to upper classes may have more flexibility or autonomy to seek and explore sexual participation relative to others (Schillmeier, 2007). Research which includes participants with socioeconomic diversity would clarify the role of social class in sexual participation.

Second, the qualitative methodology used within this study comes with certain limitations. Interpretive inquiry allows for some data contours to be emphasized more than others (Mayoux, 2006). For instance, the data collected is mediated by the investigator's ability to ask questions or probe answers which allowed respondent's to comprehensively articulate their concepts, conceptualizations and conceptions of sexuality with disability. In doing so respondents may have found it easier to express some or certain sexual schema and not others. While the in-depth interview technique used within the study provided insight about the meanings people with Cerebral Palsy give to their sexual lives diary methods in which participants self-observe may have been more useful. The diary method involves frequent reports on the events and experiences of participant's daily lives over a period of time (Bolger, Davis & Rafaeli, 2003). Based on this process the diary method may have been useful in capturing the particulars of sexual experience and schema in a way that could not be possible using relatively short interviews. Research which explores constructions of sexuality with Cerebral Palsy using diary methods would further clarify the findings of this study.

Third, sexual script theory was the theoretical basis for this research. Sexual script theory however, delineates sexual influences into public, interactional and private sexual schema. The results from the present inquiry indicate that public, interactional and private sexual schema are interdependent in their effect on constructions of sexuality with Cerebral

Palsy. Interdependence of theoretical constructs introduces interdeterminancy (Dworkin 1985). This is to say that sexuality as constructed by people with Cerebral Palsy cannot be dissected and explained within the confines of public, interactional or private sexual schema. The findings of this study emphasize that people with Cerebral Palsy are agents in the construction of their sexuality. Bandura's social cognitive theory (1997, 2006), which highlights people as social agents, may therefore be a better explain some aspects of constructions of sexuality with Cerebral Palsy. Research which employs Bandura's social cognitive theory and constructions of sexual with disability would be beneficial to further understanding agency and sexuality with disability.

This thesis also acknowledges that member checks with participants of the results possibly could result in unique insights, clarifications or different conceptions and interpretations (Lincoln & Guba, 1985). The member checking process would be most constructive if both the investigator and the participant looked over the results in person. However, with respondents in Canada and rural/remote Australia the geographic dispersion meant that member checking was not feasible. The results and the interpretations presented in this thesis are based on the investigator's understanding and interpretations of participant's thoughts. In order to maintain participant agency and voice in the generation of knowledge in future research member checking should be undertaken.

Conclusion

This thesis sought to explore, understand and to develop existing knowledge and theory on how people with Cerebral Palsy constructed their sexuality. The finding that constructions of sexuality with Cerebral Palsy are primarily influenced by interactional sexual schema is significant. It highlights the role of sexual participation through sexual exploration. This thesis has demonstrated – through the utilization of sexual script theory –

the complexity of individual constructions of sexuality and the overlapping nature of sexual schema in some people with Cerebral Palsy.

The findings from this thesis will initiate important discussions around the theoretical and practical implications of sexual agency with disability. Primarily, sexual theory needs to be more cognizant of sexual agency as primary in the construction of sexuality with significant disability. In addition, healthcare providers and people with Cerebral Palsy must work as partners in sexual health in order to support positive and agentic constructions of sexuality with significant disability.

In summary, this thesis emphasizes that people with Cerebral Palsy are intelligent and cognizant participants in the construction of their sexuality. Their understandings, articulations and descriptions of their sexuality speak to their awareness and interest in their sexuality and issues related to it. Through their creation of and participation in innovative pathways to sexual participation, people with Cerebral Palsy exemplify the fact that they are sexual beings and agents who empower themselves.

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Appendix A: Systematic Literature Search Results

Reference	Purpose of the Study	Participants/Population	Methods
<p>Xenakis, N., Goldberg, J. (2010) The Young Women's Program: A health and wellness model to empower adolescents with physical disabilities <i>Disability and Health Journal</i>, 3 (2), pp. 125-129.</p>	<p>The goal of the Young Women's Program (YWP), established in 2006, is to help young women adopt healthy lifestyles by exposing them to a carefully planned curriculum. The program provides a variety of classes and workshops, expert instruction, and access to resources and a network of peers and mentors. The ultimate goal is for the participants to apply the concepts learned in the group sessions to identify and evaluate their personal goals and develop health and wellness plans for achieving these goals.</p>	<p>Women with physical disabilities aged 14 - 21.</p>	<p>Data were obtained from several sources: a self-administered program evaluation, program recruitment and retention statistics, and an assessment of whether individual health and wellness goals were achieved.</p>
<p>Dune, T.M., Shuttleworth, R.P. (2009) "It's just supposed to happen": The myth of sexual spontaneity and the sexually marginalized <i>Sexuality and Disability</i>, 27 (2), pp. 97-108.</p>	<p>We subsequently argue that expectations of spontaneous sex as the pinnacle of "good sex," may negatively impact the sexual lives of people who may be sexually marginalized such as those with HIV/AIDS and STI's, female sexual dysfunctions, erectile dysfunction and mobility impairments.</p>	<p>People who are sexually marginalized</p>	<p>Theoretical analysis. Through a brief exploration of the influence of modern mass media, Simon and Gagnon's theory of sexual scripts, and discussion of several inherent tensions within the myth, the present paper problematizes the logic behind this belief.</p>
<p>Davis, E., Shelley, A., Waters, E., MacKinnon, A., Reddihough, D., Boyd, R., Graham, H.K. (2009) Quality of life of adolescents with cerebral palsy: Perspectives of adolescents and parents <i>Developmental Medicine and Child Neurology</i>, 51 (3), pp. 193-199.</p>	<p>The aim of the present study was to use qualitative techniques to identify the important facets and domains of quality of life for adolescents with Cerebral Palsy.</p>	<p>23 primary caregivers and 17 adolescents between 13 and 18y with Cerebral Palsy</p>	<p>Interviews based on their Quality of Life instrument for children and their caregivers (CP QOL-Child)</p>

<p>Wazakili, M., Mpofu, R., Devlieger, P. (2009) Should issues of sexuality and HIV and AIDS be a rehabilitation concern? The voices of young South Africans with physical disabilities <i>Disability and Rehabilitation</i>, 31 (1), pp. 32-41.</p>	<p>The purpose of this study was to record the voices of disabled young people regarding their experiences of sexuality and HIV and AIDS and to determine the role of rehabilitation professionals in this regard.</p>	<p>Sixteen young people with physical disabilities, aged 15–24 years participated in the study. Four of whom had Cerebral Palsy.</p>	<p>Individual in-depth interviews were conducted with each participant, followed by focus group discussions comprising four to six participants.</p>
<p>Wiwanitkit, V. (2008) Sexuality and rehabilitation for individuals with cerebral palsy <i>Sexuality and Disability</i>, 26 (3), pp. 175-177.</p>	<p>The concept of sexuality counseling for individuals with cerebral palsy have been proposed for a long time but not well known.</p>	<p>People with Cerebral Palsy</p>	<p>Theoretical analysis.</p>
<p>Jemtå, L., Fugl-Meyer, K.S., Öberg, K. (2008) On intimacy, sexual activities and exposure to sexual abuse among children and adolescents with mobility impairment <i>Acta Paediatrica, International Journal of Paediatrics</i>, 97 (5), pp. 641-646.</p>	<p>The aim was to describe experiences of intimacy and sexual activity and exposure to sexual abuse among children and adolescents with mobility impairment, and to relate these experiences to socio-demographic data, disability characteristics and well-being.</p>	<p>141 children and adolescents aged 7–18 years.</p>	<p>Semi-structured interviews. Interpersonal experiences of intimacy and sexuality, socio-demographic data, disability characteristics and well-being were registered.</p>
<p>Antle, B.J., Mills, W., Steele, C., Kalnins, I.V., Rossen, B. (2008) An exploratory study of parents' approaches to health promotion in families of adolescents with physical disabilities <i>Child: Care, Health and Development</i>, 34 (2), pp. 185-193.</p>	<p>To investigate within a family context the health promotion efforts of parents on behalf of a child with a physical disability.</p>	<p>15 families (11 two-parent and 4 single-parent) having a child 11–16 years of age with a physical disability including cerebral palsy (7), spina bifida (3), muscular dystrophy (3) and other conditions (2)</p>	<p>The Long Interview Method.</p>

<p>Nosek, M.A., Hughes, R.B., Robinson-Whelen, S. (2008) The complex array of antecedents of depression in women with physical disabilities: Implications for clinicians <i>Disability and Rehabilitation</i>, 30 (3), pp. 174-183.</p>	<p>This article discusses the complex interrelation of elements of the physical, psychological, social, and environmental life context of women with physical disabilities and the association of these elements with significant disparities in rates of depression and access to mental health care for this population.</p>	<p>Women with physical disabilities.</p>	<p>Literature and concept review.</p>
<p>Wiegerink, D.J.H.G., Roebroek, M.E., Donkervoort, M., Cohen-Kettenis, P.T., Stam, H.J. (2008) Social, intimate and sexual relationships of adolescents with cerebral palsy compared with able-bodied age-mates <i>Journal of Rehabilitation Medicine</i>, 40 (2), pp. 112-118.</p>	<p>To describe the social, intimate and sexual relationships of Dutch adolescents with cerebral palsy compared with their able-bodied age mates.</p>	<p>A total of 103 adolescents with cerebral palsy without severe learning problems aged 16-20 years.</p>	<p>We used a structured interview and questionnaires to assess subject characteristics such as age, type of cerebral palsy, gross motor function and level of education. Main outcome measures on social, intimate and sexual relationships are the Life-Habits questionnaire, the Vineland Adaptive Behaviour Scale, and a structured interview developed for Dutch studies in able-bodied persons and persons with spina bifida. Experienced competence was assessed with the Dutch version of the Self-Perception Profile of Adolescents and the Physical Disability Sexual and Body Esteem Scale. These data were compared with matching reference data, mainly from able-bodied (Dutch) adolescents.</p>
<p>Alouf, B. (2007) Care of the adolescent female with cerebral palsy <i>International Journal on Disability and Human Development</i>, 6 (1), pp. 3-10.</p>	<p>This article discusses the various psychosocial and behavioral manifestations of adolescence as it they relate to the girl with cerebral palsy. A discussion of common concerns regarding menstruation and cycle control as well as contraception and sterilization is also included.</p>	<p>Young females with Cerebral Palsy</p>	<p>Review article</p>

<p>Lease, S.H., Cohen, J.E., Dahlbeck, D.T. (2007) Body and Sexual Esteem as Mediators of the Physical Disability-Interpersonal Competencies Relation <i>Rehabilitation Psychology</i>, 52 (4), pp. 399-408.</p>	<p>To examine whether body and sexual esteem mediated the associations between sexual satisfaction, perceived disability severity, and social perceptions of the disability and interpersonal competencies</p>	<p>326 adults with a range of physical disabilities</p>	<p>Web-based survey. Main Outcome Measures: Perceived interpersonal competence in initiating relationships and being assertive in negative situations.</p>
<p>Sanders, T. (2007) The politics of sexual citizenship: Commercial sex and disability <i>Disability and Society</i>, 22 (5), pp. 439-455.</p>	<p>This paper exposes the existing relationships and practices between men with physical and sensory impairments who seek out commercial sexual services from female sex workers.</p>	<p>Men with physical disabilities and female sex workers.</p>	<p>Theoretical and literature analysis.</p>
<p>Wiegerink, D.J.H.G., Roebroek, M.E., Donkervoort, M., Stam, H.J., Cohen-Kettenis, P.T. (2006) Social and sexual relationships of adolescents and young adults with cerebral palsy: A review <i>Clinical Rehabilitation</i>, 20 (12), pp. 1023-1031.</p>	<p>To investigate possible barriers to successful social and sexual relationships in adolescents and young adults of normal intelligence with cerebral palsy.</p>	<p>Literature about the social and sexual relationships of adolescents and young adults with cerebral palsy</p>	<p>A literature review based on a PubMed and PsycINFO search for the period 1990 - 2003. Included were studies focusing on one or more of the outcome parameters (i.e. social, intimate and sexual relationships) or on associated factors that described relationships with the outcome parameters. Fourteen papers were selected. Two studies investigated exclusively people with cerebral palsy whereas 12 concerned people with a congenital disability and/or physical disabilities, including people with cerebral palsy. All studies addressed adolescents or adults of normal intelligence.</p>
<p>Rurangirwa, J., Braun, K.V.N., Schendel, D., Yeargin-Allsopp, M. (2006) Healthy behaviors and lifestyles in young adults with a history of developmental disabilities <i>Research in Developmental Disabilities</i>, 27 (4), pp. 381-399.</p>	<p>Measure select Healthy People 2010 Leading Health Indicators in young adults with and without a history of developmental disabilities (DD) using a population-based cohort.</p>	<p>482 young adults</p>	<p>Young adults were interviewed to assess the prevalence of seven Leading Health Indicators: physical activity, overweight and obesity, tobacco use, substance abuse, responsible sexual behavior, injury and violence, and access to healthcare.</p>

<p>Taleporos, G., McCabe, M.P. (2005) The relationship between the severity and duration of physical disability and body esteem <i>Psychology and Health</i>, 20 (5), pp. 637-650.</p>	<p>The current study investigated the association between the severity and duration of physical disability and body esteem.</p>	<p>A total of 1196 participants took part in the current study. Participants had a mean age of 36.39 years (SD 10.41; range 18–69). There were 748 participants (367 males, 381 females) who identified as having a physical disability and 448 participants (171 males, 277 females) who identified as not having a physical disability.</p>	<p>People with physical disabilities completed a questionnaire that included all of the measures, while people without physical disabilities only completed the demographic questions and the measure of body esteem.</p>
<p>Murphy, N., Young, P.C. (2002) Sexuality in children and adolescents with disabilities <i>Developmental Medicine and Child Neurology</i>, 47 (9), pp. 640-644.</p>	<p>This review presents a discussion of the sexual development of children and adolescents with disabilities, described in the framework of body structure and function, individual activities, and societal perspectives presented in the World Health Organization's International Classification of Functioning, Disability and Health. Issues of sexual development, gynecological care and contraception, sexual functioning, societal barriers, sexual victimization, and sexuality education are presented.</p>	<p>Children and adolescents with disabilities</p>	<p>Theoretical review</p>
<p>Di Giulio, G. (2003) Sexuality and people living with physical or developmental disabilities: A review of key issues <i>Canadian Journal of Human Sexuality</i>, 12 (1), pp. 53-68.</p>	<p>This paper examines key issues related to sexuality within the disabled population. It begins with an examination of how the traditional model of sexual response (i.e. Masters & Johnson) often does not apply well to people with physical disabilities. Societal, parental, and staff attitudes towards the sexuality of people with developmental disabilities are critically examined. Sexuality related obstacles and systemic barriers to sexual health faced by people with physical and developmental disabilities are reviewed (increased HIV/AIDS risk, vulnerability to sexual exploitation and abuse, reduced access to sexuality education for disabled youth, reduced access to privacy, sexuality related information and health care, and sexual partners).</p>	<p>People with disabilities</p>	<p>Theoretical review</p>

<p>Taleporos, G., McCabe, M.P. (2003) Relationships, sexuality and adjustment among people with physical disability <i>Sexual and Relationship Therapy</i>, 18 (1), pp. 25-43.</p>	<p>The current study investigated the association between relationship status and the psychological adjustment, sexual esteem and sexual behaviour of people with and without physical disability.</p>	<p>A total of 1196 participants completed the study, 748 participants (367 men, 381 women) had a physical disability and 448 participants (171 men, 277 women) were able-bodied. The age range of participants was 18 to 69 years, with a mean age of 36.39 years (SD = 10.41)</p>	<p>People with physical disabilities completed a questionnaire with all of the measures outlined below, while people from the comparative group only completed measures 1,2,3,4,5 and 6</p>
<p>Neufeld, J.A., Klingbeil, F., Bryen, D.N., Silverman, B., Thomas, A. (2002) Adolescent sexuality and disability <i>Physical Medicine and Rehabilitation Clinics of North America</i>, 13 (4), pp. 857-873.</p>			<p>Theoretical review</p>
<p>Greydanus, D.E., Rimsza, M.E., Newhouse, P.A. (2002) Adolescent sexuality and disability <i>Adolescent Medicine</i> 13 (2), pp. 223 - 240.</p>	<p>This chapter reviews normal adolescent development with specific reference to sexuality. Potential effects of chronic illness and disability on this process are reviewed, including coital behavior, sexual abuse, sexual dysfunction, and sexual offending. Management of sexual issues in chronically ill or disabled adolescents is considered, including comments about gynecologic needs of disabled girls.</p>	<p>Adolescents with chronic illness or disease.</p>	<p>Theoretical review</p>

<p>Chance, R.S. (2002) To love and be loved: Sexuality and people with physical disabilities <i>Journal of Psychology and Theology</i>, 30 (3), pp. 195-208.</p>	<p>In this article, the author discusses the sexuality and heterosexual experiences of adults with various physical disabilities. She explores possible effects of disabilities on sexual self-concept, romantic relationships, and sexual activities as well as describes some practical steps that can be taken to remedy specific difficulties. The author also briefly relates some personal experiences as a woman with chronic fatigue syndrome and fibromyalgia who is married to a man with cerebral palsy. Implications for clinical practice are discussed.</p>	<p>People with physical disabilities...case study of a woman with chronic fatigue syndrome and fibromyalgia who is married to a man with cerebral palsy.</p>	<p>Theoretical review</p>
<p>Taleporos, G., McCabe, M.P. (2002) The impact of sexual esteem, body esteem, and sexual satisfaction on psychological well-being in people with physical disability <i>Sexuality and Disability</i>, 20 (3), pp. 177-183.</p>	<p>The current study investigated the association between sexuality and psychological well-being in people with physical disabilities.</p>	<p>A total of 1,196 participants completed the study. There were 748 participants who had a physical disability and 448 participants who were able-bodied.</p>	<p>People with physical disabilities completed a questionnaire with all of the measures outlined below, while people from the comparative group only completed certain measures.</p>
<p>Cheng, M.M., Udry, J.Richard (2002) Sexual behaviors of physically disabled adolescents in the United States <i>Journal of Adolescent Health</i>, 31 (1), pp. 48-58.</p>	<p>examine differences in some aspects of sexual behavior between physically disabled and nondisabled adolescents in the United States school-based sample of 7th to 12th graders, were used</p>	<p>A total of 1153 adolescents were identified as physically disabled, mainly with limb difficulties</p>	<p>Physical disabilities were measured in terms of functional limitation and activity restriction. We studied their exposure on school sex education, contraceptive knowledge, sex attitudes, and popularity. Their experiences in romantic attraction and sex were analyzed by multinomial logistic regression methods, controlling for age, pubertal development, and other sociodemographic variables.</p>

<p>Taleporos, G., McCabe, M.P. (2002) Body image and physical disability - Personal perspectives <i>Social Science and Medicine</i>, 54 (6), pp. 971-980.</p>	<p>The current study used qualitative methodology to investigate the body image concerns of people with physical disabilities.</p>	<p>Three males and four females aged between 22 and 50 years, in Melbourne, Australia, participated in the study. Three participants were heterosexual, two were homosexual and two described their sexual identity as predominantly heterosexual but 'bicurious'.</p>	<p>The data were gathered through individual interviews of approximately 2h duration, where participants responded to a set of predetermined open-ended questions.</p>
<p>Anderson, P., Kitchin, R. (2000) Disability, space and sexuality: Access to family planning services <i>Social Science and Medicine</i>, 51 (8), pp. 1163-1173.</p>	<p>In this paper we examine, from a social perspective, access to family planning clinics for disabled people. We argue that disabled people are commonly understood to be either asexual, uninterested in sex or unable to take part in sexual activity, or sexual 'monsters' unable to control their sexual drives and feelings.</p>	<p>Family planning clinics</p>	<p>Theoretical review. To illustrate our arguments we present the findings of a short questionnaire survey of all family planning clinics in Northern Ireland. Physical access to these clinics was partial, and access to information and services were extremely limited.</p>
<p>Murphy, K.P., Molnar, G.E., Lankasky, K. (2000) Employment and social issues in adults with cerebral palsy <i>Archives of Physical Medicine and Rehabilitation</i>, 81 (6), pp. 807-811.</p>	<p>To assess the social and employment status of adults with cerebral palsy.</p>	<p>Adults with Cerebral Palsy. Volunteer participants (n = 101), all with cerebral palsy, between the ages of 27 and 74 years, living independently in the community.</p>	<p>Detailed medical history, physical examination, and functional rating in the PULTIBEC system were performed on all study participants; they also responded to a standardized social adaptation questionnaire.</p>
<p>Berman, H., Harris, D., Enright, R., Gilpin, M., Cathers, T., Bukovy, G. (1999) Sexuality and the adolescent with a physical disability: Understandings and misunderstandings <i>Issues in Comprehensive Pediatric Nursing</i>, 22 (4), pp. 183-196.</p>	<p>The purpose of this descriptive study was to examine the areas of sexual knowledge, sexual behavior, and beliefs about sexuality among adolescents with congenital physical disabilities.</p>	<p>The sample consisted of 15 males and 14 females, ranging in age from 12 to 22 years. 41% had Cerebral Palsy.</p>	<p>The Sexual Knowledge Interview Schedule (SKIS) was administered to all participants during face-to-face interviews. In addition, the participants were asked questions regarding their ability to engage in intimate relationships and their future childbearing potential.</p>

<p>Earle, S. (1999) Facilitated Sex and the Concept of Sexual Need: Disabled students and their personal assistants <i>Disability and Society</i>, 14 (3), pp. 309-323.</p>	<p>This paper explores the complex issue of facilitated sex, an issue that has received very little attention by the disability movement. It draws on a small, qualitative study of a personal assistance scheme in a British University, and on interviews and correspondence with disabled students and personal assistants. The paper discusses the way in which disabled students define their sexuality as a 'need', but highlights how this view is not shared by those providing assistance.</p>	<p>Disabled students and their personal assistants.</p>	<p>Theoretical review</p>
<p>Hardoff, D., Millul, J. (1997) Education program on sexuality and disability for parents of physically handicapped adolescents <i>International Journal of Adolescent Medicine and Health</i>, 9 (3), pp. 173-180.</p>	<p>The purpose of the project was to expose parents of physically handicapped teenagers to issues of sexuality in disabled adolescents.</p>	<p>Parents of adolescents with physical disabilities</p>	<p>Group meetings were held within a school for youngsters with cerebral palsy and muscular dystrophy, where a sexuality education program was provided for the adolescent students. Two groups, each containing parents of five severely physically handicapped adolescents, met once a week for six weeks with a pediatrician and a school counsellor. The topics discussed included: The right of the disabled person to sex education; biological changes and developmental tasks during adolescence; masturbation; menstruation; the struggle for independence in the disabled adolescent; sexual gratification in handicapped teenagers; attitudes of non-disabled society toward sexuality and disability.</p>
<p>Stevens, S.E., Steele, C.A., Jutai, J.W., Kalnins, I.V., Bortolussi, J.A., Biggar, W.D. (1996) Adolescents with physical disabilities: Some psychosocial aspects of health <i>Journal of Adolescent Health</i>, 19 (2), pp. 157-164.</p>	<p>To examine the psychosocial issues related to growing up with a physical disability.</p>	<p>Of the 101 students 48% had Cerebral Palsy</p>	<p>Adolescents with physical disabilities aged 11-16 years were compared with a Canadian national sample of adolescents using the Health Behaviours in School-Aged Children (HBSC), a World Health Organization Cross-National Study survey.</p>

<p>Nosek, M.A., Rintala, D.H., Young, M.E., Howland, C.A., Foley, C.C., Rossi, D., Chanpong, G. (1996) Sexual functioning among women with physical disabilities <i>Archives of Physical Medicine and Rehabilitation</i>, 77 (2), pp. 107-115.</p>	<p>Three a priori hypotheses were tested: (1) There are significant differences in sociosexual behaviors of women with physical disabilities compared with women without disabilities; (2) the sexual functioning of women with disabilities is significantly related to age at onset of disability; (3) psychological factors explain more of the variance in the sexual functioning of women with physical disabilities than do disability, social, or environmental factors.</p>	<p>The questionnaire was mailed to 1,150 women with physical disabilities who were recruited as volunteers or through independent living centers. Each woman gave a second copy of the questionnaire to an able-bodied female friend, which comprised the comparison group. The response rate was 45%, with 475 cases and 425 comparisons eligible to participate. The most common disability type was spinal cord injury (24%), followed by polio (18%), muscular dystrophy (11%), cerebral palsy (11%), multiple sclerosis (10%), joint disorders (7%), and skeletal abnormalities (5%).</p>	<p>Case-comparison study using written survey.</p>
<p>Rousso, H. (1993) Special considerations in counseling clients with cerebral palsy <i>Sexuality and Disability</i>, 11 (1), pp. 99-108</p>	<p>Written from a professional and personal perspective, this article describes some of the key social and sexual issues facing people with cerebral palsy.</p>	<p>People with Cerebral Palsy</p>	<p>Theoretical review</p>
<p>Blum, R.W., Resnick, M.D., Nelson, R., St Germaine, A. (1991) Family and peer issues among adolescents with spina bifida and cerebral palsy <i>Pediatrics</i>, 88 (2), pp. 280-285.</p>	<p>The purpose of this study was to identify the patterns of family and peer interactions.</p>	<p>One hundred two youths with spina bifida and 60 adolescents with cerebral palsy between the ages of 12 and 22</p>	<p>completed written psychological measures as well as an in-depth structured interview.</p>

<p>Joseph, R. (1991) A case analysis in human sexuality: Counseling to a man with severe cerebral palsy <i>Sexuality and Disability</i>, 9 (2), pp. 149-159.</p>	<p>Four key areas in sexuality and disability are discussed: (1) recognition of the individual with a severe disability as a sexual being, (2) masturbation as a valid sexual activity, (3) seeking an appropriate romantic involvement, and (4) the process involved in making a referral to a sex surrogate. The entire course of treatment is outlined along with the impressions of the counselor.</p>	<p>This article is a case analysis of a 25-year-old man, named Michael, who has cerebral palsy, generalized athetosis. His physical disability is severe and he has a profound speech disorder. Michael is functioning cognitively within the range of borderline intelligence. Michael requested human sexuality counseling. At the onset of counseling Michael stated that due to his physical disability he was neither able to masturbate nor could he find a sexual partner.</p>	<p>Case study</p>
<p>Brown, D.E. (1988) Factors affecting psychosexual development of adults with congenital physical disabilities <i>Physical and Occupational Therapy in Pediatrics</i>, 8 (2-3), pp. 43-58.</p>	<p>To gather information regarding self-concept, the roles of family, peers, educators and health care providers in development of sexual identity, sources of sexual information, and prevalence of sexual abuse.</p>	<p>26 adults with congenital disabilities</p>	<p>Tennessee Self Concept Scale, 100 statements about personal feelings and relationships</p>
<p>Esibill, N. (1980) Sexuality and disability: A model for short term training <i>Sexuality and Disability</i>, 3 (2), pp. 79-83.</p>	<p>This paper describes a training exercise in sexuality and disability combining didactic and experiential techniques and employed in one class session of an undergraduate course in psychological aspects of disability.</p>	<p>class interpretations and personifications of disability and sexuality</p>	<p>After brief discussion to define and synthesize sexuality and disability, the class of 25 was divided into four groups, each being assigned a disability: multiple sclerosis, paraplegia, cerebral palsy, and bilateral above-knee amputation. Groups were told to assume the disability and then determine what concerns they would have about it and its relationships to sexual activity.</p>
<p>Battle, C.U. (1974) Disruptions in the socialization of a young, severely handicapped child <i>Rehabilitation Literature</i>, 35 (5), pp. 130-140.</p>	<p>A brief review of some fundamental aspects of the process of socialization in the normal child is presented with a simultaneous comparison of disruptions in that process in the life of a child with a handicap.</p>		

Appendix B: Gross Motor Function Classification System for Cerebral Palsy (GMFCS)

(Palisano, Rosenbaum, Walter, Russell, Wood & Galuppi, 1997)

Milestones	Level I	Level II	Level III	Level IV	Level V
Before 2nd Birthday	Infants move in and out of sitting and floor sit with both hands free to manipulate objects. Infants crawl on hands and knees, pull to stand and take steps holding on to furniture. Infants walk between 18 months and 2 years of age without the need for any assistive mobility device.	Infants maintain floor sitting but may need to use their hands for support to maintain balance. Infants creep on their stomach or crawl on hands and knees. Infants may pull to stand and take steps holding on to furniture.	Infants maintain floor sitting when the low back is supported. Infants roll and creep forward on their stomachs.	Infants have head control but trunk support is required for floor sitting. Infants can roll to supine and may roll to prone.	Physical impairments limit voluntary control of movement. Infants are unable to maintain antigravity head and trunk postures in prone and sitting. Infants require adult assistance to roll.
Between 2nd and 4th Birthday	Children floor sit with both hands free to manipulate objects. Movements in and out of floor sitting and standing are performed without adult assistance. Children walk as the preferred method of mobility without the need for	Children floor sit but may have difficulty with balance when both hands are free to manipulate objects. Movements in and out of sitting are performed without adult assistance. Children pull to stand on a stable surface.	Children maintain floor sitting often by "W-sitting" (sitting between flexed and internally rotated hips and knees) and may require adult assistance to assume sitting. Children creep on	Children floor sit when placed, but are unable to maintain alignment and balance without use of their hands for support. Children frequently require adaptive equipment for sitting and	Physical impairments restrict voluntary control of movement and the ability to maintain antigravity head and trunk postures. All areas of motor function are limited. Functional limitations in sitting and standing are not

	any assistive mobility device.	Children crawl on hands and knees with a reciprocal pattern, cruise holding onto furniture and walk using an assistive mobility device as preferred methods of mobility.	their stomach or crawl on hands and knees (often without reciprocal leg movements) as their primary methods of self-mobility. Children may pull to stand on a stable surface and cruise short distances. Children may walk short distances indoors using an assistive mobility device and adult assistance for steering and turning.	standing. Self-mobility for short distances (within a room) is achieved through rolling, creeping on stomach, or crawling on hands and knees without reciprocal leg movement.	fully compensated for through the use of adaptive equipment and assistive technology. At Level V, children have no means of independent mobility and are transported. Some children achieve self-mobility using a power wheelchair with extensive adaptations.
Between 4th and 6th Birthday	Children get into and out of, and sit in, a chair without the need for hand support. Children move from the floor and from chair sitting to standing without the need for objects for support. Children walk indoors and outdoors, and climb stairs.	Children sit in a chair with both hands free to manipulate objects. Children move from the floor to standing and from chair sitting to standing but often require a stable surface to push or pull up on with their arms. Children walk without	Children sit on a regular chair but may require pelvic or trunk support to maximize hand function. Children move in and out of chair sitting using a stable surface to push on or pull up with their arms.	Children sit on a chair but need adaptive seating for trunk control and to maximize hand function. Children move in and out of chair sitting with assistance from an adult or a stable	Physical impairments restrict voluntary control of movement and the ability to maintain antigravity head and trunk postures. All areas of motor function are limited. Functional limitations in sitting and

	Emerging ability to run and jump.	the need for any assistive mobility device indoors and for short distances on level surfaces outdoors. Children climb stairs holding onto a railing but are unable to run or jump.	Children walk with an assistive mobility device on level surfaces and climb stairs with assistance from an adult. Children frequently are transported when travelling for long distances or outdoors on uneven terrain.	surface to push or pull up on with their arms. Children may at best walk short distances with a walker and adult supervision but have difficulty turning and maintaining balance on uneven surfaces. Children are transported in the community. Children may achieve self-mobility using a power wheelchair.	standing are not fully compensated for through the use of adaptive equipment and assistive technology. At Level V, children have no means of independent mobility and are transported. Some children achieve self-mobility using a power wheelchair with extensive adaptations.
Between 6th and 12th Birthday	Children walk indoors and outdoors, and climb stairs without limitations. Children perform gross motor skills including running and jumping but speed, balance, and coordination are reduced.	Children walk indoors and outdoors, and climb stairs holding onto a railing but experience limitations walking on uneven surfaces and inclines, and walking in crowds or confined spaces. Children have at best only minimal ability to perform gross motor	Children walk indoors or outdoors on a level surface with an assistive mobility device. Children may climb stairs holding onto a railing. Depending on upper limb function, children propel a wheelchair	Children may maintain levels of function achieved before age 6 or rely more on wheeled mobility at home, school, and in the community. Children may achieve self-mobility using a power wheelchair.	Physical impairments restrict voluntary control of movement and the ability to maintain antigravity head and trunk postures. All areas of motor function are limited. Functional limitations in sitting and standing are not fully compensated

		skills such as running and jumping.	manually or are transported when travelling for long distances or outdoors on uneven terrain.		for through the use of adaptive equipment and assistive technology. At level V, children have no means of independent mobility and are transported. Some children achieve self-mobility using a power wheelchair with extensive adaptations.
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Appendix C: Pilot and Main Study Interview Guides

Pilot Study Interview Guide

In designing the pilot study interview guide, three possible constructs of sexuality were included: public, interactional and private. The intention here was to derive a multi-layered data set from each participant. In doing so this study tried to incorporate conceptualizations of sexuality which influence the construction of individual sexuality in contemporary societies (Simon & Gagnon, 1973). The use of these three socio-sexual constructs aimed to provide a richer, multi-dimensional and more credible data set than simply discussing interactional constructions of sexuality, for example, would have generated. As such, the pilot study interview guide comprised of the following sections; demographics and severity of disability, private sexual scripts, interactional sexual scripts, public sexual scripts and conclusion.

1. Demographics and severity of disability

- a. What is your age?
- b. How do you sexually identify?
- c. What is your form of Cerebral Palsy?
- d. What is your medical history?
- e. Does your form of Cerebral Palsy require you to receive assistance from others or devices to go about your daily tasks?
- f. Do your care needs influence your sexuality? If yes, how so?
- g. How do you harmonize your care needs and your sexual needs in a way that works for you?

2. Private sexual scripts

- a. Can you please describe your early sexual thoughts or feelings to me?

- b. How would you describe yourself sexually?
 - c. What do you think makes you sexually desirable?
 - d. What do you find sexy about yourself?
3. Interactional sexual scripts
- a. Please explain the details of your romantic or sexual history.
 - b. What would you consider the most important sexual transitions in your life?
 - c. Can you describe to me the best sexual experience(s) you have had?
 - d. In your opinion what makes 'good' sex good?
4. Public sexual scripts
- a. Where did you learn about sex? What did you learn about sex?
 - b. What do you think makes someone sexually desirable to others?
 - c. What would your ideal sexual partner be like? Look like?
 - d. What is your idea of romance?
 - e. How would you define or explain the term sexual spontaneity?
 - f. How does your explanation of sexual spontaneity fit into your sexuality?
 - g. What factors have influenced how you experience your sexuality?
5. Conclusion
- a. Is there anything else about your sexuality that you would like to include?
 - b. Is there anything else about your sexuality that you think I should know?

Main Study Interview Guide

The main study interview guide was used for data collection and comprised of the following sections; demographics and severity of disability, private sexual scripts, interactional sexual scripts, public sexual scripts and reflective summary.

6. Demographics and severity of disability

- a. What is your age?
- b. How do you sexually identify?
- c. What is your form of Cerebral Palsy?
- d. What is your medical history?
- e. What are your living arrangements?
- f. Does your form of Cerebral Palsy require you to receive assistance from others or devices to go about your daily tasks?
- g. Do your care needs influence your sexuality? If yes, how so?
- h. How do you harmonize your care needs and your sexual needs in a way that works for you?

7. Private sexual scripts

- a. Can you please describe your early sexual thoughts or feelings to me?
- b. How would you describe yourself sexually?
- c. What do you think makes you sexually desirable?
- d. What do you find sexy about yourself?

8. Interactional sexual scripts

- a. Please explain the details of your romantic or sexual history.
- b. What would you consider the most important sexual transitions in your life?

- c. Can you describe to me the best sexual experience(s) you have had?
- d. In your opinion what makes 'good' sex good?

9. Public sexual scripts

- a. Where did you learn about sex? What did you learn about sex?
- b. What do you think makes someone sexually desirable to others?
- c. What would your ideal sexual partner be like? Look like?
- d. What is your idea of romance?
- e. How would you define or explain the term sexual spontaneity?
- f. Does your explanation of sexual spontaneity influence the way you experience your sexuality?
- g. How does your explanation of sexual spontaneity fit into your sexuality?
- h. What factors have influenced how you experience your sexuality?

10. Reflective Summary

- a. Since your first sexual feelings has anything changed your view of your sexuality?
If yes, how so?
- b. Did these changes influence how you experience your sexuality? If yes, how so?
- c. Is there anything else about your sexuality that you would like to include?
- d. Is there anything else about your sexuality that you think I should know?

Appendix D: Establishing Networks Telephone Script

Protocol

The researcher telephoned major Cerebral Palsy foundations, associations and organizations (i.e. Cerebral Palsy Foundation, Spastic Centre, Cerebral Palsy Australia, The Centre for Cerebral Palsy) in Australia and requested their participation in the project. Discussions were held with the media coordinators of major Cerebral Palsy foundations, associations and organizations as follows;

Introduction:

Hi my name is Tinashe Dune and I am presently conducting research at the University of Sydney as was wondering if I could speak with you about having my recruitment advertisement on your website or in your newsletter(s).

- If the media coordinator agrees or asks questions proceed to project explanation.

Project explanation:

My project is primarily about how people with Cerebral Palsy construct their own sexuality and what factors influence that. In order to promote participation in the project it would be great if I could send you my recruitment advertisement to go up on the events or research page of your website.

- If the media coordinator is interested find out how to proceed.
- Establish who to liaise with or send the advertisement to

Appendix E: Study Advertisement



The University of Sydney

Do you have CEREBRAL PALSY? Do you want to talk about SEX?

Making Sense of Sex with People with Cerebral Palsy

VOLUNTEERS WANTED!!!

A PhD student from The University of Sydney is looking for participants for a study which investigate the ways in which people (of all sexual orientations) with moderate to severe cerebral palsy perceive the prevalent idea that good sex is spontaneous and the effect that this perception may have on their sexuality. This study is also interested in how people with CP construct their sexuality in relation to public, interactional and private social and sexual influences.

Participants will be asked to engage in one or two interviews. These may be conducted in person, over the phone, by email or via online questionnaire at www.surveymonkey.com/s/cpstudy. The project has been approved by The University of Sydney and The Spastic Centre Human Research Ethics Committees.

If you would like to participate or to receive more detailed information about the project please contact Ms Tinashe Dune: 0416 015 304, email: t.dune@usyd.edu.au.

Appendix F: Letter to Establish Organizational Networks



The University of Sydney

Ageing and Human Development

Faculty Research Group

ABN 15 211 513 464

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Request for Assistance with Research Project

Dear _____ (Organization Name),

The University of Sydney recognises your affiliation to the disabled community in Sydney and is requesting your assistance in the recruitment of participants over the age of 18 with moderate to severe cerebral palsy for a research project. The project is entitled 'Making Sense of Sex with People with Cerebral Palsy' and is being conducted by a PhD student under my supervision, Ms Tinashe Dune.

The study will investigate the ways in which people with moderate to severe cerebral palsy perceive the prevalent idea that good sex is spontaneous and the affect that this perception may have on their sexuality. This study is also interested in how people with CP construct their sexuality in relation to public, interactional and private social and sexual influences. A copy of the Participant Information Sheet, which contains more information about the project, is enclosed.

We would be most grateful if your centre would be willing to allow Ms Dune to make a brief presentation about the study to a meeting or other gathering of your client group. Following the presentation she would leave the room, allowing opportunity for interested participants to collect printed information. This will contain contact details and a reply paid envelope. Those wishing to know more and/or to participate in the study will be able to contact the researcher by phone, email or mail.

If you have any questions or would like more information, please do not hesitate to contact me. We sincerely look forward to your reply and would be honored to work with you.

Elias Mpofu

Appendix G: Participant Information, Snowballing Information and Consent Forms



The University of Sydney

Ageing and Human Development

Faculty Research Group

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Email: elias.mpofo@sydney.edu.au

PARTICIPANT INFORMATION STATEMENT

Research Project: Making Sense of Sex with People with Cerebral Palsy

(1) What is the study about?

This research aims to investigate the ways in which people (of all sexual orientations) with moderate to severe cerebral palsy perceive the prevalent idea that good sex is spontaneous and the effect that this perception may have on their sexuality. This study is also interested in how people with CP construct their sexuality in relation to public, interactional and private social and sexual influences.

(2) Who is carrying out the study?

The study is being conducted by Dr. Elias Mpofo, Associate Professor, University of Sydney, Dr Joanne Arciuli, Senior Lecturer, University of Sydney, and student researcher, Tinashe Dune (B.A. Hons. Psychology), Doctor of Philosophy Candidate, University of Sydney.

(3) What does the study involve?

The study would involve your participation in one or two semi-structured, in-depth interviews with the student researcher, Tinashe Dune. If you have any communication difficulties or would like a break you are welcome to have more interview sessions. The interview (s) will focus on your major life events and daily experiences as a person with cerebral palsy. Also, the student researcher will ask what you think of the idea that good sex is spontaneous, how you create your sexuality and maintain a positive sexual self-concept (body image, sexual esteem and sense of desirability). The interviews will last 1 - 1 ½ hours and be held at a location of your convenience, over the telephone or via email. If you would like to be interviewed in a private office at the University of Sydney, we will pay return taxi fare from your place of residence. You will be provided with a transcript of your interviews and be given the opportunity to change, delete, or add to the information gathered within 2 weeks of being provided with your transcript. The face-to-face or telephone interviews will be audio-taped, with your permission. Only Tinashe, and Drs. Mpofo and Arciuli will be able to listen to the audiotapes or see the email interviews.

(4) How much time will the study take?

The interview session may take approximately 1 – 1 ½ hours, but if you need we can stop the interview and arrange another time to continue.

(5) Can I withdraw from the study?

Participating in this study is completely voluntary. You are not under any obligation to consent. If you do consent you can withdraw at any time without prejudice or penalty, and without giving any reason for withdrawing. You may stop the interview at any time, if you do not wish to continue. You can also choose not to answer any particular question. Withdrawing from the study will not affect your relationships with your disability service provider. There may be a risk that you may develop feelings of distress during and/or following your participation due to the nature of the topics discussed. If you withdraw from the study, any information provided to the researchers will be destroyed. Counselling services will be available should you become distressed and require assistance. If you wish, we can send you additional information about the study in writing before you decide.

(6) How will the results be used?

The results will be used for the completion of a PhD thesis, publications in journals, book chapters and presentations in scientific meetings.

(7) Will anyone else know the results?

All aspects of the study, including results, will be strictly confidential and only Tinashe Dune, Elias Mpofu and Joanne Arciuli will have access to participants' information. A report of the study may be submitted for publication and may be presented to conferences, but no individual participant, any other person, or organisation, will be identifiable in any such report or presentation.

(8) Will the study benefit me?

This study will not benefit you directly.

(9) Can I tell other people about the study?

You may tell other people about the study.

(10) What if I require further information?

If you would like to know more at any stage, please feel free to contact; Tinashe Dune, Doctoral Candidate, University of Sydney, Tel: 0416 015 304, Fax: 9351 9540, email: t.dune@usyd.edu.au or Elias Mpofu, Professor, University of Sydney, email: elias.mpofu@sydney.edu.au.

(11) What if I have a complaint or concerns?

<p>Any person with concerns or complaints about the conduct of a research study can contact the Senior Ethics Officer, Ethics Administration, University of Sydney on (02) 9351 8627 8175 (telephone); (02) 8627 8180 (facsimile) or gbriody@usyd.edu.au (Email). OR The Spastic Centre Ethics Committee on (02) 9479 7200 or ethics@tscnsw.org.au</p>
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This information sheet is for you to keep



Tinashe Moira Dune / Elias Mpofu

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PARTICIPANT INFORMATION STATEMENT

Research Project: Research Project: Making Sense of Sex with People with Cerebral Palsy

This is an invitation for you to participate in a research project, which is described in more detail below. You have received this information anonymously, from someone who feels you may be interested in it. That person will not know whether you agree to participate or not.

(1) What is the study about?

This research aims to investigate the ways in which people (of all sexual orientations) with moderate to severe cerebral palsy perceive the prevalent idea that good sex is spontaneous and the effect that this perception may have on their sexuality. This study is also interested in how people with CP construct their sexuality in relation to public, interactional and private social and sexual influences.

(2) Who is carrying out the study?

The study is being conducted by Dr. Elias Mpofu, Associate Professor, University of Sydney, Dr Joanne Arciuli, Senior Lecturer, University of Sydney, and student researcher, Tinashe Dune (B.A. Hons. Psychology), Doctor of Philosophy Candidate, University of Sydney.

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The study would involve your participation in one or two semi-structured, in-depth interviews with the student researcher, Tinashe Dune. If you have any communication difficulties or would like a break you are welcome to have more interview sessions. The interview (s) will focus on your major life events and daily experiences as a person with cerebral palsy. Also, the student researcher will ask what you think of the idea that good sex is spontaneous, how you create your sexuality and maintain a positive sexual self-concept (body image, sexual esteem and sense of desirability). The interviews will last 1 - 1 ½ hours and be held at a location of your convenience, over the telephone or via email. If you would like to be interviewed in a private office at the University of Sydney, we will pay return taxi fare from your place of residence. You will be provided with a transcript of your interviews and be given the opportunity to change, delete, or add to the information gathered within 2 weeks of being provided with your transcript. The face-to-face or telephone interviews will be audio-taped, with your permission. Only Tinashe, and Drs. Mpofu and Arciuli will be able to listen to the audiotapes or see the email interviews

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(6) How will the results be used?

The results will be used for the completion of a PhD thesis, publications in journals, book chapters and presentations in scientific meetings.

(7) Will anyone else know the results?

All aspects of the study, including results, will be strictly confidential and only Tinashe Dune, Cherry Russell, Elias Mpofu and Russell Shuttleworth will have access to participants' information. A report of the study may be submitted for publication and may be presented to conferences, but no individual participant, any other person, or organisation, will be identifiable in any such report or presentation.

(8) Will the study benefit me?

This study will not benefit you directly.

(9) Can I tell other people about the study?

You may tell other people about the study.

(10) What if I require further information?

If you would like to know more at any stage, please feel free to contact; Tinashe Dune, Doctoral Candidate, University of Sydney, Tel: 0416 015 304, Fax: 9351 9540, email: t.dune@usyd.edu.au or Elias Mpofu, Professor, University of Sydney, email: elias.mpofu@sydney.edu.au.

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This information sheet is for you to keep



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PARTICIPANT CONSENT FORM

I,[PRINT NAME], give consent to my participation in the research project

TITLE: Making Sense of Sex with People with Cerebral Palsy

In giving my consent I acknowledge that:

1. The procedures required for the project and the time involved have been explained to me, and any questions I have about the project have been answered to my satisfaction.
2. I have read the Participant Information Statement and have been given the opportunity to discuss the information and my involvement in the project with the researcher/s.
3. I understand that I can withdraw from the study at any time, without affecting my relationship with the researcher(s) or the University of Sydney now or in the future.
4. I understand that my involvement is strictly confidential and no information about me will be used in any way that reveals my identity.
5. I understand that being in this study is completely voluntary – I am not under any obligation to consent.
6. I understand that I can stop the interview at any time if I do not wish to continue, the audio recording will be erased and the information provided will not be included in the study.

7. I consent to:

- | | | | | |
|------------------------|-----|--------------------------|----|--------------------------|
| i) Audio-taping | YES | <input type="checkbox"/> | NO | <input type="checkbox"/> |
| ii) Receiving Feedback | YES | <input type="checkbox"/> | NO | <input type="checkbox"/> |

If you answered YES to the "Receiving Feedback Question (ii)", please provide your details i.e. mailing address, email address.

Feedback Option

Address: _____

Email: _____

Signed:

Name:

Date:

Appendix H: Independent Audit Attestation Letter

Independent Audit by Nicole Hartman (not real name) *Doctoral Candidate*

Tinashe M Dune (*Doctoral Candidate*) requested that I complete an independent audit of her qualitative dissertation titled 'Making Sense of Sex with People with Cerebral Palsy'. The audit was conducted between February 20th and 28th, 2011. The purpose of this audit was to ascertain the extent to which the results of the study are trustworthy.

In order to assess trustworthiness Lincoln and Guba (1985) delineate two tasks in the audit process:

- 1) Examination of the PROCESS of the inquiry to ensure that informants are represented fairly in recorded accounts and,
- 2) Examination of the final PRODUCT to ensure accuracy; in particular that the findings are supported by the data.

In order to meet the outlined purpose of this audit the following materials were reviewed thoroughly:

- 1) The dissertation proposal, dated September 2008. Particular attention was paid to sections addressing the purpose of the study, research questions, critical ethnographic design, selection of informants, proposed data collection and analysis methods, verification strategies, the researcher's role in the study, and the interview protocols.
- 2) Forms requesting permission to conduct the study, participant consent forms and the University of Sydney and Spastic Centre Review Board approval and amendment letters.
- 3) Coded (via NVivo and line-by-line analysis) transcriptions of interviews (organized chronologically) and corresponding digital audio files conducted throughout the study's recruitment period.
- 4) Copies of the newsletters and webpages of the organizations which published the details of the project for the recruitment of participants.
- 5) Peer-reviewed journal articles published by Ms. Dune (and colleagues).
- 6) Member Checking telephone script and results used to assess credibility.
- 7) A review of Ms. Dune's assessment of transferability.
- 8) A chronology of data collection.
- 9) An extensive outline of the category scheme for data analysis. Codes and their locations were organized/listed by three main categories (public, interactional and private).
- 10) A digital folder of files, labelled "Thesis Writings" which included drafts from all the chapters and appendices included in the dissertation.
- 11) A list of materials included in the audit trail.
- 12) Hard copies of draft chapters which included constructive guidance and suggestions from Dr Elias Mpofo and soft copies with "track changes" from Joanne Arciuli.
- 13) The first completed draft of the dissertation, dated February 19th, 2011.

Following the completion of the assessment of the materials made available:

- 1) It is the auditor's opinion that the focus of the study remained consistent with the proposed focus. Ms Dune did, however, slightly reframe her research objectives and questions as it became apparent to her that she was not adequately addressing constructions of sexuality by people with Cerebral Palsy. This revision is to be expected since qualitative research is an emerging process and initially research questions are tentatively posed. In addition, data collection and verification strategies followed those proposed in the methods section of the proposal. Data analysis procedures slightly changed in that Ms Dune also utilized a manual line-by-line analysis instead of using Nvivo as initially planned. She was also much clearer at the end of the process than at the proposal stage regarding how she approached data analysis. Initially, I had some difficulty making sense of her notes about the evolution of her dissertation included in the audit trail and her manual colored, cut and paste and Nvivo coding system. However, when Ms Dune and I met she walked me through the process and materials pertaining to analysis and specifically outlined the steps she used. The suggestions I made about increasing clarity and brevity within the dissertation were attended to.
- 2) During the audit meeting with Ms Dune, I noted that accuracy of the transcription of interviews. I listened to four digital files; two of which were transcribed by Ms Dune and two which were transcribed by RapidType transcription services. I then noted upon the transcriptions inaccuracies in the text. I listened to at least five pages of each interview (a total of 22 pages) and noted as few as three errors and as many as twenty errors per 5-6 page set. Overall, transcription was exceptionally accurate. The inaccuracies identified were very minor, including single words that were omitted or mistranscribed and/or short phrases that were omitted. In my estimation, the minor inaccuracies did not impact the overall content of the transcriptions.
- 3) It appears that the trustworthiness of the study can be established in that the findings seem to be clearly grounded in the data. The researcher carefully designed her project and employed a number of verification strategies (including the assessment of credibility, transferability, dependability and confirmability) to ensure the accuracy of the data. The data were presented in detail in Chapter 7 using extensive informants' quotes and descriptive language. Having reviewed all the materials provided to me it appears that the data accurately represents informants' perspectives. The conclusions, discussed in Chapter 8, flow logically from the data presented in Chapter 7. Comparing those chapters to transcripts, documents, and analytic methods, the conclusions of the study seem warranted.