

## **“Allowing Yourself to Sexual Freedom”: Making Sense of Sexual Spontaneity with Disability**

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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. One such sexual schema is that of sexual spontaneity. This research explored how people with cerebral palsy construct sexual participation particularly in relation to sexual spontaneity and the role it played in how they described their sexuality. This project utilized a hermeneutic phenomenological approach to explore these questions. Seven in-depth, semi-structured interviews were conducted with five men and two women with moderate to severe cerebral palsy. Sexual spontaneity was primarily 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. 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.

**Keywords:** Sexual spontaneity, disability, Australia, Canada, sexual satisfaction, cerebral palsy

### **INTRODUCTION**

A large portion of research has explained sexual behaviour and sexual functioning using a medical model (i.e., Achtari & 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, p. 98) 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**

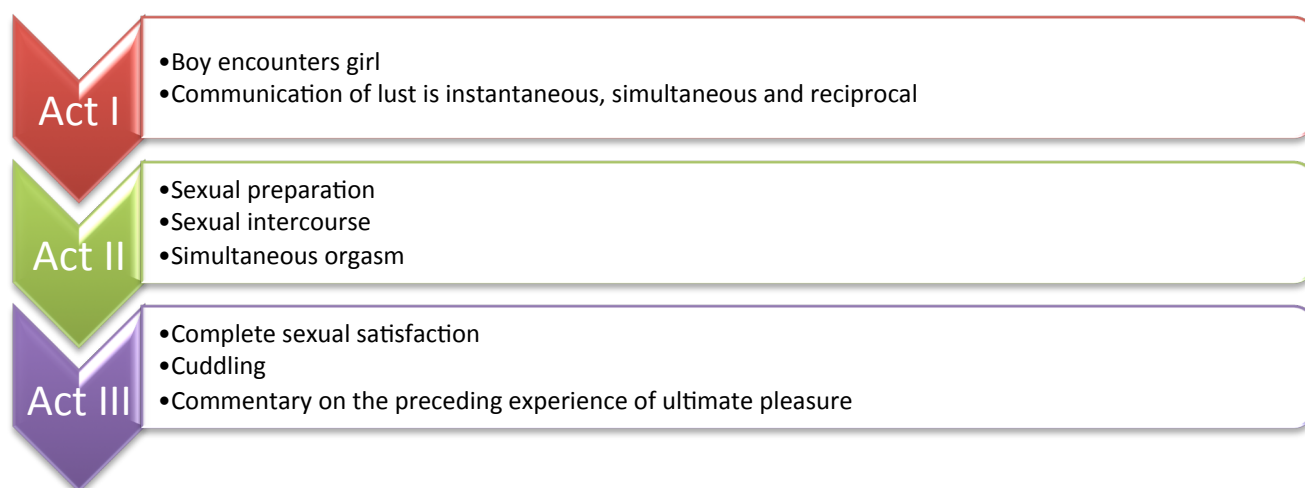
Public schemas guide the individual within collective life—meaning that they dictate the requirements needed to fulfill specific roles including the process by which a person enters those roles and how they should behave within them (Pryor & Merluzzi 1985; Ronen 2010; Serewicz & Gale 2008). Public events 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.” Public 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. 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. The construct of interpersonal schemas reinforces the relevance of public 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). 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 schemas 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). 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. 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). 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.

Public, interactional and private events and scripts influence individual constructions, and inevitably expression of sexuality (Barbour 2008; Caplan 1987; Simon & Gagnon 1986; Weeks 2010) and sexual spontaneity. 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. Script of Sexual Spontaneity (Dune & Shuttleworth 2009, p. 100)**

Figure 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 (see Dune 2014a), interactional (see Dune 2013) and private (see Dune 2014b) 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 (Dune & Pearce 2010). 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 (Esmail, Darry , Walter & Knupp 2010).

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 (Dune 2013, 2014a, 2014b). 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, Mathieu, Julien & Chartrand 2003; Shuttleworth 2000; Shuttleworth 2006). As such, the specific ways in which people with cerebral palsy personalize sexual scripts is a matter for study.

### **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. As such, this portion of the aforementioned doctoral work aimed to better understand: 1) how people with cerebral palsy construct the term sexual spontaneity, 2) how they conceptualize the script of sexual spontaneity in their lives and 3) what role their conceptualization of the script of sexual spontaneity play in their construction of sexuality?

### **METHODS**

This paper presents an excerpt of results from a doctoral project which used a hermeneutic phenomenological approach to explore the salience of sexual scripts (public, interactional and private) in constructions of sexuality by people with cerebral palsy (see Dune & Mpofu 2015 for through description and testing of procedures and protocols used). In-depth interviews were conducted with duration of one to two and a half hours. A semi-structured interview guide was used for data collection and comprised of the following sections: demographics and severity of disability, private sexual scripts (see Dune 2014a), interactional sexual scripts (see

Dune 2013), public sexual scripts and reflective summary (see Dune 2014b). Interviews were conducted via email, telephone and/or face-to-face (based on participant preference).

Interview participants were asked questions related to sexual spontaneity to ascertain if any private, interactional and/or public constructions of sexuality influenced the way in which they understood and experienced sexual spontaneity. For example, 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.

The data were analyzed for content by identifying topics and substantive categories within participants' accounts in relation to the study's objectives. In addition, 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. Due to the rich and contextual nature of the data, participant's responses have been presented in their conceptual entirety.

### **Participant recruitment**

This study included seven participants; five men and two women. Four of the participants were from Australia and three from Canada (see Table 1). The study recruited from Canada and Australia in order to enhance the possibility of finding members of the target population to participate.

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 author 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.

In Canada, participants were sought through the Attendant Care Program in Ottawa, Ontario, Canada. 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 author 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.

**Table 1. 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
<b>John</b>	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
<b>Mary</b>	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
<b>Brian</b>	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
<b>Leah</b>	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
<b>Ian</b>	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
<b>Trevor</b>	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 interview

<b>Alex</b>	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
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## RESULTS AND DISCUSSION

In terms of sexual spontaneity, participant responses indicate that they had constructed it as a derivative of sexual exploration embedded within an interactional framework. 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 previously with regards to the (hetero)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. For instance, in popular culture (public sexual scripts) sexual freedom is used as an incentive 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). Thus, when considering the script of sexual spontaneity (as sold by popular media) being free from planning is constructed as an unrealistic expectation. However, for the participants in this study being free from planning was not a hindrance to expressions of sexuality with cerebral palsy and instead a gateway to sexual freedom. 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.*

Alex's indication of sexual choice and decision-making indicate that people living with life-long disability are capable of being sexual agency – and rightfully so. As defined by the World Health Organization (2015) 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, p. 64) suggests that sexual agency is not only the right to choose but also to seek knowledge and assert sexual desires. In addition, Wilkerson (2002, p. 35) 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.

As such, 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. 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. 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.*

In previous publications (Dune 2013, 2014a, 2014b), several participants felt that it was rare to find an individual who was willing to reconstruct typical sexual expectations with them. However, four of the seven participants were able to explore their sexuality and that of others without the restrictions (perceived or otherwise) perpetuated by normative sexual scripts and expectations. Thus, 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) (see Dune 2013).

Although 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 that people with disabilities 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.

## 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 paper 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.

Sexual spontaneity primarily featured as a derivative of sexual exploration and was regarded key to being sexually connected to oneself and others. 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.

The results suggest that people with cerebral palsy may learn more about themselves and others in doing so. For instance, Esmail, Esmail and Munro (2001, p. 274) 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 is required in order to provide more information about sexual participation with life-long disability. Doing so promotes the inherent sexuality of people living with disability and their desire for fulfilling, satisfying and exciting (in however they describe it) sexual lives.

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