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"We walk that boundary. It's a tightrope." : A Grounded Theory Approach to the Experiences of Direct Support Professionals Who Work With People With Intellectual Disability and Possibly Sexualized Challenging Behavior

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"WE WALK THAT BOUNDARY. IT'S A TIGHTROPE." : A GROUNDED THEORY APPROACH TO THE EXPERIENCES OF DIRECT SUPPORT PROFESSIONALS WHO WORK WITH PEOPLE WITH INTELLECTUAL DISABILITY AND POSSIBLY SEXUALIZED CHALLENGING BEHAVIOR

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DISSERTATION

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Dedication

To Dara. My love. My life.

To my parents – from kindergarten to here and all the steps between.

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The journey of qualitative research has taken me on paths where the guidance and support of many has kept me on track, pushed me to take steps when I thought I could do no more, and showed me the light at the end of the tunnel.

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Heimerl kept me in this field years ago when I felt there was no path forward. He has continued to be one of the most inspiring co-workers/friends I could ever hope to have. Jim Haaven's relentless mind, encyclopedic knowledge, and complete availability has been irreplaceable in my work and led to the genesis of many of the ideas behind this project. I am forever indebted.

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ABSTRACT

Matters of sexuality and concepts of risk have played a central role in the development of systems of supports for people with intellectual disability (ID) in the United States during the past 150+ years. As community based programs have risen in prominence since the deinstitutionalization movement of the 1970s men and women working as Direct Support Professionals (DSPs) have been tasked with a myriad of responsibilities which may at times include enacting supports or limitations on the sexual or possibly sexual actions of people with ID. How DSPs experience their jobs, understand, and make decisions regarding sexuality is an area of investigation that has received little attention to date. When possibly sexual actions by people with ID are classified as challenging (i.e., possibly sexualized challenging behavior; pSCB), our understanding of the roles, duties, and experiences of DSPs working in community-based systems has been unaddressed in the literature. This study sought to examine the perspectives of DSPs working at a single provider agency, which has a history of supporting individuals with ID and a wide array of pSCB. A grounded

theory approach was utilized to analyze the recorded and transcribed statements of 12 participants who individually completed a semi-structured interview. Results of this research revealed participant experiences and perspectives that reflected many aspects of historical systems development and related literature. An overall grounded theory of Being Between was developed via multiple levels of coding and analysis of transcribed data. In essence, participants described the experience of supporting people with ID and pSCB as navigating between a series of internal and external factors (e.g., risk and rights; seeing the potential for change and not; variations in professional roles and relationships). Member checking procedures with participants were utilized to reduce the influence of researcher subjectivity and help ensure that the findings of this research matched the experiences of participants. Findings were also compared to research from other fields (i.e., concepts of moral distress) and further analyzed from Foucaultian perspectives on sexuality, power and the subject, and the panopticon. While the findings were limited due to the small sample size and single study site, the results of this research begin to give voice to the men and women who work in support of individuals with ID and pSCB and guide avenues for future research in this domain.

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"[V]irtually total avoidance of risk has been built into the lives of the mentally retarded by

limiting their spheres of behavior and interactions in the community, jobs, recreation,

relationships with the opposite sex etc." (Perske, 1972, p. 24).

"[O]ur culture's inability or refusal to deal with very real sexual needs of the retarded

has been the primary impediment to every farsighted ideological proposal since

Wilbur's advocacy of community placement in the 1850s" (Conway, 1976, p. 62).

"It can be easy to feel an urgent need to use whatever means are necessary to reduce risks as

quickly as possible. It can be easy for professionals to lose sight of just how much power

they hold over the people in their charge. Finally, it can be easy to believe that one is not

capable of causing harm to people in our care or custody" (Prescott, 2014, p. 1).

CHAPTER 1 INTRODUCTION

Overview

Societal attitudes towards the sexuality of persons identified as having intellectual disability (ID) have influenced policy and practice for the past several hundred years (Scheerenberger, 1983; Trent, 1995). Individuals identified as having ID have experienced periods (e.g., ~late 1800s through ~1960s) when their sexuality was primarily viewed as a threat to society (Trent; Woodill, 1992). Such beliefs were correlated with practices of sometimes lifelong institutional placement (Elkins & Andersen, 1992; Trent) and non-consensual sterilization (Elkins & Andersen; Popenoe, 1928; Trent). Circa the mid 1900s this attitude changed to one of individuals identified with ID being considered at risk of sexual exploitation (Richards et al., 2009). The result was much the same, as institutional care was then considered a manner of protecting people with ID from possible harm (Richards et al., 2009; Trent). As the movements of normalization (Nirje, 1969; Wolfensberger, 1972) and self-determination caught steam (e.g., Wehmeyer & Schwartz, 1998; Shapiro, 1994), in the mid 1970s and 1980s respectively, institutional care was gradually replaced with community-based residences and habilitation services in many parts of the world (Felce, 1999; Iacono, 2010; Lakin & Stancliffe, 2007). By 2005, these movements resulted in over 150,000 (as compared to just over 11,000 in 1977) community-based or 'typical' residential settings for people with ID operating in the United States alone (Prouty, Smith & Lakin, 2006). During this period the sexuality of individuals with ID has become framed as an issue of human rights (Richards et al., 2009) and access to the same choices as every other citizen (Nirje, 1969; Perske, 1972).

As a result of these changes in service models much of the day-to-day support received by individuals with ID has become the responsibility of individuals working as Direct Support Professionals (DSPs; Hewitt & Larson, 2007; Larson, Lakin, & Hewitt, 2002; Test, Flowers, Hewitt, & Solow, 2003). These frontline staff (AKA paid carers, support staff, direct support, etc. *ad almost infinitum*) may be responsible for duties that run the gamut from household chores to addressing periods of sometimes dangerous challenging behavior (Hewitt & Larson, 2007). Support of individuals' sexuality may, at times, also be a part of the DSP role (Aunos & Feldman, 2002). While a variety of professional consultants and therapists may contribute to individual planning regarding support of an individual's sexuality, DSPs are in a unique position of 'boots-on-the-ground' application of these plans in environments where there may be little direct oversight or presence of management (Hewitt & Larson, 2007). As historical societal attitudes have influenced models of care, it is likely that the experiences of DSPs regarding the sexuality of those they support plays a significant role in how these duties are performed and the resultant quality of support received by individuals with ID (Ioannu, Griffiths, Owen, Condillac, & Wilson, 2014).

During this transitional time in the nature of support services and the resultant adjustment in styles of individual support, there has been limited concomitant interest in development and provision of sexuality education aimed at various stakeholders (Griffiths, Wilson, Lewis, & Stoner, 2008). This deficit may be found at all levels of service from recipient to lay and professional providers.

Regardless of educational efforts at any level there remains the situation of individuals with ID who engage in actions, interpreted as sexual, directed towards self or others, in manners that challenge societal or residential norms, abridge legal boundaries,

and/or may result in physical or intense emotional harm to self or others (Lindsay, 2002).

Beginning in the early 1980s, in response to the above, there has been increasing attention

paid to best practices in supporting individuals with ID and co-occurring challenging

behaviors that may be interpreted as sexual. In such situations individuals working as DSPs

may play vital roles in the continuous navigation of the interplay between perceived or

assessed risk and human rights (Ioannou et al., 2014). While efforts have been made in

sexual attitude assessment and educational programs aimed at DSPs (e.g., McConkey &

Ryan, 2001), there has been a paucity of research informed by the lived experiences and

perspectives of DSPs themselves. As introduced above and examined in detail below, much

of the history of systems of supports for people with ID has been driven by concepts of

sexuality, risk, and rights. Due to the fact that the current systems of supports in the United

States are significantly dependent on the work of DSPs, a rich description and analysis of

their perspectives may serve to discover theory that aids in building targeted education,

enhances employment retention, improves the usability and efficacy of intervention or

support recommendations, and contributes to the quest for sustainable systems.

Definitions

Enmeshed within all of the above are issues of terminology. Absent concise and

consistent definition of terms it becomes exceedingly difficult to understand who and what

aspects of behavior one is referencing. For purposes of internal consistency I provide the

following definitions in reference to the terms *intellectual disability, DSP,* and *possibly*

sexualized challenging behavior.

Intellectual disability. I use the term intellectual disability (ID) in this paper in

accord with Schalock et al. (2010) wherein ID is defined as a condition

characterized by significant limitations in both intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18. The following five assumptions are essential to this definition:

1. Limitations in present functioning must be considered within the context of community environments typical of the individual's age peers and culture.

2. Valid assessment considers cultural and linguistic diversity as well as differences in communication, sensory, motor, and behavioral factors.

3. Within an individual, limitations often coexist with strengths.

4. An important purpose of describing limitations is to develop a profile of needed supports.

5. With appropriate personalized supports over a sustained period, the life functioning of the person with intellectual disability generally will improve (p. 1).

Certain referenced studies utilized varying terms or definitions of ID due to temporal or geographic differences. In these cases, I will specify the terms and/or measures used by the referenced authors.

Direct support professionals. There is an exceedingly wide array of terms used to describe the employees who provide day-to-day frontline services to individuals with ID. These terms may include: direct support staff (c.f. Holburn, Cea, Coull, & Goode, 2007), direct support professionals (c.f. Hewitt & Larson, 2007), carers (this term appears to usually apply to family members who provide support but in the case of Spanos et al., 2013 it was

used to describe non-family paid staff), support workers (c.f. Dunn, Clare, & Holland, 2008), support staff (c.f. Miller, Schleien, & Bowens, 2010), service providers (c.f. Buys, Aird, & Miller, 2012), disability support workers (c.f. Donley, Chan, & Weber, 2011; Iacono, 2010), direct care counselors (c.f. Jerome, Kaplan, & Sturmey, 2014), housing support worker (c.f. Hatton, Wigham, & Craig, 2009), community house staff (c.f. Borbasi, Bottroff, Williams, Jones, & Douglas, 2008), community living staff (Wiese, Dew, Stancliffe, Howarth, & Balandin, 2013), relief support worker (c.f. Dunn, Clare, & Holland, 2008), and paid disability caregivers (c.f. Wilson, Stancliffe, Parmenter, & Shuttleworth, 2011). Not to mention the basic but widely used vernacular of simply, 'staff' (c.f. Devereux, Hastings, & Noone, 2009; Furniss, Loverseed, Lippold, & Dodd, 2012). Test, et al. (2003) identified approximately 155 distinct job titles provided to persons in this line of work – *in the state of North Carolina alone.* To add to this confusion: (a) at times more than one term may be utilized within the same article (e.g., Windley & Chapman, 2010); or (b) any one of the above terms (e.g., 'direct support workers' in Disley, Hatton, & Dagnan, 2012) may be used to describe a slew of different positions including nurses, professional therapists, as well as DSPs. The overwhelming disparity of terminology and application thereof creates an omnipresent issue in the compilation of data on this specific topic.

For purposes internal consistency and in acknowledgement of the preferred terminology of the National Alliance for Direct Support Professionals (NADSP; 2001) I utilize the term direct support professionals (DSP) throughout this text to refer to individuals "whose primary job responsibility (50% or more of their hours) is to provide support, training, supervision, and personal assistance to people with disabilities" (Larson, Hewitt, & Anderson, 1999, p. 38).

Possibly sexualized challenging behavior. In general, issues of what may be considered sexually appropriate or inappropriate, adaptive or maladaptive, legal or illegal, deviant or within normal limits are inextricably bound by familial, cultural, geographic, political, and historic-temporal factors (Ellis, 1927; Herdt & Polen-Petit, 2013). As introduced above and elucidated below, the history of sexuality for people with ID has been typified by practices of protectionism and framed in terms of risk – either to or from individuals with ID. The manners by which sexuality and sexually concerning patterns are defined may influence research findings, intervention, and structure of support systems (Lockhart, Guerin, Shanahan, & Coyle, 2009). Lockhart et al. noted the lack of consensus in the literature regarding the definition and terminology surrounding possibly sexual, challenging behavior of individuals with ID. These authors noted that while much research has been conducted in this arena, such projects have "not appear[ed] to have driven empirical literature in this area and have not generalized beyond [the reviewed] author's own studies" (p. 294). In an attempt to address these deficits Lockhart et al. conducted a series of interviews with "staff from managerial, clinical, and frontline positions" (p. 295) in an Irish agency specializing in community-based supports for people with ID. Utilizing analysis of themes from participant statements along with examination of agency incident reports the authors compiled a definition, which posited:

> '[s]exualized challenging behaviors' [SCB] are those that are deemed inappropriate as a result of the nature of the behavior (including touch or contact, exposure or display, masturbation, language, communication or images, invasion of personal space or boundaries, fetishism, or aggressiveness linked to sexual arousal) or the setting in which they occur (i.e., a public or observed place). These behaviors may be self-

directed or directed at others, including targeting or fixating on individuals. Where

others are involved, the contact may be unwanted or nonconsensual. These behaviors

occur on a continuum from minor behaviors up to and including sexual assault. In

addition, the behavior may interfere with normal activity or be harmful or distressing

to self or others. (p. 299)

Lockhart et al. specified that use of the term sexualized challenging behavior must not be

utilized to "further disempower or stigmatize…[or] conceptualized as a deficit intrinsic to the

individual [but instead] to emphasize that this behavior challenges the services and their staff

to find more effective ways of understanding the origins and functions of an individual's

behavior" (p. 294) in an effort to develop and achieve more robust and individualized

systems of supports. Further, the above definition "does not include any reference to

behavior that would be considered normal and acceptable in a person without disability of the

same age…and echoes the importance [the authors] place on behavior impinging on the

individual's community presence, autonomy, and dignity" (Lockhart et al., p. 299).

I acknowledge that prominent practitioners and theorists in this field of inquiry (e.g.,

Blasingame, Boer, Guidry, Haaven, & Wilson, 2014) have recently recapitulated the term

"problematic sexual behaviors (PSB)…defined as sexually offensive conduct that places

either the client or others at risk for harm or social prejudice" (p. 3). This term PSB has,

however, a potentially pathological connotation that may 'problematize' the individual with

ID rather than envisioning the *situation* as a challenge to be overcome with significant onus

placed in the scope of the systems of supports. In addition, the PSB definition is vague and

without sufficient inductively formed exemplars necessary for examination or expansion.

In all cases, we are faced with a concerning confounding of terms. By grouping all

potentially sexual behaviors together under a unitary term, whether it is SCB or PSB, we place socially serious, potentially forensic events (e.g., rape, sexual penetration of a minor) under the same banner as ostensibly less intrusive actions (e.g., 'excessive' masturbation, use of graphic language). As demonstrated in the historical analysis below, this has occasionally resulted in the term 'sexual offense' being used as a default label regardless of if the event was a legally defined criminal 'offense' of a sexual nature or simply something that someone found 'offensive' due to perceived sexual content. The delicacies of referring to one event as a 'sexual offense' versus another termed 'sexually offensive' is a semantic intricacy comprehended perhaps only by specialists. Such loose or vague terminology may have a profoundly stigmatizing effect on the individuals so labeled and lead to interventions or restrictions based upon label rather than individual needs (false positives). Likewise, there is the possibility that by deferring to umbrella clinical jargon, practitioners may miss, overlook, or underestimate severity of risk to others (false negatives). Such intermixture of terms and potentially over-inclusive definition is not a new event in this field of study. In one of the first pieces to examine this literature Murphy, Coleman, and Abel (1983) noted that studies examining "sexual acting out" (p. 588) in people identified as having "mental retardation" (p. 581) "no attempt was made…to define 'acting out'. A variety of behaviors from private masturbation to rape could have been assumed under the term" (p. 588). Thompson and Brown (1997) also identified a pattern of overly broad classification in regard to sexual behaviors in people with ID. They noted, "any attempt to define appropriate, inappropriate and offending sexual behaviour is a great reflection on the people producing the definitions as on the behaviours themselves" (p. 141). In certain ways this contemporary confusion of nomenclature may reflect the past 150+ years of general American-societal unease with

almost any aspect of sexuality in regards to people identified as disabled.

Nonetheless, such is the context of the current investigation. The identification of terminology and related definitions is essential regardless of inherent limitations and we are faced with a devil's bargain. As Lockhart et al.'s (2009) coinage and definition of SCB (a) stemmed inductively from a service provider perspective; (b) acknowledged the potential role of environmental and cultural factors; and (c) was framed within a context of support rather than pathology or diagnosis, I will use the term sexualized challenging behavior in this text as defined above and with the same intent as outlined by Lockhart et al. In addition to this, certain behaviors may *appear* to be sexual when, in fact, there is no discrete sexual intent motivating said behavior. For example, an individual may be observed to touch his or her genitalia in a repeated fashion while in areas of a residence or community wherein such touching may be labeled as masturbatory and considered 'inappropriate'. Further, this behavioral pattern could be labeled as 'sexual' and 'challenging'. While this is a possibility, it is important to consider that there may be *no* sexual component to this pattern. It may be that the individual has a medical condition (e.g., rash, irritation), which is motivating the touching. By simply labeling the pattern as 'sexual' due to the location of the touching without consideration of other factors a cascade of interventions and labels may ensue. As outlined by Hingsburger, Griffiths, and Quinsey (1991) and recapitulated by Griffiths, Hingsburger, Hoath, & Ioannou (2013) these situations may be referred to as 'counterfeit deviance'. These authors outlined a series of hypotheses (e.g., educational history, medical conditions, effect of medications, social opportunities) that must be considered before assuming a behavioral pattern is sexual and prior to labeling a behavior or preference as deviant. Thus, it is imperative that professionals engage in a series of rule-outs regarding

other explanations for an individual's patterns. Until such evidence is gathered, the behavior is only provisionally or possibly sexual in nature. In deference to this hypothesis I have elected to slightly alter Lockhart et al.'s (2009) term of sexualized challenging behavior to the more careful *possibly sexualized challenging behavior* and use the acronym pSCB throughout the text.

Problem Statement

Despite any and all efforts at best-practice education, treatment, and support plan formulation, the duty for consistent day-to-day applied practice in community settings with people with ID and a history of pSCB – often resides with DSPs. Understanding how these individuals conceptualize, navigate, and experience these types of behavior, concepts of risk and rights, and related work may be essential in creation of theory and resultant techniques for further development of interventions at both system and individual levels. The lived experience of DSPs is an area that has been underrepresented in the literature regarding ID to date (Hastings, 2010). More specifically, these voices are nearly absent in the literature regarding pSCB (Hollomotz, 2014). Likewise, the assessment and resultant management of pSCB in persons with ID has only recently gained a presence in the professional literature (Blasingame et al., 2014). While Lockhart et al. (2009) examined methods of definition and delineation of pSCB from a service provider perspective, the authors were not focused upon the day-to-day lived-experience of DSP provision of support to individuals with ID and a presence of pSCB. Further, to date, there has been no investigation that has thoroughly addressed the crossroads of DSP experience and their community-based work with individuals with ID and a presence of pSCB in the United States.

Purpose of this Study

The purpose of this study was to investigate the lived experience of DSPs who provide support to individuals with ID and a history of pSCB. The primary research question of this study was:

1. How do DSPs describe their experiences in working with individuals with ID and a history of pSCB?

Underlying queries to this topic were:

1. How do DSPs in the study sample define or describe behavior that may be of a sexualized, challenging nature?; and

2. How do DSPs conceptualize risk and rights when supporting individuals with ID and a history of pSCB?

History and Context of the Situation Under Study

Concepts of sexuality risk and rights may be seen as a keystone in the genesis and development of many systems of supports for people with ID over the past 125 years. The work of DSPs in the current system of the United States did not emerge from a vacuum into an era of risk, rights, and advocacy. Indeed, these men and women work in positions informed by a tidal pull of historical influences. In order to adequately frame the topic of this study it is necessary to thoroughly explore the process of these historical influences/beliefs regarding sexuality and ID along with related attempts of controlling, containing, or supporting the sexual lives of people with ID. To this end, the following section situates the topic of this study within general trends of practice (i.e., eugenics, segregation/ isolation, normalization/education, consent, human rights, and societal or individual risk) regarding sexuality and ID during the American historical era of the 1600s-2010s. As such, many of the

sources examined below are position or opinion pieces with relevant research publications interspersed. More specific reviews and analyses of the peer-reviewed research in this topic area may be found in Chapter Two. The general focus of this examination is the historical path of services and models of support in the United States. It should be noted, however, that this area of study is often an international conversation in the literature. Secondary to this, many of the sources below may come from areas of the globe other than the United States. Where this is the case, the discussion will focus on if or how these international perspectives were reflected in practice, application, or response in the United States.

Organization of the Historical Literature

The separation of topics based upon general practice trends is not intended to imply that there were clean breaks in thinking and practice between these eras. Rather, trends examined below were chosen in order to increase ease of understanding of changing historical perspectives. Indeed, there is much crossover of philosophy evident in the literature between and across examined eras. As is evident in the discussion below, at times one may see correlates and reemergence of practices from neighbored or distant eras as well as the continuation of certain concepts or practices over the course of 100+ years.

Use of Varying Terminology

In order to reflect the original intent and scope of source material, I defer to the terminology utilized in the original source when summarizing or quoting these texts. While use of outdated or currently pejorative terms may, at times, lead to discomfort, it is important to retain the historically utilized term in order to minimize potential confounding of ideas due to suppositions or findings that may have been grounded in temporally or geographically

divergent terms. In general discussion or summative sections unrelated to examination of primary sources I revert to the term ID.

From 'Care' to 'Educate' to 'Contain'

Efforts toward organized, systematic, institutional or state-supported residential care and education for people with ID in the United States began in the mid 1800s (Baumeister, 1970; Crissey, 1975; Ferguson, 2004; Meyers & Blacher, 1987; Trent, 1995). There were, however, early American colonial period efforts at securing government support for individuals seen as unable to care for themselves. As Baumeister (1970) reported, "Maryland, in 1650, was the first colony to pass a law authorizing the appointment of special guardians to feebleminded children" (p. 4). Ferguson (2004) added to this history stating, "by 1742 the Rhode Island colony had officially authorized town councils to assume full responsibility for the care of mentally disabled persons" (p. 44). The model of care for people identified as 'feebleminded' in the eighteenth and nineteenth century United States remained mostly community and family-based with a related reliance on jails and 'insane asylums' to house those unable to care for themselves (Baumeister, 1970). Ferguson (2004) specifically noted the rise of the almshouse in the early nineteenth century as a seminal event in the move towards institutional care. The almshouses of this period were intended to serve as temporary dwellings for individuals with financial hardship but rapidly became a primary source of residential and functional support for those labeled as mentally ill and/or feebleminded (Ferguson, 2004).

A greater interest in the general potential of education emerged in the early part of the nineteenth century (Crissey, 1975). Coupled with this was a specific interest regarding education and rehabilitation in the lives of individuals previously seen as uneducable

(Baumeister, 1970; Crissey, 1975; Trent, 1995). This refocus from maintenance to rehabilitation and education has been partially attributed to the late eighteenth century work of Jean-Marc-Gaspard Itard in France and his efforts to educate and rehabilitate the 'Wild boy of Aveyron' (Itard, 1802; or see Crissey, 1975; Trent, 2004). Many doubted the work of Itard (Trent, 1995, 2004) yet there were a growing number of early nineteenth century European doctors and educators that believed people identified as feebleminded could gain skills thorough specific educational systems (Trent, 1995). This belief was given more credence due to the established success of education for people with hearing and/or visual deficits (Baumeister, 1970; Trent, 1995). Edward Seguin, a French citizen and former student of Itard's was one of the most passionate and dedicated of these early advocates for special education (Crissey, 1975; Trent, 1995). When Seguin came to the United States in the early 1850s the stage was set for a move to larger residential facilities with a focus on education or training (Ferguson, 2004; Trent, 1995).

Seguin's primary focus was on the *education* of people identified as feebleminded (Crissey, 1975; Trent, 1995). Howe and others who followed Seguin's philosophy initially aimed for these schools to be a temporary residence for those they served with the ultimate goal of educated and ostensibly improved individuals returning to their families and communities (Baumeister, 1970; Trent, 1995; White & Wolfensberger, 1969). In the early days of these specialized schools and institutions there was a significant focus on admitting only individuals seen as having the potential to benefit from the educational efforts (Baummeister, 1970). As Trent (1995) reported, however, "even from their earliest years… superintendents admitted students whose limitations were great and whose eventual release

was doubtful" (p. 29). From the 1850s into the 1890s the institutions and state schools grew in physical size, overall number and general population (Trent, 1995).

While there were reports of some significant individual success in the early years of institutional expansion (White & Wolfensberger, 1969) there began to be a programmatic drift from a goal of temporary education to a practice of long-term custodianship (Baumeister, 1970; Trent, 1995). In the 1860s a pattern emerged that instead of graduating from the school and returning home, many of the individuals who had completed their training went on to "remain at the school as workers" (Trent, 1995, p. 28). Trent (1994) reported that by the 1870s and 1880s "(m)ost superintendents found themselves preaching the educational purpose and function of their facilities while preparing the way for custody" (p. 29).

As Trent (1995) expanded, this move from education to custodianship was mirrored by a replacement of educator/principle directors with medical officer/superintendent directors. Impetus for this change in services from school to hospital to asylum/colony came from external pressures to take more individuals in to care and internal pressures led by superintendents who wanted to expand their own professional legitimacy and job security (Trent). Financial distress in the United States from the panic of 1857 and the Civil War only added to the pressure to move from transitory schools to custodial institutions (Trent). Additionally, Trent pointed out that there was an associated change in terminology regarding the students who began to be referred to as *wards* or *inmates*. Individuals also began to be differentially separated according to ability and potential (Trent). Instead of 'schools' or other educationally-based titles, these facilities began to be named 'colonies' and 'cottages' adding to the gestalt that these were more or less permanent dwellings (Trent). These

changes were also reflected in the larger professional community with the establishment of one of the first professional organizations in this arena – The Association of Medical Officers of American Institutions for Idiotic and Feeble Minded Persons (Trent; Now the American Association on Intellectual and Developmental Disabilities). Indeed as Trent concluded, "(b)y the end of the 1880s, the cottage or colony plan became the dominant structural and operational model of most American institutions" (p. 89).

White and Wolfensberger (1969) characterized this programmatic change as a move from idealism and education to one of protectionism and "sheltering the deviant from society" (p. 5). The originators and educational idealists who saw the potential in those they served were being replaced with a new generation of institutional directors who viewed individuals from a medical management point of view and as potentially threatening to the larger society (Trent, 1995; White & Wolfensberger, 1969).

There is little to no mention of sexuality as a concern or specific topic of interest within this time period. This paucity of examination regarding sexuality could be attributed to a sense that 19th American society avoided the topic in general (Foucault, 1976/1990). Foucault (1976/1990) hypothesized, however, that western society of the 1800s did not deny or attempt to eliminate sexuality from public discourse and examination but rather

> put into operation an entire machinery for producing true discourse concerning it…as if it was essential that sex be inscribed not only in an economy of pleasure but in an ordered system of knowledge…Thus sex gradually became an object of great suspicion: the general and disquieting meaning that pervades our conduct and our existence, in spite of ourselves; the point of weakness where evil portents reach

through to us; the fragment of darkness that we each carry within us: a general

signification, a universal secret, an omnipresent cause, a fear that never ends. (p. 69)

Per Foucault (1976/1990), by the late 1800s, there was an underlying current of

trepidation and anxiety regarding sexuality held in conjunction with what Taylor and Searl

(1987) described as a fear of "the combined effects of urbanization, industrialization, and

immigration [which] resulted in the rise of the first large-scale social problems in American

society" (p. 13). Responses to these factors swept rapidly through the policies and practices

of American institutions for people with ID and came to dominate public conversation and

professional practice (Kanner, 1964). For the first time in the United States people with ID

were coming to be seen as a threat. Fear of the risk of genetic contamination would come to

dominate the conversation for the next several decades, culminating with the implementation

of wide spread, non-consensual, human eugenical sterilization and/or decades long

institutional isolation.

Eugenics - Sexuality and ID as a Risk to Society

According to Kanner (1964), the term 'human eugenics' was first coined by Galton in

1883 and referred to "the conditions under which men of a high type are produced" (Galton,

1919/2005, p. 29). Concerned primarily with "innate moral and intellectual faculties" (p. 3),

Galton contended "in every race of domesticated animals, and especially in the rapidly-

changing race of man, there are elements, some ancestral and others the result of

degeneration, that are of little or no value, or are positively harmful" (p. 2). With continual

references to the process of livestock husbandry, Galton concluded that it was the

responsibility of his contemporaries to seek ways to "deliberately and systematically" (p.

197) "assume a…part in furthering the great work of evolution" (p. 196). Such concerted

efforts would, Galton presumed, eliminate weaknesses of reasoning, patterns of criminality, insanity, and other ostensibly undesirable qualities of the human race.

As Galton's premise and others' early work into genetic inheritance (e.g., Mendel, 1866/1901) settled into the American mind, the focus on education for people with ID waned, and was replaced by concern that the traits of people with ID would disrupt the make up of society (Trent, 1995). Family lineage studies contemporary to Galton (e.g., Dugdale, 1877 - regarding *The Jukes*) and continuing into the early 1900s (e.g., Goddard, 1912 – regarding *The Kallikaks* and c.f. Smith & Wehmeyer, 2012) served to further embed the idea that the sexuality of and reproduction by people with ID was dangerous and must be stopped (Kanner, 1964; Smith & Wehmeyer, 2012).

During this era individuals with certain conditions were often envisaged as containing inherent risk as a matter of their genetic make-up. As evidenced below, there were discussions and inference of risk on an individual to individual basis (i.e., rape or other sexual crimes) however the main thrust of the eugenical argument imbibed individuals with 'feeblemindedness' as endogenously risk laden to the very fabric of human society. This mindset has been referred to as 'the menace of the feebleminded' (Trent, 1995; or c.f. Millikan, 1929) and was led by the intellectual inheritors of Galton who saw it as their charge to put his ideas into applied and focused practice. Once this philosophical and pseudo scientific foundation had been laid, techniques for mitigating this risk were proposed. Per Kanner (1964),

> the eugenicists gave much thought to means of reducing the number of mentally
> retarded. A committee of the American Breeder's Association, convening in 1911,

reviewed ten possible reactions to the existing problem with the view of purging from

the blood of the race the innately defective strains. (p. 135)

Arguing for institutionalized sterilization, Rentoul (1906) "failed to see any other plan by

which we could prevent the present large total of mental degenerates from begetting

degenerates and so handing on their degeneracy to their offspring" (p. 319). Exemplifying

the philosophical change from the educational standpoint of the mid 1800s Rentoul (1906)

wished to

emphasize the fact that these 'defective' persons are the most dangerous citizens, and

especially from the procreation standpoint. They are a 'faked' class of humanity:

'faked' by the 'specializing physician', 'faked' by the schoolteacher, and 'faked' by

the tailor. But they mislead the public. The so-called education of 'defectives' is one

of the most dangerous points with which we deal…[for] they cannot be schooled in

the sense understood by the public. (p. 320)

From a list that also included encouraging suicide, euthanasia, and scientific breeding -

sterilization and segregation became the primary chosen means of accomplishing the

eugenical goal (Kanner, 1964; Reilly, 1987). Importantly, some theorists contended that the

wholesale buy-in to determinative genetics was misplaced arguing, "we should ever insist

that when considering why the defective delinquent is what he is, one must take into account

surroundings as well as mental capacities, nurture and well as nature" (Healy, 1915, p. 121).

Such a person-environment etiological hypothesis was, however, in the clear minority at the

time and intervention practices became dominated by the eugenics movement. While some

extralegal sterilization practices may have occurred prior (Kanner), "beginning in 1907,

states began to pass laws that allowed, and in some cases required, the involuntary

sterilization of those with developmental disabilities and mental retardation. Within 10 years,

17 states had passed sterilization laws" (Diekema, 2003). For many years, legal challenges to

these laws were roundly confirmed (Burgdorf & Burgdorf, 1977) as non-consensual

sterilization was, in various state courts, found to be "unconstitutional as cruel and unusual

punishment, violations of due process, or violations of equal protection" (Diekema, 2003, p.

22). In 1927, however, the US Supreme Court, under the leadership of Chief Justice Oliver

Wendell Holmes, famously concluded, "three generations of imbeciles are enough" (*Buck v.

Bell,* 1927, p. 274*).* According to Lombardo (1985) this decision and subsequent state laws

effectively "sanctioned sterilization operations on 60,000 Americans" (p. 30). While the

situation and ultimate decision in *Buck v. Bell* may have been informed by specific

relationships, agendas, and possible collusion between plaintiff and defendant attorneys

(Lombardo), the case represents the legal culmination of a general movement towards

compulsory, often non-consensual, eugenical sterilization of individuals then identified as

feebleminded in the United States. As Diekema (2003) posited, while *Buck v. Bell* has never

been overturned by the Supreme Court, it has come "to be seen as bad law on both factual

and constitutional grounds [as Carrie Buck] was a young woman of normal intelligence who

had been institutionalized not because of mental retardation, but to hide the shame of her

pregnancy, a pregnancy that resulted from rape" (p. 22). Further, as outlined by Diekema

(2003) and Gould (1984) there was questionable evidence that Carrie Buck, her mother

Emma, or her daughter Vivian could have been identified as individuals with

feeblemindedness as defined at the time. Nonetheless, "in the years following *Buck v. Bell*

the number of states with sterilization laws increased to 30" (Diekema, 2003, p. 22).

As the twentieth century progressed, the ongoing practice of forced sterilization continued to be given credence in the professional literature via both practice based examples and philosophical musings. In this literature there is evidence that the elimination of sexual offense and general criminological patterns became a main focus of eugenical practice along with the originating concepts of improving genetic stock. Craft (1936) described eugenical sterilization in South Dakota reporting,

> [i]n its practical application only those who seem likely to have children are sterilized. Patients that are expected to remain in the institution for the feebleminded, those who are well supervised at home, persons nearing middle age without showing any tendency toward sex offenses, and defectives who are physically incapable or so unattractive that mating is improbable, are not sterilized. (p. 379)

These practices, Craft argued, led to decreased cost to the state and reduced patterns of "sexual offense" (p. 387) by a factor of seven while "none of the patients was found to have any sexual changes that had been caused by sterilization [and] the married patients have experienced no change in libido" (p. 387). In a similar vein, Selling (1939) posited,

> no one with any criminological experience would attempt to belie the statement that were all of the feebleminded to be removed from the community the crime picture would change remarkably and, as a matter of fact, a very great number of crimes would no longer be committed or, if they were committed, would be committed so sporadically as not even to constitute social problems. (p. 178)

In his review of 1078 cases of sexual offense Selling argued the evidence suggested "the more vicious and animalistic types of offense [definition not provided] may be those delegated to the feebleminded, but, of course, not to the exclusion of the dull normal" (p.

182). Selling attributed the presence of sexual offense in 'feebleminded' individuals as "due to the fact that he (sic) has been unable to learn the social significance of such unacceptable conduct, that he is limited in his ability to acquire education and hence, acts in a primitive fashion uncontrolled by either knowledge or self-acquired training" (p. 186).

As "public attitudes regarding forced sterilization began to change toward the end of the Second World War" (Diekema, 2003, p. 22), the conversation regarding sterilization moved from a call for compulsory surgery to one that contended, "[w]e know enough about the transmission of certain bad genes to support a policy of *voluntary* sterilization, under suitable safeguards…[in order to] relieve the burden of their fertility" (Titmuss, 1944, p. 57, italics added). By framing the eugenical argument in regards to *protection of individual* rather than *protection of society*, Titmuss presaged the 'eternal child' conceptualization, which would emerge in the following decades. Corollary to this change were increased calls for "positive eugenic policy, that is, the encouragement of the increase of good types as contrasted with the elimination of bad types" (Darwin, 1952, p. 154). Such transformation of opinion from previous advocates of forced sterilization stemmed in part from retrospective analyses of the German eugenical practice wherein it was surmised that "[g]enerally, the consequences of negative eugenic measures by the State on a people's entire genetic substance cannot be overlooked. Experience up to 1945 proves that disregard of life, of human individuality and personality must result in the destruction of people and community" (Harmsen, 1955, p. 231). Similar postulates led Osborn (1956) to contend "if eugenics is to make any progress in the foreseeable future, we will not only have to drop the idea of assigning genetic superiorities to social or racial groups, but we will even have to stop trying to designate individuals as superior or inferior" (p. 17).

Around this same period calls for a return to education and non-surgical treatment began to be proposed in the literature. For example, East (1947) posited, "there is reason to believe that a solution may be attained in many cases [of sexual offense] if modern psychotherapeutic, psychiatric and educative measures are applied for a sufficient time in a special penal institution" (p. 16). From a more prevention focused angle, Kratter and Thorne (1957) "affirm[ed] the necessity for more understanding and acceptance of that aspect of living [sexuality] which is more or less common to us all and which does not in any way exclude the most retarded persons" (p. 44). These authors described a sexuality education curriculum piloted at the Caswell Training School, State School for Exceptional Children. This appears to be perhaps the first such curriculum described in the literature and stemmed from the fact that "for many years within the institution…a 'moral' code prohibited and enforced through punishment the holding of hands, having secret conversations together, and kissing was almost regarded as an unforgivable sin" (p. 47). Developed in concert with the "house parents" (p. 44) who presumably worked in roles akin to today's DSPs, the described educational program included topics of anatomy, physiology, hygiene, masturbation, and pregnancy along with efforts to curb or eliminate homosexual relations in the institution. There was, however, "no instruction or discussion of sexual intercourse [as] there [was] no desire to stimulate any interest in sexual experimentation" (p. 46). Despite the emergence of these educational ideals, it would take nearly another quarter century for such practices to take root.

Acknowledging the tide of change near the mid twentieth century, Osborn (1956) summarized, that while Galton

envisaged the eugenic movement as something that would sweep the world and make man at last the master of his own destiny on earth. It has not happened. The eugenic movement is now nothing but a few small handfuls of men in various countries…They are not influencing public opinion. The very word eugenics is in disrepute in some quarters…We must ask ourselves, what have we done wrong? I think we failed to take into account a trait, which is almost universal and is very deep in human nature. People simply are not willing to accept the idea that the genetic base upon which their character is formed is inferior and should not be repeated in the next generation…They have constantly refused and we have all but killed the eugenic movement. (p. 21)

As a possible panacea for this decline in negative eugenical buy-in, Osborn (1956) proposed eugenicists "stop telling anyone they have an inferior genetic quality [and instead] build a system of voluntary unconscious selection" (p. 22). In such a system Osborn posited that beneficial environmental and parental traits could become embedded in literature and public outreach campaigns and thus change procreative habits without direct action. By 1958 the Eugenics Society's *Statement of Aims* (The Eugenics Society, 1958) did not outline any specific goals or activities related to intellectual disability or sexual offense whether related to ID or not. By 1963 this same society adjusted further and accepted integration of environmental influences into their main platform (Schenk & Parkes, 1968).

Institutional Isolation of Sexuality – Out of Sight, Out of Mind

The emergence of studies regarding human sexuality (e.g., Kinsey, Pomeroy, & Martin, 1948; Kinsey, Pomeroy, & Martin, 1953; Masters & Johnson, 1966) increased American acceptance and discussion of sexuality as a generally 'normal' and important

component of the human experience. Concurrent with this changing attitude, and the decline of eugenics described above, "[s]terilizations in most state institutions came to a halt, and the mid-1960s represented the low point for numbers of persons subjected to involuntary sterilization in the United States" (Diekema, 2003, p. 22). As Carruth (1973) contended, however, despite these wider societal changes, "for a significant minority of the population – the mentally and socially retarded – the expression of human sexuality continue[d] to be actively suppressed" (p. 153). Conway (1976) connected this suppression of sexuality directly to

> our culture's inability or refusal to deal with very real sexual needs of the retarded
> [which] has been the primary impediment to every farsighted ideological proposal
> since Wilbur's advocacy of community placement in the 1850s. (p. 62)

While many individuals with ID lived in environments other than public facilities (Robinson & Robinson, 1965; Taylor & Searl, 1987), the main location of this suppression was, as Conway (1976) intoned, the segregated institution.

Due, at least in part, to the fear driven conceptualization of genetic risk prevalent in the early twentieth century there was steady growth in the number and population of institutions for people with ID (Scheerenberger, 1983; Trent, 1995). Lakin (1979) reported that the number of public institutions "for people with mental retardation" (p. 102) in 1880 stood at 10 with a population of 2,429 or 4.8 per 100,000 of the general population. By the late 1970s an estimated "207,356 (83.7%) of the 247,780 persons with ID receiving residential services [in the United States] lived in public and private institutional settings" (Lakin & Stancliffe, 2007, p. 151). In essence, "the belief that certain people belong in institutions came to be taken for granted" (Taylor & Searl, 1987, p. 20) and "through a

failure on the part of professionals and the public to reach a consensus on the sexual question of the mentally defective, institutionalization triumphed by default" (Conway, 1976, p. 63).

At this time of expanded institutional care came a concurrent conceptualization of people with ID as eternal children (Griffiths, 2007). From this perspective, sexuality of people with ID was considered either non-existent, of a primal simplicity, or, in short, "innocence is expected to prevail; therefore, sexuality must be negated" (Morgenstern, 1973, p. 160). Wallin (1956) reflected this position stating, "mentally deficient girls become sex offenders [definition not provided] not primarily because they are oversexed (many are, in fact, undersexed), but because of lack of protection and because of their weaknesses – lack of judgment, and control, and because of an inability to resist victimization" (p. 99). Similarly, in an otherwise comprehensive, textbook length, examination of the topic of mental retardation, Robinson and Robinson (1965) only mentioned sexuality in relation to Freudian psychosexual developmental stages and the statement that "[s]exual offenses [undefined] among girls almost invariably resulted in institutionalization" (p. 527) wherein negation of perceived sexual behavior was a treatment goal.

Perhaps reflecting this suppressive stance, there was a relative dearth of research or practice-based literature regarding sexuality and ID during the 1950s and 1960s (Bass, 1964). As Rhodes (1993) stated, "in the two decades following [World War II], the living conditions of persons with mental retardation did not differ significantly from the pre-war years" (p. 18). Treatment in the institutions began to center around interventions grounded in behaviorism (e.g., Foreman, 1962) and concerns about sexuality were suggested as a key informant of institutional placement (Edgerton, 1967; Hobbs, 1964). Specifically, Hobbs (1964) found "[a]nti-social or immoral behavior of the subject, defined as: acts involving destruction of

property, physical violence, theft, promiscuous or perverted sexual behavior, sexually

molesting younger children, and unmanageable behavior in the home" (p. 207) were

significantly correlated with individuals being placed in congregate facilities. Edgerton

(1967), based on an ethnographic study of previously institutionalized individuals, agreed

stating, "for many of these individuals, real or fancied sexual misconduct was the ostensible

reason for their original institutionalization" (p. 103). In a foreshadowing of the person-

environment conceptualizations of the normalization movement examined below, Hobbs

(1964) contended, "the institutionalized group was strikingly less socially competent than the

group seen in the community. The most likely explanation is that socially inadequate

individuals tend to be institutionalized and that institutionalization contributes further to their

social inadequacy" (p. 210). Bass (1964) underlined this sentiment and proposed an

expansion of "family living courses [as the mentally retarded] need more help in controlling

their sexual impulses because they have less opportunity to express themselves in other

areas" (p. 59). Bass, however, stopped short of addressing the issue in institutional settings

and instead focused on such education for individuals living in various community settings.

Blanchard (1966), working in a large state institution in California, addressed the problem

more circuitously and examined socially unacceptable language of "mentally retarded

patients…repressed by necessity [who use]…unacceptable words which are often obscene

and accompanied by obscene gestures" (p. 10). Blanchard noted, "sex words predominate the

swearing pattern" (p. 12) and implied that medication was used to reduce prevalence. In

summary, the limited literature of the time intoned that while sexual concerns were seen as a

significant variable in institutional placement, and the lack of educational opportunities was

noted but mainly focused those living in the community, certain institutional interventions

appeared centered on elimination of all forms of anything even vaguely sexual by individuals with ID.

Apart from the above, we are left with remnants of sometimes disturbing anecdotal recollections regarding the practices of the time. For example, Robinson and Robinson (1965) noted, "attendants and housemothers [in institutional settings] were found…to favor strict authoritarian techniques which tend to suppress aggression and sex" (p. 532). Similarly, in describing his first-hand experience working in institutions of the 1960s and early 1970s, Gordon (1973) noted,

> [a]t a time when the residents of this institution consisted only of males, much of the available staff energy was spent in punishing or curbing homosexual behavior, but now with females included, the staff's main thrust is against any expression of heterosexuality…[and] a great deal of the staff's energy was obviously being devoted to catching or curbing the masturbators. (p. 68)

Friedman (1971) corroborated similar conditions stating, "under conditions of nearly complete repression and denial of the sexual drive, the maturing mentally handicapped child becomes increasingly bewildered and anxious in an environment filled with concrete and symbolic sexual stimuli" (p. 365). Friedman recounted visiting an institution he chillingly described as a

> monstrous cottage whose inmates were locked in solitary cells, for the most part without clothes, and fed bowls of enriched protein flour mixed with water three times a day. One of the cells was occupied by a severely retarded 11-year-old child with Down's [sic] syndrome, who crouched naked on a cold stone floor. When questioned on the reason for the child's confinement, the supervisor replied flippantly, 'This will

teach him a lesson not to play with another boy's penis'. Thousands of residents of

that particular institution and the many hundreds of thousands in similar institutions

are taught a 'good' lesson during their lifetime confinement – how to suppress and

deny their sexual needs from fear of seclusion or severe punishment. In most

institutions open masturbation and homosexual activities are dealt with by isolation,

physical punishment, or restriction of privileges. (p. 366)

In an attempt to locate the source of this eliminative attitude Menolascino (1972) noted

how the 'abnormal sexual behavior' frequently associated with the symptom of

mental retardation can be a result of the individual's hunger for meaningful personal

relationships which in turn may be the result of the staff orientations of institutions

that house many of our mentally retarded citizens and which program the retardate's

behavioral repertoire in a negative manner. (p. 40)

 Deisher (1973) added,"[t]here is no clear-cut policy regarding what kind of [sexual] activity

should be allowed in the institutions, and that the attitudes of the staff are mainly a reflection

of personal values and ideas" (p. 152). In relation to the topic of this research, these authors

appear to be the first to introduce the importance of the role and actions of people working as

support staff regarding sexuality and ID. Gordon (1971) took a wider perspective stating,

"[a]dministrators blame their staffs for such anti-sex attitudes…yet the administrators are the

ones to blame for they have provided their institutions and schools with irresponsible

leadership" (p. 68). Collectively, these early theorists and practitioners identified the source

of concern not within individuals but within the surrounding systems of supports.

　For individuals with certain conditions living outside the institution, legal restrictions

held over from the course of the eugenics movement also served to reduce sexual behavior.

Scheerenberger (1983) reported that 39 states imposed legal restrictions on marriage for people with certain conditions or allowed for annulment of marriages based upon intellectual status Further, general sexual relations involving individuals identified as "epileptic, insane, or feebleminded" (Taylor & Searl, 1987, p. 18) were, in some states, considered a legal offense to be met with fine and/or imprisonment. Thus, within the institutional and legal world of the mid twentieth century, elimination of sexuality became a common goal (Scheerenberger, 1983; Trent, 1995) to be achieved via denial, segregation, punishment, and codified discrimination. As the 1960s came to an end, however, liberating trends would begin to take hold and set the course toward themes that continue to dominate the literature of the early twenty-first century.

Normalization and Sexuality – The Role of Environment and Education

In 1972 Perske wrote the seminal text *Dignity of Risk and the Mentally Retarded*. While brief, this piece introduced English-speaking audiences to a necessity of equity in human experience that reverberates into many current constructions of policy and practice. Perske's (1972) work was based on his experiences in northern Europe and stemmed directly from the principles of normalization introduced by Nirje (1969) and expanded by Wolfensberger (1972). According to Nirje (1969), the road to normalization included the principles (among others) that all individuals, regardless of perceived or measured intellectual status, should have access to "normal developmental experiences of the life cycle [and] having one's choices, wishes, and desires taken into consideration and respected" (p. 183). Perske contended that opportunity to experience life outside of institutional settings was rare if it occurred at all. As Perske (1972) stated, "such overprotection endangers the…person's human dignity and tends to keep him from experiencing the normal taking of

risks in life which is necessary for normal human growth and development" (p. 24). Perske saw this practice of protection as encompassing not just discrete situations but as a global effort to control. In his words, "virtually total avoidance of risk has been built into the lives of the mentally retarded by limiting their spheres of behavior and interactions in the community, jobs, recreation, relationships with the opposite sex etc." (p. 24).

As examined below, similar thinking would directly challenge the definitional foundations of what constituted 'appropriate' sexuality and related etiological theories regarding behavioral concerns for people with ID. Riding the wave of larger social movements (e.g., civil rights, sexual revolution, educational reform) in the mid to late twentieth Century United States these 'normalized' foundations served as the building blocks for deinstitutionalization, self-advocacy, and more robust examinations of human rights for people with ID (Roos & McCann, 1977). New concepts of risk, related to sexuality and ID, emerged concurrently and led to our current era's systems of supports. As philosophy and practice changed, so would the role and resultant experiences of those providing direct support.

Changing conceptualizations of disability and sexuality. Whereas many theorists of the early twentieth century, operating from a medical model, located the source of disability squarely and solely within the body, brain, and heredity of individuals, literature of the 1970s evidenced a growing acknowledgement of the role environment might play in expression of supposed sexual pathology. In a similar vein to Healy's (1915) postulate of nature-nurture in regard to mental deficiency and criminality, Johnson (1973) remarked,

> [t]ypically, the retarded, being more closely supervised and scrutinized and having
>
> less privacy than other persons, are more likely to manifest behavior [of a sexual

nature] which, because it is visible, is regarded as a symptom of retardation rather

than of the goldfish-in-a-bowl circumstances in which the retarded commonly live.

(p. 58)

Gordon (1973) underlined this opinion stating, "[i]nstitutions for the retarded are not

designed or operated to ensure privacy, [therefore] the definition of what constitutes privacy

in an institution must be very liberal. Bathroom, one's own bed, the bushes, and basements

are private domains" (p. 69). In conjunction with the growing acceptance of the theory of

person-environment interaction, writing of this era also began to criticize the manner by

which the base term of 'mental retardation' was defined and delimited. As Murphy (1973)

pointed out, basing standards of difference on intelligence tests could be considered

inherently biased toward a white male European standard. He extended his argument stating

"if the birds constructed such test, we would all doubtless get low marks in building nests,

hatching eggs, flying, and catching worms. We would be labeled hopeless imbeciles and

perhaps be compulsorily sterilized by our well-meaning rulers" (p. 130). Johnson (1973)

furthered this sentiment stating,

> [l]abels like 'mentally retarded' tend to both create and conceal the *individuals* under
>
> them. It is therefore hazardous to suppose that such a label necessarily provides any
>
> useful information when dealing with any given person, either with regard to his [sic]
>
> capacity to learn or his interest in sex…Thus it is apparent that the mentally retarded
>
> individual is, in most ways, not readily distinguishable from the rest of us in relation
>
> to sexuality. (p. 58, 60; italics in original)

As the progressive voices outlined above settled into the conversation and the

developmental model of ID took root (Roos & McCann, 1977) there was an explosion of sex

education proposals and programs. In an early example of this trend Floor, Rosen, Baxter, Horowitz, and Weber (1971) compared pre and post discharge reports regarding socio-sexual behavior problems of "forty-nine previously institutionalized, mentally handicapped females" (p.106). The individuals were grouped as either "High Problem [or] Low Problem" (p. 108) with the 'high' classification "requir[ing] that the individual's sexual activity in the community had resulted in severe economic, employment, or personal difficulties to the point of dysfunction [leading to] help from some outside source" (p. 108). Specific examples included "indiscretions with men, living with men, premarital pregnancies, and illegitimacies" (p. 108). The authors found a significant positive correlation between historical reports of socio-sexual problems in the institution and occurrences once living in the community. In a clear break from the eras examined above, the authors did not contend that this pattern was indicative of endogenous degeneracy common to 'mental deficiency'. Instead, they noted,

> sex-related infractions in the institution…often involved infractions of institutional rules for behaviors usually considered a part of normal adolescent development outside the institution. Females demonstrating such behaviors may be signaling their need for appropriate counseling, structured learning experiences and support rather than repressive strategies more typically employed by institutions…[Therefore], appropriate co-educational and socialization experiences should be an important aspect of the community preparation experience of institutional residents. (Floor et al., 1971, p. 111)

Reflecting the crossroads of the times Floor et al. concluded, "the issue resolves itself primarily into a moral and value judgment: i.e., whether the purpose of the institution is to

protect society from potential social failures or to take the risks of properly preparing an individual for community living" (p. 112). Contemporary with this growing call for a more humanistic perspective, the late 1960s and early to mid 1970s witnessed a plethora of position papers (c.f. Friedman, 1971; Gordon, 1971; Menolascino, 1972; Meyerowitz, 1971; Vockell, 1971), stakeholder attitude examinations (c.f. Goodman, 1971; Sengstock, 1967 as cited in Vockell, 1971), and descriptions of sexuality education programs for people with ID (c.f. Bass, 1964; Johnson, 1969; Selznick, 1966; Thurman, Bassin, & Ackerman, 1976). Perske (1973) tempered this enthusiasm stating,

> years of attempting to de-sex or deny the sexuality of the retarded sometimes generates a sense of guilt. This, coupled with new attitudes toward sex, can present the danger of moving too abruptly toward another extreme. People might work feverishly to set up emergency committees to discuss the sex education of the mentally retarded. They might struggle to find the perfect curriculum for sex education and crash courses reaching the mechanics of sex could emerge. The mentally retarded might be forced to learn too much to fast, regardless of their sensitivities or where they are in their development. (p. 7)

In short, much of the literature of this era indicated a movement towards more permissive practices, a focus on education, and a perspective less focused on pathology. According to Taylor and Searl (1987), "[t]hroughout the 1970s, all trends in the field of disabilities seemed to move in one direction – toward expanded rights, increased social acceptance, fuller integration, and increased funds for programs and services" (p. 41). Griffiths (2007), however, highlighted the frequent disparity between philosophy and practice stating, "[b]y the late 1970s, most facilities reported teaching sex education to some

degree, but sexual activity, with the exception of masturbation continued to be met with disapproval and prohibition" (p. 575). There is also evidence that many were still struggling to break free from the reliance on sterilization practices of the preceding decades. Gordon (1973), who argued vociferously for redefinition of privacy and less control-based practices in institutions, also contended, "[c]onsideration should also be given to achieving greater acceptance of…voluntary sterilization as a protection for those retarded persons who could function well in a marriage if they did not have children" (p. 69). In a similar vein, Bass (1978) stated, "surgical contraception on an individualized, voluntary basis can make an important contribution to the two prime goals of the American Association on Mental Deficiency, namely, normalization and prevention" (p. 399). Friedman (1971) acknowledged these positions but questioned the "'blessings' of voluntary sterilization…[as] voluntary option and consent for the retardate are in most cases meaningless because he and his parents are told that this is the way it should be. No other options such as birth control, family protective services, or intensive day care are offered" (p. 368). Nevertheless, with the rising tide of exposés (e.g., Blatt & Kaplan, 1966; Rivera, 1972a and 1972b), political spotlighting by figures such as Robert F. Kennedy, and general social movements of normalization, the sexual revolution and civil rights era (Taylor & Searl, 1987), significantly fewer individuals with ID would be living in institutional settings. As examined below, concerns about sexuality would hamper many of these developments and continue to play a pivotal role in support systems as the twentieth century came to a close.

Sexuality in a Time of Deinstitutionalization and Self-Advocacy

As the movement towards deinstitutionalization in the United States picked up steam through the late 1970s and 1980s, individuals identified as ID moved in great numbers into

typical community locations (Lakin & Stancliffe, 2007). Many of the physical institutional variables were eliminated and the landscape of perspectives on ID "shifted to a position based almost exclusively on the protection of individual rights" (Rhodes, 1993, p. 20). During this same period people identified as disabled began to find a public voice and demand access to what had been kept distant (Roos & McCann, 1977; Shapiro, 1994). In brief, the path from containment to community gave rise to the self-determination movement whose central tenets include "each individual [being] empowered to pursue an individually determined satisfying life" (Brown, Gothelf, Guess, & Lehr, 1996, p. 17) and encouragement of "the attitudes and abilities necessary to act as the primary causal agent in one's life and to make choices and decisions regarding one's quality of life, free from undue external influence or interference" (Wehmeyer, 1992, p. 305). Control of choice in behavior, however, is made of more than brick and mortar and "moving individuals out of hospital does not itself empower them to live ordinary lives" (Manthorpe, Walsh, Alaszewski, & Harrison, 1997, p. 72). `As Heshusius (1982) highlighted, individuals labeled as mentally retarded and the professionals in charge of support programs were often at odds regarding the importance of sexuality and there was a significant attitudinal and experiential divide between these groups. Despite the burgeoning support for access, integration, and equality, Hirayama (1979) noted "while it is easier to obtain consensus for the right to education among diverse interest groups such as staff, parents, and community people, it is harder, perhaps nearly impossible, to seek consensus among these groups about the management of sexual behavior" (p. 108).

Schilling and Schinke (1988) summarized the varying public attitudes and practices of this period as composing four distinct groups: (a) strong advocacy; (b) moderated

advocacy; (c) value-free position; and (d) negative position. These stances were not novel but, instead, may be seen as a cumulative representation of all the various historical theories regarding sexuality and ID described in preceding sections. In brief, Schilling and Schinke's composite represented a continuum from robust vocal support and encouragement including proactive education (i.e., strong advocacy) to a "belief that mentally retarded persons should not engage in any sexual conduct" (i.e., negative position; Schilling & Schinke, p. 35). In demonstration of the change from previous decades Schilling and Schinke's examination noted that the negative position "has few outspoken professional adherents, [and thus], its logical underpinnings [were] not articulated in the literature" (p. 35). Nonetheless, Schilling and Schinke noted that during the 1980s, regardless of attitudinal position, there was a growing mindset that individuals with ID were at a higher risk of developing psychosexual pathology (i.e., paraphilia) and resultant commission of sexual offense. The authors contended that much of this belief stemmed from reliance on data from samples of individuals already incarcerated, which, for various reasons, may have resulted in skewed estimates of prevalence. So, while the deinstitutionalization and advocacy movements gained traction in general support systems, "sexual misconduct appear[ed] to account for a large proportion of the socially disapproved behavior that result[ed] in the [continued] removal of mentally retarded persons from society" (Schilling & Schinke, p. 44). Haaven (personal communication, January 14, 2015) confirmed this historical interpretation positing that during the 1980s and early 1990s many individuals remained in controlled institutional settings due to concerns about possible sexual misconduct.

Thus, during this time period one may imagine the position of a person working in direct support. Sexuality had become a topic of interest from all ends of the field.

Educational and advocacy efforts were expanded rapidly but the day-to-day work in many sectors continued to be guided by formal or informal impetuses that appear, at times, to have demanded diametrically opposite responsibilities. One may see or read evidence indicating the role of 'staff' was intoned at an increased rate in this literature. One may not, however, hear what, specifically, these individuals had to say about their experiences navigating the cultural rip tides of procedure, philosophy, and inter or intra personal positions.

  Measuring attitudes and expanding education. Attempting to identify to locus of these conflicts Hall and Sawyer (1978) posited that while legal restrictions played a part in sexual repression, "the day-to-day personal environment in which the retarded individual lives…appears [to be] another avenue by which the sexual freedom of retarded individuals can be jealously guarded" (p. 35). These authors suggested specific policy development and related staff trainings regarding sexuality, rights, and professional duties as a way to address these concerns. Hirayama (1979) further specified, "the problems of sexuality of the retarded, by and large, lie in the attitudes of the people who are around the retarded rather than in the mentally retarded persons themselves" (p. 127). In response to these postulates, investigations regarding sexual attitudes of care providers entered the literature. Hall (1978) and Coleman and Murphy (1980) provided early examples of such work. Hall found that a general seminar on sexuality and rights was effective in changing some restrictive attitudes of support staff working in an institution in the southeastern United States. Coleman and Murphy on the other hand, found generally accepting attitudes of sexual rights paradoxically coupled with restrictive practices stemming from misunderstandings, misinterpretations, and fear of risk or harm.

In short, it was becoming apparent that the experience and actions of people working in direct support positions was a keystone in the sexual lives of individuals receiving services. Consequently, there came a burgeoning interest in development of attitudinal measures. Miller and Leif (1979) developed the *Sex Knowledge and Attitude Test* (SKAT) which had "two major objectives: to measure changes in [staff] knowledge and attitudes after a course program in human sexuality and to demonstrate the deficiencies of medical and nursing education in preparing health professionals to aid patients with sexual problems" (p. 282). Four years later Brantlinger (1983) noted "[u]nfortunately, existing instruments on sexuality [such as the SKAT] do not examine beliefs about handicapped individuals…[and] existing measures of attitudes toward mentally retarded clients fail to examine beliefs about sexuality" (p. 17). In an effort to bridge this divide Brantlinger developed the *Sexuality and the Mentally Retarded Attitude Inventory* (SMRAI). Utilizing this instrument Brantlinger demonstrated significant change in stated attitudes and applied practice toward sexuality in a California institution. Specifically, Brantlinger found that, following an intensive staff training, "masturbation by clients in their beds was no longer reported and punished…[and] a more tolerant attitude toward homosexuals had been adopted" (p. 21).

With the flood of calls for sexual education and rights present in the literature of the 1970s and the burgeoning self-determination movement, one might expect that the 1980s were destined to be a time of widespread and concrete action. Ames (1991) however noted instead, "the nineteen-eighties were the decade of reaction to AIDS and were characterized by a retreat from many of the philosophical and programmatic advances made in the expression of individual choice in lifestyle" (p. 114). In a similar vein, Abramson, Parker, and Weisberg (1988) contended that despite moves toward community-based practice, too-

stringent interpretations of consent and related restrictive policies, perhaps related to public health concerns secondary to AIDS, continued to prevent normalized access to sexual expression for people with ID and often led to continued institutional placement. As they succinctly stated, "[o]bviously, when personal freedom is abridged for one group, human rights in general are correspondingly compromised" (p. 333). Kempton (1991) added to this summary noting that during the 1980s there was a rising awareness of sexual abuse against people with ID. Secondary to the AIDS epidemic and concerns about sexual abuse of people with ID "special education [regarding sexuality] and training to ward off or handle sexual abuse flourished" (Kempton, 1991, p. 106) including pioneering work such as the Circles program (Champagne & Walker-Hirsch, 1983). These advances however, were significantly tempered due to increasing public concern about people with ID committing sexual offenses in the community (Kempton, 1991; Murphy, Coleman, & Abel, 1983) which, in many ways, was similar to the fears expressed in literature of the early and mid 1900s. People with intellectual disability were again seen concurrently as 'at-risk' and 'posing a risk' due to sexuality. This juxtaposition was evident in the emerging formal programs that were applied in institutional and community settings.

Applied practice in and out of the institution. While the attitudinal work described above served as frameworks for designing and measuring the effect of educational programs for providers, programs in the community and institutions were slowly moving forward with addressing issues of applied practice. As Craft and Craft (1981) stated, during this time "much of the literature reflects a mingling of the old fears and anxieties with a desire to channel positively the sexuality which is inherent in every human, whether handicapped or normal" (p. 502). It was in this dynamic of changing service models and seeming disparity

between attitude and practice that the field was challenged to find solutions for particular individuals with ID who demonstrated ostensibly sexual behavior in ways that interfered with a path to full inclusion. Brantlinger (1983) summarized the theory-to-practice logjam of the period stating,

> [t]he key characteristics of modern thinking about sexuality are an emphasis on personal choice and a greater tolerance for a variety of sexual values or styles. Yet the rights of the retarded are inevitably governed, not by law, but by the feelings and behaviors of those who supervise them. If there is a cultural lag among direct contact workers about what sexual behaviors are acceptable or what information appropriate, then the rights concerning the sexual expression of those under their care continue to be denied. (p. 17)

Brantlinger's (1983) intense focus on the role of 'direct support workers' is tempting to accept in its parsimony. The problems this and other authors noted could be squarely laid upon the shoulders of individuals working side by side with individuals in the various programs. If only they would come along then all might be settled. What Brantlinger failed to note, however, was the hierarchical systems within which the direct support worker fulfilled his or her duties. As examined below, discrete, sometimes highly aversive, behavioral interventions, aimed at areas of sexual concern, were created by the licensed professionals and handed over to the direct support workers for application. Whatever a worker's attitude, values, or opinions to start, engaging in such programs was sometimes a matter of retaining employment via obedience to authority. As demonstrated by Milgram (1963) individuals may act in ways diametrically opposed to their stated values (e.g., engaging in actions they genuinely believe are causing severe harm to another person) when directed by a perceived

authority figure. Further as examined by Haney, Banks and Zimbardo (1973), in the now infamous Stanford prison experiment, individuals placed into simulated institutional roles, even for a brief time, may take on markedly different or novel behavioral tendencies. In this experiment one-third of undergraduate volunteers placed in the role of 'guard' "became more aggressive and dehumanizing than would have been expected" (p. 69). It may be, therefore, overly simplistic to lay the 'blame' for restrictive or eliminative practices on the shoulders of any one group in a system.

Sexuality and behaviorism in the institution. As described by Shilling and Schinke (1988) certain incidences of sexual 'misconduct' may not have fallen into the realm of legally defined sexual offense against others but also included concerns about "inappropriate nudity [and] constant masturbation" (Schilling & Schinke, p. 38). Behavioral programming, based on techniques from the applied behavioral analysis literature (Baer, Wolf, & Risley, 1968), was used in some cases to address such matters of sexual concern. Hurley and Sovner (1983) described a series of case studies involving individuals identified as mentally retarded, living in institutions, who exhibited patterns of concerning behavior that was presumed to be sexual in nature. Among the techniques described were: (a) elimination of visits with family secondary to "approaching a woman less than 18 years old" (cost response; p. 13); (b) hand slapping, ignoring, and "having the boy take five to ten milliliters of lemon juice into his mouth each time he masturbated" (aversive conditioning; p. 14); (c) events of disrobing in public followed by re-dressing and "having to assist other residents in improving their appearances by buttoning or zippering up any undone clothing…straightening out any rumpled or twisted clothing, combing their tousled hair, and going to the clothing supply room to retrieve any missing footwear" (restitution; p. 14); (d) public disrobing followed by

"requiring [the individual] to put on three pairs of underpants, one pair of shoes, one pair of shorts, one pair of pants, a bra, a short sleeve blouse, two T-shirts, and a second blouse" (overcorrection; p. 14). In the summer months the authors note that this procedure was adjusted to requiring the individual "to dress and undress herself 10 times in 30 minutes (negative practice); (e) verbal recognition of desired behavior (positive reinforcement); and (f) replacement of "fetishistic masturbation" (p. 15) by an 8 year old boy with relaxation techniques rewarded with candy and praise (in vivo desensitization). The goal in each presented case was complete elimination of the behavior of concern. Hurley and Sovner noted that educational efforts were always attempted first, though often found to be ineffective. Thus, "care should be taken to insure that [behavior programs] are applied in a humane way, and that the most positive techniques are used first" (p. 16). In deference to how certain practices would be accepted by other concerned parties Hurley and Sovner noted, "private masturbation is generally considered to be a normal sexual act in [mentally retarded] persons, but it may offend the staff and conflict with the beliefs of the family. In such situations, treatment plans must take into account the attitudes of staff and family" (p. 13). No guidance was provided as to how this might be done or if this process necessitated deference toward the care providers' position over the position of the individual receiving services. In each case one may imagine the day-to-day experiences of the individuals working in direct support roles who were charged with enactment of these interventions. Likely there were individuals in these positions whose experiences could be found at all ends of the spectrum. Some may have believed restriction and elimination were the proper route from the start and enactment of the above styles of intervention was a match to their position. Others may have held personal positions closer to a model of rights and support.

Nevertheless, these individuals would have been required to complete the intervention no matter how emotionally or literally noxious. Understanding how those responsible for program application experienced their work may have shed light on these dynamics. Unfortunately, their voices in this matter were, again, silent in the literature.

Initial examples of community practice. While behaviorally based interventions such as Hurley and Sovner (1983) were described in relation to institutionally based services, other practitioners were exploring manners of applied sexuality service provision in community settings. In perhaps the earliest example of a community-based effort in North America that specifically focused on support of sexuality for individuals with ID who had crossed social or legal boundaries Murphy, Coleman, and Haynes (1983) described a specialized outpatient treatment program in the southern United States. These authors noted "there is a dearth of literature in this area, and many treatment techniques currently employed require certain cognitive and verbal abilities that may be lacking or limited in the retarded sex offender" (p. 22). In response to this, Murphy et al. (1983) utilized a combination of physiologic tests to assess deviancy (e.g., penile plethysmograph), behavioral treatment to reduce deviant arousal (i.e., electrical aversion, satiation, covert sensitization, and discrimination training), social skills training, and sex education. In general, the techniques described by Murphy et al. (1983) were the standard treatment model for people labeled as sexual offenders in the general population that had been adjusted to accommodate differences in communicative ability and processing perhaps present in individuals then identified as mentally retarded (J. Haaven, personal communication, November 14, 2014). As the authors were focused on off-site, outpatient treatment considerations they did not address the

manners by which these practices were/could have been translated and enacted by residential support staff.

Contemporary with Murphy et al. (1983) and Hurley and Sovner (1983), Griffiths, Hingsburger, and Christian (1985) described the Canadian-based York Behavior Management Services treatment program. While not located in the United States, this project was originated by practitioners who have since occupied a seminal space in the literature and resultant practices in America's system of supports (J. Haaven, personal communication, November 14, 2014). This "community-based program for treating persons with developmental handicaps who display paraphilic behavior" (Griffiths et al., 1985, p. 49) was less focused on discrete, sometimes aversive, behavioral interventions and instead included targets of prevention, individualized treatment planning, and "a *holistic approach* which took into account all of the individual's psychosocial needs…[including] relationships in all areas, not just related to sexuality" (p. 50, emphasis in original). Licensed specializing professionals managed the assessment and focused treatment ends of this program. The daily enactment of this service and coaching of individuals in the program depended upon

> a highly-coordinated network of support persons…including group home staff [and] workshop staff…who [were] responsible for identifying periods of high risk for re-offense, supporting the person at times of risk, providing consistent feedback regarding the development of prosocial behavior…and advocat[ing] for the individual in order to ensure that throughout this process his rights are not jeopardized. (Griffiths et al., 1985, p. 51)

Whereas the experiences and actions of the individuals providing day-to-day support in programs such as that described by Hurley and Sovner (1983) were not mentioned at all,

individuals in similar positions in Griffith et al.'s program were central to assessment, treatment, and mechanisms of direct support.

As examined above, sexuality focused programs of the early 1980s evidenced sometimes drastically different philosophies of intervention or support. Hurley and Sovner (1983) presented a reductive approach (i.e., behavior seen in isolation from environment). As Craft and Craft (1981) contended however, these approaches may stem from the fact that

staff feel themselves under pressure to avoid any hint of scandal…result[ing] in devaluing, if not actual repression of sexuality which means that any such expression is seen in terms of a 'problem' for which a 'solution' must be found, the 'solution' looked for being a cessation of the behavior. (p. 495)

In contrast, Murphy et al. (1983) and Griffiths et al. (1985) positioned the notion of concerning sexual expression by people with ID within the larger fields of sexual offense, psychiatric diagnosis (i.e., paraphilia), and treatment while simultaneously confirming the necessity of rights, and education. Griffiths et al. took this many steps further and underlined the essential input of well-trained support personnel as both program facilitators and clinical contributors. Again, while the concrete actions individuals working in such disparate settings is more or less implied, descriptions of their lived experiences are unaccounted for in the literature. What they thought, how they processed the nature and logic of the work, and the means by which they balanced duties, beliefs, and experience in regards to rights and restriction are all lost to the ether of time.

In summary, as the 1980s came to an end there continued to be significant division between philosophy and practice regarding sexuality and ID. In response, certain authors presented a more vociferous and biting critique concurrent with a reconceptualization of

individuals with ID as more than the sum of measurable behaviors. It was at this juncture that

more robust person-environment models re-emerged in the literature concerning sexuality

and ID. Hingsburger (1990) postulated,

> the reduction of developmentally handicapped people's [sexual] needs to biological
>
> urges is a tempting proposition. By taking sexuality out of the context of human
>
> interaction and human interchange, sex becomes simple behavior. Simple behaviors
>
> can be programmed away. The fires of passion are dealt with by the fire extinguisher
>
> of programming. Behaviors can be programmed; loving need never be discussed. (p.
>
> 12)

The reductionist view according to Hingsburger (1990) was coupled with an underlying fear

of risk he termed "handisexophobia…defined as

ohmygodtheymaygettogetherandengageinsexual-

behaviorandgetpregnantorsickandiwillgetfiredbecausethesupervisorwillpassthebucktome-

ophobia" (p. 13). Again, per Hingsburger, the individuals in direct support roles for people

with ID continued to work at the intersection between sexual rights and restriction.

Due to this divide between evident attitude and continued restrictive practices

Schilling and Schinke (1988) called upon practitioners to further develop theory and related

treatment or support programs. Over the following few years practitioners began to expand

their presence in the literature and demonstrate how the field might finally move past this

ultimate barrier to community-based services.

Further development of specialized programs. In 1990, Haaven, Little, and Petre-

Miller published *Treating Intellectually Disabled Sex Offenders: A Model Residential

Program*. This critical work described an inpatient program at the Oregon State Hospital that

included multimodal assessment, education, and general sex offender treatment - adjusted for individuals with differing cognitive abilities. While this program occurred primarily in a controlled environment, it also included components of community re-integration and support for individuals followed post discharge. Essential in this aspect of the program was the creation and maintenance of social connections and supports utilizing unpaid individuals in the community. Contemporary with Haaven et al. (1990), Griffiths, Quinsey, and Hingsburger (1989) expanded their description of the community-based York Behavior Management Services program first published in 1985. Together, these programs captured the zeitgeist of North American practice moving into the final decade of the twentieth century. In each case, rather than being blanket, one-size-fits-all models of intervention, programs were tailored to the unique presentation and needs of the supported individuals and significantly reliant on well trained DSPs or informal community support persons. This individually modified approach reflected a growing formalized concept of the possibility of multiple etiologies as informants of sexualized challenging behavior in people with ID.

Treatment and Support in the Era of Rights and Risks – The Path to the Present

By the early to mid 1990s, philosophical frameworks, legal statutes, and models of treatment, and support programs were in place that continue to inform conversations and practices regarding sexuality, sexual offense, and ID into our current era (Blasingame et al., 2014). Therefore, at this point in the historical examination it is logical to move from the overall chronological format used above and divide the conversation into discrete themes present in the literature of the past 25 years. Each of the themes (i.e., assessment, treatment, rights, and risk) are individually addressed and traced in the literature of the preceding two and a half decades. Again, while the focus of this proposal concerns aspects of practice in the

United States, much of the literature in this topic stems from international sources. As such, the following examination reflects trends of a wider geography.

Emergence of a formal theory of etiology – counterfeit deviance. During the several decades preceding the 1990s various authors (e.g., Bass, 1964; Craft, 1987; Hall & Sawyer, 1978; Healy, 1915; Johnson, 1973; Menolascino, 1972; Schilling & Schinke, 1988) argued against notions of inherent biological differences as a blanket causative factor in perceived sexual problems for people with ID. Instead, these and other authors picked around the edges of environmental and experience-based theories of etiology regarding sexualized challenging behavior in people with ID. Hingsburger, Griffiths, and Quinsey (1991) formalized these concepts and coined the term 'counterfeit deviance'. Hingsburger et al. (1991) postulated that, in certain cases, instances or patterns of sexualized challenging behavior were not the result of an underlying psychiatric pathology (i.e., paraphilia) but rather, possibly, as the outcome of myriad individual historical variables related to environment, experience, biology, and treatment. As defined in the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5; American Psychiatric Association (APA), 2013) paraphilic disorders involve the presence of an "atypical sexual interest" (p. 343) accompanied by clinically significant personal distress and/or preferences for actions that involve causing another's distress, injury, or death, or involve unwilling or non-consenting partners. Reflecting many of the person-environment arguments from the early 1970s Higsburger et al. (1991) contended that many sexually concerning behaviors, regardless of perceived or actual severity, "arise from living in a system in which appropriate sexual knowledge and relationships are not supported" (p. 51). Specifically, Hingsburger et al. (1991) identified 11 hypotheses that practitioners could consider in design and

implementation of treatment and support programs. These hypotheses included: (a) structural

considerations (i.e., restrictive environments leading to 'sneaky' sexual patterns); (b)

modeling and enactment of observed inappropriate actions of others; (c) use of inappropriate

sexual behavior to gain attention or avoid unwanted interactions or situations; (d) lack of

opportunity for typical relationships leading to attempts to access partners who are unwilling

or outside of cultural norms (e.g., staff or children); (e) poor notions of culturally appropriate

courting routines; (f) general lack of sexual knowledge; (g) inability to achieve orgasm (due

to factors of biology, environment, and/or history of punishment) leading to perpetual

arousal; (h) history of sexual trauma; (i) poor match between socio-sexual mores and

professionals' understanding of individuals sexual expression; (j) discrete medical conditions

that may lead to behavioral patterns wrongly interpreted as sexual; and (k) the effects of

medication on libido. Thus, according to Hingsburger et al. (1991) some of the supposed

diagnosable pathology attributed to ostensibly deviant sexual actions could be seen instead as

a complex algebra involving a plethora of factors both internal and external to a person with

ID. Such etiologic sensitivity was, in many ways, in conflict with the general (non-ID) sex

offender assessment and treatment models. For example, Caparulo (1991) contended that

there was too much emphasis placed on rights and the stigma of labeling when working with

individuals identified as mentally retarded who had a history of sexual boundary concerns.

From his perspective "[i]f the resident *behaves* like a sex offender then he *is* a sex offender"

(p. 313, italics in original) and, regardless of etiology, should be subject to adjudication and

sometimes invasive or aversive interventions such as overcorrection, response cost, and

facial screening. Thus, depending on the philosophies of the evaluator in conjunction with

the practices of the residential setting, individuals working in direct support positions may

have encountered radically different clinical perspectives regarding the sexual behavior of individuals with whom they worked. These perspectives likely translated into specific trainings and related treatment or supervision recommendations to be enacted by the support staff.

Hingsburger, Dalla, and Tough (2010) and Griffiths, Hingsburger, Hoath, and Ioannou (2013) recapitulated and expanded on Hingsburger et al.'s (1991) postulates. Specifically, Griffiths et al. (2013) proposed further hypotheses such as: (a) the expanded role of abuse history; (b) malicious peer pressure; (c) the role of power and control or lack thereof in the lives of people with ID; (d) more specific syndromal considerations (e.g., Smith-Magenis syndrome); and (e) further specified psychiatric considerations (e.g., bipolar disorder). Noting that some in the field may have taken a black and white view of counterfeit deviance (e.g., if there is a lack of education it cannot be a paraphilia) the authors stated,

> it is important to understand that these hypotheses only assist a clinician in determining appropriate treatment regardless of the existence of paraphilia. It [is] also possible, according to 'counterfeit deviance' for an individual with a disability to have a paraphilia that was exacerbated by the presence of another hypothesis (p. 472)…[Further], [t]he hypotheses were not meant to be a diagnostic tool, rather areas of investigation to persuade assessors to ask questions…'think outside the box' and inside the life of a person with a disability and to show caution in making diagnoses based on the offence behavior alone. (p. 478)

Griffiths et al. (2013) noted that, since the original publication, "few researchers have explored the prospect of alternate motivations and causes of deviant sexual behavior" (p. 473). Regardless of etiology or etiologies, people with ID must often navigate a complicated

landscape of legal definitions in order to engage in sexual activity. These issues of consent, competency, and capacity have continued to be examined in the literature of the contemporary period.

Consent, competency, and capacity. During the final decade of the twentieth century the conversation in some parts of the literature regarding sexuality and ID became more focused on issues of consent and capacity. This, in conjunction with development of clinical theories of etiology (above), a rising concern over sexual predation, and use of actuarial measurement tools focused on sexual offense and recidivism (both below), set the stage for examinations of risk and rights that continue to have reverberations in the early decades of the twenty-first century.

Abramson, Parker, and Weisberg (1988) summarized the path of arguments regarding consent for sexual relationships for people with ID. The authors noted,

if mentally retarded individuals cannot satisfy the legal definition of competency (capable of expressing themselves) they are often presumed by caretakers to be unable to provide legal consent to a sexual act. But consent as a legal concept was designed as a protection against sexual coercion, not to deny sexual expression. (p. 328)

Kaeser (1992) more bluntly summarized the situation of the time stating "[s]tatutory regulations would suggest that anytime two people with mental retardation are engaged in a mutual sex expression it is a crime" (p. 41). In a similar vein, Stavis (1991) noted that several legal statutes originating in the 1960s had established constitutional rights to sexuality (specifically procreation, birth control, and abortion), which included people with disabilities. These provisions, per Stavis, did much to move the conversation forward but did little to

address the issues of consent, capacity, and protection from harm. In this legal vacuum Stavis argued,

> facilities and programs which provide care and treatment to people with mental disabilities are often left to their own devices in determining how to respond to their dual obligations – to recognize and promote the rights of their clients and to protect them from harm and exploitation. (p. 132)

While these issues may be considered overly large and perhaps seem beyond the scope of the day to day work of DSPs, Stavis rightfully contended that these concepts trickle down into "obligations of caretakers and treatment professionals who must abide by these laws, or face consequences which can be serious enough to include prosecution for crimes or civil rights violations" (p. 132). Continuing this discussion, Sundram and Stavis (1993) described the "widespread confusion that exists within the service delivery system regarding" (p. 448) rights and risk. Sundram and Stavis acknowledged that there was confusion in applied practice stemming from state laws, professional obligations, and the Constitutionally derived duty to protect. The authors continued on to describe a litany of case law and findings that at times, they contended, appeared to be in direct conflict with one another. Despite this legal morass Sundram and Stavis argued "it is essential that programs that undertake responsibility to provide residential services to individuals with developmental disabilities learn to reconcile the seeming conflicts between these obligations" (p. 450). Kaeser (1992) concurred, stating, "[b]alancing the need to protect people with mental retardation from harm with their inherent right to express their sexuality is a very difficult challenge for the service provider. Unfortunately, it appears as though this balance has continually fallen on the protection from harm side" (p. 36). Of course, while agency policy, practice guidelines, and

trainings may have been developed in response, individuals working as DSPs in these

environments would necessarily be involved in real-time judgment calls and application. As

Craft and Brown (1993) pointed out,

> [w]hether staff members like it or not, whether they acknowledge it or not, they are
>
> enormously powerful in the lives of people with learning disabilities. Powerful in
>
> terms of the physical environments that are provided in day and residential service;
>
> powerful in terms of the social environments they create; powerful in the spoken and
>
> unspoken feedback they give about client aspirations and behaviour; and powerful in
>
> offering models of adult men and women with adult lifestyles making adult choices.
>
> (p. 3)

Furthering this position, Craft and Brown argued

> [t]here *is* a path between over- and under- protection of service users. It will be a
>
> different path for different individuals, but the process of delineating it should be
>
> guided by service principles of good practice rather than be left up to one member of
>
> staff. (p. 12, emphasis in original)

Absent such principles or guidance, "[s]exuality, in effect becomes a source of immense

stress for staff whose personal values and professional skills jostle for place in this

organizational vortex" (Craft & Brown, 1993, p. 17).

Attempting to address the seeming void of principles and guidance Spiecker and

Steutel (2002) contended

> [b]ecause both prudential and moral thinking of people with mental retardation are
>
> more or less deficient, care professionals have to act as their substitutes by doing part
>
> of the thinking for them. This complicated task makes professional caregivers at least

partially responsible for the [sexual] activities of individuals with mental retardation.

(p. 166)

Specifically, Spiecker and Steutel (2002) argued that care professionals working directly with individuals identified as mentally retarded must gain the ability to understand, identify, and apply standards of "additional consent" (p. 168). They elucidated this concept more explicitly stating, "in other words, care professionals not only have the task of thinking and deciding on behalf of people with mental retardation, they also have the task of determining when such additional thinking and deciding is called for" (p. 167). In response to this position, Greenspan (2002) noted the "overtones [in Spiecker and Steutel (2002)] of a now largely discredited past in which the rights, particularly the sexual rights of people with mental retardation were violated in the most egregious of ways" (p. 172). Greenspan agreed with Spiecker and Steutel (2002) regarding the need for "more attention to be paid to the sexuality of people with mental retardation. The emphasis in caregiver training, however, should be on helping them to become better sexual educators rather than better sexual police officers" (p. 178). Steutel and Spiecker (2002) retorted

> we do not deny that such people [i.e., people identified as mentally retarded] have welfare rights in the domain of sexuality. Our firm conviction is that they do have a welfare right that entails the positive duty of care providers to give them the support they need if they want to have sex that is in their best interests. For the very reason that they should be denied a sexual right of self-determination, they have a welfare right that entails the positive duty of caregivers to help them in determining which form of sex would serve those interests. (p. 192)

In essence, while the above reflected a lively intellectual exchange, it also may be seen as representative of many of the overall conversations regarding sexuality and ID that occurred in the decades before and the decade following. Where and how to draw the line in the duties of DSPs remained and remains elusive.

It must be noted that the authors above were addressing general sexual relations and not specifically addressing how the risk and rights formulations may adjust or be affected by the presence of pSCB. When discrete or perceived risk enters the equation, the role of DSPs and related web of decisions becomes ever more tangled. Bogaki, Armstrong, and Steumpfle (2004) noted "[t]he tension between these perspectives may hinge on differing uses of the word 'competency' within the disciplines of law and psychology" (p. 5). These authors described validation of a tool, the *Social Sexual Awareness Scale* (SSAS), intended to bridge these gaps with "consideration for the legal construct of competency and the needs of the courts, [in accord] with emerging guidelines for interdisciplinary cooperation between psychology and law" (p. 6). Unfortunately, there have been no applied studies of this tool since this publication. Further efforts towards formal measurement of risk in regards to pSCB are described in a following section.

As this conversation has moved into the twenty-first century, wider political bodies have entered the discourse. Most prominently, in 2006 the United Nations adopted the Convention on the Rights of Persons with Disabilities (UNCRPD) which "recognize[ed] the importance for persons with disabilities of their individual autonomy and independence, including the freedom to make their own choices" (Preamble Part n; p. 3). While not directly addressed, choices regarding sexual relationships would, ostensibly, be included under this statement. The United States, as of the time of this writing, has not ratified this convention.

Ratification, however is only part of the situation, for although the language of the UNCRPD

appears unequivocal, authors such as Foley (2012) have noted significant stumbling blocks in

application. Per Foley (2012),

> [a] major difficulty in relying on legal instruments such as the [UNCRPD] to bring
>
> about real change…is a wider problem with rights based discourse generally.
>
> Namely, while the law and the legal rights it bequeaths appear to enjoy an objective
>
> ontological status which removes them from the fray of moral and political
>
> controversy, the truth of the matter, and especially where issues of self-determination
>
> for adults [with ID] are concerned, is they do no such thing. As to what such rights
>
> really mean in practice, and consequently how they are to be protected remains a
>
> subject with legal confusion and moral disagreement. (p. 389)

In summary, over the past 25 years discourse in the literature remains little changed

in regards to sexuality, rights, and intellectual disability. There continues to be an intellectual

back and forth about the perceived or actual capacity of persons with ID to consent. No clear

consensus has been reached. Perhaps the biggest 'stick in the spokes' in the move from

philosophy to practice has been the underlying and concurrent focus on risk in regard to

sexuality and ID. While theorists themselves could not come to consensus in these matters,

those working as DSPs could not sit idly by and speculate. Instead, these men and women

continued to arrive at work every day where ink on pages had to be translated into action or

inaction regarding risk and rights. Decisions regarding sexuality are complicated enough

when occurring in a calm emotional environment and "it is in extending such rights to others,

and certainly the more severely disabled, that many begin to have doubts and for whom

greater anxieties are experienced" (Ames, 1991, p. 115). Unfortunately, during this same period, the general atmosphere regarding sexuality and ID was anything but calm.

Risk as a formal and measurable concept in sexuality and ID. The above discussions of etiology, rights, and consent were concurrent with a renewal of an attitude similar to the menace of the feebleminded era. Spurred by certain high profile cases of egregious sexual assault by individuals identified as mentally retarded (e.g., Gary Minnix in Seattle; Earl Shriner in Tacoma) the 1990s witnessed a wave of public outcry, moral panic, and a resultant explosion of sexually violent predator laws aimed at prevention of such events (Jenkins, 1998; Vess, 2011).

In general, during this time, America was also encountering a rise of interest in the concept of risk. Beck (1992) coined the term 'risk society' to describe the manner by which nearly every topic of public interest had become framed in terms of what bad may occur and how might we prevent it. The area of sexual offense and ID was fertile ground for the language and analysis of risk and there were increased efforts to provide concrete methods of measurement regarding issues without clear definitional boundaries (Thomson & Brown, 1997). The literature and research in this domain is wide ranging and includes many avenues of specialty. In keeping with the focus of my research I focus on the aspects of this domain that have relevance for the potential role of DSPs working with individuals with ID who reside in community settings.

As noted by Tully, Chou, and Browne (2013) "prior to the development of more formal risk assessment tools, professionals relied on unstructured clinical judgment to assess the risk posed by sex offenders. However research began to reveal that the accuracy of unstructured clinical judgment was little better than chance" (p. 288). In order to address

these burgeoning questions, an increased attention was paid to the development of actuarial

tools to measure risk of sexual offense and related possibility of recidivism. According to

Blasingame et al. (2014)

> [t]here is good reason to propose that these tools have improved our ability to assess
> and manage risk and that their use may also help explain the significant decreases in
> observed rates of sexual reoffending…However, the *majority* of the most popular
> tools [used in sexual offense risk assessment] were developed for the *majority* of
> clients…This means that assessment, treatment, and management professionals
> working with other groups such as…individuals with…intellectual disabilities, have
> been at something of a disadvantage. (p. 10, italics in original)

Lindsay, Elliot, and Astell (2004) began to address this imbalance and develop the

concept of static and dynamic risk factors related to pSCB for people with ID. As stated by

Lindsay et al. (2004), "[s]tatic predictors are aspects of an offender's history, which cannot

change, e.g., number of prior offenses or age at first arrest" (pp. 299-300). Dynamic factors

were described potentially encompassing 35 variables ranging from treatment history to

presence of mental illness. Salient to the present examination, Lindsay et al. included

"allowances made by staff [and] staff complacency" (p. 301) as potential dynamic factors

derived from their clinical experience. While the concept of static and dynamic risk factors

had been developed with individuals without assessed presence of ID, findings of Lindsay et

al. (2004) suggested that, while there was overlap, certain of the risk factors identified as

pertinent in people without ID were not predictive in people with ID. Stemming from the

work of Hanson and Harris (2001) regarding dynamic risk conceptualizations, Boer, Tough,

and Haaven (2004) expanded on Lindsay et al.'s (2004) postulates and proposed that

dynamic factors be further divided into "stable dynamic items [and] acute dynamic items" (p. 279). Per Boer et al. (2004), stable dynamic items (i.e., those that are less prone to change over time) included but were not limited to: (a) staff attitude toward individuals with ID and a history of pSCB; (b) individual-specific knowledge of staff members; and (c) consistency of supervision provided by staff. Acute dynamic items (i.e., those that are more inclined to change over time) included but were not limited to: (a) introduction of new staff members; and (b) staff ability to adjust to an individual's changing support needs. Over the following decade this conceptualization evolved into creation of the *Assessment of Risk and Manageability of Individuals with Developmental and Intellectual Limitations who Offend Sexually* (ARMIDILO-S; Boer, et al., 2013). The ARMIDILO-S has been noted as one of, if not the only, tool that is both designed specifically for individuals with ID and includes significant consideration of dynamic factors (Wheeler, Clare, & Holland, 2013). In addition, preliminary evidence has suggested that the ARMIDILO-S exhibits promising predictive validity in regards to recidivism (Blacker, Beech, Wilcox, & Boer, 2011; Lofthouse et al., 2013) and appears to have clinical utility for community-based services for people with ID (Cookman, 2012). As best application of the ARMIDILO-S depends on the longitudinal participation of DSPs in the assessment process, it has the added benefits of: (a) providing a space for their input regarding suggestions for changes in support; (b) serving as an educational process regarding the concept of risk, rights, and related factors; and (c) results in recommendations for adjustments to support or behavioral programs that may be monitored over time (J. Haaven, personal communication, February 18, 2015). In applied practice these recommendations often address both ways of better managing areas of risk while simultaneously confronting areas where an individual's rights may have been needlessly

compromised due to providers' inaccurate understanding of risk or over-investment in concerns of liability (J. Haaven, personal communication, February 18, 2015). Via inclusion of specific focus on the role of DSPs, these methods of assessment may be seen as a formal, blossoming, composite of developments and theories whose seeds were planted during the 1970s and 1980s.

In summary, the past two decades has seen marked development in the conceptualization of risk in regards to sexuality in people with ID. The field has moved from utilizing tools, normed on people without ID, that focused only on unchangeable historical factors to creation of tools specific for people with ID that address the changing nature of services in overall clinical formulation and design of support plans. Tailored assessment tools such as the ARMIDILO-S have captured the zeitgeist of the risk and rights movements present in the preceding decades while concurrently providing focus on the essential role of DSPs in assessment and planning. Even when combined, however, theories of function, delineation of competency, and methods of tailored assessment constitute an incomplete system of support. Without treatment or support programs that *absorb* and *enact* the above areas, the changes remain on paper rather than in practice. Fortunately, as examined below, the late twentieth and early twenty-first centuries have witnessed development in applied practice as well.

Contemporary examples of practice and training. To return to a topic addressed above, as outlined by Hingsburger et al. (1991) and again by Griffiths et al. (2013), the theory of 'counterfeit deviance' postulated that, in certain instances, individuals with ID may present with behavioral patterns or preferences which appear to be sexually motivated or perhaps deviant when, in fact, the etiology and/or function of the behavior may be traced to

factors including, but not limited to, the individual's (mis)treatment history, medical conditions, effects of medication, or errors due to lack of understanding or education. Before labeling an individual with a psychiatric condition or acting as if the behavior is indeed sexually motivated practitioners are cautioned to rule-out or eliminate other explanations less driven by assumptions of pathology. Determination of etiology or function may lead to more focused, individual-specific, options for treatment or intervention. Rather than have one-size fits all approach to intervention (i.e., assumed sexual 'offense' always leads to specific sex offender treatment) practitioners applying this model must be able to access and refer to a variety of possible courses for support. To this end, educational endeavors regarding sexuality and sexual expression may represent a cornerstone of possible intervention and support options. Over the past 25 years there has been ongoing development of sexuality education programs at many levels of the service system. An overview of these endeavors is presented below. A detailed review of the research regarding the role of DSPs in sexuality and ID may be found in Chapter Two.

Sex education and ID services. Lack of access to sexuality education and related resources has been suggested as a significant barrier to individuals with ID being able or 'allowed' to engage in sexual relationships (Lafferty, McConkey, & Simpson, 2012; Matich-Maroney, Boyle, & Crocker, 2007) and as a potential factor in expression of pSCB (Hingsburger et al., 1991; Griffiths et al., 2013). In certain geographic areas such as China (Yau, Ng, Lau, Chan, & Chan, 2009) and Turkey (Isler, Beytut, Tas, & Conk, 2009) education regarding sexuality and ID have been found to be absent. When educational programs are offered, the quality of these endeavors may be variant and lack in certain, potentially key, aspects. For example, educational programs directed towards individuals

with ID in the Netherlands have been found to lack in specified outcome measures and related evaluation while also containing shallow use of theory and lack of participant input leading to unclear efficacy (Schaffsma, Stoffelen, Kok, & Curfs, 2013). Similar findings have been reported in the United States (Blanchett & Wolfe, 2002) and Canada (Gougeon, 2009). Access to sexuality education in American public schools may vary in relation to perceived severity of ID (Barnard-Brak, Schmidt, Chesnut, Wei, & Richman, 2014). Matich-Maroney et al. (2007) referred to this pattern of incomplete or inequitable educational practices stating, "[d]espite the tremendous progress of the last 35 years, the sexuality-related needs of this population have continued to suffer from a 'benign' neglect within the intellectual disabilities system" (p. 346). Attempting to address this deficit Matich-Maroney et al. described "a broad-based framework for conceptualizing the range of sexuality-related issues/needs of [people with ID] and their relationship to service provision…[referred to as the] Psychosexual Assessment and Treatment Continuum (PSAT)" (p. 316). In the PSAT conceptual model the authors addressed issues of policy, assessment, and intervention across domains of psychoeducation, interpersonal relationships, trauma, psychosexual disorder, and forensic issues. Unfortunately, following this publication no further data has been presented in the literature regarding this program. In a similar vein, Walker-Hirsch (2007) presented a series of works related to aspects of sexuality education and support for people with ID. Topics addressed in Walker-Hirsch included cultural considerations, parent perspectives, managing risks and rights, as well as gay, lesbian, bisexual, and transgender issues. Contributions such as Matich-Maroney (2007) and Walker-Hirsch (2007) exemplify the coalescence of the various postulates and programs regarding sexuality and ID that began in

earnest in the 1970s. While the movement may have been slow, these works suggest that it has been, at least, steady.

 As important as education is presumed to be, there has been evidence that suggests an individual's exposure to sexuality education and/or level of sexual knowledge may not be related to risk of sexual offense or re-offense by persons with ID (Lockhart, Guerin, Shanahan, & Coyle, 2010; Talbot & Langdon, 2006). Thus, the educational experiences provided to DSPs may aid in further development increasingly comprehensive systems of supports. Corollary to these patterns of sexual education for people with ID examined above, the literature reflects limited movement in the education of DSPs regarding sexuality and related human rights for people with ID. According to McConkey and Ryan (2001) 47% of surveyed "residential care staff" (p. 85) working in community settings in for people with ID in Northern Ireland reported encountering concerning, possibly sexual, behavioral events. Only 22% of these same respondents reported having received any training regarding sexuality and ID. This pattern may not be uncommon as, per Taylor, Keddie, and Lee (2003), "[w]hilst, the value of training for staff working with sexually aggressive clients, in order to increase knowledge and confidence and reduce burnout, has been discussed by several commentators, this need is often not given enough attention or priority" (p. 204) in applied practice or research. Exposure to educational curriculum regarding sexuality and ID may result in increased knowledge base and attitudinal change for DSPs (Ryan & McConkey, 2000; Sumarah, Maksym, & Goudge, 1988) but, similar to the above, effect on objective behavioral adjustment is less clear (Ryan & McConkey, 2000).

 A careful process of ruling-out alternate explanations may lead to fewer individuals being needlessly exposed to intrusive or 'sex offender' specific interventions and, instead,

provided education or environmental support tailored to specific needs. There are, however, individuals with ID who, after careful application of a grounded clinical judgment process (c.f. Schalock & Luckasson, 2013) may be accurately identified as having a paraphilic disorder. The presence of a paraphilic disorder may contribute to behavioral patterns that are contrary to current legal or social boundaries. Due to factors of competency many of these individuals may never have faced charges or adjudication within criminal or civil proceedings (Blasingame et al., 2014). Even when the legal process was seen to its end, treatment programs often consisted of protocols designed for individuals without ID (Blasingame et al., 2014). Over the past 15-20 years the field has attempted to address these disparities via specialized intervention and support programs.

Treatment protocols. In brief, there are four major, contemporary trends in the treatment of individuals with ID who concurrently fulfill criteria for paraphilic disorders. Per Blasingame et al. (2014) these trends are the: (a) Self Regulation/Pathways Model (Ward & Hudson, 1998); (b) Good Lives Model (Yates, Prescott, & Ward, 2010); (c) Old Me-New Me Model (Haaven, 2006; Haaven & Coleman, 2000); and (d) Risk-Needs-Responsivity Model (Andrews & Bonta, 2010). Summarizing the best practice aspects of these varied yet related treatment models Blasingame et al. (2014) identified several core commonalities including but not limited to "intervene[ing] in offending patterns,… address[ing] environmental influences and concerns,…increas[ing] basic skills for community engagement,…[and] develop[ing] wrap-around risk management supports within the community" (p. 16). While licensed practitioners may conduct the scheduled, formal, treatment or educational sessions, DSPs working in the community must understand and enact the recommended observation, support or intervention protocols in real time. The role of DSPs within these aspects is

directly related to "the impact of supervisory factors that may function to increase or reduce risk for sexual re-offense" (Blasingame et al., 2014, p. 21). Treatment protocols, regardless of how well grounded or empirically supported, comprise just one constituent in comprehensive systems of supports. How such protocols may fit within the overall layers of a system is the next link in the chain.

   Examples of community practice. As deinstitutionalization expanded, community based programs were challenged not just to treat but to provide daily residential support to individuals with ID and a documented history of sexual offense or concerning pSCB. Per McGrath, Cumming, and Burchard (2003) the number of specialized residential programs in the United States more than doubled (from 186 to 399) between 1986 and 2002 with approximately 85% of these programs being based in community settings (i.e., non-institutional). McGrath, Livingston, and Falk (2007) provided the only program description of such a community based residential service in the United States. Specifically, McGrath et al. (2007) reported on a statewide program in Vermont, which, from 1993 to 2004, provided varied levels of support or supervision to more than 100 individuals with "mental retardation" (p. 392; criteria from the fourth edition of the DSM (APA, 2000)) and a history of sexual offense. McGrath et al. (2007) defined sexual offense as "a sexually abusive act that would constitute a criminal sexual offense in Vermont" (p. 392) whether or not the individual had been charged, convicted, or incarcerated. These offenses ranged in topography from non-contact events (e.g., exhibitionism, public masturbation) to hands-on, sometimes violent events directed at others which may have involved children, use of deadly weapons, or resulting in physical harm. In the study sample (n=103) 64 individuals were described as receiving 24-hour supervision. An additional 27 were described as receiving "some

supervision, less than 24 hours" (p. 395). Per McGrath et al. (2007) "residential

providers…taught social, daily living, community participation, and sexual risk management

skills" (p. 392). Recidivism (i.e "known to have committed a sexual misbehavior [while in

the residential program] that, if prosecuted in Vermont, would constitute a criminal offense"

(p. 393) rates in this sample were reported as 10.7% (n=11) in the 11-year follow up period.

This rate, found to be in line with rates of recidivism from the general population, suggested

"that a jurisdiction can manage a wide range of sex offenders with intellectual disabilities in

community settings in a relatively safe, cost-effective, and humane manner" (p. 394). While

the numbers tell one side of the story, the experiences of the DSPs providing this range of

supports were not examined.

Cambridge (2012) described a program for an individual, diagnosed with "mild

learning disability" (p. 259) and autism, residing in a community based specialized service in

the United Kingdom (UK). While not representative of an American program, this work is

included due to Cambridge's focus on the role of DSPs (referred to as 'staff') in the

enactment and sustainability of support protocols. The individual in the study had a

documented and clinically assessed "sexual fetish" (p. 259; commonly used interchangeably

with the term paraphilia) "involving the use of nappies [i.e., diapers] for masturbation and the

collection of various baby paraphernalia" (p. 260). Rather than taking a reactive or restrictive

response to this pattern the author described the intervention as guided by the following

principles:

    1. Advocate on his behalf for his right to the safe sexual expression of his fetish;

    2. Place his sexual rights at the forefront of the work and the outcomes sought;

3. Be honest and open to him and other relevant parties about the issues that surfaced and resolution strategies;

4. Be nonjudgmental about his sexual fetish;

5. Seek to provide good and informed information and advice;

6. Seek to resolve conflict and strive to reach the least restrictive outcome for him; and

7. Seek to skill and empower the manager and staff of his service to recognise and respond to his rights and to work positively and constructively with him. (pp. 260-261)

Cambridge further specified that, in order to have a "lasting and positive impact on [the individual's] life,…[it was essential to] work with his support staff in relation to the consistency of the day-to-day support relating to his sexual fetish" (p. 261). Acknowledging the role of culture and context Cambridge cautioned,

not everyone charged with supporting people with learning disabilities is likely to agree with the positive support of sexual fetish because of their personal values or faith beliefs. Consequently, people who do not adhere to a rights-based approach to supporting the sexual fetish of men with learning disabilities should not be expected to provide such support directly…[Therefore], when conducting such work, it is also important to assess the capacity of the management and support system to progress such interventions and sustain positive change. This may require some direct work with the staff group and with developing-related (sic) policies, procedures, and guidelines within the service to promote consistent responses and agreed courses of action. (p. 263)

Noting the work of Brown (2011) Cambridge added "[i]t will also be important to acknowledge the considerable role emotions play in decision-making in such support contexts" (p. 263). From this brief but important aside one may intone that, in order to create sustainable systems of supports around sexuality and ID, the field must attempt to access and understand the lived experience of DSPs secondary to their in vivo decisions at the crux of risk and rights.

Summary of the Historical Perspective – What is Missing?

The above exploration of the role of sexuality in the development of services for people with ID may be boiled down to two basic concepts – rights and risk. From the design of large scale systems of supports, to conversations around the interdisciplinary table, the interpretations of these concepts often drive policy, practice, and directly affect the individuals, labeled as ID, who receive supports. As evidenced above, risk and rights are by no means static concepts with definitions of clear consensus. Instead, they are moving targets – pushed and pulled by the temporal tides of nomenclature, politics, law, geography, religion, and individual experience. Many words (often in direct conflict) have been written regarding 'what to do', 'how to do it', and 'why this makes sense'. Each author in this discourse was presumably acting from a position of 'best interests' as they conceptualized at the time of publication. While theorists and practitioners have had a clear voice in these conversations, the direct and personal perspective of individuals working in day-to-day direct support roles has, with few exceptions (e.g., Ioannou et al., 2014), been underrepresented in the literature. In essence, what should be a conversation between multiple parties (theorists, licensed practitioners, DSPs, and people with ID) has consistently been one-sided. This is problematic, as, in order for change to take root and branch, 'big thinking' must logically be

followed by a series of 'small actions'. For the most part, those doing the thinking and writing about 'what to do' may be functionally divorced from the *in vivo* enactment of policy at the individual level. All of the presumed great ideas in theory must fit logically within the overwhelming scope of duties and roles fulfilled by individuals working as DSPs (Chapter 2). Without such fit, sustainable development of systems may become akin to using a hammer to place random pieces in a jigsaw puzzle – they will fit if you force, but the overall picture is not what it could be. According to Fullan (2001), one of the primary elements in creating sustainable change is the process of acknowledging, accessing, and sharing the "tacit knowledge" (p. 80) of individuals involved at all levels of a system. This implies that the organization must frame the giving and receiving of knowledge as a responsibility and must "reinforce such sharing through incentives and opportunities to engage in it" (Fullan, p. 86). The 'organization' of research in ID has a responsibility to not just share knowledge of the 'credentialed experts' but to capture the expertise of the individuals working as DSPs. By exploring the lived experience of individuals responsible for turning thoughts into actions and policies into practice we may gain a deeper understanding of what works, what does not, and why. The resultant development of theory derived inductively from these data may allow for a dovetailing of philosophy, people, and practice with fewer noticeable seams and reduced need for sometimes forceful tools.

Underlying Assumptions

From my personal and professional history as well as academic studies I have developed a particular take on the interactions between the spheres of research, systems of supports for people with ID, sexuality, rights, and risk. In the sections below I aim to briefly elucidate my personal positions.

Researcher Positionality and Theoretical Framework

What follows is a relatively short statement of my general positionality and related theoretical framework. A more detailed and expanded examination of my personal history from an autoethnographic stance is presented in Chapter Three.

In the tradition of Lincoln and Guba (1985) I consider myself a naturalist. While I value the contribution of studies that outline statistically significant findings for the majority, and use ostensibly objectivist measures in parts of my professional practice (e.g., the *Diagnostic and Statistical Manual of Mental Disorders*, survey tools, symptom checklists), I am most interested in the stories that reside outside of the middle deviations and at the tails of the distribution - the individual 'subjects' whose results were 'insignificant'. I believe that shedding light and spilling ink on these particular instances may help us all move the curve forward. I am also a mental health counselor with extensive experience conducting a range of interview types, in an array of contexts, with a multitude of individuals, over the course of nearly 20 years. As such, I have utilized many of the methods described below. Through this practice I have found that when people tell stories, they tell us less about particular events than they do about their particular self – the ways they see and interpret the unceasing tides of change in which we all swim. No two people I have interviewed, no matter the measure, have answered questions in the same fashion. I have often found the use of categories in human sciences to be akin to hammering square pegs in round holes – it will fit if you hit it hard enough (and cut off the corners). I would prefer to simply describe the peg where it is and let it hammer its own image into me. In addition, I tend to lean towards a theoretical position of social construction (e.g., Berger & Luckman, 1966) as continually informed by the presence of power (e.g., Foucault, 1982). In brief, I believe the realities we agree upon

are ever changing and the product of ongoing micro and macro interactions, and negotiated definitions, in conjunction with the ongoing presence of historical negotiations of 'permission' to interact and define.

In short, I tend to ask questions of the world from a naturalist perspective (Lincoln & Guba, 1985). I believe there are multiple truths rather than one unitary truth behind any query. I have an extensive history of work in the fields of mental health counseling and behavioral supports for people with ID. I have worked as a research assistant in several projects in these domains. I currently oversee the statewide system of behavior support consultation in New Mexico. I have 15 years of University level academic training in these fields. Through these experiences I have developed certain assumptions and biases that may affect how I ask questions, seek answers, and analyze or interpret data.

My biases and strongly held beliefs

Collectively, my personal and professional experiences introduced above (and expanded in Chapter Four) have led to some particular positions, biases, and beliefs that are relevant to this study. As subjectivity and researcher bias are considered inescapable elements in naturalist research it is essential to elucidate these aspects of what I brought to the project. Rather than delving deeply in to the statements below, I let them stand on their own. I return to these biases and positions in later analysis sections of this project.

Strongly held beliefs.

- Dignity of risk and human rights are a constant refrain in many aspects of support for people with ID in our current system of support;

- Issues of sexuality are regularly framed in these terms but few professionals seem to understand how to consistently enact support from these frameworks;

- When confronting issues of sexuality and ID, DSPs are at the crux of the risk and rights process;

- There are DSPs who do an exemplary job of balancing the issues of risk and rights regarding sexuality on an individualized and daily basis;

- There are also DSPs who struggle with how to support rather than control or manage the sexual expression of people with ID;

- This may often be due to the competing voices around the table – the demand that nothing go wrong coupled with the mandate to not violate rights;

- We are still trying to integrate and sometimes eliminate attitudes and practices that can be traced to all portions of the historical conversation regarding sexuality and ID;

- The default position in our current system of support is to restrict, limit, contain, and monitor.

Areas of potential bias related to this specific study. Along with the above areas of strongly held beliefs that are related to my general experience of working in the field of supports for people with intellectual disability, my efforts at data collection and analysis may also be influenced by certain specific relationships and professional endeavors. These biases could potentially serve as 'blinders' and directly or indirectly affect the manners by which I see or fail to see patterns in the data. Areas of potentially influencing bias include but may not be limited to (a) my history of work as a Behavior Support Consultant in the New Mexico systems of supports; (b) my historical and ongoing involvement in the Preliminary Risk Screening and Consultation (PRSC) program managed by the New Mexico Department of Health; (c) my relationship with the agency used as the study site; and (d) inherent power

differentials secondary to the preceding areas. I consider each of these in greater detail below.

History of work as a Behavior Support Consultant. From 2001-2012 I worked as a Behavior Support Consultant (BSC) in the Developmental Disabilities Waiver (DDW) program in New Mexico. In this position I wrote approximately 100 behavior support plans related to DDW services for people with ID. Many of these plans included specific consideration of sexual or possibly sexual behavioral concerns and related educational, preventative, and reactive strategies. As part of this work I trained hundreds of DSPs in the philosophies of positive behavior support as well as the specific plan strategies. In short, I was, and continue to be highly invested in this area of support for people with ID. I am strongly committed to the underlying philosophies and aims of positive behavior support and specifically dedicated to the human rights aspects of sexuality for people with ID. I believe I had a significant effect on shaping the practices of DSPs in these regards. Due to this history of work it is possible that I may hear what I want to hear in the responses of participants and misinterpret, ignore, or undervalue statements that may not align with my values. In short, I am at risk of theoretical bias and theory confirmation. As outlined in Chapter 4 I engaged certain methods (i.e., constant comparison, analytic memo writing, critical friend, peer debrief, member checking, external auditors) that aided in recognizing and attenuating this dynamic.

Involvement in systems development. As I outline in Chapter 3, over the past 15 years New Mexico has created systems of supports for people with ID unique in the United States. One specific portion of this system is the Preliminary Risk Screening and Consultation (PRSC) service (see Chapter 3 for a thorough description of the PRSC). In

brief, the PRSC service is concerned with provision of technical or clinical assistance for interdisciplinary teams who support people with ID and pSCB. This includes a specific focus on matters of risk, rights, and daily support practices. I have been indirectly and directly involved in the creation, ongoing development, and maintenance of this service. Specifically, I served as a Behavior Support Consultant (BSC; see above paragraph) on many teams that utilized the early versions of PRSC. I provided feedback to the Department of Health employees and contractors related to my experience in this service. In 2012 I began work as the Statewide Clinical Director of the Bureau of Behavior Support (BBS). BBS oversees and coordinates the PRSC service. Our duties include: (a) management of the consultant contract; (b) presence at and contribution in nearly every PRSC session; (c) review of all resultant consultation notes; (d) follow-up with interdisciplinary teams regarding recommended adjustments in service and support for the person with ID; (e) maintenance of the PRSC database; and (f) ongoing efforts toward improving this system. I have presented on the PRSC service at local and national conferences as well as a national webinar. Clearly, I am highly invested in this portion of our supports system. I am dedicated to the underlying philosophies and applied practices embedded in the PRSC service. As DSPs are often key participants in the PRSC service I have interacted with and provided guidance to many DSPs working with people with ID and pSCB. I believe we have effectively changed practices of daily support in several cases. Again, it is apparent that I am highly invested and thus there is a potential for this investment to create bias in data collection and/or analysis. As outlined above, I utilized several methods common to qualitative research in an effort to attenuate or recognize the potential effect of this bias.

Relationship with the site of research. Albuquerque is often referred to as a 'big, small-town'. While there is a significant population in the Albuquerque metro area, it frequently has the feel of a small town in that one is nearly constantly running into familiar people. This quality is further enhanced when considering the community of providers supporting people with ID in our waiver system. In addition to this general familiarity, my work history and current professional position, has, and continues to, involve direct work with the agency wherein this study was conducted. This is true of all agencies in the state that provide residential supports to people with ID within the DDW system. As the study site agency has a specialty of providing support to people with ID and pSCB, I have had extensive clinical contact with many of the direct service employees at the agency. I have worked as a BSC and from my position as BBS Clinical Director with certain DSPs at this agency for the past 14 years. Due to the agency specialty, many of the individuals to whom they provide supports have been participants in the PRSC process as introduced above. I have provided individual specific trainings regarding behavior support as well as trainings regarding risk and rights to this agency on several occasions. In short, I feel as if I both understand and have potentially influenced the culture of this agency. Again, due to my tenure in this system, this is true of many agencies in the state and is not particular to the study site. Undoubtedly the above had the potential for introducing several areas of bias or blinders into the study. Again, the processes of analytic memo writing, member checking, critical friend, and external auditors were used to aid in the recognition and mitigation of these biases.

Inherent power differential. During the years I worked as a BSC I often referred to 'The State'. This term was used to describe both the larger Department of Health as a whole

as well as individual state employees who would frequently become involved in oversight of particular situations. 'The State' was never uttered in what might be considered a happy or eager tone. Instead, it was often invoked with a sense of dread, anxiety, or distaste. State involvement was often seen as interference. Indeed, at times, it was. The State has power. The State can tell you that your practices are wrong. The State can impose penalties or shut down agencies. I am now The State. While we have worked diligently (e.g., a primary focus on support and usable education for providers of services) over the past several years to correct some of the misconceptions or poorly enacted practices, the stereotype of The State remains. Despite my beliefs that we have effected meaningful change through our efforts I will be in a position of clearly uneven power differentials within this research project. Participants working as DSPs have very little power within our current systems. For better or worse, I currently have a great deal of influence in our current systems of supports. While I may explain clearly and repeatedly that my work within the research project is unrelated to my work with the Department of Health, 'The State' remains a key master status and inherently affects the relationship. Due to this, individuals may be wary of participation or participants may intentionally or inadvertently adjust their responses according to what they believe I want to hear or what they 'should' say. Power differences may be inherent in any interview process. There is the one who asks questions and the one who answers; the one who investigates and the one who is investigated. In the current study these dynamics may be more dramatic. In order to address this differential I aimed to exercise care and diligence in my framing of the project and the embedded aim to accurately represent the voices of people working as DSPs. Secondly, I included specific questions in the interviews intended to help illuminate or provide space for participants to express thoughts regarding this power

differential. Lastly, in analysis sections, I examined the role of power as it relates to the topics of ID, pSCB, and this specific research project.

Theoretical Positioning – Foucault

In many ways the process of conducting research is akin to the practice of photography. The various tools engaged during investigation may be compared to the hardware used and artistic choices engaged when travelling from field to frame. Specifically, while paradigm may influence choice of camera and lens, topical interest influences what subjects we take pictures of, and application of methods relates to how we manipulate the controls. Theory determines scope of focus as well as the filter a researcher chooses to place over the lens – only certain wavelengths are allowed to pass to the developed image. Without careful attention to each, we may find ourselves looking at our research 'photographs' with little recognition of the process we took to get there.

Below is an examination of a theory, through which I filtered collected data. The decision to use Foucauldian perspectives stemmed from my own experiences, preferences, and bias. While these factors influence my decision, I propose that analyses stemming from a Foucauldian perspective are in concert for the aims of this project. As this project was inductive in nature and utilized a grounded theory approach (Chapter 4), novel concepts emerged from the data.

Foucault

Foucault (1975/1995) postulated, "[p]ower produces…reality" (p. 194). Via a technique of a deep historical archaeology, Foucault (1982) examined the methods by which power has become "rooted in the system of social networks" (p. 793). This system then enacts power at many levels with tendrils that creep into the permissions given and actions

taken by individuals. The particular constructions that become rooted, branch forth, and lay seed may be determined by whose voice has the inherited/imbibed power of which Foucault spoke. In relation to the current topic, it is the power of the academic investigator that creates the reality of projects and embedded interpretations. To extend Foucault (1982), the "human beings [who participate in research] are made subjects" (p. 777) as their responses are sieved through the mesh of power to become 'results'. Research findings or conclusions, due to the institutional system of production, are provided the impetus of inherited influence to become essential parts of the human narrative on what is considered 'correct', 'true', or in essence, *real.*

If it is true that "[p]ower produces…reality" (Foucault, 1975/1995, p. 194) then we are left with the question of what forces produce power and, specifically to the topic of this research, how said power may influence definitions of and efforts to mitigate or attempt to control risk in individuals as well as larger groups. Nettleton (1997) stated, "through the mechanisms of government, the self is fundamentally related to power" (p. 212). While the common understanding of 'government' as a state or nationwide structure of organized political and regulatory offices certainly fits within this definition, Nettleton was speaking more to the larger Foucauldian concepts of governmentality (Foucault, 1978) and the 'subject' (Foucault, 1982). In the Foucauldian lens, the notion of power laid not just in the towering institutional edifices of official rulers and systematized hierarchies - though these certainly caught his attention (Foucault 1975/1995). Power, in Foucault's (1982) concept, was also a historically embedded, entrenched presence throughout all human interactions

> "which categorize the individual, marks him by his own individuality, attaches him to
>
> his own identity, imposes a law of truth on him which he must recognize and which

others have to recognize in him. It is a form of power which makes individuals

subjects" (p. 781).

In this manner the often-elusive presence of power may be seen as the ocean in which we all

swim. Much like the old fish who comments to the young fish, "Water sure is cold today,"

and the young fish responds, "What is water?" - the tidal pull of power surrounds us all, and

yet remains easily unrecognized, invisible.

Language and definition lay at the heart of Foucault's archaeology of human power

dynamics. Those who define, decide. Once decided, the mechanism of power and control

may then be enacted upon the individual whose "soul is the effect and instrument of a

political anatomy" (Foucault, 1975/1995 p. 30). This interplay of semiotics, decision, and

control is evident throughout any conversation regarding human risk. Indeed, from a

Foucauldian perspective, the explosion of assessment and management of human risk

processes may be seen as another step in "the progressive objectification and the ever more

subtle partitioning of individual behavior" (Foucault, 1975/1995, p. 173). Risky choices may

lead to harm, but "the definition of…harm is, of course, open to interpretation" (Owen &

Griffiths, 2009, p. 16-17). Power becomes relevant when considering who it is that is

permitted to interpret, to define, to decide. From a Foucauldian standpoint, the locations of

these permissions are the result of a tsunami pull of historical events surrounded by corollary

adjustments in language and values. This "technology of power" (Foucault, 1975/1995, p.

30), which is "rooted deep in the social nexus" (Foucault, 1982, p. 791), is an inescapable

factor in the discussion and analysis of risk and rights.

In the context of this study, a perspective informed by the works of Foucault

regarding the Panopticon (Foucault, 1976/1990), the creation of 'the subject' in human

sciences (Foucault, 1963/1994), the role of socio-historical loci of power (Foucault, 1982), and sexuality (Foucault, 1976/1990) was engaged to examine participant statements of their experiences. The interplay of codified or unofficial rules in areas of the system which determine DSP duties and roles, the relationship between a DSP and the individual(s) he or she supports, methods of determining the balance between risk and rights, and the manners by which presumed sexual behaviors by people with ID are labeled are potential areas in which aspects of power may present. In conjunction with examination of data from a position of social construction, the addition of Foucauldian examinations of power provided a deeper understanding of DSP's reported experiences.

Significance of the Study

Hastings (2010) noted, "support staff have been relatively neglected as a focus of research within our field" (p. 207). He postulated that this general dearth of literature has had "more to do with a lack of attention to theory and specifically building a theoretical/conceptual understanding of the role that support staff fulfill" (p. 207). In his brief review Hastings found that what literature there has been may be seen as falling into two basic camps: (a) research that has framed DSP work, performance, or effect from a training needs or 'problem' perspective; and (b) research that has examined the "emotional needs of support staff" (p. 208). Following this brief summary of the literature base, Hastings argued that research deficits exist in regards to "an understanding of how support staff talk about and perceive their relationships with the individuals they support, and also how individuals with intellectual disability perceive their relationships with support staff" (p. 208). He went on to specify, "methodologically and theoretically, our understanding of the positive aspects of support staff roles and relationships is underdeveloped. Thus, these issues are clear priorities

for further research" (p. 209). To further hone in on the specific questions of this research, Holomotz (2014), in a limited content analysis of research regarding ID and "sexual offenders" (p. 189), found no studies that approached the topic from the standpoint of DSPs working in the community. Hollomotz concluded that such work "could, for instance, help to enhance outcomes [for people with ID and pSCB] by focusing on aspects of social, rather than health care. Such research could further support rehabilitation, risk management and community reintegration" (p. 195). Ioannou et al. (2014) recently addressed some of these paucities. Ioannou et al. was, however, conducted in Canada and thus may not be considered reflective of the variables of risk, rights, legal boundaries, and systems of supports in the contemporary United States.

The present study addressed a heretofore unrepresented area of research pertaining to the experience of DSPs working in an American community based program specifically in regard to their work with individuals identified as ID who exhibit pSCB.

CHAPTER 2 INITIAL REVIEWS OF RELATED RESEARCH

Overview

The topic of DSP experiences in supporting individuals with intellectual disability

(ID) and possibly sexualized challenging behavior (pSCB) encompasses a wide array of

specific areas of inquiry. In order to understand the state of research in these confluent

domains, I reviewed research regarding:

(a) The general roles, duties, experiences, and related effects of people working as

DSPs in the lives of people with ID in community-based settings; and

(b) The views, attitudes, and practices of DSPs in regard to supporting the sexuality

of people with ID who live in community settings;

(c) Stakeholder views, opinions, or experiences regarding work with individuals with

ID and pSCB in any type of support setting.

As the above topics are aimed at elucidating discrete aspects of the problem under inquiry I

have reviewed and examined each separately. The chapter concludes with a synthesized

analysis of all three reviews.

Overall Intent of the Initial Reviews of the Research

It must be noted that prominent grounded theory practitioners (i.e., Charmaz, 2006;

Glaser & Strauss, 1967), whose work informs the utilized methodology (Chapter Three),

have strongly recommended that comprehensive research reviews only take place *after* data

collection and constructing of theory. This ordering is intended to lessen the possibility of

"importing preconceived ideas and imposing them on your work" (Charmaz, 2006, p. 165).

Nonetheless, thorough familiarity of the research base may enhance the researcher's

"sensitiv[ity] to rendering explicitly the subtleties of the relationships in [the] data" (Glaser,

1978, p. 72). From this perspective a pre-established comprehensive understanding of the research may allow for "a critical stance toward earlier theories…[through which] extant concepts are treated as problematic [leading the researcher to] look for the extent to which their characteristics are lived and understood, not as given in textbooks" (Charmaz, 2006, p. 166). Based on these recommendations it is my intent in these reviews of the research to lay a foundation upon which to later critically compare and analyze theories that emerge during data analysis. In addition, during the course of data analysis and theory construction it become apparent that other domains of research were germane to this area of inquiry. Therefore, further brief reviews of such research were conducted post data collection and analysis.

Terminology

As addressed in Chapter One, the terms used to describe individuals working in non-specialized, non-licensed, positions of daily support with individuals with ID are intensely varied and may differ depending on geography, policy, language, and history of practice. In order to minimize confounding of terms or intent of the researchers in the summaries of specific research projects below, I have deferred to the terms used by the author(s) of each study. When speaking globally, such as in the introduction, headers, and general discussion sections, I will revert to the term DSP. At times my definition of DSP may not be wholly reflective of the researched populations. Use of a unitary term in these sections is not intended to imply an assumption of an overall gestalt in practice. Instead, my intent is to reduce constant recapitulation and re-navigation of terms that would distract from the overall conversation.

The terms *community living* or *community-based* used in this section is generally intended to refer to a service, per Mansell and Beadle-Brown (2010), that involves:

1. Using accommodation located among the rest of the population, which is adequate, appropriate, and accessible to the individual;

2. Using the range of accommodation options ordinarily available to the wider population;

3. Enabling people, to the greatest extent possible, to choose where, with whom and how to live;

4. Providing whatever help is required to enable people to participate successfully in the community. (pp. 105-106)

Further, these types of residential services must be of a relatively small scale with no more than 6 residents per dwelling (Mansell & Beadle-Brown, 2010). Certain of the studies reviewed in this section may not completely fulfill the above definition. At times, too little information was provided to clearly understand the composition of the residential service. In erring on the more liberal side of the definition, and in order to include as many studies as possible, studies that seemed 'on the fence', were included. Descriptions of the residential or other settings as provided by the authors are included in the summary of each study below.

Review 1: Research Regarding the Roles and Duties of DSPs

Sexuality is just one of a myriad of components for which DSPs may have professional duties and responsibilities. Before addressing the ways in which DSPs might envision and enact practices related to sexuality it is necessary to provide context to their jobs as a whole.

The aim of this review is to examine trends and findings of recent research that has addressed the role and effect of Direct Support Professionals (DSPs) in the lives of individuals with intellectually disability (ID).

The past thirty-five years has seen an extensive change in the residential support patterns for persons identified as ID (Braddock et al., 2011; Lakin & Stancliffe, 2007; Mansell & Beadle-Brown, 2010). The predominating trend in North America has been typified by moves away from large-scale congregate settings (e.g., traditional institutions and intermediate care facilities) and towards typical residential settings (e.g., homes and apartments) integrated in the general community (Braddock et al., 2011; Lakin & Stancliffe, 2007). Similar patterns have been noted in Australia (Iacono, 2010), and the United Kingdom (UK; Felce, 1999). These developments, spurred by the deinstitutionalization movement and underlying paradigmatic shifts toward normalization (Wolfensberger, 1972) have changed the lived experience of individuals with ID and the systems that aim to provide necessary supports. Prouty, Smith, & Lakin (2006) reported on the discrete numbers involved in these changes in the United States. These authors found a 1384% increase (from 11,006 to 152,322) in the raw number of organized community-based residential settings for individuals with ID between 1977 and 2005. The increase in community-based housing options resulted in over 270,000 individuals with ID moving out of institutions and into small-scale (i.e., six or less residents) residences (Prouty et al., 2006). These changes were provided further impetus via the 1999 U. S. Supreme Court decision *Olmstead v. L. C.* In *Olmstead* the ruled that, in some cases, use of institutional care for people with intellectual disability was a violation of the Americans with Disabilities Act (1990). Following this decision there have been further reductions in institutional care and associated increases in

community-based residential choices (Smith, Lakin, Larson, & Salmi, 2011). While some

moderate larger-scale homes (i.e., 16 or more residents) and institutional settings (i.e.,

hospital-like congregate care) remain, and provision of full choice in specific residence is a

significant concern (Stancliffe et al., 2011), the lay of the land in residential services in the

United States is largely a polar opposite to what it was in the late 1970s.

Corollary with the changes outlined above there has been a significant increase in the

numbers of individuals employed to provide day-to-day support to those enrolled in service

systems (Hewitt & Larson, 2007; Larson, Lakin, & Hewitt, 2002; Test, Flowers, Hewitt, &

Solow, 2003). Hewitt and Larson (2007) estimated that circa 1999 "~530,750 [full time

equivalent (FTE)] DSPs supported people with ID in community residential settings" (p.

180). These authors cited a report by the Office of the Assistant Secretary for Planning and

Evaluation (2006), which estimated that "with current service utilization patterns,

demographic trends, and DSP turnover rates, an additional 900,000 FTE DSPs will be needed

annually by the year 2020 to support persons with ID" (p. 179). This would, of course, be

worrisome even if the role of DSPs were straightforward and easy to delimit. Unfortunately,

as further elucidated below, the job of DSPs is both difficult to define and encompasses an

overwhelming range of skills and duties that can include "habilitation, health needs, personal

care, hygiene, employment, transportation, recreation,… housekeeping,…and generally assist

individuals…to lead a self-directed family, community, and social life" (McKeon, 2003, p.

H10301). In addition, as evidenced in the research examined in this review, the day-to-day

work of a DSP is often one of intensely individual relationships and care. As Craft and

Brown (1993) stated "[t]his is the staff role. It is about enabling individuals by a process of

encouragement, facilitation, and the imparting of skills to exercise power over their own lives

and to make their own choices at their own pace" (p. 14). In summary, the range of DSPs'

efforts can be powerfully personal to the individuals receiving support (De Schipper &

Schuengel, 2010), difficult to measure (Hostyn, Petry, Lambrechts, & Maes, 2011; Test et

al., 2003), and associated with high levels of stress, occupational burnout, and correlated

turnover (Chung & Harding, 2009; Hewitt & Larson, 2007; Innstrand, Espnes, & Mykletun,

2004; Test et al., 2003). A wide angle review of the research is a necessary first step in the

attempt to contextualize the contemporary overall role of DSPs in the lives of people with ID.

Recent Reviews

Despite the presence of a wide variety of statements about the importance and effect

of DSPs in various aspects of the care of individuals identified as ID, I was unable to locate

any specific cumulative review of the research regarding perceived or formally measured

effects that these providers may have within the service system. Reviews related to recruiting

and retention (Hall & Hall, 2002; Hewitt & Larson, 2007), burnout (Devereux, Hastings &

Noone, 2009) and the effect of DSP attitudes on factors such as sexuality (Aunos & Feldman,

2002) were part of the related general literature base but none of these spoke to the specific

research question at hand. Hastings (2010), however, provided a brief but focused piece with

pointed reference to and summary of the literature concerning research regarding the role and

effect of DSPs. While Hastings' (2010) work cannot be considered a comprehensive review,

it is one of the few entries in recent literature to address this subject at all. In a more recent

brief commentary, Bradshaw and McGill (2015) confirmed, "[w]e know relatively little still

about what helps develop and maintain a positive staff culture" (p. 12). This is perhaps due to

the very dearth of information and research on this topic of which Hastings spoke. In

addition, Hastings is widely published in the literature and research regarding the training,

roles, and effects of DSPs in the lives of people with ID over the past 20+ years (e.g., Dowey, Toogood, Hastings, & Nash, 2007; Hastings, 1997; Hastings, 2002; Hastings, 2005; Hastings & Horne, 2004; Hastings & Remington, 1994a; Hastings & Remington, 1994b; Noone & Hastings, 2009; Noone & Hastings, 2010; Noone & Hastings, 2011; Totsika, Toogood, Hastings, & Nash, 2008). As Hastings (2010): (a) appears to be well-positioned to understand and present state of the research in this topic area; (b) provided a contemporary summary of the state of research; and (c) provided clear suggestions for further investigation, his (2010) work was selected as the point of entry for the current review.

Hastings (2010) noted, "support staff have been relatively neglected as a focus of research within our field" (p. 207). He postulated that this general dearth of research has had "more to do with a lack of attention to theory and specifically building a theoretical/conceptual understanding of the role that support staff fulfill" (p. 207). In his overview Hastings found that what literature there has been may be seen as falling into two basic camps: (a) research that has framed DSP work, performance, or effect from a training needs or 'problem' perspective; and (b) research that has examined the "emotional needs of support staff" (p. 208). Following this brief summary of the literature base, Hastings argued that research deficits exist in regards to "an understanding of how support staff talk about and perceive their relationships with the individuals they support" (p. 208). He went on to specify, "methodologically and theoretically, our understanding of the positive aspects of support staff roles and relationships is underdeveloped. Thus, these issues are clear priorities for further research" (p. 209).

Research Questions for Review 1

The specific questions to be addressed in this review were:

(a) What is the current state/direction of research regarding the perceived or measured roles, impact, and experiences of individuals working as DSPs with individuals with ID?

(b) Is there evidence of a continued focus on the problems or deficits of DSPs?

(c) Is there evidence of an increased focus on the "positive aspects of support staff roles and relationships" as suggested by Hastings (2010, p. 209)?

Method

Eighteen articles were identified for this review using a combination of electronic database search, and citation review. The literature was searched for studies that included data on DSP roles, duties, or perceptions thereof.

Inclusion and Exclusion Criteria

Searches were limited to research articles published in English language, peer-reviewed journals between 2009 and February 2015. The starting point of 2009 was selected as while Hastings (2010) addressed some research from that year it is possible, due to delays between writing and publication, that certain parts of the literature may not have made it into his summary. Beyond this, inclusion criteria consisted of any article that (a) utilized DSPs working in community living settings for adults (i.e., non-institutional or specialty wards) in respondent group or as the target of study/intervention (e.g., Salmon, Holmes, & Dodd, 2014 was not included as although this study clearly included individuals working in DSP roles, the "residential homes [were located] on the grounds of an old long-stay hospital for people with learning disabilities" (p. 144)); and (b) concurrently provided some information regarding DSP roles, duties, effects or opinions thereof - even if this was not the specific

focus of the project. This wider definition was utilized in order to provide as complete a picture as possible of the related research since 2009.

Articles were excluded if they:

(a) were included in Hastings' (2010) summary;

(b) had a sole focus on topics such as hiring, retention, or workforce statistics without assessment of the impact, effect, or role of DSPs in the life of a person or persons with ID;

(c) focused solely on factors or experiences of burnout or stress as these topics have been reported on thoroughly and formally reviewed (Devereaux et al., 2009);

(d) focused solely on these topics as related to parents and unpaid/'natural' supports;

(e) utilized DSPs in respondent groups that also included other types of respondents (e.g., psychologists, nurses, program managers) but did not break down findings/themes by said groups (e.g., Dalton & Sweeney, 2013; Donley, Chan, & Webber, 2011; Hutchinson et al., 2014; Ryan, Guerin, Dodd, & McEvoy, 2011);

(f) stated the use of a possible group of DSPs but did not describe the actual job/role/location of service with enough specificity to ensure that this respondent group fit within the aims of this review (e.g., Chapman, 2014; Hutchinson et al., 2014; Lalor & Poulson, 2013; McConachie, McKenzie, Morris, & Walley, 2014; Mérineau-Côté & Morin, 2014; Redman, Taylor, Furlong, Carney, & Greenhill, 2012; van Asselt-Goverts, Embregts, Hendriks, & Frielink, 2014; Wilkinson, Greenwod, Wang, White, & Culpepper, 2014); or

(g) were located in residences that had more than six residents (e.g., Antaki, Finlay, & Walton, 2009; Dunn, Clare, & Holland, 2008) as these congregate care

environments may represent a different type of service (Lakin & Stancliffe, 2007;

Mansell & Beadle-Brown, 2010).

Electronic Database Search

In order to ensure as complete an attempt to locate all available research regarding

DSPs as possible, searches of Academic Search Complete, Academic Search Premiere,

Anthropology Plus, Education Research Complete, PsycARTICLES, and PsychINFO were

conducted using the basic stem-terms of "staff" OR "support" OR "worker" OR "carer"

AND "duties" OR "roles" OR "effect" OR "impact" AND "mental retardation" OR

"intellectual disability" OR "learning disability". This search generated 3,526 entries. The

titles and reported keywords of all entries were reviewed for possible connection to the field

of intellectual disability and focus on DSP roles, expectations, or experiences. The abstract of

all articles that appeared to have a connection was then reviewed. If the abstract appeared to

indicate relevance to this review the full text of the study was read in full and compared to

inclusion and exclusion criteria. A total of 12 articles were selected for review subsequent to

this process.

Citation Search

The reference list of each screened full-text article found via electronic database

search was reviewed by the author for other studies that appeared relevant. Studies that

appeared to fit within the limitations of this review were obtained and read in full. Six

additional studies were yielded via citation search resulting in a total of 18 reviewed studies.

Analysis Procedures

Full-text versions for each reviewed article were obtained and read in full by the

author. Data from each study were compiled regarding aim(s) of the research, methodology,

sample size and location, composition of a comparison group (if utilized), findings, and strengths/limitations.

Following Hastings' (2010) historical summary of research patterns and recommendations for future directions, reviewed articles were divided into two groups: (a) those that focused on examining potential DSP job performance deficits and/or improvement and training strategies; and (b) those that focused on the lived experiences or positive effects of DSPs.

Results

There is undoubtedly some crossover in the assigned categories for the studies reviewed. In cases where such overlap occurred I assigned the study to a category based on what the authors stated or I surmised as the primary focus. Brief descriptions of these delineations are included to start each category section. With the exception of the studies initiated by the team of Bigby and Clement in Australia, the reviewed studies are presented in order of publication date. The group of ethnographic research published by the aforementioned team is included separately at the end of section (b) as their presence in the literature is singular and, I believe, best presented as a whole.

Primary Focus on DSPs' Possible Job Performance Deficit or Improvement Strategy

Studies (n=8) were assigned to this category if the primary focus was on analysis of DSP concrete job-skill performance/knowledge or the application of a training/intervention on job skills. Critical reviews of these 8 studies are below.

Utilizing a pre-test, post-test design, Stancliffe, McVilly, Radler, Mountford, and Tomaszewski (2010) examined the effects of "staff" (p. 312) training in, and implementation of, Active Support with 41 residents identified as ID (ID criteria of the Australian

Intellectually Disabled Persons' Services Act, 1986; 14 female, 27 male; average age of

44.24) of "nine government-operated group homes [3-6 residents] in a large Australian city"

(p. 313). The authors defined Active Support as "a model of support intended to bring about

meaningful everyday activities by people with intellectual disabilities" (p. 312). Increasing

participation is one of the main goals of Active Support "with other outcomes [e.g., adaptive

behavior, challenging behavior] receiving less consistent attention" (p. 312). Stancliffe et al.

utilized an Active Support training program, blended from different sources, which included

text, didactic lectures, video programs, and checklists/schedules used in interactive training

sessions. Either the authors or residential managers trained by the authors delivered the

material to the staff working in the participating residences. Assessments were conducted

prior to training and again 5-8 months post-training. The assessment utilized gauged

residents' variety and independence in domestic participation (via the *Index of Participation*

in Domestic Life), adaptive and challenging behavior (via the *Inventory for Client and*

Agency Planning), and level of depression (via the *Depression Scale*). The authors reported

domestic participation scores increased for 30 of the 41 (73%) participants with ID while

remaining stable for eight (20%) and decreasing slightly for three (7%). Adaptive behavior

measures of personal and community living skills also evidenced significant improvement.

Certain measures of challenging behavior (i.e., self-injury and withdrawal) improved in 9 of

the 11 participants who had previously evidenced these patterns. Stancliffe et al. noted that

while pre-test scores of depression were low for the group in general, 29 of the 41

participants evidenced improvement. Each of the four participants who had the highest (i.e.,

endorsed more items on the scale) pre-test level of depression evidenced "substantial

reduction at post-test" (p. 317). No data were provided regarding DSP experience or opinion of these interventions.

Strengths of Stancliffe et al. (2010) included the presence of a relatively large sample size representing several different settings and participants with a stated (though not fully defined) diagnosis of ID. The length of time between pre and post test (average of 154 days) adds to the argument that this training may have more than a short-term effect though there was little data regarding possible threats to external validity (e.g., other training the staff may have received between tests, medication or changes in medical status of the individuals identified as ID). The authors noted that their findings were similar to previous similar studies and thus added to the burgeoning evidence base for Active Support training. Limitations of this study included the absence of a control group and a relatively homogenous sample in terms of geography and cultural/language group. The absence of data regarding opinions of participating staff is a concern in that their attitude and perspective may influence longitudinal sustainability. In regards to the aims of this review, the findings of Stancliffe et al. suggested that focused training for staff may result in "consistently positive client outcomes" (p. 319) such as reduction of psychiatric symptom severity and increase in adaptive functioning.

Phillips and Rose (2010) examined "residential staff" (p. 204) attributions concerning factors of placement breakdown in community-based services for individuals with ID in a non-specified area of the United Kingdom. Placement breakdown was defined as: (a) residential agency serving notice of need to move "before an alternative residential service had been identified" (p. 204), or (b) any move to a specialist location that was followed by a move to a different community residence; or (c) any move to a "specialist unit that lasted for

6 months or more despite the individual being 'fit for discharge'" (p. 204). The authors, via

referral from health and social services programs and community behavioral or psychological

programs, identified two non-experimental (i.e., not randomly assigned to conditions) groups

of individuals with ID (no definition provided) and challenging behavior (defined as "a score

of 35 or below on the behavioural items of the *Disability Assessment Schedule"*, p. 205). One

group (n=20) was defined as the "Breakdown Group" (BG; p. 204) while the other was

termed the "Maintained Group" (MG; p. 204). The members of the BG had experienced one

of the breakdown conditions described above during the 2006 calendar year. Members of the

MG had evidenced "sufficiently challenging behavior [necessitating] external help" (p. 204)

but had maintained residential location for at least three years. DSPs who had previously

worked with members of the BG or currently worked with members of the MG were

identified by home managers and recruited for participation. In some cases up to five

residential staff served as respondents regarding a single individual with ID. In other cases no

residential staff were identified to respond to certain scales. No significant differences were

found between MG and BG in regards to aspects of individual demographics or

characteristics of the residential service programs. Likewise, per the measure of challenging

behavior, there was no significant difference between the MG and BG. Factors found to be

correlated with membership in the breakdown group included: (a) higher residential staff

ratings of the individual's community self-sufficiency skills, (b) higher estimates of control

of challenging behavior by residential staff respondents, and (c) less interaction with DSPs.

The authors concluded that these data "impl[ied] a role for staff attributions in placement

breakdown" (p. 208) though they cautioned "the analysis conducted only indicates an

association between ability, attributions, and helping behaviour and does not imply any

temporal sequence or causal direction" (p. 208-209). Phillips and Rose concluded by suggesting interventions to minimize potential for residential breakdown could include specialized training and supervision of residential staff working with individuals with ID and challenging behavior.

Phillips and Rose (2010) benefited from a model of study that included well matched, though administratively selected, groups of individuals and residential programs. While this aided in some threats to internal validity there was little information provided on the detailed intellectual, medical, psychiatric, or behavioral conditions of the members of the MG and BG. It is possible that certain topographies of challenging behavior, while resulting in similar scores on standardized tools, are significantly different in terms of the effect on residential staff. Likewise, confounding medical conditions or differences in intellectual status may have played contributing roles in placement breakdown. While the use of residential staff reports on this topic may help to elucidate contributing variables, there was also a lack of information on personal qualities of these participants and 'in their words' opinions regarding why/how breakdown occurred. In regards to the aims of this review, Phillips and Rose provided some starting points for understanding how residential staff attributions may effect the life of a person with ID but lack of detail hampers confidence in the findings.

Damen, Kef, Worm, Janssen, and Schuengel (2011) trained 72 "professional caregivers" (p. 581; 13 male and 59 female with mean age of 30) in the Contact program of communication strategies for individuals with ID and visual impairment. The professional caregivers involved in the study worked in 12 residential homes for people with ID in the Netherlands. Professional caregiver participants were selected for the study based upon interest in improving their skill sets in regards to specific individuals they supported. These

DSPs then identified specific residents in their support to also participate. Twelve consenting

individuals (7 male, 5 female) identified as ID ("two with moderate ID, five with

severe…and five with profound" (p. 584) as measured with the Vineland Z scales were

recruited based upon professional caregiver referrals. These participants ranged in age from

13 to 54 years (M=35). Individuals with ID and "serious behavioural problems, a hearing

impairment or severe epilepsy were excluded" (p. 584). Two interaction coaches (trained and

supervised by the developers of the Contact program) were utilized to provide the education

and support to the professional caregiver participants. The Contact program utilized in this

study included group based training and coach facilitated video feedback of interactions to

"establish good quality interaction with [an individual] with complex communicative

difficulties" (p. 583). The authors used an AB-design across subjects (two baseline followed

by three post-intervention observations) to measure the effect of the program on

communication frequency, caregiver initiatives responded to by clients, client initiatives

responded to by caregivers, and affective mutuality. Group-based baseline measures of these

domains were completed, the Contact program completed, and post intervention data

collected and presented via traditional single-subject visual graphs. The data were also

analyzed via various statistical procedures. The authors reported, "onset of the intervention

coincided with improvements in important aspects of the quality of interaction between

clients and professional caregivers" (p. 592). Visual analysis of these data appears to indicate

a relatively small change from baseline to intervention though the authors reported that

statistical analyses revealed significant effect. No significant differences were noted between

clients or settings. Fifty-nine of the participating professional caregivers provided feedback

regarding the social validity of the intervention. The majority of this group (63%) rated the

overall program as intermediately effective ('2' on a 3-point scale) and no respondents described or reported negative effects.

Damen et al. (2011) benefitted from use of multiple settings and a set of participants who were primed for participation. This study provided interesting data on the possible effects of a specialized training program for professional caregivers working with individuals who may have more intensive support needs. Limitations included short baseline and intervention periods, lack of an alternate condition, along with a relatively small set of participants with ID. These issues may lead to concern as to the stability of the baseline data prior to intervention, the potential causal relationship of intervention to change, the longitudinal effect of intervention, and the possibility of generalization to other individuals. In relation to the aims of this review, the gathering of social validity data from professional caregivers is promising. This practice acknowledges the importance of provider opinions and reactions related to the complicated interventions and intensive trainings, which are integrated into an already varied type of work.

Taggart, Truesdale-Kennedy, and McIlfatrick (2011) conducted a series of interview-based focus groups with "residential care staff" (p. 43) and nurses in Northern Ireland regarding the roles they play in breast screening services for women with ID. Ten of the 29 participants were identified as "residential workers" (p. 43) with the balance composed of nursing staff. In line with the focus of this review I will summarize the data provided specifically regarding residential care staff responses/findings. All participants had reported experience with supporting women with ID (no definition provided) in access/participation in breast screening. The interview sessions were semi-structured and the guiding questions were based on previous literature-based findings as well as the author's experience in this field.

The sessions were divided into three parts representing topics of general knowledge, experience, and barriers to client participation in screenings. Thematic content analysis was utilized to review the participant responses. Four themes were identified: (a) knowledge and awareness of breast screening and breast cancer (p. 45); (b) how staff support women with ID to access breast screening services (p. 46); (c) factors enabling and inhibiting women with ID regarding breast screening (p. 47); and (d) solutions to overcoming inhibiting factors (p. 48). Per the authors, findings suggested that residential care staff were somewhat familiar with some of the signs and symptoms of potential breast health problems but missed some key factors. Residential care staff reported being unaware of accessible literature regarding breast screening and expressed concern that the women they support would have limited understanding of these medical issues due to cognitive conditions. These participants also reported that the screenings are often unpleasant for the individuals they support, leading to resistance to participate. This was further complicated as the residential care staff reported experiences of very little outreach/promotion from medical clinics. Participants as a whole saw a need for increased accessible literature and materials regarding breast screening to share with the women they support as well as training curriculums for staff. Review of data with participants resulted in no changes to the authors' findings or analyses.

Taggart et al. benefitted from capturing the lived experience of residential care staff in the participants' own words. As with any small-scale qualitative study, arguments can be made as to the potential transferability of these data. In addition there was a lack of information about the specific conditions of the individuals supported by participants. It is unclear if the same factors might apply when working with an individual with pervasive support needs as compared to when working with a person with lower levels of support need.

Such research is important though as it may provide a jumping off point for different methods of study and analysis. This study provided a window into one of the very personal and complicated situations that some residential care staff may encounter at many times in their work. Certainly the quality and style of care provided in this personal and possibly anxiety producing situation may affect the life of a person with ID in profound ways.

Zijlmans, Embregts, Gerits, Bosman, and Derksen (2011) developed and applied an emotional intelligence (EQ) training program for "staff members working in two residential settings in the Netherlands" (p. 221) that support people with ID (no definition provided). The authors noted, "staff working with clients with [ID] who display challenging behaviour may contribute to the continuation of this behaviour, because it causes emotional reactions such as anxiety, anger, and annoyance" (p. 219). Zijlmans et al. hypothesized that training in EQ may help staff develop skills that would mitigate such concerns. Sixty staff members completed participation in the study. Half were assigned to the experimental group and half to the control group. A small portion of the group assignments were non-random due to various conflicts in scheduling and location. All participants were described as "working with youngsters or adults with ID and challenging behaviour" (p. 222) and received a pre-test on EQ (the *Bar-On EQ-i*). Thirty-one individuals with ID were also recruited and utilized with connected staff in the video interaction portion of the study. No measures were reported regarding these participants' experiences. These participants were described in terms of level of ID (i.e., mild, moderate, severe) and psychiatric diagnoses though no information was provided as to the methods/tools used to identify/define these possible conditions. Participants assigned to the control group received no additional training and continued to perform their jobs as usual. Participants assigned to the experimental group received a series

of didactic training on EQ, feedback regarding the results of their scores on the *Bar On EQ-i* and assistance in developing personal as well as client-specific improvement plans. Ongoing feedback and assistance was provided at several points during the study and included analysis of video sessions taken of the staff member while working with the identified client. All training and ongoing feedback were facilitated by trained, licensed psychologists. In addition, a panel of experts judged the pre and post-training EQ skills of participants in the experimental group. Following all trainings, video analyses, and feedback, the participants in both groups received the same measure of EQ. Taggart et al. reported "changes of emotional intelligence of the experimental group were significantly larger compared with the control group" (p. 226). Expert panel judgments also indicated a significant improvement in the EQ performance of the experimental group. As noted by the authors, specific treatment skills and client behavior/opinion were not assessed during this study.

Zijlmans et al. (2011) benefited from a carefully designed protocol that included a control group. In addition, several locations were utilized representing more than one agency, which adds to the possibility of generalization. The application of a well-defined training and intervention program with ongoing individualized support is another clear strength. As EQ is more of a global concept, rather than a discrete, job-specific skill, it may have a more holistic effect on staff performance across a wide array of professional duties. Unfortunately no data were provided regarding the staff perception or reaction to the training. The protocol described was time intensive, personal, and at times may have been critical of participating staff. Training staff on specialized intervention styles is important but these protocols must be evidenced to fit the staff preferences and needs if they are to be longitudinally viable. Certainly, individuals with ID are affected on many levels through the style of interaction

provided by staff members (e.g., feeling supported versus feeling like a burden; treated as a 'job' versus treated as a person). This study provides a window into one possible 'general style' rather than 'specific skill' program.

Beadle-Brown, Hutchinson, and Whelton (2012) utilized a pre-test post-test design to assess possible effects of a training curriculum in Active Support. Specific variables measured concerned "user experience with a particular focus on choice, skills, and challenging behaviour" (p. 293). Participants were recruited from the roles of "a not-for-profit service provider in South-East England" (p. 292) who had exhibited significant policy and practice-level interest in integrating Active Support programming. The 29 participants with ID who were present in services throughout the study were described as living in "community-based houses with 24-hour staffing" (p. 292) with a mean age of 44. Based upon data from the Short Adaptive Behavior Scale, these individuals were classified as having significant support needs. No information was provided regarding definition or assessment of ID in this sample. Likewise, medical (other than a brief statement that 22% had a diagnosis of epilepsy) and psychiatric data for these individuals was absent. These individuals did not receive any direct treatment or intervention as part of this study. Instead, intervention was focused on policy and training issues at the agency and staff level. Pre-test and post-test measures were conducted covering a range of choice, engagement, and activity present in the lives of these participants. Observational as well as standardized measurements (i.e., *Adaptive Behavior Scale Part 1*; (SABS), *choice-making scale*, *Index of Participation in Daily Living*, *Index of Community Involvement*) of these data were utilized. In addition, data were collected regarding the "characteristics of staff, the training they had received and to seek their views on their experience at work" (p. 295). Intervention after pre-test involved

policy changes, trustee engagement, introductory classes and a range of didactic and experiential facilitated trainings for all professional and family stakeholders on the elements of the Active Support program. Residential staff provided the responses to questionnaires at pre and post-test. Results suggested significant positive changes in: applied practices of Active Support, engagement in meaningful activities (social and non social), receipt of staff assistance, participation in community and daily life, and choice. No significant change was noted in measures of community involvement, adaptive behavior or challenging behavior. It was noted that individuals "with the most severe disabilities…showed significant increases in SABS scores" (p. 298). Although there were difficulties in follow-through and matching of pre and post data, the staff members who submitted responses reported "average higher levels of satisfaction, higher quality of management, and more practice leadership from their managers" (p. 301) as compared to baseline.

Beadle-Brown et al. (2012) benefited from a multi-level training at many levels of the service system in which the study was conducted. By focusing on staff-level interactions and measures they provided a clear look at how these types of interventions may seep down into actual practice. The absence of a control group is a limitation and prevents causal interpretations. As staff members were the main respondents, the authors chose not to gather interrater or test-retest reliability data regarding their responses as the burden on staff was deemed to be high already. By choosing to investigate a program with a high level of pre-existing interest findings may be limited in generalizability. In regards to the aims of this review, Beadle-Brown et al. represents an example of how intervention involving management levels of an organization may serve to indirectly affect staff performance/skills, which in turn may affect the individuals receiving service.

Herron and Priest (2013) utilized a vignette-based questionnaire to examine "support workers'" (p. 27) knowledge about signs and symptoms of dementia in older persons with ID. Fourteen support workers "working in one UK county were recruited from two non-NHS organizations providing services for people with intellectual disabilities, mental health problems and complex needs" (p. 30). These support workers were described as being employed in several different service models including residential, community support, and day services. While the general method of the study was described as qualitative in nature, the authors chose to use a privately completed questionnaire as they theorized that face-to-face interviews may have prevented participants from disclosing areas of "poor knowledge, incorrect judgments, or faulty decision-making" (p. 30). The vignettes included in the questionnaire described three hypothetical situations designed to represent beginning, moderate, and advanced stages of dementia in a 72 year old male with ID. Questions posed post-vignette were generally open-ended (e.g., "what do you think is happening here?"). Demographic and work experience data were also collected for each participant but was not included in the article. Herron and Priest utilized a multi-stage, inductive thematic analysis to examine the responses. Identified themes were: explanations, actions, obstacles, and experiences. Via this analytic procedure, the authors concluded that while nearly all participants described experience and training in this topic, there was a general dearth of ability to identify signs or symptoms of dementia until such qualities became overt. Participants were noted to ascribe several different possible explanations (e.g., abuse, physical problem, depression) for the ostensibly dementia-related behaviors described in the vignettes. Herron and Priest reported that, in general, respondents were able to identify

appropriate potential actions for care/referral related to the scenarios even when their attribution of cause was incorrect.

Herron and Priest (2013) benefitted from a focus on the skills/abilities of front-line support workers in regards to a specific, often-complicated medical presentation. The use of questionnaires rather than interviews limited this study as the authors noted that many responses were quite brief and sometimes disconnected to the posed query. The authors' concern about staff abilities to accurately identify dementia based upon a written vignette regarding a hypothetical case of an individual they did not actually know or work with is perhaps too strong. The support workers in this study were generally able to identify that something of concern was in play and propose appropriate referral for further investigation. To imply that support workers should be able to independently identify specific medical conditions in hypothetical scenarios is perhaps an overestimate of their essential skills and duties. Likewise, dementia (especially in the early stages) may often be difficult to differentiate from other psychiatric or medical conditions. In relation to the aims of this review, Herron and Priest presented a further area of specific, specialized knowledge that is, they argued, expected in the day-to-day role of support workers.

Jerome, Kaplan, and Sturmey (2014) utilized a multiple-baseline-across-participants design to assess the effects of focused training on behavioral data collection skills and accuracy of three "direct care counselors" (DCC; p. 531; also referred in text as 'support staff') working in the New York City metropolitan area. All participants were female and had worked in the field of ID support for four months, one year, or 13 years. They ranged in age from 22 to 38 years old. All were observed in regards to data collection regarding two individuals with "profound ID" (p. 531; definition/ description not provided) chosen "based

on the high frequency of their target behaviors" (p. 531). Prior to baseline data collection, two qualified observers conducted a series of frequency-within-interval observations regarding an operationally defined target behavior. Agreement of these observers was noted to be 100% across three 15-minute sessions. Participating DCCs were then asked to record data regarding the same target behavior in the same manner. The same brief, scripted instruction on data recording was provided to all participants at initial baseline sessions. This process continued until the authors determined stability of baseline data. The first intervention phase consisted of a 5-15 minute in-service training which explicated the defined target behavior, importance of accurate data collection, and more explicit instructions on the recording method. Participants were asked to repeat back this information. This was immediately followed by another session of data recording (Intervention Phase One). The second level of intervention consisted of the same in-service instructions in addition to direct, praise-based, immediate feedback and discussion of DCC performance with suggestions for improvement. Throughout all sessions at least one observer also recorded behavioral data. Dependent variables included "(a) overall point-by-point agreement between the observers and participating staff, (b) their occurrence agreement, and (c) their non-occurrence agreement" (p. 532). All participants were noted to evidence increase in overall agreement of accurate data collection from baseline to in service phase and again from in service to in service plus feedback phase. During the final phase, all participants' performance neared 100%. Similar patterns were found regarding percentage of non-occurrence agreement. The authors contended that via this design and findings, experimental control of dependent variables was established.

Jerome et al. (2014) benefitted from a carefully explained and time-frugal set of interventions, which directly addressed a sometimes-key aspect of DCC duties. The multiple baseline design aided in demonstration of experimental control. Visual analysis of the data indicated clear changes between each condition for all participants. The lack of data regarding demographics, condition, and behavioral topographies of the observed individuals with ID limits some of the potential external applicability of these data. In addition, no data regarding social validity was reported. It was unclear if these interventions were seen as acceptable or useful for the DCCs or if the agency management felt it was a good use of paid time. Nonetheless, Jerome et al. demonstrated a method of intervention/training that was both brief and seemingly effective. In relation to the aims of this review, as Jerome et al. contended, accurate data collection may affect professional behavior planning and medication regimens for individuals with ID – two very important aspects of how DCC performance influences the lives of the people they support.

Primary Focus on DSP Lived Experience or Positive Effect of DSPs

Studies (n=9) were assigned to this category if they analyzed or reported primarily on the lived perspective of DSPs, or any stakeholders' opinion or observation of a possible positive or promising aspect of existent DSP job performance.

Hamilton (2009) utilized in-depth interviews and in-residence observations to examine the sexual attitudes, beliefs, and practices of thirteen "direct support workers in Aotearoa/New Zealand" (p. 306). The location residence was described as small-scale (i.e., four or less residents) community-based supported living homes. Hamilton's research questions were as follows:

What happened when sexually related behaviours occurred in an agency group home? What kinds of sense did workers make of these behaviours? What assumptions did workers draw on to explain these behaviours? How did these assumptions influence worker's responses? What were the outcome effects of these responses on the people who lived in these homes? (p. 306)

Based on an analysis of interview transcripts and field notes from observation Hamilton surmised that there was evidence of mixed, potentially conflicting, attitudes towards sexuality present in the statements and actions of many workers. For example, Hamilton described the presence of underlying and overt binary assumptions of: normal-abnormal, able-not able, appropriate-inappropriate, natural-not natural (and so forth). These opposing beliefs, according to Hamilton, came to light when discussing concepts or actual instances of sexuality that occurred in the homes where they worked. Residential workers who participated in this study often framed their duty as that of "protectors…or empowerers" (p. 309) of people with ID. According to the author, such roles and assumptions influenced how staff responded and interpreted day-to-day management of the residents' sometimes-sexual expressions. Hamilton referred to this framing as "doing normal" (p. 309). If the actions or preferences of a person with ID in these residences fell within the perceived 'normal' spectrum of sexuality, the residential workers were more likely to provide assistance and support. If preferences or actions fell outside of these bounds, staff response was often one of reaction and containment. Hamilton noted that on the surface, many statements made by interviewed direct support workers regarding sexuality could be interpreted as rights-based or 'positive' but upon closer examination he found that response depended more on concepts of 'normal', 'acceptable', or 'appropriate' than stated opinion.

Hamilton (2009) illuminated the subtleties of interpretation that direct support workers may have to make on a daily basis. While he focused solely on aspects of discrete or perceived sexual behavior of people with ID, the role and effect of the workers was palpable. In each instance the actions or non-actions of a support worker either allowed or disallowed an individual with ID from engaging in an activity they ostensibly wanted to do. The lived-experience of these support workers was evident in the transcript excerpts and detailed descriptions of place offered by Hamilton. Likewise, Hamilton was able to both capture the experiences of the direct care staff while simultaneously providing concrete examples of how these experiences influence the way individuals with ID are viewed and responded to. Hamilton did not mention any method regarding sharing or checking these data with the participants so therefore, their views on his interpretations were unavailable.

Hatton, Wigham, and Craig (2009) conducted a job analysis concerning the roles and duties of "direct support staff" (p. 54; also referred to as 'support staff', 'housing support staff' and 'staff' in the text) who were employed in "community-based housing services…within North West England" (p.56). Following informed consent procedures, the authors conducted a series of expert panel and small-group interviews with family members of people with ID (n=38), people with ID (n=82; term undefined in text, referred to as 'service-users' in data set), direct support staff (n=122), and service managers (n=115). In the course of the initial group work participants were queried regarding qualities, attributes they associated with skilled and unskilled direct support staff performance. The initial 'brain-storming' sessions were followed by clarification meetings, consensus agreement by those on each expert panel, creation of behavioral examples, and seven-point, likert-type ratings of relative importance of the agreed upon terminology/ descriptions. The method was adjusted

for participants identified as ID and included dyadic interviews with each member of the

expert panel and a three point rating of "'good', 'bad', and 'OK'" (p. 57) qualities. This

resulted in a total of four measures of job performance – one from each represented group.

Additional data were collected regarding family members (i.e., general demographics),

participating direct support staff (i.e., general demographics, recent objective job

performance data, a measure of burnout, a measure of intended turnover, and a self

assessment measure of job performance) and participants with ID (i.e., general

demographics, behavioral and medical information). The complete set of questions from each

of the four finalized measures was included in the article. The service-user measure was

comprised of 18 items and included aspects of direct support staff listening, honesty, humor,

and mood among others. The family member measure contained 27 items and included

aspects of forward planning, reliability, appearance, and honesty. The self-rated measure

completed by direct support staff contained 26 items and included aspects of responsibility,

listening, honesty, ability to be calm in a crisis, and self-initiation. The manager-rated

measure contained 23 items and included aspects of respect, common sense, listening skills,

and flexibility. Hatton et al. compared the group generated scales and found, "while the four

job performance measures [did] not seem to contain conflicting items, they certainly

contain[ed] differences of emphasis, with the service user measure focusing more on

relational issues and the staff measure focusing more on self-care" (p. 58-59). The scales

were then utilized to rate specific participating direct support staff and compared to direct

support staff demographic information. The only significant association was "female staff

being rated as showing better job performance by service users" (p. 59). Comparison to

service user data suggested "male service users being rated as receiving better job

performance by managers" (p. 60). When compared with scores from the measure of burnout (Maslach Burnout Inventory), "higher service user job performance scores were associated with lower staff-related emotional exhaustion…and higher support staff self-rated job performance scores were associated with lower depersonalization…and higher personal accomplishment" (p. 60). Other associations were found between the job performance scores submitted by service users and the degree of choice and flexibility in schedule.

This study benefited from the open-ended gathering of opinion from several groups of stakeholders including "service users" identified as having ID. By utilizing clearly defined processes for narrowing these data Hatton et al. (2009) provided a framework for creation of staff performance measures in a specific agency. In regard to limitations, the authors noted "small sample sizes for some groups, particularly family members, result[ed] in many analyses being underpowered or not possible" (p. 61). In addition, while this study involved several agencies, all were from the same general geographic area and "the generalizability of the job performance measures…is unclear; to other staff roles, other countries, diverse ethnic and cultural groups and people with severe intellectual disabilities" (p. 61) or more pervasive support needs. As the authors noted, the measures also tended to be skewed toward more personal characteristics (e.g., humor, honesty) rather than discrete job duties. It is unclear if these types of qualities may be improved by training. In reference to the specific target of this review, Hatton, et al. provided a clear picture of the many ways DSPs may be valued and have positive effect (e.g., creation of relationships, emotional support, providing access to the community) in the lives of people with ID.

Miller, Schleien, and Bowens (2010) examined the role of "support staff" (p. 35) in the provision of inclusive recreation programs for adults and children in the United States.

Using multiple case study design "within a descriptive framework" (p. 38) the authors investigated a purposeful sample of 15 such programs previously identified as "best practice" (p. 38). Miller et al. conducted a series of semi-structured interviews (some in-person, some via phone with employees at various levels). The presence and engagement of support staff were "consistently identified…as critical to inclusion success" (p. 39). Specific key roles of support staff were described by respondents and included: (a) facilitation of communication to various stakeholders; (b) direct support of communication and engagement between participants identified as having disabilities and those not so identified; (c) physical assistance; (d) gradual development of social and leisure-based skills; and (e) general advocacy. The presence of support staff was also gauged as a key aspect of lowering participant-staff ratios thus allowing for more individualized interactions. Certain respondents did not see level of previous experience in disability supports as a contributing variable to success. Others described it as essential. Excitement, enthusiasm, and individual-specific, pre-service training of support staff were often endorsed as critical elements of program success. The presence of degreed professional facilitators to help guide and coach support staff was also generally reported as an essential element.

Miller et al. (2010) benefitted from the targeted sampling process in order to identify elements of 'what works'. The consistent endorsement of the essential role of direct support staff led the authors to investigate this further and elucidated the highly varied skills these individuals demonstrate in their day-to-day, frontline work. The study was limited by lack of direct, observational data and comparison to programs identified as in need of improvement. Nonetheless, Miller et al. provided another example of the direct and meaningful effect

support staff may play in areas of individualized inclusion, communication, and advocacy for persons identified as ID.

Windley and Chapman (2010) investigated the views of "support workers" (p. 310) in the UK regarding perceived role(s), training and support needs as related to their work with people identified as having learning/intellectual disability. Data were collected via three focus groups and five semi-structured interviews. Participants were described as eight support workers (5 female, 3 male; mean age not provided) who "all…had experience [and training regarding] working with people with profound and multiple learning disability or people with challenging behavior" (p. 313). One participant had less than one year of experience while four reported between one to ten years, and three reported more than ten years of experience. Agency managers initially identified and aided in recruitment of all participants. These managers may have considered factors of scheduling, ability, and temperament when referring participants to the project. Windley and Chapman used a phenomenological approach to the research process that allowed them to adjust and hone ongoing areas of investigation based upon responses in earlier stages. Specifically, initial queries were informed by a review of literature related to the general topic. The authors reviewed transcribed content of the initial focus group sessions and individual interviews, identified themes, and used these themes to direct topics for subsequent group or individual sessions. Participants were asked to review identified themes at several points "to ensure congruence of meaning" (p. 313). Agreed upon emergent themes (p. 313) were: (a) values and roles; (b) skill development, management, supervision; and (c) effective working within houses. Participants tended to express facilitation of quality of life and health as primary values with the addition of resident autonomy also being a common theme. This was framed

as in conflict with a common perspective that another main role was to protect the individuals with ID from harm, abuse or accident. Respondents emphasized the importance of having a caring temperament and tolerance as being a key to success. In the second theme-area (skill development, management, and supervision) participants expressed that much of the initial experience in the field is one of trial and error, on the job learning, modeling of and feedback from other more experienced staff members. Respondents agreed that ongoing training was an essential component of being successful as support staff. They identified individualized behavioral management and communication skills as particular areas of interest along with stress management programs for staff in particular. There were mixed opinions of the value of management and specialized team consults with these groups being seen as helpful but inconsistent or too top-down.

Windley and Chapman (2010) benefitted from a tight focus specifically on frontline residential staff. By examining relevant issues and concerns from the words of these individuals the authors were able to hone the research as it progressed and thus more fully capture what was important from the perspective of the participants. In addition by using methods of member-checking the authors increased the likelihood that their findings matched the lived experience of those who participated. This is in contrast to some research methods that have a pre-ordained topic of interest and utilize 'canned' tools that may miss some other important variables. The small sample size, limited geographic spread, and potential bias in recruiting limits the potential for transferability. Nonetheless, Windley and Chapman provided a potential starting point for similar research into the perspectives and needs of support workers.

Using an ethnographic style of research Wilson, Parmenter, Stancliffe, and

Shuttleworth (2011) provided a deep perspective on life in three Australian community-based

group residences for people with ID. The authors delineated that residents were classified as

"moderate to profound" (p. 277) and provided examples of support needs that may be

associated with these labels. Each residence was managed by a separate agency. Specifically,

the authors observed practices in the homes, interviewed "paid disability support workers"

(p. 278; 15 female, 3 male), and reviewed relevant artifacts from the agencies' records. While

the locations of research were described as representative, the authors did not specify the

manner of selecting or recruiting participating agencies or individual participants. Wilson et

al. approached the study with a focus on gender-roles (male in specific) in sexuality. As such,

interview and observation (no notation of duration or frequency) surrounded topics related to

"the theoretical construct of masculinity…with focus on the topics of sexual health,

masculinity, gender, and gendered caring roles" (p. 278). Grounded theory with a constant

comparative framework was utilized in repeated examination of transcripts, field notes, and

archival documents. Via this method the authors identified themes in the data that suggested

a significant interplay between support worker beliefs, perceptions of duty-to-care, and

actions related to allowing or disallowing certain possibly sexual behaviors. The authors'

compilation of these working theories led them to coin the term "conditionally sexual" (p.

278). In essence, Wilson et al. theorized that there was a hierarchy of necessary 'conditions'

to be met if a young man's efforts at sexuality were to be supported rather than managed or

restricted. Such conditions involved the care worker's underlying values combined with in-

the-moment opinion and belief about the origin of the behavior, the possible payoff to the

behavior, and concern over allowing individual expression within their understanding of

'duty of care'. There was little external guidance/policy present in the agencies regarding sexuality or how to assure duty of care was met. When the mixture of these factors/conditions were in certain alignment (e.g., seen as biological, care worker with 'open' values regarding sexuality, no involvement of other) then the individual may have been more likely to receive support. If these factors presented differently (e.g., seen as 'odd', directed toward other, care worker with less 'open' values regarding sexuality) then the response may be more restrictive. Via this series of dynamics, Wilson et al. concluded that direct care workers in the studied locations played a role of "interactional gatekeepers" (p. 272) between what types of sexual expression were and were not 'allowed' in the homes. Specifically, the authors contended that the main determining features in this interplay were the combination of underlying worker values about sexuality (e.g., concepts of normal versus inappropriate sexual behaviors) in conjunction with how the person's level of disability was framed. People with more intensive support needs were likely to be given increased leeway as their actions were interpreted as more 'innocent'. Wilson et al. surmised that, in general, staff in the study sites were "performing admirably, often with ethically and morally challenging issues, within an inadequate policy structure" (p. 286).

Through this relatively brief ethnographic lens Wilson et al. (2011) provided one of the more detailed examinations of the experiences and lived practices of direct care workers. While specifically concerning the topics of sexuality and young men with ID, this study adds to the others reviewed in carving out yet another facet of the daily responsibilities for individuals working in residential settings. The authors were among the few who reported on methods of triangulating interview data with on site observation and analysis of documents. By triangulating these data with agency artifacts the authors were able to demonstrate a

cluster of evidence in support of many of their findings. On the flip side, it was generally

unclear if these study sites were randomly or purposefully sampled. While the findings were

promising, understanding the method of sampling might add to prospective transferability for

researchers investigating similar situations. Methods of cross-checking findings and

summaries with the participants or agencies were not addressed in the article. In relation to

the topic of this review, Wilson et al. evidenced that people working in direct care positions

may be frequently left to make significant decisions regarding the actions of individuals with

ID without consistent guidance or support from agency levels. These decisions, sometimes

based on personal experience or preferences rather than professional guidelines, may then

directly effect what a person with ID is allowed or not allowed to do within his or her own

home.

Wiese et al. (2013) utilized focus group and individual interviews with "community

living staff" (CL staff; p. 980) that supported individuals with ID in "community

accommodation services in Australia" (p. 981). No discrete definition of ID was provided but

the participating community living staff were only included if they worked in a residential

setting with individuals over 40 years old. Thirty-three CL staff were recruited for

participation (28 female, 5 male; mean age of 44). All participating interviewees were

required to either have experienced the death of an individual they supported or be expecting

a death in the near future. Wiese et al. reported "[m]aximum variation in the purposive

sample was achieved, with 12 participants who had not yet experienced a client death, nine

who had experienced sudden and traumatic deaths, and 12 who had experienced deaths

predated by extended periods of end-of-life care" (p. 982). Only nine of the sample reported

receiving prior training in the topic of death and dying. In Phase One of the study participants

were divided into four focus groups. These groups were facilitated by the first author and untilized a semi-structured format. Phase Two consisted of 23 individual interviews and three individual follow-up interviews. Verbatim transcriptions of all interviews were created. The authors utilized "grounded-theory techniques of theoretical sampling and constant-comparative method" (p. 982) to structure their analysis of these data. These methods led the authors to hone Phase Two questions/topics based upon data from Phase One. Credibility was sought via provision of transcripts to participants and a review session with the nine participants who chose to attend. There was no disparity noted from these participants. Final drafts of the research summary were also sent to certain participants and endorsed without correction. Following thorough, reflective coding the authors identified themes of: (a) *in-principle client knowledge* which "comprised participants' reflections on whether people with disability should have knowledge about dying" (p. 984); (b) *in-practice client knowledge* which "comprised participants' experiences of supporting their clients to know about dying" (p. 984); (c) *client capacity* which "captured participants' views about a client's ability to understand about dying and death" (p. 987); and (d) *client exposure to dying* which "captured participants' reports of the extent to which clients are exposed to dying" (p. 988). Several subthemes were identified in each category as well. Wiese et al. provided verbatim participant quotes for each of these categories and subthemes. The authors surmised that "although community living staff may hold an in-principle belief that older people with ID should know about dying, this does not always equate to in-practice engagement with clients on the topic" (p. 988). In general, the authors contended that results indicated these CL staff engaged with individuals very little in regards to the topic of death and dying. The authors proposed that such disparity may be informed by lack of opportunity, staff's personal

experience of death and dying, and/or the perceived or actual capacity of the supported

individual. Wiese et al. also drew from the data that when staff had opportunities to engage

with individuals about death/dying, they were more likely to do so when the opportunity was

'concrete' (e.g., going to a funeral, looking at pictures) rather than abstract (e.g., talking

about religion, verbal exploration of the general topic). Perceived client capacity was also a

driving issue according to the authors' analysis. When CL staff considered these topics they

tended to describe difficulty in matching content to the individual's ability (perceived or

actual) to comprehend and often did so rarely and often only when the opportunity arose

endogenously. The authors theorized, "two interconnected appraisals [regarding client

capacity] are thereby required, arguably necessitating not only swift, but also sophisticated

decision making" (p. 989). Wiese et al. expressed some concern that these findings may

indicate an "abrogation of responsibility to address the fundamental issue, that of the right of

people with ID to know about dying and death" (p. 989). They recommended future research

be directed towards methods of increasing CL staff skill in addressing these issues.

  Utilizing a tool "developed by the study authors with input from relevant

stakeholders, unions, and support staff" (p. 745) Hensel, Lunsky, and Dewa (2014)

conducted a cross sectional survey of 383 (318 male, 65 female; mean age of 38)

"community residential group home staff" ('staff'; p. 743) working in Ontario, Canada. The

survey was designed to assess staff perceptions of aggressive behavior demonstrated by

"adults with intellectual disabilities" (p. 743; definition not provided) in residential settings.

The authors defined aggression as "as any verbal, non-verbal or physical behaviour displayed

by the client that was threatening or caused harm to self, others or property" (p. 745).

Respondents were asked to complete items pertaining to: (a) total frequency of aggressive

events; (b) most severe form of aggression over four categories (towards respondent, towards others, client self-injury, and aggression towards property; (c) overall perceived severity of aggressive events (0-100 scale wherein 100 represented "extremely severe" (p. 745) over the 6 months prior to the survey. Item 'b' above was further subdivided in regards to whether the reported aggressive event was verbal only, physical but without injury, or physical with resultant injury. Finally, respondents were asked in a yes/no fashion "if they felt they had experienced emotional difficulties [undefined] related to their exposure to aggression in the workplace" (p. 745). Per Hensel et al., results indicated "some amount of exposure to client aggression…was endorsed by the majority of the sample" (p. 746). Specifically, 23.7% (n=80) of respondents indicated that they had experienced high degrees of aggression in all item areas listed above. Of this group 66% responded 'yes' to the item pertaining to experience of emotional difficulties. An additional 13.9% (n=47) of respondents indicated that all the aggressive events they experienced were of low severity. Nonetheless, nearly 50% of this group indicated that they had experienced emotional difficulties as a result of the event(s). Hensel et al. interpreted these data as "suggest[ing]…that even if aggression is not severe, staff may be at times distressed by it and may still require support" (p. 748). In an effort to attenuate perceptual bias the authors compared respondent ratings of severity to "a standardized severity score…computed by generating z-scores for the four aggression subtypes…and then summing these values" (p. 745). Certain clusters of respondents were found to have either: (a) reported a low severity perception when the standardized score was high; or (b) reported a high severity perception when the standardized score was low. The authors stated these data "appear[ed] to indicate a discrepancy between the objective severity of the aggression (based upon the frequency of its occurrence and a measure of whether or

not injury occurred) and the staff's perception" (p. 747). Hensel et al. speculated that certain discrepancies (i.e., standardized score = high but report of perception = low) may have been due to a variety of factors including individual tolerance for aggression, regularity of exposure to aggression, or reluctance to "rate the behavior as severe, for example because they just view it as 'part of the job'" (p. 747). At the other end of the distribution, the individuals who reported high severity in situations rated as low by the authors, may have done so due to factors such as a single event of markedly high severity which skewed their overall perception, a general quality of fear of aggression, or being prone to "experience a psychological impact" (p. 748). In general, events of self-injury were associated with less severe ratings of perception while events of witnessing harm to another were associated with high severity ratings. Hensel et al. reported that the study was limited by: (a) use of a cross-sectional design (i.e., causation cannot be inferred); (b) recall bias due to retrospective report by respondents; (c) absence of corroborating data; (d) response bias (i.e., those who chose to respond may have represented a portion of the population prone to either over or under reporting); and (e) inability to discern if the aggressive events reported by any one respondent were exhibited by multiple clients or mostly associated with particular individuals receiving supports. The authors suggested that further work, which includes longitudinal and more robust subjective data, would increase understanding of these interactions and potentially reduce "negative staff outcomes" (p. 750).

While Hensel et al. (2014) was limited due to the factors identified above, this study adds to the understanding of the role and experiences of individuals working in community-based direct support positions. Specifically, rather than simply counting aggressive events, the authors began to explore the concept of perception in regards to sometimes exceedingly

challenging behavioral events. Via this lens, Hensel et al. provided a glimpse into the staff's experiential or phenomenological world. Regardless of the ostensibly objective ratings of severity one may contend that it is the individual's perception of the event that determines short and long term response. Per DSM-5 (APA, 2013), post-traumatic stress reactions may be precipitated by even a single event of actual or threatened severe injury. Most likely, some of the aggressive events reported by participants in this study would have crossed this exposure threshold. Unfortunately, while Hensel et al. began to address the emotional effect of aggressive events, the yes/no format of the query failed to define 'emotional difficulty'. For some respondents this may have been endorsed secondary to being 'simply shaken up' with only fleeting emotional response that passed without secondary behavioral symptoms. For others, experience of single or repeated aggressive events of perceived high severity may have resulted in clusters of pervasive symptoms (e.g., sleep disturbance, flashbacks, upsetting memories, avoidance, emotional detachment) associated with DSM-5 defined mental disorders (e.g., acute stress disorder, post traumatic stress disorder). Due to these factors, the authors were correct in suggesting the need for more in-depth and participant driven subjective exploration in this topic.

Deep Ethnography of Group Homes in Australia

In 2010 Clement and Bigby published *Group Homes for People with Intellectual Disabilities: Encouraging Inclusion and Participation.* This work was complied following several years of in depth ethnographic study in group homes located in Victoria, Australia. This project was preceded and followed by a set of topic-specific journal articles (reviewed below) stemming from the years of data collection as well as secondary analyses. As Clement and Bigby (2010) formed the basis for the reviewed works it contains some key

definitions or descriptions that were also applied to their related research. Group homes, per

Clement and Bigby provide "accommodation for between 4 and 6 people where extensive or

pervasive staff support is provided to the residents both in the home and when leaving it to

use community based settings" (p. 15). The authors, while addressing many aspects of group

home supports (e.g., management, policy, paperwork), also focused on the role and actions of

"staff [who have] control over the day to day running of each house" (p. 51). Specifically,

Clement and Bigby envisioned the role of staff to encompass a wide array of basic duties

while concurrently providing for people with ID to become engaged, present and integrated

into the community, and able to experience all of the aspects of an "ordinary life" (p. 19).

These tasks, per the authors, necessitate that staff understand underlying concepts and in vivo

application of related effective practices concerning choice, independence, and rights for

people with ID. Often, they found, staff have significant difficulty understanding how

general policies and agency philosophy may be germane and applicable to the specific

individuals they support. Throughout this publication, Clement and Bigby (2010) presented

in depth descriptions, observations, and interpretations related to the above. The work

concluded with examples of applied practices in management and daily support that, they

contended, served to achieve more "positive outcomes" (p. xx) for people with ID. The peer-

reviewed publications secondary to this work are summarized and reviewed below.

Bigby, Clement, Mansell, & Beadle-Brown (2009) presented two separate research

endeavors. In study one (S1) Bigby et al. engaged ethnographic methods to investigate

aspects of residential supports for

25 residents, who lived in five purpose built houses in the community, and some of

their staff. The houses were located in residential areas of Melbourne, and

accommodated four, five, or six residents. Houses were staffed 24 h a day, and had

been open for less than 12 months when the fieldwork commenced. (p. 365)

All of the participating residents had recently been moved to the community residences

following closure of a large congregate institution in the Australian state of Victoria. The

authors described the residents as having "intellectual disability" (p. 364) though "no formal

testing of residents was conducted but updated assessments [no method described]

undertaken before they left the institution indicated they all had severe or profound ID" (p.

365). The participating staff members in S1 had a varied history – some had worked in

institutional settings for years while others were new to the field. In S1 Bigby et al. aimed to

investigate "resident participation and inclusion in the community and in their daily lives" (p.

365). To this end, the authors conducted 216 hours of observation in five separate houses

(range per house of 36-59 hours), and completed eight semi-structured interviews "to seek

[participant] views on goals of the service, nature of support provided by staff and

community participation of residents" (p. 366). The observation portion of S1 resulted in

extensive field notes totaling 159,196 words. All interviews were transcribed. Throughout

and following data collection Bigby et al. utilized inductive processes of constant

comparison, and analytic reflection coupled with credibility checks by critical friends and

participants, to initiate and continue the process of interpretation and code formulation. From

initial analyses the authors identified a central concept related to staff attitude regarding

support of people with ID. Using research from the study of human attitude, Bigby et al.

further split the concept of attitude into affective, behavioral, and cognitive components.

Once these codes were developed "the data were reread looking for all examples that

illustrated both positive and negative staff attitudes towards goals of choice, inclusion, and

participation, which were then grouped into subthemes" (p. 367). With an overarching title of "Let's be realistic, it's not feasible for this group" (p. 366), subthemes were identified as (1) "'It won't make any difference'; (2) 'Residents are too different'; and (3) 'It's too hard because…'" (p. 366-367). Within these subthemes observation and interview data described several "actions…by staff that overrode or disregarded residents' choice, and gave preference to their own views" (p. 368). These qualities seeped down into basic everyday choices such as what residents chose to wear or how to wear it. At certain points the researchers indicated that they broke from strict observation and confronted or questioned some of the staff-resident interactions. In some of these instances "an approach used by some staff that avoided direct challenge was to mock or ridicule ideas about inclusion or participation, with the implicit suggestions 'you [the researcher] must be joking'" (p. 369). Various environmental, personal and organizational factors were expressed by staff as to why goals of choice and community involvement were out of residents' reach. Specifically, per the authors,

> [t]hese ranged from significant to trivial and were associated with the negative attitudes of community members to residents, the characteristics of residents such as their age, degree of impairment or motivation, insufficient staff and resources, the risks to residents or staff and the complexity and difficulty of the task that confronted staff. (p. 370)

The authors noted that the actions or inactions of staff in the above observations and statements were in direct conflict with the stated goals and policies of the agency as described by upper management. The managers whom the authors queried expressed frustration and little hope that much could be done to improve staff performance. Based upon

the totality of data in S1, Bigby et al. surmised "some staff do not see it as feasible to involve people with severe and profound ID in choice and participation in the community or their home. This group are 'excused' from the goals of an ordinary life by reason of their disability" (p. 370).

In study 2 (S2) of this project Bigby et al. sought to "test the confirmability of the findings [of S1]" (p. 370). To this end, the authors recruited "144 direct-care staff and first-line managers supporting adults with ID in residential, in-home support or day services in Victoria" (p. 371). Participants (a convenience sample composed of individuals who had attended certain training workshops) in S2 were asked to complete "a short questionnaire based on the Staff Experience and Satisfaction Questionnaire…comprised of 20 statements about people with ID with which participants were invited to record their agreement on a 5-point scale" (p. 371). Two versions (general and individual) of this tool were created and distributed randomly. The general version asked participants to rate statements about the abilities of people with ID as a whole. Those receiving the individual form were asked to respond to the same queries but in regard to a specific person with ID to whom they provided support. Participants responding to the individually framed prompts were further asked to specify if the individual they were referring to "had mild or moderate ID, severe and profound ID, challenging behaviour, physical impairments, sensory impairments, epilepsy or communication difficulties" (p. 372). Both versions of the questionnaire included an identical second section of four questions that "asked whether 'Community care is better than institutional care for': carers/support workers, for the community, for all people with ID, and for all people receiving services (elderly, mentally ill, children, people with disabilities, etc.). These questions were included to detect any difference between the groups answering

'general' and 'individual' forms of the questionnaire" (p. 371). Demographic and professional work history data were also collected from all participants. Following statistical analyses, Bigby et al. found the following at significant levels: (a) female respondents had a more positive attitude when answering generally; (b) there was no gender-based difference in positive versus negative responses on the individual form; (c) "people rating an individual they know rather than people with ID in general expressed somewhat less positive attitudes" (p. 372); and (d) presence of challenging behavior and reported severity of ID were correlated with less positive attitudes. Collectively, the results of S2, in tandem with the findings of S1, "suggest[ed] that although staff in services agree with the principles of choice, inclusion, and participation for people with ID in general, some staff find it difficult to accept they can be applied to people with more severe ID" (Bigby et al., p. 373). The authors noted that such disparity cannot be seen as solely the result of some endogenous qualities of the staff. Rather, they contended, non-specific and widely framed government or agency policies may result in a situation wherein

> policy must be applicable to a diverse population of people with disabilities. In the absence of clear explication in policy, it is understandable that staff struggle to interpret the meaning of these broad and ill defined concepts for people with severe ID. (p. 374)

Bibgy et al. suggested that these findings indicate a need not for clearer or more enforcement of policy but for increased and longitudinal attention to how staff members individually understand the reasoning behind and application of these often complex concepts of rights, risk, and choice.

Bigby et al. (2009) demonstrated a thorough method of both describing and analyzing the lived experience of staff working in community settings for people with ID. The combination of ethnographic and focused questionnaire methodologies is a clear strength. Via these endeavors the authors were able to provide a project of both breadth and depth not present in any of the other studies reviewed in this section. While the definition or measurement of intellectual disability was not specified, the richness of detail provided a much more tangible understanding than rote statements of scores on various tests or measures. Likewise, this project included significant direct quotes and lengthy field note excerpts added to the clear credibility of this research. The authors' methods of triangulation (i.e., combination and comparison of observation, interview, member checking) and secondary analyses (i.e., peer debrief and consult) were clearly stated and based on best practice. In regards to the aims of this review, Bigby et al. allowed for a greater understanding of the various forces that influence staff practice and experience.

Clement and Bigby (2011), using portions of the data collected as part of Clement and Bigby (2010) applied a model of *"program theory"* (p. 555, including structure, orientation, and procedures as defined below, italics in original throughout) to analyze a "reputed exemplary residential support service for adults with intellectual disability and severe challenging behaviour in Victoria, Australia" (p. 554). In review of the literature the authors noted, "[i]t is possible to read widely about the value of 'important programmatic components', the 'internal organization' of services, 'service design features' and 'effective managerial and professional support'… without gaining a clear idea of what this looks like in practice" (p. 555). Attempting to fill this research gap the authors deductively assessed factors of "*Structure*…the major parameters of the setting; *Orientation*…the service's aims

and therapeutic direction in operational terms; and *Procedures* define[d as] how staff work with residents" (p.555) in the aforementioned residential setting. As a first step, Clement and Bigby determined that the residential program as a whole was acceptable for the aims of the study (i.e., "sufficiently well conceptualized to allow a formal evaluation" (p. 555)). This was accomplished through meetings with the CEO and managers and review of the program's guiding documents. Subsequent to determination that the agency met inclusion criteria, Clement and Bigby gathered data from "'contemporary' [agency] documents,…[t]hirty-seven hours of observations made over a 3-week period in two supported houses,…[and] 15 semi-structured interviews…with senior managers and other staff, which, amongst other things, evaluated people's levels of knowledge about *program theory"* (p. 556). The authors engaged a triangulation procedure of comparing sets of data to each other but contended,

> 'trustworthiness' [was] not such an issue in this article where we are primarily
>
> concerned with using the data to outline the *program theory* and illustrate the practice
>
> framework. Describing the *program theory* publicly in this journal is, in a sense the
>
> ultimate 'member check' where academics, policymakers and practitioners can judge
>
> its 'credibility'. (p. 557)

Overall, the authors found this program to have a clear practice framework (i.e., goals and expectations, free of jargon, with clear operational definitions, and consistently communicated to all employees) containing elements of active listening, positive language, choice and control, plan of the day, and active support. In each of these elements Clement and Bigby provided examples from staff statements, guiding documents, and observational field notes that demonstrated a connection between agency philosophy and individual practice. Staff were noted to evidence consistency between what they stated they aimed to do

in support of people with ID (interview data) and what they were observed to do in vivo (from field note data). Specifically, staff were observed to provide a wide array of choices in line with individuals' communicative preferences or physical limitations, consistently use positively framed and individualized feedback, and interact in a way that "demonstrated enthusiasm, warmth, use of respectful language and a sense of enjoying each other's presence though the immediate situation might present some challenges" (p. 559). The authors concluded that the studied program evidenced a clear program theory, which resulted in positive outcomes for both people with ID and the staff providing supports. Clement and Bigby noted that the presentation of these data and findings may provide a sense that these practices are easy to enact, when in fact, they are not. They noted that despite the clear definitions, training, and oversight the direct care staff continue to encounter daily situations (e.g., 'risky' choices) wherein in-the-moment judgment of individual factors must be applied without direct supervision. They concluded "[i]n stating that support workers have to exercise judgment in supporting people with severe challenging behaviour, we are suggesting that evidence for practice does not come from research alone, but comes from other sources, such as practical experience" (p. 563).

As with the other publications stemming from the larger project (Clement & Bigby, 2010), Clement and Bigby (2011) demonstrated a thoroughness of investigation not present in other research of this topic. Deductive application of an existent theory (from other literature on general organizational functioning in human services) allowed for a quality of analysis differing from that found in most qualitative research. Rather than 'just' applying codes and evidencing detail, Clement and Bigby (2011) were able to demonstrate clarity of

process that may allow for both generalizability and transferability of findings. In their words,

> [t]here exists a significant amount of 'knowledge' about intellectual disability and how to provide services for people with severe challenging behaviour. We suggest that one of the most important tasks for managers in human service organizations is to implement this knowledge. (p. 563)

In relation to the topic of this review, Clement and Bigby (2011) communicated that it is not just the actions and inactions of staff that affect the lives of people with ID. Indeed, the multiple hierarchies (i.e., agency policy, social atmosphere, government requirements) may all trickle down to the words and actions occurring in a community residence. As evidenced in this study, when these factors work in concert, there may be a symphony of results rather than a cacophony of conflict.

In the most recent article to stem from the work of Clement and Bigby (2010), Bigby, Knox, Beadle-Brown, Clement, and Mansell (2012) "aimed to conceptualize the potential dimensions of culture in all group homes and describe the culture in underperforming group homes" (p. 452). 'Culture' in Bigby et al. was derived from

> Schein's (1992) definition…: 'A pattern of shared basic assumptions that the group learned as its problems of external adaptation and internal integration, that has worked well enough to be considered valid and therefore to be taught to new members as the correct way to perceive, think, and feel in relation to those problems' (p. 12). (p. 455)

In this piece, the authors applied a secondary analysis to portions of the data collected as part of the larger ethnographic project (Clement & Bigby, 2010) the methods of which are

described above. When reconsidering the original data set Bigby et al. noted "a pervasive theme [of] the development of norms in each of the houses that appeared to affect resident engagement in activities and community participation" (p. 455). Bibgy et al. used a deductive analytical approach to explore the Clement & Bigby (2010) data for concepts related to "work practices and resident outcomes such as 'the hotel model' and O'Brien's (1987) distinction between 'community participation' and 'community presence'" (p. 454). The authors noted concerns from the literature regarding secondary analytical processes such as "the researchers' closeness to the data set" (p. 455) that could result in theory confirmation rather than a more objective consideration of the data. In order to address this threat to credibility Bigby et al. enlisted researchers (second, third, and fifth authors) who had not been involved in the collection or analysis of the primary study. These authors "thus had no preconceived ideas around the themes emerging from the primary study and, hence, provided the distance to balance the closeness" (p. 455). In addition, Bigby et al. used methods of triangulation (comparing different types of data to each other) constant comparison, and peer debriefing to enhance credibility. From this method of secondary analysis Bigby et al. identified five dimensions of culture in the studied group homes. In each of these five dimensions the authors first utilized a neutral label, then a label intended to describe how this feature might present in an underperforming group home, and last, "a descriptor that captured the essence of that last category of culture [i.e., underperforming]" (p. 456). These five dimensions were:

(a) "Alignment of power-holders' values: Misalignment with organization's values – 'We're not going to do it that way'" (p. 456);

(b) "Regard for residents: Otherness – 'Not like us'" (p. 457);

(c) "Perceived purpose: Doing for – 'We look after them'" (p. 458);

(d) "Working practices: Staff centered – 'Get it done so we can sit down'" (p. 459); and

(e) "Orientation to change and new ideas: Resistance – 'Yes but'" (p. 461).

Within each dimension, Bigby et al. provided examples from field notes, interview transcripts, and agency documents. The authors described manners by which staff actions, interactions, and inactions served to emotionally or physically distance from people with ID, delay or dismantle plans for changing the way things were done in the houses, have residents do what staff wanted to do as a primary goal, and treat the residents as a group rather than as individuals with separate preferences and needs. Overall, the authors found that the staff-driven culture in these underperforming group homes had "impact…on residents in terms of a lack of engagement, community participation, choice, and personhood" (p. 462). They further noted that these variables were similar to (though not as harsh or restrictive) conceptualizations of institutional culture and were dominating the lives of the residents with ID despite size or location of the service. Bigby et al. were careful to elucidate that the observed concerning practices were not somehow the fault of the staff alone. They noted "a complex interaction of multiple external as well as internal factors" (p. 464) stemming from unclear policy, inconsistent management follow-up, and surficial training for staff. In summary, Bigby et al. stated,

> [t]he evidence from this study suggests that dimensions of culture are mutually reinforcing, iterative or interactional rather than being simply a linear model that moves from left to right, from the values of the power-holders, to regard for residents, to perceived purpose of staff work, to working practices, and finally to orientation to change. (p. 464)

In summary, the body of work stemming from Clement and Bigby (2010) provided a comprehensive view of the lives lived in particular group homes in Australia. Rather than a potentially myopic consideration, focused on just one aspect of these environments (e.g., staff, residents, agency policy) the authors reviewed above revealed manners by which these constituents acted and interacted to affect the lives of people with ID. This team's dedication to clear practices, richness of detail, and description of participants allowed for a multilayered presentation of both breadth and depth. The use of differing means of analysis between reviewed studies further enhanced the manners by which this deep set of data may be transferred and considered by academics and practitioners alike.

Discussion of Review 1

Of the 18 studies examined in this review eight contained a focus on DSP training or skill interventions. Overall the reviews indicate that DSPs themselves have reported a desire for more training (cf. Windley & Chapman, 2010). Higher degrees of training for DSPs may lead to more confidence and specific skill development, which in turn could lead to more positive outcomes for individuals identified as ID. The types of trainings represented in this review ranged from global interventions such as increasing emotional intelligence (Zijlmans, et al., 2011) and enhancing the use of Active Support (Beadle-Brown, 2012) to specific topics of communication (Damen, et al., 2011) and data collection (Jerome et al., 2014). Certainly there is no lack of specific skills and programs of support in which DSPs may be trained. The combined issue of turnover and high-cost of training (Hewitt & Larson, 2007) however, creates a potential situation of diminishing returns. As more trainings are added, the cost of training each individual employee rises. As there is a noted high degree of turnover in DSP positions this increased spending may, in many cases, be money spent on nothing. In

order to increase the likelihood that trainings will be both cost-effective and meaningful to participants it is essential that the voices of DSPs are included in the direction and focus of these programs. When skill-development aligns with a perceived need, there may be increased likelihood of satisfaction and understanding. This could, in theory, reduce some of the turnover in service.

The direct opinions, views, practices, and experiences of DSPs appear to have been included at an increased frequency (n=10) from that noted by Hastings (2010). At times, however, these individual voices are lost when aggregated with other types of service providers. While studies that combine data across clearly different types of respondents (e.g., nurses, agency directors, and DSPs) provide an important window into the *general* experience of work in this field, the specificity of DSP experience can be lost in the shuffle. This creates an issue of comprehensive generation of theory in that it is exceedingly difficult to pinpoint what works when concepts and opinions are not clearly delineated. Windley and Chapman (2010), Hatton et al. (2009), Hamilton (2009) and Wilson et al. (2011) all provided solid examples of how the ground-up perspective of DSPs may be assessed in a specific, meaningful, and detailed manner. The body of work (Bigby et al., 2011; Bigby et al., 2012; Clement & Bigby, 2010) stemming from Clement and Bigby (2010) appears to occupy a distinct space in this body of research. Rather than separating out DSPs, these authors were able to represent the ecology surrounding DSP practices in general while further elucidating how DSP actions or inactions are just one part of an interactive network of large and small scale influences. Via studies such as these it becomes easier to fit the pieces of the puzzle together in the path to theory development as suggested by Hastings.

By considering the diversity of findings in the sample of studies that focused upon DSP experience and positive effect it is evident that the range of competencies DSPs must attain is mountainous. Together, these studies suggested that DSPs must not only be personally engaging, independent, self-motivated, humorous, patient, reliable, easy-going, honest, and organized (among many other factors) but also exhibit skill in dealing with nebulous matters of death and dying, emergent sexuality, gender roles, advocacy, and social skill building (among many others), *as well as* concrete skills of house management, clear communication, transportation, and physical assistance (again, among *many* others). It is difficult to imagine any other 'entry level' job that has this level of demand, diversity, and dedication from day one. In addition, the position of DSPs is one of constant and individualized adjustment with direct effect on the lives of individuals with ID. Each individual supported may require or prefer a different mix of these skills and abilities with different residents in the same house potentially having wildly divergent areas of identified support need (Windley & Chapman, 2010; Bigby et al., 2012). All of this, in conjunction with the noted problems of low pay in this arena (Hewitt & Larson, 2007), and the issue of turnover is a given. When turnover occurs, its effects are not just felt by the human resources department. The impact on trust, daily experience, and security of the individuals with ID is surely and sorely felt. The learning curve for a new hire begins again, and a personal relationship must be created anew. Perhaps by increasing focus on what individuals with ID and DSPs themselves have to tell us about what is really important, and compiling theory to be tested, paths of less resistance may be carved in the mountainside and we can all walk them together.

Finally, there appears to be a geographic bias in the studies that have addressed these topics. The overwhelming majority of reviewed studies (N=12); as well as the majority of studies read but eliminated via exclusion criteria) were conducted in the UK or Australia. Only two of the 18 reviewed studies were conducted in the United States. Cultures of support are likely as variant as physical geography. The views of DSPs and individuals with ID cannot be assumed to be constant across latitude and longitude. Without further studies from a more robust representation of language and geographic we may be left with a body of research that attempts to speak *to* all but can never achieve speaking *for* all.

Limitations of Review 1

As the current review: (a) was limited to research published 2009 to present, (b) stemmed from the thorough but non-systematic, review by Hastings (2010), and (c) there has been no (known to this author) comprehensive review of this topic to date, it is possible that certain important aspects of the related literature have been unintentionally omitted. A careful examination of the past 35 years of literature, with careful attention to how terms vary geographically and temporally, may help to better elucidate the topic. Such a wide-ranging, thorough, historical review was beyond the scope of the current project. In addition, the relatively short time frame examined (2009-February 2015) may be too brief of a period for follow-through related to Hastings (2010) recommendations to have become evident in published literature. Attention to, and integration of newly published literature in this domain must continue in order to gain a better understanding of trends. Nevertheless, in retrospect, as the method utilized resulted in a fairly large number of reviewed studies (n=18), included examples of method from many traditions, as well as a set of intensely detailed ethnographies

and secondary analyses (Bigby et al., 2012; Clement & Bigby, 2010; Clement & Bigby, 2011), I elected to retain the limitations as outlined near the start of this review.

Next, the extreme variety of terms used to describe the job title of DSPs may have resulted in some studies being unintentionally absent from this review. For example, the body of work stemming from Clement and Bigby (2010) was found only via citation search and did not appear in the results of electronic database searches. Should an author have utilized a more colloquial term and/or overlooked provision of keyword tags related to the terms used in my literature search methodology, said article would likely not have been located. In addition, the specific definition of who may be considered a DSP is difficult to pin down. Does the term DSP include all 'non-professional' (i.e., no applied advanced degree) personnel who work in direct contact with persons with ID? This could expand the topic to cover individuals who work as managers in residential settings or individuals in specialized supported employment sectors, respite services, or substitute care for families. Widening the definition of DSP to these various positions would likely multiply the intensity of confusion regarding terminology as each of these positions may also be referred to via various terms that may not have been included in the terms used in the search methodology described above. Likewise, by expanding the definition, it may become so diffuse as to prevent clear understanding of the ways one particular group of individuals (i.e., those providing paid, day-to-day, frontline, individual supports) have, and might, affect the lives of individuals with ID. This is analogous to issues in terminology that confuse compiling of data in regards to psychiatric diagnosis and prevalence in persons with ID (Buckles, Luckasson, & Keefe, 2013). In the case of mental health definitions however there are existent frameworks and classification systems as well efforts to establish international standards. In reference to job

titles of DSPs there is no text that I know of, past or present, which provides functional operational definitions.

The exclusion of articles that included DSP respondents among a larger group but did not specifically detail the variation of responses/findings between groups is another potential limitation. For example, Disley, Hatton, and Dagnan (2011; and also noted in Bradshaw & Goldbart, 2013) examined the opinions of a wide array of residential service providers in the UK. Their sample included nurses, professional therapists, agency managers, as well as "support workers" (p. 299). Many of the findings outlined in this study are quite personal, insightful, and indicative of the multiple roles and views individuals in this line of work may play. By aggregating the data for all respondents however it was impossible to delineate if the views and opinions differed between these groups. Certainly the roles and responsibilities of a licensed nurse or specialized therapists are different (perhaps less diverse) than those of frontline support workers. Being that support workers represent the largest pool of employees in this field (Hewitt & Larson, 2007) it is, at times, essential to hear their voices and views *alone* rather than as part of a diverse chorus. By excluding such articles it is possible that some valuable data were absent from this review but, in essence, it would be difficult to pinpoint what said data might have been.

Review 2: Research Regarding Sexuality in the Work of DSPs

As historical societal attitudes have influenced models of care, it is likely that the attitudes of DSPs regarding the sexuality of those they support plays a significant role in how these duties are performed and the resultant quality of support received by individuals with ID. As examined in Chapter One, DSPs have worked at the crossroads of theory and applied practice regarding sexuality and ID throughout the American history of systems of supports.

The present review examines research published between 2001 and early 2015 that has reported on the experiences, attitudes, or opinions of DSPs regarding the sexuality of people identified as ID living in community-based residences.

Previous Reviews

Aunos and Feldman (2002) provided a review of the research concerning attitudes toward the general topic of sexuality in persons with ID. Covering published studies from 1974 through parts of 2002 this review examined the topics of general sexuality, sterilization, and ability to parent in the progression from the normalization movement through the shift to person-centered planning and rights-based supports. In the portions of this review that examined research on "direct care staff" (p. 286) Aunos and Feldman found that the reviewed evidence suggested comfort with general physical contact (e.g., kissing, hand-holding) but these same providers commonly expressed, "persons [with ID] should be discouraged from having sexual [intercourse]" (p. 286). Direct care workers' concern about parental reactions, legal culpability, and pregnancy were all common factors in less permissive attitudes. Age and frequency of religious service attendance were identified as negatively correlated with any positive attitudes in this topic. Education in sexuality was associated with more positive attitudes. In conclusion, Aunos and Feldman stated, "despite the progress made since the 1970s, it appears that [those who work with] persons with intellectual disabilities [were] strongly against procreation,…in favour of sterilization" (p. 293) and held restrictive opinions regarding the right to sexual relations. Notably, there were few qualitative/naturalist-based studies in this topic as summarized by Aunos and Feldman. The majority of reviewed articles were survey-based and focused on stated attitudes rather than participant descriptions of applied practice.

As Aunos and Feldman (2002) appear to have written the most recent comprehensive review of this topic, their work will serve as the main reference point for the current examination.

Research Questions for Review 2

The specific questions to be addressed in this review were:

(a) Have there been changes in measured, stated, or observed attitudes, and/or practices regarding sexuality and ID by those working as DSPs?;

(b) Is there evidence of stability or changes in patterns of contributing factors (i.e., age, education, religion) regarding DSP?;

(c) Have there been changes in distribution of research methods (i.e., an increase in qualitative methods)?;

(d) Does the research reveal disparity between stated attitudes and practice based applications?; and

(e) What are common current recommendations for improvement and future areas of research regarding sexuality, ID, and the work of DSPs?

Method

Fourteen articles were identified for this review using a combination of electronic database search, and citation review. The literature was searched for studies that included data on DSP attitudes regarding sexuality and intellectual disability. Specific inclusion and exclusion criteria were as follows.

Inclusion and Exclusion Criteria

Inclusion criteria were: (a) peer reviewed publications between 2001 and February 2015; (b) studies that included DSPs in a respondent group; and (c) studies that addressed

specifically intimate/physical sexuality such as masturbation and intercourse. While stemming from the work of Aunos and Feldman (2002), the cutoff point of 2001 was established in order to capture any studies that may have been released between the time of Aunos and Feldman's submission and date of publication.

Exclusion criteria were: (a) studies reviewed by Aunos and Feldman (2002); (b) studies that included only a sample of respondents working in inpatient facilities or identified institutional settings (i.e., secure wards, specialized large scale facilities) regardless of the terminology used to describe their position/role; (c) studies that included DSPs in one of multiple respondent groups but did not delineate findings by said groups with enough detail for interpretation; and (d) studies that focused on certain aspects of sexuality (e.g., hygiene, menstruation) but did not include data on physical/relational aspects of sexuality (e.g., dating, intercourse, masturbation).

Electronic Database Search

In order to ensure as complete of an attempt to locate all available research regarding the topic described above searches of PsychINFO, Education Research Complete, Academic Search Complete, and PsycARTICLES were conducted using the basic stem-term of "sex" AND "support" OR "staff" OR "carer" OR "worker" AND "attitude" OR "opinion" OR "view" OR "value" OR "experience" AND "mental retardation" OR "intellectual disability" OR "learning disability". This search, conducted in February of 2015, generated 701 entries. The titles and reported keywords of all entries were reviewed for possible connection to the field of intellectual disability and sexuality. The abstract of all articles that appeared to have a connection was then reviewed. Thirty-two studies were screened in following abstract review. Full text versions of these thirty-two studies were obtained and read in full to assess

fulfillment of inclusion and exclusion criteria as described above. Twenty studies were eliminated. Elimination was mostly due to problems identifying the nature of DSP working environment and/or insufficient division of results by participant group. Via this portion of the process, 13 studies were identified for review.

Citation Search

I screened the reference list of each full-text article found via electronic database search for other studies that appeared relevant. Studies that appeared to fit within the limitations of this review were obtained and read. One additional study was yielded via citation search. This complete process led to the total of 14 studies included in this review.

Analysis Procedures

Full-text versions for each reviewed article were obtained and read in full by the author. Data from each study were compiled regarding sampling method, size, and location, composition of a comparison group (if utilized), tools/methods utilized, stated interpretive positions (if present), findings, and strengths/limitations. Reviewed studies are divided as follows: (a) studies that mainly utilized quantitative (positivistic) methods (e.g., questionnaires, surveys); and (b) studies that utilized qualitative (naturalistic) methods (e.g., focus group, interviews). This division was established as: (a) the choice of methodology often stems from differing types of query and thus result in decidedly different conclusions or summaries; and (b) this will serve to address research question (c) above.

It is acknowledged that the 'divide' between so-called qualitative and quantitative research is perhaps socially constructed and comes along with a slew of opinions regarding generalizability, applicability, and the nature of 'truth' (Lincoln & Guba, 1985). In some instances reviewed studies may have utilized 'mixed-methods'. In these cases I deferred to

the authors' stated intent for purposes of category assignment. Nonetheless, this division was established in order to assess if differing methods produce notably different summary results. In both conditions, studies are presented in order of publication date to further assess if there has been a pattern in topics, methods, or results on this topic over the past 12-13 years.

Certain of the studies examined below were also included in the first review of the research in this chapter. In these cases (Hastings, 2009; Wilson, Parmenter, Stancliffe, & Shuttleworth, 2011) the examination in this section focuses on the specific aspects of sexuality and the research questions listed above.

Results

Studies that Utilized Quantitative Methods

Christian, Stinson, and Dotson (2001) utilized an anonymous survey and response to vignette to examine the "values and beliefs of support staff" (p. 285) regarding the sexuality of women identified as "developmentally disabled" (DD; p. 283). The authors used the term 'developmental disability' throughout the text. The vignette (described below) used in the study, however, was reported as involving an individual with "mental retardation" (p. 285). In addition, the agency wherein the study was conducted is a prominent and well-known specialized provider of services to people with ID. For these reasons Christian et al. was included in this review. Although it appears to be a confounding of terms, I will utilize the term DD in this summary section in order to remain consistent with the author's terminology. All respondents were employed by a multi-service (i.e., residential, day program, supported employment) agency in California where the authors themselves were employed. Forty-three of 75 (57.3%) mailed surveys were returned. This represented approximately 20% of the total number of support staff employed at the agency. The survey consisted of 41 items covering

demographics and topics including but not limited to: knowledge of the agency's policies regarding sexuality, sexual desires of women with DD, ability to consent to marriage, reproductive rights, sterilization, ability to have a sexual relationship, the priority of sexuality in their day-to-day support work, and relation of these factors to level of disability. All of these items were rated via a 5-point Likert type scale (from strongly disagree to undecided to strongly agree). Responses of 1-2, and 4-5 were combined "for ease of reporting" (p. 285) in the findings creating a de facto 3-point scale (agree, undecided, disagree). A case scenario was also included as part of the survey. The scenario presented a case involving sexual relationship between a man without disability and a woman with "mild mental retardation" (p. 285) who was receiving supported living services. Additional details were provided including the concerns of the woman's mother, and the woman's concern about the lack of use of condoms in the relationship. Respondents (10 male, 30 female, 3 did not identify) had an average age of 31, worked in the field for an average of 6.6 years and ranged in educational background from high school diploma (n=8) to master's degree (n=5). Stated religious affiliation was also reported with the majority identifying as Christian. Survey results indicated that respondents overwhelmingly (93%) believed women with DD have the "same sexual desires as women without disabilities" (p. 286) and these individuals have the same rights as others in sexual expression (95.3%). Eighty-one percent of respondents agreed that it was part of support staff duties to address the sexual expression of the women they support. Only 45% felt that other service providers "recognized women with disabilities as sexual beings" (p. 286). Further, 95.4% of respondents agreed that women with disabilities could, in general, enter into marriage and sexual relations - though this was attenuated significantly when level of disability or ability to consent was considered. Nearly half of

those who responded agreed that there were more important aspects of their jobs than sexuality. Reproductive rights for women with ID were seen as relevant for 90.6% of respondents. Right to gynecological care was endorsed by 100% of respondents. An equal number saw assurance of access to such care as part of their duties of support. Level of disability was a mitigating factor in the perceived right to bear children with the 'agrees' dropping from 83.7% to 55.6% when this factor was introduced. Sterilization was endorsed as a viable option by approximately 9% of respondents. Motherhood was seen as attainable with supports by 93% of respondents. Education on sexuality for women with DD was endorsed as a necessary opportunity by 93% with 61.9% stating they would feel comfortable providing such education. Just over half of respondents reported having read the agency's policies on sexuality. In regards to the case scenario, seven respondents left this blank. Those that responded tended to state they would rely on their own judgment and provide the woman with access to education. Only 11.6% stated they would inform supervisors of the situation. The authors surmised, "in their day-to-day support to women with developmental disabilities, it is likely that some staff would be guided by the agency's sexuality policy, while others would be guided by their own values and beliefs, which may or may not be in line with agency policy" (p. 288). The authors reported the limitations of small sample size representing a single agency with clear policy and training on matters of sexuality. In addition, Christian et al. acknowledged that their own biases as agency employees might have influenced coding. They concluded with recommendations for possible training additions and a call for all agencies to carefully examine the beliefs and values of support staff regarding sexuality and disability.

Christian et al. (2001) had the strength of a detailed survey covering many aspects of sexual rights and expression thereof for women with DD. The use of a case scenario added a level of detail regarding potential support staff practices beyond simple Likert responses. Limitations were, as the authors noted, small sample size and use of single site where they themselves were employed thus limiting potential generalizability. In addition, it was unclear in the stated findings if religious affiliation was associated with any variability of data. Likewise, it was unclear if certain staff had received more than the standard agency training in sexuality. As the study was limited to topics related to ostensibly heterosexual women with DD, it is unknown if these responses would have differed in regards to male sexuality, homosexuality in general, or in relation to general human sexuality. Overall, the findings of this study suggest that support staff at this agency, while generally having a rights-based orientation, may rely on personal beliefs rather than standardized practices when addressing the sexual rights and practices of women with DD. This is a noted potential of this type of work in that support staff are largely conducting all of their day-to-day tasks independent of direct supervision (Hewitt & Larson, 2007).

Cuskelly and Bryde (2004) used an "attitude scale…developed by pooling items from previously developed instruments that focused on attitudes to sexual expression of persons with intellectual disability" (p. 257) to gauge the beliefs of various groups of respondents. "Support staff who worked in services for adults" (p. 257) in one non-governmental agency in Queensland, Australia comprised 62 (36.9%; 42 male, 20 female with a plurality between 41-50 years of age) of the 168 participants. Other respondent groups were parents of individuals with ID and a community-sample composed of local undergraduate psychology students. The authors identified eight themes present in the scale: "sexual feelings, sex

education, masturbation, personal relationships, sexual intercourse, sterilisation, marriage,

and parenthood" (p. 258). Each topic was represented by four questions in the scale with an

additional question regarding a general (non ID specific) moral stance on masturbation. Each

question (randomly ordered and evenly distributed between negative and positive language)

was associated with a 6-point Likert scale with no middle rating for 'undecided' or the like.

In the authors estimation "the most liberal views received the highest score" (p. 258). All

questions were framed in reference to "an adult with moderate support needs and an

Intelligence Quotient of 40-55" (p. 258). Cuskelly and Bryde established test retest reliability

(r=0.91) with a subsample (n=51) of the community group. Older members of the staff group

were found to be generally "more conservative" (p. 259) across all domains though responses

were stated to be "generally positive" (p. 259) in the staff group as well as other groups.

Parenthood for persons with ID generated the most conservative responses from the staff

group. Length of time in employment was found to be uncorrelated with staff response

patterns.

　　　　While Cuskelly and Bryde (2004) benefitted from a relatively large sample size, the

study was limited, as noted by the authors, in regards to lack of variation in place of

employment for support staff. It is possible that this portion of the sample was influenced by

the training or policy culture of that particular agency and not indicative of support staff

views in the wider community. The authors stated they were unclear as to how many surveys

had been distributed and thus could not make inferences regarding response rate or the

possibility that the group who chose to respond "were those most comfortable with the issue

and who had more liberal views" (p. 261). In addition, while the instrument was generally

detailed, results were presented in a manner that made interpretation of responses to specific

topics difficult. The use of the terminology 'conservative' and 'liberal' was not well defined

and presents a possible issue in interpretation as these terms may have different connotations

geographically. Likewise, the definition of ID was vague, and limited to 'moderate'.

Omission of questions regarding sexuality of people in general or homosexuality, as noted by

the authors, created complications in separating general underlying beliefs of respondents

from beliefs in reference to individuals with ID.

Drummond (2006) stated, "the burning issue in an Irish context is to find a way to

marry the prevailing Catholic ethos with the acknowledgement of the right of people with

intellectual disability to a sexual identity" (p. 28). Drummond utilized the *SAQ-ID* to assess

attitudes toward sexuality in general, as well as in reference to individuals with ID. The

sexuality-specific portion of the instrument consisted of 45 items representing subscales of:

attitudes toward the sexuality of the general population, acknowledgment of the sexuality of

persons with ID, discrimination against sexuality of persons with ID, and attitudes toward

homosexuality in persons with ID. The sample consisted of Irish "primary caregivers" (p. 31;

n=45, 10 male, 35 female). Twenty-seven respondents were identified as "staff" (p. 30) while

the balance were family members. The response rate was 23.4% of the targeted population.

General demographic information as well as religious habits were collected for all

respondents as part of the questionnaire. Results suggested that staff members (along with

parents/family) generally "hold moderate to more open attitudes toward sexuality for people

with an intellectual disability" (p. 31). Staff members were found to have more open attitudes

specifically to homosexuality for individuals identified as ID than parents. Marital status was

correlated with attitudes in the primary caregiver group as a whole with non-married

individuals ranking significantly higher (more 'open' attitudes) than married individuals.

Frequency of religious attendance and age of primary caregiver respondents were both

negatively correlated with general attitude scores (i.e., more frequent church goers or older

respondents had more closed views. More open attitudes to homosexuality and ID were

correlated with increased years of years of education. In summary the data suggested few

differences of attitude (outside of homosexuality) between the parent group and the staff

group. Mediating variables across groups were age, marital status, education, and frequency

of religious service attendance. Thus, based upon these data, an older married individual with

fewer years of education and a relatively higher frequency of church involvement may have

more restrictive views of sexuality for persons identified as ID.

Drummond (2006) acknowledged that this study might have been limited due to low

response rate. In addition, as noted by the author, the topic of sexuality may be sensitive in

the general Irish population. Therefore the group of recruited but non-responding individuals

may have represented a more 'closed attitude' sector of the population this skewing the

results. In addition, as this study was limited to closed response attitudinal questions, there

was no data collected on enacted practices of the participants. Thus, it is unclear if these

attitudes translated into varying levels of applied support. Strengths of the study included the

use of and division of results across two classes of respondents who may, at times, be at odds

in how to support a person with ID.

Bazzo, Nota, Soresi, Ferrari, and Minnes (2007) utilized a hand-delivered

questionnaire (20-item subscale of the 40-item *Sexuality and Mental Retardation Attitudes

Inventory*) to assess the attitudes about sexuality and persons with ID in a group of "social

service providers" (p. 110; n=216, 55 male, 161 female, mean age of 33.56) working in

north-east Italy. Thirty participants were identified as holding community-based "direct care"

(p. 112) roles while the balance were identified as supervisors, managers, or educators. The instrument utilized items which "refer[red] to sexual rights and sexuality stereotypes of individuals with intellectual disability" (p. 112). Response rate was stated to be 100% of the individuals recruited for participation. Responses of direct-care staff indicated a "liberal attitude" (p. 113) toward sexuality and persons with ID. The service sector in which a participant was employed was significantly associated with variance in the sample. Individuals working in managerial positions were identified by the authors as most likely to have more liberal attitudes. Direct care staff were also found to have generally liberal views though slightly less so than the managers. The authors speculated that this variation might have been due to the fact that managers have less day-to-day contact with difficult matters of sexuality than their direct support counterparts. No significant variation of attitude was noted in relation to of educational background.

Strengths of Bazzo et al. (2007) included the use of a professional diversity of respondents all of whom work in a similar service sector. By using a previously examined tool the authors allowed for comparison to other studies using said tool. The 100% response rate is also a clear benefit as it attenuates the possibility of response/non-response bias. This study was limited in the presentation of data. A more thorough breakdown of how respondents answered specific questions/topics would have been of interest even if there were no statistically significant differences between groups. Without this specificity, the reader is left with general, broad-brush findings that do little to provide a sense of detail regarding the issue addressed. In addition, without measuring the attitudes of respondents regarding human sexuality in general it is difficult to determine if responses might have varied with the presence of intellectual disability. In a similar vein, as the generic term of

'mental retardation' was utilized in the instrument it is impossible to surmise if respondent

views might have varied in regards to diagnosis or level of support needs. Issues of possible

gender-related differences (i.e., changes in attitude regarding female versus male sexual

rights) were also not measured. Lastly, there was no measure of how the participants actually

handled events or situations (whether actual or contrived). While attitude is an important

factor it is also important to see if behavior matches stated views.

Evans, McGuire, Healy, and Carley (2009) utilized an anonymous questionnaire to

"assess the attitudes of staff and family carers to the sexuality of people with an ID" (p. 913).

A total of 381 surveys were sent to the "paid staff carers" (p. 914) working in one

community-based program in the west of Ireland. Of the total, 155 (41%) of these were

returned. The same survey was sent to 380 "family carers" (p. 914) of persons with ID. Of

this total, 153 (40%) were returned. The questionnaire used was compiled by the authors

following work with focus groups involved in services for people with ID. It included a mix

of yes/no responses, Likert scale responses, case scenarios, and open-ended "qualitative

sections to allow carers to outline their suggestions for policy/organisational improvements

relevant to sexuality" (p. 915). Topics ranged from talking about sexuality with "service

users" (p. 915), sexuality education and training, rights, and relationships. The scenarios

were open response prompted with the query 'how should this situation be dealt with?'

Topics of scenarios included privacy, pregnancy, and non-intercourse intimacy for people

with ID. Results suggested that staff carers were more likely (53%) than family (29%) to be

comfortable talking about matters of sexuality with individuals identified as ID. Staff carers

were also significantly more likely to report having had such conversations. Staff who felt

unconfident in these topics named training, confusing policies, and potential conflict with

parents as significant mediating variables. A large majority of both respondent groups

endorsed friendships and non-intimate close relationships as reasonable goals for individuals

with ID. Staff carers were also much more likely to allow for the possibility for sexual

relationships for people with ID (55% if ID was described as 'mild' as compared to 0% in the

family group). This was attenuated markedly if the level of ID was described as 'moderate'

(25%) or 'severe' (8%). Ability to marry followed a similar pattern in staff responses with

'mild' reaching 48%, 'moderate' reaching 15%, and 'severe' reaching 5%. Only 4 family

respondents reported marriage as viable and only when ID was described as 'mild'. Decision

to engage in any relationship was seen as a group responsibility by staff respondents though a

large percentage (79%) reported that the service user his or her self should have the main say.

Family carers envisioned relationship decisions as primarily theirs to make (63%), with only

20% stating that the service user should be involved. Matters of privacy (i.e., unsupervised)

in relationships were seen as a right by 42% of staff respondents and 10% of family

respondents. Only 12% of staff and 9% of family reported having received any training in

sexuality and ID. An overwhelming 95% of staff stated they were interested in receiving

more training while only 55% of family carers endorsed the same. Responses to scenarios

appeared equally as disparate. Pregnancy ('mild' ID, consensual relationship) was generally

seen as a failure of support staff from the family perspectives and suggestions for

interventions were punitive. Staff responses tended more towards establishing increased

support for the woman with ID as the pregnancy progressed. In the privacy scenario (young

man with 'mild' learning disability invites girlfriend into bedroom to listen to music) both

groups tended to respond that this was his right but he may need additional support or

discrete monitoring. In the 'public report' scenario (upset community member suspected two

individuals with ID were having sex in a park) both groups tended to suggest clarification of details and exploring the topic of appropriate behavior in public with the individuals. Staff carers were more likely to suggest general discussion of sexuality. In summary, Evans et al. surmised, "the attitudes of staff carers appeared to more closely parallel [recent]…ideological advances in service-user sexuality" (p. 919).

Evans et al. (2009) benefitted from a large sample size and relatively good response rate that was consistent across both groups of respondents. In addition, the tool used for survey, while not normed, was generated through intensive input of many stakeholders and focus groups. This perhaps led to a more honed instrument for the geographic area where the study was located. The authors presented findings in a direct and thorough fashion allowing for comparisons from several different angles. The addition of open-ended scenario responses was a significant strength in that it suggested that the actual actions of respondents may tend to be in line with stated attitudes. Evans et al. was limited due to geographic specificity though this may be said of almost any non-epidemiological study with an administratively defined sample. In addition, there were no items in the survey aimed at measuring general sexual attitudes. It remains unclear if some of the attitudinal differences were informed by the presence of ID or more a function of base beliefs.

Grieve, McLaren, Lindsay, and Culling (2009) compared the attitudes of various types of "care staff" (p. 76) in regards to sexuality and individuals identified as "learning disabled" (p. 76). The total responding sample of 188 respondents (all residents of the UK) was composed of "carers" (p. 79; n=148) and "qualified nursing staff" (p. 79; n=40). Nearly 400 questionnaires were distributed, 265 were returned, but 29% of these were eliminated due to missing data. Thus, the total response rate was ~47%. A significant proportion of the

carer group (n=109) was identified as working in small community facilities while the balance worked in inpatient facilities or large nursing homes. The *Sexual Attitudes Questionnaire* was utilized for all respondents in an effort to gauge attitudes and measure group differences. This instrument covers seven topic areas (e.g., attitudes around homosexual and heterosexual relationships, masturbation, sexual and non-sexual behavior in different settings). The authors added specifiers for each question allowing respondents to provide different answers dependent upon classification of learning disability (i.e., mild, moderate, and severe/profound) though no discrete definition of these terms was provided in the report (other than a brief mention of the ICD-10, 1992) or to respondents. Overall findings suggested that staff working in smaller community based settings were more likely to have "liberal attitudes" (p. 80) regardless of implied level of disability. Community-based staff were also found to have more positive attitudes toward the topic of homosexuality. Gender and age of respondents were not found to contribute to variability across groups. Grieve et al. concluded with a strong statement of the need to educate care staff as they stated a high degree of conservative (i.e., restrictive) attitudes were present in the total sample.

Grieve et al. (2009) was provided strength by a relatively large group of respondents representing a diverse sector of locations and job types. The response rate was fair but this was attenuated slightly by the elimination of a significant amount of surveys due to missing data. There is the possibility that the group of individuals who chose not to respond represented a distinct subgroup and thus the results could be skewed. This study was also limited in similar manners to other survey research discussed above. For instance, if questions regarding attitudes about sexuality in general (without reference to ID) had been included this may have shed light on another mediating variable. Likewise, static,

hypothetical queries without detail regarding an individual's support needs or history are markedly different than real world or applied scenarios. Without these data it is difficult to know if the stated attitudes match practice-based behavior.

Gilmore and Chambers (2010) examined the attitudes of 169 "disability support staff and 50 employees of leisure and service industries" (p. 22) utilizing the *Attitudes to Sexuality Questionnaire – Individuals with an Intellectual Disability (ASQ-ID)* and *Individuals from the General Population (ASQ-GP).* These questionnaires were sent in pairs – one copy regarding male sexuality and one regarding female sexuality. All participants were residents of Brisbane, Australia or the surrounding areas. The group identified as support staff were 69% female and worked "with adults with ID" (p. 23) though no further information was provided about the individuals they supported. The second group worked in the general community (e.g., bowling alleys, restaurants) and was described as "likely to encounter adults with an ID during the course of their employment" (p. 23). Being that 1,200 questionnaires were distributed, the response rate fell at approximately 14%. The authors noted that the respondent sample was "reasonably representative of the Australian population" (p. 24) in regards to age, gender, and educational history. Gilmore and Chambers found that the results of both groups suggested "generally positive attitudes toward the sexuality of individuals with an ID" (p. 24). Both groups however indicated significantly more comfort with the sexual freedom for people without ID than those so identified. The sexual freedom for people identified as ID was "less desirable" (p. 25) when respondents were asked about female sexuality. Males with ID were seen as more sexually impulsive than females by both respondent groups. The support staff group was noted to be significantly less positive than the leisure/service industry group about the ability of individuals with ID to

parent. This was the only significant difference between groups. No variation was attributed to age or educational history.

Gilmore and Chambers (2010) was strengthened by the use of a questionnaire that addressed general attitudes about sexuality as well as these same attitudes regarding individuals with ID. In addition, the sampling of individuals who did not work in the general disability field was a novel instance in this review. This study was limited by a very low response rate. It is possible that those who chose to respond represented a group that was more comfortable with sexuality in general.

Studies that Utilized Qualitative Methods

Parkes (2006) conducted two focus groups (n=4 and n=5) with members of the direct support "staff" from two geographically and administratively separate day-services centers in an unspecified area of the United Kingdom. Parkes stated research question was: "what are the attitudes, opinions and experiences toward sex and sexuality issues involving service users with a learning disability of day care officers working in social services day care facilities?" (p. 33). The focus groups were facilitated by the author in "a private area of the respondents' [respective] day care facilities" (p. 33). General introduction to the topic and informed consent procedures were completed on-site just prior to the recorded group meetings. Full transcripts were composed by the author and then "subjected to text-based analysis which reduced the transcripts into meaningful units" (p. 34). Via this technique the author identified seven general themes across both groups. Theme one concerned the presence of and response to sexual situations at work. Appropriateness of time and place for sexual actions (e.g., masturbation) was characterized as the most common concern rather than the sexuality itself. Participants in both groups stated that personal judgment and rapid

decision-making were common aspects of addressing such issues. Participants did not

mention the use of standardized policies or procedures in this area. Both groups described

efforts to engage outside consultation but expressed frustration at delays in response. Theme

two surrounded the "perceived vulnerability of the participants" (p. 34). In this area focus

group participants voiced concern as to how parents of individuals with ID would respond to

their actions or non-actions. Parents were framed as less open to sexuality and more

restrictive in applied practices of support. Theme three surrounded participants' concerns and

experiences within the larger staff culture of the facilities. In this domain participants

expressed concerns regarding how some staff "were acting from their own moral standpoint

and in breach of the service user's care plan" (p. 35). Theme four involved issues of how

service user's responded to others' oppressive views. Specifically, certain individuals with

ID were described as having double-lives – one set of clothes for times with parents, and one

set of clothes for time away from parents. Theme five was identified as "the emotional

impact of working with service users' sexual issues" (p. 35). While some participants related

feelings of it "being part of the job" (p. 35) others felt that they were sometimes sexually

targeted by individuals with ID in the agency. Also in this theme, participants expressed

frustration at agency or parental practices that limited or denied sexual expression and often

compared this to their own lives. Theme six surrounded how participants explained or

rationalized the sexual behaviors of individuals with ID. The limited examples provided

intoned a level of interpretation of the function of the behavior (e.g., public masturbation

framed as a 'shock tactic'). Theme seven was composed of participant views on same-sex

relationships. Again, the author's examples of this theme were limited and only included the

fact that two participants expressed some "prejudicial views" (p. 35). In one example a focus

group participant described how she immediately intervened (i.e., talked to them) when she found two male service users "messing with each other in the bathroom" (p. 35). Parkes hypothesized that this represented "unconscious homophobia/ heterosexism…and [was] unlikely to have been considered by this participant as part of legitimate expression of sexuality" (p. 35-36). Parkes concluded that the study results suggested a need for more discrete national and agency policies regarding sexual rights for people with ID. He also contended that the study demonstrated the existence of underlying homophobia in services for individuals with ID.

Parkes (2006) benefitted from the use of two focus groups representing separate agencies and the attention to the direct voices of people involved in providing day-to-day supports. Limitations of this study included a closed geographic spread within a relatively culturally homogenous area. As the focus groups were conducted on-site and involved groups of people who work together on a daily basis there is the possibility that the participants edited or adjusted responses due to perceived or actual social pressure. In addition, these types of studies are not able to be generalized to a larger population but do provide detailed insight into one particular set of participants. Parkes made several hypothetical leaps to much larger theoretical constructs (e.g., oppression, homophobia) that appeared to be based on very limited statements of participants. No mention was made of attempts to verify/cross-check the findings with participants. The aspect of fairly open attitudes and themes of conflict with other providers and parents appear to fall in line with other studies in this topic.

Abbott and Howarth (2007) interviewed 71 "direct support staff" (p. 118) representing 20 agencies (in England, Wales, Scotland and Ireland) that provided support to

individuals identified as ID. The authors stated, "[w]e wanted to know how, or if, staff and services were supporting men and women with ID to think about their relationships in general, including intimate and sexual relationships" (p. 118). Participants were recruited via disability message boards and publications as well as by advertisements in gay, lesbian, and bisexual publications. Once agency directors had provided permission, the respondent direct support staff self-selected for participation. The interview format was semi structured which, the authors contended, "allow[ed] for some comparison between staff in different services" (p. 118). All interviews were recorded and transcribed by the authors. A constant-comparative grounded theory approach was utilized to identify themes across all interviews. Identified themes were: (a) general thoughts on sexuality and relationships for persons identified as ID; (b) how bringing up topics of sexuality/relationships was seen as intrusive; (c) lack of confidence to engage in topics of sexuality; (d) policies; (e) training; and (f) concerns about other's reactions. Abbott and Howarth noted they "[i]nterviewed staff who recognized the need to develop better practice in this area a long time ago and who were doing outstanding work. Moreover, we met other staff in other services who were not." (p. 123). Many of those interviewed expressed doubt about their abilities to handle matters of sexuality and relationships for individuals with ID. Sexuality in general was a difficult topic and when the aspect of same-sex relationships was added in there was evidence of increased resistance. Participants commonly expressed that they were unwilling to broach these subjects and preferred to wait for the individuals they support to bring it up. The respondents who expressed comfort and confidence in approaching these topics generally attributed this to trainings and understanding of policy. Many staff members indicated that they were entirely unfamiliar with policies and had received little training. Of those who had received

specific training in sexuality and ID, most found it helpful in their daily work. Many participants described anxiety about negative reactions of family members or other staff members even if they felt they were respecting an individual's rights. Several participants were described as reacting to sexuality only in 'crisis' situations (e.g., residents 'caught' having intercourse) at which time they would defer to their own judgment. The authors concluded that this study pointed to a need for more direct and discrete training for direct support staff both in areas of rights and agency policy. They further contended that agencies must take a more proactive approach to opening discussions regarding same sex relationships as individuals with ID may feel it is a disallowed subject and thus never self-initiate the conversation.

Abbott and Howarth (2007) had the considerable strength of a large number of participants for an interview-based study. Considering that each interview lasted from 1.5 to 3 hours and was then verbatim transcribed, analyzed, re-analyzed and so forth, this is an enormous number of dedicated hours. In addition, the geographic spread of participants was considerable and represented nearly all portions of the UK. Such intensive work adds to the credibility of the project. There were numerous excerpts and quotes from participants included for every theme. This aspect added a robust quality not found in some other interview-based research reviewed above. Unfortunately very little information was provided regarding the details of the locations studied or the populations with whom interviewees worked. This limits the ability for other researchers to consider the transferability of the findings. In addition, no information was provided regarding member-checking procedures to ensure the credibility of findings from participants' perspectives. Likewise, no demographic information was provided. This also limits the ability to consider transferability of findings.

Löfgren-Mårtenson (2009) aimed to "identify, describe, and understand the opportunities and hindrances for young people with [ID] in expressing a variety of sexual expressions such as homosexuality and bisexuality" (p. 21). Further, the author speculated that environmental factors, such as type of received supports, may influence these topics. To that end, Löfgren-Mårtenson conducted a series of interviews with adults identified as ID, staff members who worked in residential and recreational settings, and parents of young persons identified as ID. All were from the same general area of Sweden. A total of 36 "qualitative interviews" (p. 22) were conducted with an equal representation from each group. The author analyzed the data through the lens of symbolic interactionism which views human "behavior [as] symbolic and exist[ing] in a world that is made up of these symbols…[and thus] the way we associate the symbolic meanings to sexuality affect how we think about ourselves, how we relate to others, and how others think and relate to us" (p. 23). Löfgren-Mårtenson also framed the study within the social construction paradigm stating, "one given 'truth' about sexuality does not exist, but instead is learned through what is regarded to be 'normal' or 'natural' behavior" (p. 23). Löfgren-Mårtenson found that the staff members interviewed allowed for the possibility of homosexuality in persons identified as ID but typically framed these possibilities in terms of exploration, and misunderstanding rather than actual sexual preference. Heterosexual relationships were framed by staff members and parents as more 'normal' though "no overtly negative attitudes towards homosexuality" (p. 24) were noted. In general, these respondents indicated they believed homosexuality to be uncommon in persons with ID. In addition, Löfgren-Mårtenson interpreted some responses as indicating the staff member's desire that the people they support do not engage in any behavior that may further ostracize them from peers or the

community as a whole. To that end she speculated, young people with ID may "find it more difficult than others to find outlets and opportunities for an exploration of 'non-normative' sexualities" (p. 25). Young people with ID were noted to be more resistant to the idea of same-sex relationships though the author speculated this may be due to the attitudes discussed above.

Löfgren-Mårtenson (2009) benefitted from the use of a clear theoretical frame and paradigmatic position. The use of actual 'voices' from a variety of perspectives provided more of a sense of the lived experiences individuals with ID may encounter. There was however a paucity of depth to the report on this study. Thirty-six interviews were conducted but only five quotes from participants were included and the results section was quite brief. While limitations in page length may have been a matter of fact in the journal, Löfgren-Mårtenson appeared to spend more space examining her own theoretical position than presenting the words of the participants. In addition, the author mentioned no methods of member-checking to analyze if her findings and interpretations aligned with the intent of the participants. Seemingly large society-wide theoretical leaps were made with few 'in-their-words' examples from the report as presented. Lastly, there was no definition provided of ID, few details regarding the experience or demographics of any participants, and no mention of specific support needs of the individuals with ID who were interviewed. While generalization from naturalist-based research is always a stretch, this study provided too little information to even speculate.

Hamilton (2009) examined the sexual attitudes, beliefs, and practices of thirteen "direct support workers in Aotearoa/New Zealand" (p. 306) who worked in small-scale (i.e.,

four or less residents) community-based supported living homes. Utilizing interviews

Hamilton aimed to address the following questions:

> What happened when sexually related behaviours occurred in an agency group home?
>
> What kinds of sense did workers make of these behaviours? What assumptions did
>
> workers draw on to explain these behaviours? How did these assumptions influence
>
> worker's responses? What were the outcome effects of these responses on the people
>
> who lived in these homes? (p. 306)

Hamilton found that many workers operated under binary assumptions of: normal-abnormal,

able-not able, appropriate-inappropriate, natural-not natural (and so forth), when discussing

concepts or actual instances of sexuality that occurred in the homes where they worked.

Many participants framed their work as that of "protectors…or empowerers [sic]" (p. 309) of

people with ID. The decisions made in the home were often based on in the moment

judgment-calls that Hamilton discussed as stemming these roles and assumptions.

Specifically, the author identified a pattern of staff exhibiting the concept of "doing normal"

(p. 309). In brief, this 'doing normal' belief was tied up in the binary assumptions listed

earlier. If staff members believed that an individual they supported could 'do a normal'

relationship (i.e., heterosexual, physically able, private, "vanilla sex", p. 305) then they were

more likely to support and engage. If these attributes were not present then the staff appeared

less likely to work towards supporting a relationship or general sexual expression. While

interviewed/observed staff members endorsed several ideas that may be considered indicators

of 'positive attitude' toward sexuality and persons with ID, these attitudes were dependent on

perceptions of behavioral function and individual functioning, specifics of context, and

individual details of moment-to-moment interaction. Interestingly, Hamilton noted his

repeated desire to step in and provide direction or advice during observations of these interplays. He avoided doing such as "no matter how instructive involvement in fieldwork might be, it represents an intervention in an already present system of power effects that the researcher will be in a far better position to leave than will the research subjects" (p. 312).

Hamilton (2009) provided an in depth, multi participant, examination of the dynamics present in a set of community residence and how these dynamics may affect the lives of individuals with ID. The reflexive nature of Hamilton's work as he developed theory through interview and observation provided a palpable sense of place and position not present in other reviewed studies. Likewise, Hamilton was able to both capture the attitudes of the direct care staff while simultaneously providing concrete examples of how these attitudes affect practice. Notably, Hamilton did not provide any data regarding sharing or checking these data with the participants. While potentially uncomfortable, this may have added to the picture of how differing views on sexuality and disability interact.

Using a "qualitative research design, which incorporated staff interviews, and retrospective reviews of relevant documentation" (p. 294) Lockhart, Guerin, Shanahan, and Coyle (2009) attempted to define and delimit the term 'sexualized challenging behaviors' in adults with ID. Senior clinical therapists from two ID service providers near Dublin, Ireland nominated potential interview participants. The authors then selected the final participants (5 female, 1 male, all with a minimum of 10 years experience as "staff", p. 292). The interview format, designed by the authors, was semi-structured and "designed to allow the staff to give their perspective on what constitutes sexualized challenging behavior" (p. 294-295). All interviews (mean duration of 47 minutes) were conducted individually in a private setting. In conjunction with this process, a set of archival (i.e., previous six months), agency specific

records, relating to challenging behavior and non-accidental injury/abuse, were acquired and reviewed by the authors. The authors transcribed both interview content and specific information from the records. Transcriptions were "analyzed following a content or thematic analysis approach" (p. 295). Secondary coding of certain transcripts was utilized to establish inter-rater reliability. This process resulted in identification of three main themes (p. 297) each with a set of subthemes as listed in parentheses: (a) defining sexualized challenging behavior (characteristics, setting, impact); (b) differentiating sexualized challenging behavior (characteristics, staff reactions); and (c) special challenge of sexualized challenging behavior (issues for staff, issues related to behavior, issues for person displaying the behavior). Transcript excerpt examples from both interviews and record reviews were provided for each of these areas followed by a detailed discussion of the variations present from report and interview content. Staff attitudes toward these types of incidents ranged from feelings of complexity, repulsion, confusion, and frustration with lack of training. Following compilation and review of all data the authors attempted to provide an operational definition (p. 299; see Chapter 1) of sexualized challenging behavior which they hoped "echoe[d] the importance…of the behavior impinging on the individual's community presence, autonomy, and dignity" (p. 299) without "defining a diagnostic term that could be used to further disempower or stigmatize individuals with intellectual disabilities" (p. 294).

By utilizing the direct words and records of frontline staff Lockhart et al. (2009) exemplified a manner of capturing on-the-ground expertise that may be later utilized for 'top-down' research efforts. This study is limited in that the data compiled were from a relatively homogenous geographic area. It is possible that certain mores of the particular agency or underlying beliefs of that particular region influenced some of the data. Likewise, the

reviewed records were noted to have a preponderance of reports regarding one particular individual supported by the agency. Thus some of the identified definitional themes may be skewed to that individual's particular presentation. While not specifically investigating the attitudes of support staff, enough data was presented to provide a markedly different perspective than in any of the other reviewed studies. The range of sexuality examined in this study represents a less common and less understood aspect of behavior that many DSPs may deal with on a regular basis. While many of the studies mentioned above and below surrounded issues of rights and access, Lockhart et al. provided a window into how DSPs view the sexuality of individuals with ID that falls outside of common ideas of 'appropriate' or 'acceptable'. Indeed, many of the specific behavioral patterns described (e.g., grabbing genitalia of others without permission, repeated exposure and/or masturbation in public locations) would result in legal response if they occurred outside of the ID supports field. The stated attitudes toward these events were generally negative and intense. The matter of how DSPs effectively support individuals who may exhibit such patterns remains unanswered.

Wilson, Parmenter, Stancliffe, and Shuttleworth (2011) used an ethnographic framework of interview, observation, and analysis of artifacts to examine attitudes and practices of 18 "paid disability support workers" (p. 278; 15 female, 3 male) in three Australian community-based residences. These residences represented three different provider agencies. There was no mention of how these particular homes or participants were selected. The authors were particularly interested in how "the theoretical construct of masculinity and…constructs of masculinity acted to shape the sexuality of [men and teenage boys]…with more marked degrees of intellectual disability (moderate to profound)" (p. 277). The authors defined these "more marked degrees" (p. 277) of ID as involving intensive

support needs in hygiene and communication. Interviews with workers (one hour average) were conducted in the residences. A semi-structured format was utilized with focus on the topics of sexual health, masculinity, gender, and gendered caring roles (p. 278). Author observations (documented via detailed field notes) were also conducted in the residences but no information was provided as to the length or frequency of these sessions. The authors utilized a constant comparative, grounded theory approach to identify and analyze themes present in the data. Data-driven themes (p. 278-285) included: (a) self-discovery; (b) hormonal influence; (c) pleasure; (d) staff belief system; (e) duty of care; and (f) staff as interactional gatekeeper. Examples from observation, interview transcripts, and agency artifacts (e.g., policy and procedure documents) were provided regarding each of these themes. The authors surmised an overarching theme of "conditionally sexual" (p. 278) present throughout these data. In essence this was a frame of the sexuality of males with ID *depending* on the constantly changing multi-level interactions of perceived purpose, biological condition, gratification, worker beliefs and values, and worker perceptions and practice of balancing of risk and autonomy. As the authors contended, when certain conditions were met in this stew of intermingling factors – the sexual perceptions and permissions were more open and allowing. When conditions or perceptions changed – the permissions were more restricted. The disability support workers, in the authors' estimation, served as the primary "interactional gatekeepers" (p. 279) for said permissions. Per Wilson et al., what behaviors or options were allowed passage became largely dependent on the mitigating factor of support worker values and beliefs regarding what was normal, appropriate, or acceptable in conjunction with their concepts of the effects of an individual's perceived level of ID. The authors noted a paucity of guiding agency policy to assist or

attenuate these balances of power. Despite this complex interface of nebulous duty, lack of

external guidance, and intimate interactions, Wilson et al. concluded, "staff are performing

admirably, often with ethically and morally challenging issues, within an inadequate policy

structure" (p. 286).

Wilson et al. (2011) represented a detailed and carefully analyzed attempt to capture

the lived experience of DSPs in regards to sexual supports for persons identified as ID. The

extensive use of transcript excerpts and observational summaries provided a window into the

interactions between attitude and action for those in frontline positions. By triangulating

these data with agency artifacts the authors were able to demonstrate a cluster of evidence in

support of many of their findings. This study was limited by a lack of explanation regarding

how the study sites were selected. If sites were identified due to a record of exemplary

performance then the data take on a different tack as compared to a more random selection.

Likewise, it is possible that the consenting participants represented a subset of DSPs in these

agencies who were more comfortable with topics of sexuality, which may in turn, have an

influence on the observed practices. In addition, there was no mention of methods to check

findings with the participants. The authors did not discuss any of the above potentially

limiting aspects. Wilson et al. did acknowledge that ability to transfer ("generalize", p. 287 in

their words) these findings may be limited due to the specific focus on issues of male

sexuality in the context of a staff supported group home environment for persons with more

intensive support needs.

Young, Gore, and McCarthy (2012) conducted semi-structured interviews with 10

individuals (three male, seven female, age range of 17-64) "who worked directly with adults

with ID" (p. 344). Participants were initially recruited through the first author's personal

connections (n=2), which was then followed by a "snowballing approach" (p. 344) of asking initial participants for further contacts. The aim of this study was to assess "whether the gender of people with ID is associated with staff attitudes in the UK towards the sexuality of people with ID" (p. 344). The authors developed the interview based upon topics found in related literature. It was further honed after one pilot interview. The general interview prompts were included in the report. These prompts framed questions in terms of "men and women with ID" (p. 347) with no mention of any methods of further defining 'ID' or related support needs. There was no description of length or location of interviews other than "where possible" (p. 344). Post-transcripting, thematic analysis was utilized and three recurrent topics of conversation (p. 344-345) were identified: (a) women with ID as sexually innocent; (b) men with ID as more sexually driven; and (c) motivations for intimate relationships (i.e., men framed as more physically motivated, women as more emotionally motivated). Overall, the authors concluded that participants' "unfavorable… attitudes correlate[d] with historic, restricted gender stereotypes" (p. 346).

Young et al. (2012) was a very truncated report even for "an initial qualitative study" (p. 345) and thus difficult to fully analyze. It was unclear if participants' statements may have been influenced by first or second-degree relationship with the primary author. No information was provided regarding any specifics of where these individuals worked or the nature of the individuals in their support beyond the label of ID. It is possible that these participants may not have fully fit within my working definition of DSPs though certain quotes appeared to indicate that they worked in small-scale community residences on a day-to-day basis. Excerpts from transcripts were quite brief but author interpretations relatively long and broad-brushed (e.g., "in the context of such attitudes it is unlikely that people with

ID will be supported to develop meaningful intimate relationships" p. 346). In addition, there was no mention of any member-checking process to see if the proposed findings 'rang-true' for participants.

Discussion of Review 2

Overall, the findings of this review may be read as evidence of a move towards the human rights-based conceptualization of sexuality for persons labeled as ID over the past 12-13 years. Similar to the findings of Aunos and Feldman (2002), age was negatively correlated with higher (i.e., more 'positive') attitude scores in many studies. Years of education was positively correlated with higher attitude scores also in a continued pattern from Aunos and Feldman. Only one study (Greive et al., 2009) intimated a sample that leaned away from this position. This is a marked change from the findings of Aunos and Feldman (2002) and suggests that the efforts of self-determination and social justice for persons with ID are gaining a more solid foothold. It is notable that this pattern was evidenced in areas that may be strongly influenced by underlying 'conservative' religious doctrine and practice (e.g., Drummond, 2006; Evans et al., 2009). In addition, the balance of methods in assessing this complicated subject has also shifted. Fully 50% of the reviewed studies were engaged via qualitative/naturalist methods as compared to a small minority found by Aunos and Feldman. The synthesis of methods strengthens the field as a whole as the multitude of involved questions can only be addressed via a diversity of positioning. In combination, these findings provide a breadth and depth of insight that may lead to improved theory, intervention, and outcomes for people with ID.

Despite these promising patterns, concerns remain in regard to: (a) how these matters are conceptualized, labeled, examined, and interpreted; (b) the apparent ongoing lack of

educational and policy supports for DSPs; and (c) geographic homogeneity of study areas. These matters are examined in detail below.

Attitude, Judgment, Training, and Policy

While the compiled evidence from the survey research measuring attitude towards sexuality and persons with ID appears to indicate substantial move towards more open, less restrictive opinion, this must be taken with a grain of salt. In essence, it may be a lot easier to circle a number saying you *would* act a certain was than it is to *actually* act that way. There may be a substantial divide between 'how I wish I was', 'how I think I am', or 'how I think I should answer this question' versus 'how I actually behave'. Noted attitude-behavior researchers Ajzen and Fishbien (1977) found that "[m]easures of attitude will serve to predict behaviors to the extent that [these measures] involve identical target, action, context, and time elements" (p. 914). In other words, for an attitudinal scale to have robust predictive validity, said scale must *specifically* describe exact details of the involved conditions. To complicate matters further, 'in the moment' mood of an individual has been proposed as a key variable in consistency between stated opinion and enacted behavior (Elen, D'Heer, Geuens, & Vermeir, 2013). As these authors noted, integrating assessment of mood into measures of attitude is difficult even when involving something as ostensibly simple as deciding what to eat. From these perspectives, simply asking if an individual approves of sexual relations between people with ID may elicit a 'positive' response. This type of query does not however, engage contextual variables that may influence subtler, less generalized attitudes and related behaviors. Evidence of this divide was found in studies such as Hamilton (2009) and Wilson et al. (2011). In both of thee detailed observation/interview-based studies DSPs were framed as having somewhat 'open attitudes' based upon recorded

statements. Applied practice however, was found to be "conditional" (Wilson et al., p. 275) or based on perspectives of "doing normal" (Hamilton, p. 309). Sexuality and perceived sexual behaviors of individuals with ID (along with the *enormous* array of other work related responsibilities) may reasonably be expected to influence the day-to-day mood of a person working as a DSP. Thus, if we base our perspective of progress in this topic on telescopic attitude measures alone, we may miss great disparity evident under the microscope of applied practice.

Related to the above, several reviewed studies (Abbott & Howarth, 2007; Christian et al., 2001; Hamilton, 2009; Parkes, 2006) found that DSPs often utilize subjective personal judgment in day-to-day and more longitudinal processes of supporting the sexuality of an individual with ID. Lockhart et al. (2009) endeavored to take some of the personal judgment out of classifying/interpreting a particular set of behaviors (i.e., 'sexualized challenging') but the enacted decisions regarding support of a person so inclined went unaddressed. Add to this the common finding of DSP lack of knowledge of policy (Christian et al., 2001; Abbott & Howarth, 2007) or insufficient/absent policy (Lockhart et al., 2009; Wilson et al., 2011) and we find ourselves in a situation wherein "this limitation forces staff to assume the role of interactional gatekeeper, while bearing in mind their duty of care, leaving staff little to guide them but their own belief system" (Wilson et al., 2011, p. 285). Several authors suggested increased efforts in specific training for DSPs (Evans et al., 2009; Grieve et al., 2009; Hamilton, 2009; Lockhart et al., 2009) and DSP participants enthusiastically endorsed access to training as well (Christian, 2001; Lockhart et al., 2009). Being that these same recommendations were made following the review by Aunos and Feldman (2002) I can do little but continue this recommendation.

The 'Terms' of Agreement

As briefly examined in the opening sections, this field of study is fraught with blurry definitional divides. The reviewed studies utilized a wide variety of terms and definitions to refer to individuals identified currently as ID. In many cases, no clear definition was provided whatsoever. Each of these terms and definitions, or lack thereof, comes along with social and individual connotations. How participants conceptualized these implied understandings is impossible to garner from basic survey data. The data from observational qualitative methods was more explicit in these regards. Rather than focusing on a vague, hypothetical 'other' represented by a one or two word label, some of these studies (e.g., Abbot & Howarth, 2007; Hamilton, 2009) were able to provide a richness of detail that, as discussed above, is explicit in the relation of congruence or conflict in the attitude-behavior cycle. When such detail is absent (e.g., Löfgren-Mårtenson, 2009; Young et al., 2012) it is akin to watching the trailer for a movie and then trying to assess character motivations. If attitude-related behavior depends on contextual detail, then the details of labels assigned to individuals and the environments in which they live or work must be provided. Otherwise we may just read the abstract and assume we understand the findings. Qualitative methods may be more suited to this initial 'spilling of ink' and efforts must continue to provide the rich descriptions that may allow the necessary generation of theory in regards to the understudied phenomenon of successful DSP practice (Hastings, 2010).

In addition to the above, the use of the terms 'liberal' and 'conservative', 'positive' and 'negative' to describe individuals' attitudes toward sexuality are at best confusing, at worst problematic. All of these terms are intensely value laden. Liberal and conservative are intricately wound in the current anatomy of local and global politics. The actual meaning of

these terms may vary geographically. Such broad-brush labels imply an intensely diverse

connotation of opinions on all matters of socio-political interactions. Sexuality for persons

with ID is a controversial enough topic as it is. To bring in such charged terms as a matter of

practical definition may re-muddy the waters that seem to be settling.

Further, to simply refer to a DSPs' opinion, that may on the surface appear

restrictive, as 'negative' omits all of the various details discussed above. Before the

application of any such global label, one must make some effort to understand and

acknowledge:

(a) The *specific* individuals (and their correspondent values, opinions, and

preferences) that the respondent supports (e.g., Hamilton, 2009);

(b) The *specific* sexuality situations they are tasked to manage - often independently

with little training, oversight, guidance, or policy (Lockhart et al., 2009; Wilson et

al. 2011);

(c) DSP efforts to achieve a tenuous balance between autonomy (i.e., 'dignity of

risk') and beneficence (i.e., 'duty of care'), often on a moment-to-moment basis,

and again with system deficits in training and policy (Lockhart et al., 2009;

Wilson et al. 2011) or conflicts between policy and practice (Bigby et al., 2009);

(d) Under the social pressures of the input and direction of parents, guardians, and the

larger civil and criminal legal-liability system (Abbott & Howarth, 2007;

Christian et al., 2001; Cuskelly & Bryde, 2004; Evans et al., 2009; Parkes, 2006);

while also

(d) Consistently navigating the rest of a person's life-wide support needs (Hewitt &

Larson, 2007); and

(e) That DSPs do all of this for less pay than most, if not all, other provider-levels in

ID services (Hewitt & Larson, 2007) which logically may affect 'mood' and

resultant attitudinal reports.

Only once all of these factors are considered can one even approach the relative 'value' of

these provider's attitudes or decisions. Of course, progress towards equity of rights and

access is positive. But these progressions occur in a complicated situation and value-

dependent context. As Wilson et al. (2011) contended, "[b]y ignoring these socio-structural

barriers and instead focusing on staff attitude, staff become yet another 'symbol' of

oppression to the lives of people with ID" (Wilson et al., 2011, p. 286). Future studies must

strive to achieve more than umbrellas of assessment regarding concepts that are already

difficult to define. Further, we may be able to glean more from stories of success than

examinations of failure. As implied in the list above – 'failure' may originate from a

multitude of known vectors. The manners by which certain individual DSPs or agencies

navigate the plethora of pitfalls in the effort to ensure equity and access for all has not been

adequately addressed in the literature.

'Where' are we with Sexuality and ID?

Of the 14 reviewed studies, only one, (Christian, et al., 2001) originated in the United

States. The balance was represented by sites and samples in the UK and Ireland (n=7), Italy

(n=1), Sweden (n=1), Australia (n=3), and New Zealand (n=1). Considering that the United

States may have more total individuals labeled with ID living in community-based residences

(and consequently more individual DSPs) then the other represented countries combined, this

discrepancy is shocking. Similar inequity in geographic spread of research has been noted in

regards to the prevalence of psychiatric diagnoses in persons with ID (Buckles, Luckasson &

Keefe, 2013). With America's level of diversity in language and mores, and recent large-scale social-policy shifts (e.g., growing support and enactment of marriage equality for same-sex couples) the current period is ripe for investigating these topics. In essence, further studies must involve a more robust geography of perspective lest we base movement on the few who choose to publish.

Limitations of Review 2

Of course, no review is without limitation and the present is no exception. In a similar vein to the above, reviews on this topic are innately bounded by terminology. My methods of searching for related literature contained a multitude of terms and synonyms via which I hoped to achieve maximum coverage. In an effort to capture the wide array of titles for DSPs I included stems from the many studies I have previously read as well as some based on personal experience. Nonetheless, it is possible, if not likely, that certain studies, which may have fulfilled inclusion and exclusion criteria, were inadvertently overlooked in citation review or not generated by the search terms. On the other side of this process, certain studies that were included may have involved respondents that did not fully fit the definition of DSP provided in Chapter One. In cases such as these (e.g., Young et al., 2012) I chose to err on the 'liberal' side of the equation in hopes of capturing as many related studies as possible. While standardization of job titles would aid in this process – in the global field of supports for persons with ID this is likely not tenable. This situation may be improved by authors of all studies regarding DSPs, irrespective of paradigm, spending at least a brief time collecting and reporting on who it is that is being measured, described, interviewed or observed. In addition, the field would benefit from creation of a consensus definition perhaps initiated by the National Association for Direct Support Workers.

It must be clearly stated that this review is limited due to a lack of studies representing or examining the voices of people with ID. It is, after all, *their* lives and most personal of experiences we have discussed. The fact that part of our practice involves making the very private into the very public (e.g., team meetings, behavioral plans about sexuality, outside consultants) is a difficult conundrum to manage. All of the good theory and practice in the world comes to nothing if it does not match the preferences of those ultimately subject to its power. Unfortunately, inclusion of studies from this perspective was beyond the scope of the current project. In a recent study of valued qualities in DSPs, (Hatton, Wigham, & Craig, 2009) respondents identified as ID named aspects of respect of privacy, putting the individual's needs first, and "how much will they let you get on with your own life?" (p. 63) as key criteria. Certainly these qualities may be related to matters of sexuality. To fully match policy with applied practice, this area of the literature must be examined and expanded.

Review 3: Research Regarding Views, Opinions, or Experiences in Working with People with ID and pSCB

As evidenced in Review 2 above there have been recent developments in the research regarding the roles and views of DSPs regarding general sexuality and people with ID in general. The aspect of individuals experiences, views, or opinions of working with people with ID and behavior labeled as sexually offensive, a sexual offense, or pSCB is a specific subtopic of this research area that requires analysis secondary to the topic of this dissertation. As this area of research is generally sparse, the focus on DSP specific data (as utilized in reviews 1 and 2 above) has been widened here to include *any* providers of services to people with ID. Likewise, the focus on specific locations of service has also been replaced in this

review to include any milieu providing support or treatment to people with ID. While such extended focus of review may diverge from the specific topic of my research, review of this related research provided relevant comparative content at later stages of analysis.

Previous Reviews

After a series of searches utilizing various terms, no comprehensive review of research regarding support providers' roles, experiences, views, or opinions regarding work with people with ID and pSCB or sexual offense was located. The closest to this topic appears to be Hollomotz (2014) who conducted a content analysis of "80 articles across 20 academic journals" (p. 189) in order to assess the research regarding "sex offenders with intellectual disabilities" (p. 189). Hollomotz's focus was research published in this domain since the beginning of the twenty-first century. His specific research questions were: "[w]hat data collection methods were used? To what extent were the views of people with ID represented in the published work? What are the subject affiliations of the authors? What topics were covered?" (p. 192). The specific aim of analyzing the involvement or representation of people with ID was "abandoned, as it became evident that few such studies exist" (p. 192). Further, Hollomotz was unable to locate any research pertaining to sexual offense or pSCB by people with ID in several journals that present a specific focus on sexuality and disability, forensic aspects of sexuality, or sociological aspects of ID. He concluded, "[a]fter further investigation, it became apparent that this under-representation is indicative of the relative lack of engagement by social scientists with this field" (p. 193). Demonstrating the relatively small research community invested in this topic, Hollomotz found that forty-five of the 80 analyzed publications involved contributions of just 5 authors. Based upon his analysis Hollomotz concluded,

forensic health professionals are currently left to develop and pursue innovative

assessment and treatment methods with limited support from other disciplines. Social

scientists could, for instance, help to enhance outcomes by focusing on aspects of

social, rather than health care. Such research could further support rehabilitation, risk

management and community reintegration. (p. 195)

As Hollomotz (2014) appears to have attempted the most recent, if not only,

examination related to this topic, his work will serve as the main reference point for the

current review. Upon searching the related research (see method below), however, it appears

that there were certain studies (i.e., Hubert, Flynn, Nichols, & Hollins, 2007; Lockhart et al.,

2009; MacKinlay & Langdon, 2009; Robertson & Clegg, 2002; Taylor, Keddie, & Lee,

2003) not included in Hollomotz (2014). For the purposes of comprehensive analysis, these

studies are included in the present review.

Research Questions for Review 3

The specific questions to be addressed in this review were:

 (a) What is the state of the research regarding roles, views, opinions, or experiences

of individuals working with people with ID and pSCB?;

(b) What methods have been used to conduct research in this area?;

(c) To what extent and by what manners have DSPs been represented in this

research?; and

(b) What are common current recommendations for improvement and future areas of

research regarding ID and pSCB and the work of people who provide support?

Method

Eight articles were identified for this review using a combination of electronic database search, and citation review. The literature was searched for studies that included data on DSP attitudes regarding sexuality and intellectual disability. Specific inclusion and exclusion criteria were as follows.

Inclusion and exclusion criteria. Inclusion criteria were: (a) peer reviewed publications at any date up to February 2015; (b) studies that included any professional, paraprofessional, or other stakeholder group (e.g., parents) in a respondent group; and (c) studies that addressed specifically the views, opinions or experiences of respondents regarding sexual offense or pSCB by people with ID. While stemming from the work of Hollomotz (2014), no cutoff point was established as preliminary investigation revealed certain studies Hollomotz did not include or review.

As the research in this domain is sparse, my intent was to capture as many of the recent or not previously reviewed studies as possible. Therefore, the only discrete exclusion criterion were: (a) studies reviewed by Hollomotz (2014); and (b) studies where 'offense' was investigated and may have included sexual offense but either too little definitional information was provided or the results were congregated without specific attention to offenses of a possibly sexual nature (e.g., Cant & Standen, 2007)

Electronic database search. In order to ensure as complete of an attempt to locate all available research regarding the topic described above searches of PsychINFO, Education Research Complete, Academic Search Complete, and PsycARTICLES were conducted using the basic stem-term of "sex" AND "offense" OR "challenging" OR "problem" AND "support" OR "staff" OR "carer" OR "worker" AND "mental retardation" OR "intellectual

disability" OR "learning disability". This search, conducted in March of 2015, generated 181 entries. The titles and reported keywords of all entries were reviewed for possible connection to the field of intellectual disability and sexuality. The abstract of all articles that appeared to have a connection was then reviewed. Thirteen studies were screened in following abstract review. Full text versions of these thirteen studies were obtained and read in full to assess fulfillment of inclusion and exclusion criteria as described above. Six studies were eliminated secondary to inclusion or exclusion criteria. Elimination was mostly due the research having a focus on sexual abuse directed towards individuals *with* ID rather than potential pSCB *by* people with ID. Via this portion of the process, 7 studies were identified for review.

Citation search. The author screened the reference list of each full-text article found via electronic database search for other studies that appeared relevant. Studies that appeared to fit within the limitations of this review were obtained and read. One additional study was yielded via citation search. This complete process led to the total of 8 studies included in this review.

Analysis Procedures

I obtained and read full-text versions for each reviewed article. Data from each study were compiled regarding sampling method, size, and location, composition of a comparison group (if utilized), tools/methods utilized, stated interpretive positions (if present), findings, and strengths/limitations.

One of the studies examined below (Lockhart et al., 2009) was also included in the second review of the research in this chapter. In this case the examination in this section focuses on the specific aspects of pSCB and the research questions listed above.

Results

McKenzie et al. (2001) noted, "[i]ndividuals with a learning disability who commit sex offences or engage in serious sexually inappropriate behaviour present a challenge to community care policies" (p. 56). Via use of an anonymous questionnaire the authors aimed to examine:

> The number of health and social care staff who have supported or currently support a client with a learning disability who displays sexual offending or sexual offending type behaviour and who have received training in this area. Staff feelings towards the client and his behaviour. Staff confidence and areas of difficulty in supporting clients with such behaviours and strategies that would make this job easier. (p. 58)

The study participants were composed of 81 "social care staff" (p. 59) and 15 "nursing staff" (p. 59) all working in a specific area of England at one of two service providers. The group of social care staff was described as "provid[ing] residential support to clients with a learning disability" (p. 59). The participating nursing care staff "were employed by the health service to provide medium security accommodation to sex offenders with a learning disability in a community setting" (p. 59). No further information was provided regarding the specific duties associated with these positions. McKenzie et al. did not provide a definition for the term 'learning disability'. In review of the relevant literature the authors surmised that individuals with learning disability may encounter differences in how potentially illegal, possibly sexual, actions are addressed by service provider agencies as well as criminal courts. In some cases an individuals actions may be in violation of the law but are not adjudicated. In other cases the same or very similar actions may be adjudicated and result in sentencing. Due to these differences McKenzie et al. "refer[ed] to 'sexual offending type behaviours' and

'sexual offences' to differentiate between those same behaviours which have been dealt with differently in the legal system" (p. 57). Further delineation as to what types of actions may constitute a sexual offense or offending type behavior was present in the participant responses described below. After agreeing to participation, the respondents were provided an author created, seven-item, open response questionnaire, which also gathered basic demographic information (i.e., age and gender) and an estimate of years of work in the field. These sections were followed by two Likert style questions related to participant perceptions of confidence and difficulty in their work with people with learning disability and sexual offense or offending type behavior in comparison to challenging behavior in general. Findings indicated "59% of social care staff were supporting a client who had offended/had a sexual offending type behaviour. All healthcare staff, by definition, supported this group" (p. 59). Only the participants who reported working with individuals who had demonstrated these behaviors were included in the analyses. Respondents described the range of sexual offense or sexual offending type behaviors as encompassing sexual assault towards adults or children, sexual attraction towards minors, exposure, verbal threats of a sexual nature, "inappropriate masturbation" (p. 61), and rape. The authors found that 22.9% of the social care staff and 0% of the health care staff reported having received training in work with people with a learning disability and possible sex offense history/pattern "despite the fact [they worked] in a specialist facility" (p. 63). Both groups reported poor confidence and high perceived difficulty in this type of work. Per McKenzie et al., social care workers reported significantly higher perceptions of difficulty with safety issues being predominant. Negative attitudes towards the situation were found in both groups but "social care staff were significantly more likely than health care staff to hold a negative attitude toward the

behaviour, …while health staff were significantly more likely to hold a negative attitude toward the person" (p. 60). Years of experience was found to be positively correlated with a higher reported confidence in the respondent pool as a whole. Overall, McKenzie et al. found "this study would suggest that a high percentage of social care staff are being expected to support this client group with insufficient knowledge and training" (p. 65) perhaps leading to perceived difficulty and negative attitudes towards individuals receiving supports.

McKenzie et al. (2001) benefited from comparing two groups of respondents who work with a similar population but have differing roles in the support structure. The differences in response to the same queries suggests that professional roles or training may influence individual experience as well as applied practice. The study was limited by a relatively small sample in an isolated geography which may hamper generalization. The absence of clear definition regarding learning disability and description of participant roles or professional expectations is also a limiting factor in this work. Without such information it becomes difficult to know who it is that is being supported or providing support. Due to this, the potential for comparison to similar groups in other agencies or geographies is tenuous at best. Nonetheless, this is one of the few reviewed studies to include a group of participants who appear to fill a role similar to that of DSPs as defined in Chapter One.

Robertson and Clegg (2002), working out of the United Kingdom, conducted individual interviews with six "[q]ualified social workers and community nurses who had some experience of sex offending in men with learning disabilities" (p. 172). In these interviews participants were

> encouraged to discuss male service-users they had worked with who had behaved in
>
> sexually offensive ways and had mild/moderate learning disabilities. Factors affecting

participants' risk appraisals and their confidence in their risk judgment skills were

gathered through open questions about risk. (p. 172)

No definitions were provided regarding the terms 'mild/moderate learning disabilities' or

'sexually offensive'. Utilizing the Leeds Attributional Coding System the authors identified

statements in interview transcripts seen as connected to risk or participants' confidence in

their method of risk assessment. After coding of individual transcripts "the analyses were

then summarized, utilizing the most similarly coded attribution statements from all six

interviews" (p. 172). Per Robertson and Clegg, analysis revealed that participants identified

internal and external influences on themselves as well as service-users. Internal factors that

affected participants' self confidence in risk appraisal were identified as past experience,

related and recent work, file review, an understanding of the literature, and methods of risk

planning. External factors that affected participants' confidence in risk were identified as

poor records, time constraints, "overly positive attitudes of other staff toward the service

user" (p. 173), insufficient support from supervisors, lack of training, and few to no codified

expectations for practice. External factors related to risk posed by service-users were

described by participants as match of individual needs with geography of program

placement, supervision plans, and participant relationships with provider agencies. Internal

service-user attributes contributing to risk were identified as demeanor, low frequency of

concerning behavior, physical size, and lack of empathy. In summary, Robertson and Clegg

stated, "[t]his very experienced group of staff described making strenuous efforts to obtain

sufficient information to develop a balanced view of the risks their clients posed" (p. 174).

Overall, external factors such as training and records were suggested as the most dominant of

participant concerns while interpersonal qualities of service-users were cited less frequently.

Per Robertson and Clegg "[t]his raises the question of whether or not staff in general are striving so hard to reduce the differences between themselves and service-users that they might fail to acknowledge crucial differences when possible abusive behaviour may be taking place" (p. 174). The authors noted "[t]he limitations of the study, including the small number of participants and the modest reliabilities of the attribution codes, preclude broad transferability of findings" (p. 174). Further, Robertson and Clegg suggested "improved risk assessment will not take place if sexual abuse by service-users continues to be minimized by staff and service providers…constructive steps can be taken by services to support staff in taking control of their risk management duties" (p. 174).

Robertson and Clegg (2002) benefitted from the use of a previously designed manner of assessing participant attributions in qualitatively generated data sets. This may allow for similar studies to replicate methods with greater fidelity. Unfortunately, the lack of definition of terms (i.e., learning disability and sexually offensive) limits the ability to generalize or transfer findings. In addition the use of two different sets of service providers (i.e., nurses and social workers) without reporting on the data from each group separately, may have masked variability due to cultures of the specific disciplines (Morse, 2007). Finally, the small sample size (n=6) potentially further limits any attempts at generalizability (Charmaz, 2006).

Taylor et al. (2003) reported on "the initial stages of the development of the staff training programme…in a UK hospital that…provides specialist services to people with disabilities, primarily ID" (p. 204). The two and a half day training and related pre- and post-training measures described in this research were provided to 66 "qualified and unqualified staff working in inpatient and community settings" (p. 204) as part of their work at or with

the hospital. The training was specifically focused on aspects of treatment and support for men with ID and a history or pattern of "sexual aggression" (p. 203) or identified as "sex offenders" (p. 204). No definitions were provided for the terms 'ID', 'sexual aggression', or 'sex offender'. In addition, though no definition was provided of the terms 'qualified and unqualified' the participants were further described as "42 members of staff (mainly nurses) from the inpatient hospital forensic services and 24 staff (a mix of community nurses and social workers who worked in community teams for people with ID" (p. 205). Taylor et al. reported, "[t]he workshop was not explicitly aimed at skills development. Rather it was intended to raise awareness, provide information and introduce participants to a range of issues in this clinically complex and challenging area" (p. 204). Via pre-training questionnaires participants indicated poor understanding of the issue, lack of related skills, and poor confidence as main concerns with 61% reporting having had no previous training in the subject area. As "[t]he workshop was designed to provide a modular, flexible approach so that the experiences, priorities, and interests of the participants could be taken into account…the direct carer as 'social therapist' concept was considered in some detail" (p. 205). Prior to and following completion of the training, participants were asked to complete the *Sex Offender Knowledge and Attitudes Questionnaire.* The *Workshop Evaluation Questionnaire* was completed by participants post training. The authors stated results from these pre- and post-training measures "show there were significant improvements in participants' knowledge and attitudes…[regarding] work with people with ID and histories of sexual aggression" (p. 208). They cautioned, however, "[b]ecause these observations are based on the participants' self reports, caution should be exercised with regard to any conclusions reached since there is no way of knowing if they are accurate" (p. 208).

Taylor et al. (2003) presented the only study in this review that attempted to analyze the effect of training for any staff working with people with ID and pSCB. This is notable in that all of the other studies in this review suggested that training was an essential component as endorsed by respondents. In addition, by tailoring the training to participant areas of interest, the authors demonstrated that such endeavors need not be 'canned' or scripted but instead may be adjusted to meet the needs of those in attendance. The absence of definitions of key terms is, however, an inescapable limitation of this study. Without some definitional base it is difficult to tell of what or to whom exactly the authors were referring. In addition, as the authors noted, self-report data may be difficult to assess in terms of actual effect on participant behavior or practice. There is also the possibility that participants' ratings of improvement may have been partially influenced by a desire to report positively to the researchers who were also the seminar leaders.

Based out of England, Hubert et al. (2007) conducted semi-structured interviews with the mothers of five adolescent boys, identified as "learning disabled" (p. 363) who had a history of sexual offense. No definition was provided for the terms 'learning disabled' or 'sexual offense'. Quoted statements from participants intoned certain aspects of these terms such as "having sex with younger boys" (p. 372), or "going for girls and boys at school" (p. 372), or "accused of rape" (p. 372) regarding sexual offense and "[h]e's more like an eight year old in a way" (p. 371) or "his inability to express himself" (p. 372) regarding 'learning disability'. The mothers were recruited for the study as their sons had been in a specialized psychotherapy "group…set up for adolescents who have been sexually abused and whose sexual behavior indicated that they [had] become abusers" (p. 364). All of the boys lived in the same residence as their interviewed mothers. While the authors described collection of

interview data from a variety of sources (i.e., the boys themselves, teachers, and "paid carers" (p. 364)) the published study

> focus[ed] solely on the experiences and perspectives of the mothers…[as] it is the
>
> mothers who have been the enduring figures in the lives of these boys who, in the
>
> eyes of almost everyone outside the family, have been transformed from victims to
>
> pariahs. (p. 364)

The authors did not identify any discrete method of transcript analysis other than, "[t]he interviews were analysed thematically, through both reading and re-reading of the transcripts, and using the NVivo software package" (p. 365). Via this analysis the authors identified themes regarding: (a) early abuse; (b) the current family situation; (c) management of care for their sons; (d) "making sense of their lives and circumstances" (p. 369); (e) the use or effects of group psychotherapy. Hubert et al. contended that these themes spoke to larger issues of lack of professional support in these specialized situations. Specifically, they concluded,

> it is clear [the participants] lacked competent professional support and practice ideas
>
> to guide them…[and] it is striking that even families in such volatile and vulnerable
>
> situations found that there was little professional experience or expertise available to
>
> their sons, leaving them struggling to make sense of and come to terms with, what
>
> was happening to them. (p. 373)

This general lack of services was compounded by the fact that the participants' "contact with professionals tended to arise in the context of allegations of inappropriate sexual behavior, focusing on damage limitation, rather than being part of an ongoing support service to advise and sustain families living each day in intolerable circumstances" (p. 373). Further, the

authors noted patterns of conflicted conceptualizations within the participant statements. For example, participants often simultaneously reported feelings of contempt for the actions of their sons coupled with strong emotional and protective bonds. Based on these results the authors recommended increased attention to creation or expansion of specialized support services and related government policy.

Hubert et al.'s (2007) inclusion of multiple excerpts from transcribed interviews provided a voice and depth to the study that allowed for more than a basic surface analysis. Via use of qualitative methods the authors were able to access the lived experience of a group of people in a very particular situation, while possibly low frequency, who represent a potentially under supported population in services for people with ID. This depth of exploration was, however, hampered by an absence of any definitions regarding 'sexual offense' or 'learning disability'. With such a small subject pool these data would, presumably, have been accessible and able to be addressed in some fashion if even briefly. The lack of thorough explanation of analytic methods was another limitation of Hubert et al. Without clear explication of methods utilized there may be questions as to composition of themes and validity of interpretations (Saldaña, 2013). Further, the authors did not address any aspects of their subjective experience in the project or previous roles. Absent such examination there is increased possibility of unintentional theory confirmation (Charmaz, 2006).

Lockhart et al. (2009) conducted a series of interviews with six "staff from managerial, clinical, and frontline positions" (p. 295) at an Irish agency specializing in community-based supports (i.e., residential, day services, educational programs) for people with ID. The interviews were intended to "explore [staff] views in relation to sexual

behavior…of individuals with intellectual disabilities" (p. 293). In addition to interview data the authors gathered samples of service documentation over a six-month period. While no definition was provided for the term 'intellectual disabilities', the central aim of Lockhart et al. was to use participant and archival data to compile an inductively informed, empirical definition of "sexualized challenging behavior as it is experienced within Irish ID services" (p. 294). The authors engaged "a content or thematic analysis approach" (p. 295) to apply codes or themes to the transcribed interview data. Once initial codes were devised a second researcher assisted in further refinement and an "independent rater analyzed two randomly selected interviews using the same coding framework" (p. 295) in order to assess reliability (minimum acceptable level of 70%). Via thematic comparison of interview and archival data the Lockhart et al. compiled a provisional definition of pSCB. This definition is used in the present research and may be found in Chapter One. Overall, according to the authors, participant responses suggested that pSCB held a particular status in the spectrum of general challenging behavior. Specifically, "although all challenging behaviors were [described as] inappropriate, sexualized challenging behavior was somehow even more inappropriate as being outside of usual social norms" (p. 298). Participants also commonly noted a lack of training or clear guidelines regarding staff responsibility in these circumstances. There was no process of validation (i.e., member checking) "due to time constraints" (p. 300). The authors cautioned, as the study was conducted in Ireland, "[g]iven the purported influence of culture on the attitudes and experiences of sexuality in general, it would be useful to assess if the current definition remains valid in international populations" (p. 300).

Lockhart et al. (2009) provided one of, if not the first, attempt to define the concept of sexualized challenging behavior via a 'ground-up', inductive process, informed by

individuals who provide day-to-day supports in a community setting. As they noted, previous

and contemporary terminology in this domain has been often driven by legal definitions or

professional researcher (potentially biased) theories and terminology. Further, Lockhart et al.

were clear in their repeated statements regarding the risk of stigmatization that accompanies

many terms regarding sexuality and ID. By focusing the sample in one agency, using

interviews as well as archival data, and including multiple direct quotes from participants, the

authors provided a richness of detail that may allow for transferability of findings. The

absence, however, of member checking procedures, while noted by the authors, threatens the

credibility of their overall interpretations and provisional definition of pSCB.

MacKinlay and Langdon (2009) utilized the *Attribution Style Questionnaire* (ASQ) to

gather information from 48 "direct care staff (46% male; 44% qualified nurses)…recruited

from secure forensic ID services within the East of England" (p. 809). Each participant was

required to have had at least six months experience as a "key-worker for a man with ID" (p.

809) and report awareness of the man's "history of sexual offending" (p. 809). While the

authors did not provide a full definition or method of assessment of ID, they described the

men as having a mean "full-scale IQ = 65.91; SD = 6.10)" (p. 809) and later utilized the term

"mild ID" (p. 812). No discrete definition of 'sexual offending' was provided though the

authors attempted to classify "seriousness of the index offense…[based upon] the maximum

custodial sentence that could be imposed by a court" (p. 810). Each participant was

administered the ASQ twice – once in regard to a specific, recent, general challenging

behavior (CB) of a supposed non-sexual nature exhibited by the particular man with ID with

whom they were most familiar and once in regard to the same client's index "incident of

sexual offending" (p. 810). Results of the two measures were then compared to analyze

potential differences in attribution dependent on behavior type. Using terminology from the

ASQ the authors reported "staff tended to attribute CB as internal to the client, external to the

staff, stable, global, and personal, while controllable by the client and staff" (p. 810). In

contrast, sexual offending behavior scores were similar across most domains but rated as

"uncontrollable by the staff, and slightly controllable by the client" (p. 810). When ASQ

results were correlated to ratings of seriousness of offense there was a "significant positive

correlation between attributions of universality and seriousness…This means that staff

tended to attribute more serious sexual offending as a universal feature of the client" (p. 811).

The authors cautioned against attempts to generalize these findings to other service models

(i.e., community based) as, due to the nature of secure services, "there is likely to be a focus

on order and control" (p. 812). In addition, the authors found

> the relationship between staff attributional style regarding sexual offending and
>
> general intellectual functioning suggest[ed] that staff attribute the sexual offending of
>
> those with lower general intellectual functioning as being caused by factors external
>
> to the client and uncontrollable by the client, suggesting that these clients may not be
>
> held responsible for their sexual offending. (p. 812)

The authors concluded that results suggested the staff's attributions toward this group of men

"may not be entirely correct, and indicates a need for some training of staff who are expected

to work with sexual offenders with ID…[such as] psychological models of offending and risk

assessment as applied to people with ID" (p. 812). Due to the use of strictly correlational

data, the MacKinlay and Langdon cautioned, "the findings lend themselves to development

of further research, rather than provid[ing] definite answers" (p. 812).

MacKinlay and Langdon (2009) was strengthened by the recruitment of a set of participants who all shared similar duties and experiences within the same organization. This aspect of sampling, while possibly limiting to generalizability of findings, allowed for a more in-depth exploration of a particular topic without potentially confounding variables such as history of training or differing cultures of organizations. The authors' exploration of how staff attributions may affect treatment or progress of individuals with ID provided insight into the complicated relationship that may develop between support persons and the individuals receiving services. Further, by using a standardized tool, the authors were able to compare findings to previous research in related fields. The study, as the authors noted, was limited due to the use of strictly correlational analyses. These methods may open up areas of future exploration but cannot be used to examine causative relationships. Again, this study, as several above, failed to provide any working definition of sexual offense or aggression or any clear examples of individuals' offense histories. This limits the depth of presentation and leaves questions as to what population in particular was being studied.

Hutchinson, Lovell, and Mason (2012) utilized semi-structured phone interviews "to examine how community practitioners manage the difficulties of risk assessment in relation to people with a learning disability and a history of sexually offensive or abusive behaviour" (p. 53). The twelve participants worked in a variety of disciplines including "social work (five), nursing (three), psychology (two), psychiatry (one), and independent sector case manager (one)" (p. 56) and were all reportedly involved in the practice of sexual risk assessment for people with "learning disability" (p. 56) who lived in community settings in the UK. No definition was provided regarding the term 'learning disability'. Sexual offensive or abusive behavior was also not discretely defined but respondents reported working with "a

total of 90 clients, a third [of whom were] influenced by legal mandate" (p. 56). Hutchinson et al. aimed to address three questions:

> How do community-based professionals manage the 'science' of risk assessment in relation to men with a learning disability at risk of sexual offending?; What concerns are paramount in the evaluation of learning-disabled sex offenders and their placement in community settings?; and What strategies are employed by professionals to manage risk in relation to learning disabled sex offenders living in the community? (p. 55)

Data collected from transcribed interviews was analyzed using an "elaboration of a comprehensive thematic approach" (p. 56). Coding and categorizing of these data resulted in three central themes: "(1) 'frame conflict' with regard to the risk assessment; (2) 'therapeutic performance' relating to having to do something; and (3) a 'safety outcome' concerning what happens when something goes wrong" (p. 56). In regard to theme one, the authors found "[p]articipants appeared to occupy the gap between objective and subjective elements of risk assessment, yet were simultaneously in the frame for a decision relating to what can be done; the frame conflict is therefore established" (p. 57). Based upon participant responses, the authors connected the theme of 'therapeutic performance' to "[t]he combination of public concern around sex offending behaviour, the diagnosis of learning disability, and legally sanctioned mental disorder [which] amplifies the emphasis on risk to the extent that it must dominate professional case work" (p. 58). Further in this domain, participants' "perceived absence of information sharing, lack of staff support and haphazard supervision and training…provoked feelings of vulnerability, responsibility and inadequacy around fulfilling public expectations" (p. 58). In the final identified theme of 'safety outcome' Hutchinson et

al. suggested that participant responses described "the role of the professional [as] to care for the individual with a learning disability, yet also protect the community, be aware of the relatively high level of risk and the difficulty in ensuring the necessary support, almost anticipating failure through the need to mediate between these opposites" (p. 58). The authors noted the study was limited due to the use of phone interviews and relatively small sample size.

Hutchinson et al. (2012) presented a study that benefited from use of direct (although mostly very brief) quotes from participants. Via inclusion of these data the authors both enhanced the credibility of the project and gave increased voice to those interviewed. The use of qualitative methods allowed for a depth of exploration of individual experience in an area of the research that does not currently have a robust base (Hutchinson et al.). This study was limited due to the use of non face-to-face interview procedures. The authors noted that this method, while easing participant commitment, may have reduced the depth of response and potential for further elaboration or exploration prompted by the interviewers. Similar to several studies reviewed above, there was an absence of any discrete attempt to define terms related to disability or sexual behavior. This, again, limits the ability to understand what particular population is being described and may prevent transferability. Further, as the respondent sample was relatively small and composed of practitioners from a variety of disciplines there may be some question as to how the cultures of each profession vary (e.g., the duties and training of a social worker may differ markedly from that of a psychiatrist) in regard to the posed topic. If there were professional cultural variables in these data, they were lost in aggregation of findings.

Sandhu, Rose, Rostill-Brookes, and Thrift (2012) utilized interpretive

phenomenological analysis to "explore the emotional challenges faced by staff working on a

sex offender treatment programme for people with intellectual disability" (p. 308). No

definition or assessment process related to the term 'intellectual disability' was described.

While no definition of 'sexual offense' was provided, certain excerpts from participant

statements were related to this issue including: "offending against a child or how they've

managed to manipulate and rape a victim" (p. 310); Eight individuals participated in semi-

structured interviews. Each participant was described as "staff who had been 'tutors' running

sex offender treatment groups" (p. 310) with seven of the eight also reporting experience as

health care assistants and one described as a "psychological therapist" (p. 310). The

participants all worked "within a large forensic service for clients with an intellectual

disability, located in a [UK] statutory provider of mental health, intellectual disability and

substance misuse services" (p. 309). Analysis of transcripts focused identification of themes

related to emotional experience as described by the participants. Sandhu et al. reported

themes of: (a) "the empathy challenge" (p. 310); (b) "the emotional impact of group work"

(p. 312); and "dealing with emotional challenges" (p. 313). Sandhu et al. reported using

methods of peer review and member checking to support credibility of the project and

interpretations. In each of the above domains the authors identified sometimes conflicting

viewpoints and emotional descriptions from participants. For example, some participants

described being invested in increasing empathy towards individuals in the treatment group

while others reported avoiding empathy towards group members as a rule. Many participants

reported using humor to attenuate the emotional intensity of the work. This was coupled with

a focus on seeking supervision and peer support when emotional responses were

overwhelming. Overall Sandhu et al. concluded, "[t]he results of this study suggested that the emotional experiences of participants were complex, with both shared and individual aspects a feature of the experience of working on a sex offender treatment programme for people with intellectual disability" (p. 314). The authors noted that the study was limited, as interpretive phenomenological analysis does not address "how directly experiences are available for examination because of the constraints and role of language in constructing meaning by both participants and researchers" (p. 317). In addition, the authors noted that due to the qualitative methods used, the study could not be analyzed for validity or reliability in the traditional senses.

Sandhu et al. (2012) benefitted from inclusion of a multitude of direct quotes from participants. Rather than including a brief quote here and there, each theme was exemplified by multiple, sometimes lengthy, passages from transcribed data. This provided a richness of detail that enhanced the credibility of the project as a whole. In addition, by limiting the participant pool to individuals who worked in a particular position in the organization, the authors attenuated possible 'professional culture' variables (Morse, 2007) that may have been present in other reviewed studies. The mention of peer review and member checking procedures was brief but added to the underlying aspect of credibility in this study. Sandhu et al. was limited by the analytic procedures utilized as the identified themes appeared overly broad and contained multiple points of divergence between participants. This is, perhaps, an inherent quality of interpretive phenomenological analysis as the goal is not to arrive at a unifying or central concept that may apply to all studied cases (i.e., grounded theory) but instead to "provide a rich idiographic account of the possible psychological meaning of a particular experience" (Sandhu et al., p. 316). Finally, in common with nearly all of the

studies reviewed above, the authors did not provide any, even global, definitions of key terms (i.e., sexual offense and intellectual disability).

Discussion of Review 3

In relation to the questions outlined at the start of this review the above studies are addressed in regards to research methods used, representation of community-based DSPs, and common current findings or recommendations.

Research methods. Five of the 8 studies reviewed in this section utilized qualitative methods of data collection and analysis. The three exceptions to this were MacKinlay and Langdon (2009), McKenzie et al. (2001) and Robertson and Clegg (2002). The dominant use of qualitative methods in this domain may speak to the lack of existent clear theory regarding professional practice or personal experience regarding individuals with ID and pSCB and those who provide support.

Representation of community-based DSPs in this research. Of the eight studies reviewed in this section only Lockhart et al. (2009) and McKenzie et al. (2001) utilized a group of respondents that included paid, non-licensed individuals working in community settings with individuals with ID and pSCB. Lockhart et al., however, aggregated data from a variety of individuals within an agency that included management and other professional supervisors. Due to this, there is little potential for understanding the discrete experience of the individuals working in direct support positions. In the other case, McKenzie et al. included too sparse of a definition of participant roles and too small of a sample to be of comparative value.

Of the other studies, participant or respondent groups included individuals working on specialized secure or forensic units (MacKinlay & Langdon, 2009; Sandhu et al., 2014)

licensed or professionally trained specialized practitioners (Hutchinson et al., 2012; Robertson & Clegg, 2002), mothers (Hubert et al., 2007), and individuals whose roles were inadequately specified for identification (Taylor et al., 2003). While each of the reviewed studies helped to elucidate the experience or reported opinions of the included groups, the lack of discrete examination or inclusion of community-based DSPs reveals a significant hole in the research base of this particular topic.

Common current findings or recommendations. Every study reviewed in this section, regardless of method or discrete intent, suggested that there is a dearth of specific education and/or policy regarding support of individuals with ID and pSCB. From mothers of adolescents (Hubert et al., 2007), to presumably highly trained and licensed professionals (Hutchinson et al., 2012; Robertson & Clegg, 2002), to individuals working in specialized services (McKenzie et al., 2001) participants providing direct support or assessment and treatment voiced a desire to improve their abilities concurrent with statements regarding the absence or poor quality of specific training. Perhaps the only exceptions to this were the studies that were conducted in specialized secure or forensic units (MacKinlay & Langdon, 2009; Sandhu et al., 2014). Participants in these studies were not as vociferous in reporting a need for training but respondents in both mentioned lack of clear guidelines as a concern. This is possibly due to the fact that individuals working in or with these types of services are part of an organization providing highly specialized services that may have strictly defined inclusion criteria for admission. Thus, by the very nature of the work, training would likely be more focused.

Other observations. As with reviews one and two above, the geographic distribution of this research was quite limited. Seven of the eight studies reviewed were conducted in

England. The remaining study (Lockhart et al., 2009) was conducted in Ireland. Such lack of variation inhibits a sharing of knowledge that is essential for leaders in this field to engage in order to effect sustainable systems change (Fullan, 2001). In order to understand this particular area of supports in a comprehensive fashion that integrates cultural, linguistic, political, and legal variables there must be efforts at research that spreads beyond the United Kingdom.

Limitations of Review 3

As with reviews one and two above, this review of the research was possibly limited by varying terminology. It is possible that certain studies were inadvertently missed in the search methodology described above due to authors' use of peculiar or unique terms. While the search terms were intended to be as wide as possible, nevertheless certain publications may not have appeared in the results. The search of citations in reviewed works, while intended to attenuate this possibility, did not reveal any further related research. As Lockhart et al. (2009) noted, the field of research in pSCB is hampered by divergent terms and inconsistent definitions. This may add unnecessary complication to an area of research already subject to considerable debate and disagreement.

In addition, in a continuation of a pattern noted by Hollomotz (2014) there were no studies that contained any data provided by individuals with ID. In essence, this is not so much a limitation of the review itself but a limitation of the field in general. It is possible that ethical considerations have limited the voices of individuals with ID and a history of pSCB (Hollomotz). Regardless, without the voices of those who receive, and must live within, sometimes restrictive systems of supports we cannot assume to have a complete picture of the landscape we continue to create. When this is considered in conjunction with the relative

absence of studies that included the views of individuals working as DSPs in community settings, it becomes apparent that there are significant fissures in our attempts to understand these phenomena at essential levels.

Cumulative Discussion of the Three Reviews

In total, 37 studies were reviewed in this chapter with three duplicating across reviews due to topical overlap. Despite widening temporal and/or participant limits from review to review, as the topics narrowed, so did the representative research. Specifically: (a) 18 studies published over approximately 6 years ($m = 3.0$ per year) were identified in review one (i.e., DSP roles and effects); (b) 14 studies (two repeated from review one) published over approximately 14 years ($m = 1$ per year) were identified in review two (i.e., DSPs and sexuality); and 8 studies (one repeated from review 2) published over approximately 14 years ($m = 0.57$ per year) were identified in review three (i.e., experiences and opinions regarding pSCB in people with ID). As the above reviews narrowed in scope certain essential threads were identified:

(a) The role of DSPs encompasses an exceedingly wide array of concrete and subtle actions or purposive inactions that reach nearly every facet of daily life for people with ID (Clement & Bigby, 2009; Clement & Bigby, 2011; Bigby et al., 2012);

(b) When matters of sexuality are introduced into the equation, these duties may become intensely complex, sometimes emotionally charged, affected by geographic and cultural variables, and confusing for specialized practitioners and DSPs alike (Hamilton, 2009);

(c) In circumstances where risk of harm (perceived or actual) is associated with possibly sexual expression, further emotional or professional practice complications may arise for providers at all levels (Hamilton, 2009; Taylor et al, 2003; Wilson et al, 2011)

(d) These difficulties may be compounded by a lack of clear definition of terms which multiplies as factors (e.g., DSP, sexuality, pSCB) are added to the equation;

(e) Poor or absent training and policy resulting in inconsistent support is a common refrain across all reviewed areas (Abbott & Howarth, 2007; Bigby et al., 2012; Christian et al., 2001; Clement & Bigby, 2009; Lockhart et al., 2009; Wilson et al., 2011);

(f) Decisions of how to support or limit, contain or allow, restrict, or ignore are frequently guided by individual and personal variables of DSPs and other support providers (e.g., Abbott & Howarth, 2007; Clement & Bigby, 2009; Christian et al., 2001; Hamilton, 2009; Parkes, 2006; Wilson et al. 2011); and

(g) Very little research (three of the 37) in any of the reviewed areas has been conducted in the United States.

Again, the above reviews evidence a pattern of diminishing academic interest despite the essential role of DSPs, the human rights aspect of sexuality, and the individual or societal risks that may be associated with pSCB. This pattern may be seen in comparison to the history of the manners by which the sexuality of people with ID was first functionally or intellectually eliminated, then contained and problematized, and followed by an explosion of interest that led to slow, halting, systems change (Chapter One). This dearth of research information regarding the experiences of community-based DSPs working with people with ID and pSCB may serve to continue historical trends of public or professional outcry coupled

with sometimes exceedingly slow development of sustainable specialized supports (Mansell, McGill, & Emerson, 1994). Hollomotz (2014), referring to lack of critical criminologist input in the research base, noted, "[i]t appears that disability adds a dimension to the offender identity, which sidelines this group even within a discipline which deals with marginalized populations" (p. 195). The reverse may be said as well. The presence of pSCB appears to sideline people with ID as well as those who provide supports, from a wider presence in the literature.

Moving Forward

As evidenced above, the role of DSPs can be dizzying in variation. While potentially framed as being at a 'low rung' of the ID supports system, DSPs, along with individuals identified as ID, are better framed as the true on-the-ground leaders in a system of constant change. Fullan (2001) provided a clarion call of how one may consider leadership in such a turbulent environment. Through his lens I will briefly examine some aspects of how notions of effective leadership may relate to the concerns present in the current topic of research. In the field of providing support to people with ID, there are managers, agency directors, physicians, specialized therapists and so forth. All of who may envision themselves as leading on a certain topic. This can lead to a silo effect however wherein personal/professional bias/preference tends to guide intervention interests and 'sharing the chair' is an afterthought. When we envision a person or a group as 'leaders', we tend to listen more attentively to what it is they are telling us. One of the primary tasks of effective leaders may be to create other leaders (Fullan) and fully acknowledge those who are already there, but who may be referred to by other, sometimes diminishing, terms. By focusing on what DSPs and individuals with ID have to *tell us* rather than why they will not, at times, listen to

what we are *telling them* we may achieve better relationships and a culture of knowledge

sharing that is essential for effectively and sustainably moving forward (Fullan). In essence

> establishing knowledge sharing practices is as much a route to creating collaborative
>
> cultures as it is a product of the latter. This means that the organization must frame
>
> the giving and receiving of knowledge as a responsibility and must reinforce such
>
> sharing through incentives and opportunities to engage in it. (Fullan, p. 86)

The 'organization' of research in ID has a responsibility to not just share knowledge of the

'credentialed experts' but to acknowledge, access, and share the "tacit knowledge" (Fullan, p.

80) and expertise of all involved individuals - not just those who do the research, but those

who do the work. Undoubtedly, this is not an easy path but we must "resist a focus on short-

term gains at the expense of deeper reform where gains are steady but not necessarily

dramatic" (Fullan, p. 63). By accessing the lived knowledge and perspective of DSPs we may

begin to bridge some of the gaps between governmental mandate, agency policy, personal

preference, and applied practice (Clement & Bigby, 2011).

Hewitt and Larson (2007) surmised, "without DSP stability, quality, commitment,

and competence, the opportunity of people with ID to be valued community members is

greatly diminished" (p. 182). In relation to the above, it is essential to understand that many

of the day-to-day worlds of interactions between individuals with ID and DSPs *are* filled

with success, quality, and commitment. There are surely enthusiastic, energetic, and hopeful

(Fullan, 2001) DSP leaders providing individual, meaningful support in houses all over the

world. As Hastings (2010) noted,

> an important question is why support staff stay in their roles when aspects of their
>
> work are clearly stressful, they are poorly paid, and often poorly supported. Having

some answers to this question might lead us down very different roots [sic] for

practice than questions that are more negatively focused, such as why staff become

stressed at work and why they leave their roles (p. 210)

He further suggested, "[q]ualitative research might also be helpful to inform additional

dimensions of relationships in this context that need to be incorporated into suitable

measures" (p. 209).

Thus, qualitative research regarding the experience of DSPs who work with

individuals with challenging or intense reputations may help to create a more inclusive moral

purpose (Fullan, 2001), build theory, provide starting points for quantitative exploration,

while also spotlighting the unsung leaders and success stories that currently appear to lie at

one tail of the curve of professional research interests. Again, these issues are brought into

greater relief when the topic of sexuality enters the equation. As examined in Chapter One,

sexuality may be seen as a driving force behind many of the policy and practice

developments (or lack thereof) in American systems of supports. With the addition of

sexually related *risk*, (e.g., 'offensive', 'problematic', 'challenging') the algebra becomes

significantly more complex, the research significantly less robust. Those who work as DSPs

in community settings are in a unique position of mediating the interactions of

external/environmental (e.g., agency policy, professional direction, community interaction),

personal (e.g., their own preferences, experiences, habits, biases) and *individual specific*

(e.g., supports intensity of the individual receiving services) variables (for 'bad' or 'good') in

their day-to-day efforts to engage individuals receiving supports (Bigby et al., 2012; Clement

& Bigby, 2011).

The matter of language here is again germane. Our current conceptualizations of ID (Schalock et al., 2010) direct us towards a matching of longitudinal *supports*, not comprehensive, longitudinal *agreement.* One's attitude toward a certain topic need not determine one's ability to manage related issues in a professional manner – especially if that is the job one is paid to do. In perhaps too simple of terms, I do not have to 'have a positive attitude' about coffee in order to work in a coffee shop. It may help, but certainly it is not a requirement. Following policies and procedures while at work and enacting *my* values during *my* time may meet the goals of both parties. Policy and procedure, however, can only function if the result 'works'. The men and women working as DSPs may know as much about *individuals* as textbooks or journal articles may tell professional researchers about *populations* (Bradshaw & McGill, 2015). If our 'knowledge' is going to work (i.e., improved outcomes) for people with ID and sometimes complex clinical situations, then logically it must also work (i.e., be achievable and replicable) for the individuals providing direct support.

Certainly sexuality is more complex than coffee, but the fact remains that effective work is being done by a multitude of individuals and agencies in areas of support that are sometimes even more challenging than 'simple sexuality'. For example, it would be difficult to find anyone who 'has a generally positive attitude' about individuals who sexually assault another person. Yet, work has been done in some US statewide programs (e.g., McGrath, Livingston, & Falk, 2007) for individuals with ID, to both effectively manage concerns about sexual risk to others while engaging in ongoing efforts to make sure all individuals 'have a life' rather than a series of often unnecessary walls based on attitude. To be blunt, some practices of 'managing' sexual risk in persons with ID could be considered extralegal

violations of human rights (J. Haaven, personal communication January 7, 2014) that go on

unabated due to the power differentials in who gets to decide what is 'right' and allow or

deny across a life wide series of permissions. While the dynamic assessment of the risk in

individuals with ID and a history of sexual offense is an area of burgeoning research (e.g.,

Blacker, Beech, Wilcox, & Boer, 2011) the voices of the individuals employed as DSPs in

these successful community based services are largely absent from the literature. As the role

of DSPs in these programs is seen as essential (Boer, McVilly, & Lambrick, 2007), this is a

vacuum that begs to be filled. How these DSPs, and the agencies wherein they work,

conceptualize and enact 'risk', 'rights', and 'sexuality' for persons with ID and concerning

histories represents an area of research which appears absent of theory due to a void in the

bodies of research. In order to begin to address this dearth of information, a careful and

focused examination from a qualitative perspective is outlined in Chapter 4.

CHAPTER 3 EXPANDED RESEARCHER STANCE

Overview

In the following sections I describe aspects of my personal and professional history

that I see as related to this research process. In general, as introduced in Chapter One, aspects

of these experiences may have influenced choices I made throughout the investigation. By

closely examining these experiences I aim to elucidate potential areas of bias or blinders. In

analysis sections of the final report I return to these areas in relation to the findings.

Who I Am

I am a heterosexual male in a 20+ year monogamous relationship. I am the father of

two boys aged 12 and nine. I am 'white'. I am 'middle class'. I am an American descended

from Welsh, Scottish, English and French immigrants who settled in the colonies of

Pennsylvania and Virginia in the mid 1600s. My ancestors fought on both sides of the

Revolutionary War and the Civil War. I am the child of still married parents who, while first

generation college graduates, also hold advanced degrees. Two values were prominent in my

upbringing – education and equality. Some of my earliest memories are of civil rights

marches, war protests, and attending university classes with my mother while she finished

her master's degree. These qualities inform my social position and power, influence what

questions I find important, and shape the manners by which I frame data.

Early Educational and Family Experience

Simply put – there were no people with ID visible where I grew up, in my family, or

in the schools I attended. I have asked my parents and classmates about this and no one

seems to have an answer beyond the sarcastic "Well it *was* Shaker Heights – they probably

stopped them at the border". People with ID were, therefore, a mystery to me. I can recall at

age 9 or 10 feeling frightened by a man on the train to Cleveland who had a significant physical difference and spoke in what I considered an odd manner. Shortly after approaching us, the man had a seizure on the floor of the train – something I had never seen. My fear became terror. Prior to my birth, my parents worked at a large facility they described as a 'mental asylum'. They explained to me that the man by whom I was frightened was probably sick and had a mental illness. He was 'harmless' and needed help they said. All I could remember though was their stories of how they quit working at the asylum when a patient admitted to plotting to end my mother's pregnancy via kicking her in the stomach. As I got older and branched out into the world things changed. My friends and I would often end up in the 'seedy' all night diners and coffee shops on the edge of more urban Cleveland, away from the sterile confines of our well-to-do suburb. Somewhere along the line it became apparent that while out and about I had a pattern of approaching (or being approached by) people who were behaving in odd or eccentric fashions. It became a running, albeit insensitive, joke that I was the 'crazy magnet'. While my friends would awkwardly end conversations quickly with these individuals, I would end up spending many hours ditching the planned high school party scene and instead buying bottomless cups of coffee and talking away the night about topics ranging from government conspiracies to alien abduction. Mostly I would just listen. One particular night a gentleman I had talked to many times (who had told me he was called retarded by psychologists but really, according to him, he was 'just scared and maybe a little schizophrenic') told me that I was a "better counselor than his actual counselor". When Advanced Placement Psychology was offered in my senior year – I was the first to sign up. In a still existing video from the end of our senior year I was asked what my goals were. I stated, "I just want to help the people that no one else will help. If I

help just one person in my life I think it will be worth it." During this same period a classmate who was often on the fringes of my core group began having episodes of bizarre, sometimes paranoid, behavior. He was diagnosed with schizophrenia and one night he tearfully told me how people had been stealing the music off of his CDs and replacing it with 'nonsense'. Nothing I said made any difference and, in fact, seemed to make it worse. Within a few months, he was dead. He left the facility where his family had him placed and jumped off a bridge into the Cuyahoga River. I was angry that no one stopped him, protected him, or 'did their job'. I left for college even more determined to make a difference.

Experience as a DSP and Knowledge of the Role

From 1993-1994, after graduating from high school and moving to Manhattan to attend New York University, I worked as a DSP in various community agencies supporting people with ID and/or severe and persistent mental disorders (e.g., schizophrenia, bipolar disorder). The location of my work ranged from the intensely crowded and busy streets of Manhattan to large properties in the foothills of Boulder, Colorado. Looking back at these experiences I primarily recall feeling exhausted. Similar to the sentiments of Craft and Craft (1981), I regularly felt "responsible for all the areas of residents' lives, and this [was] reinforced by the attitude of parents and management committees alike" (p. 495). The general range of duties included cooking (I could barely do this for myself at the time), cleaning (again, major personal issues), medication assistance, chart completion, hygiene, navigation and planning of community activities, skill building/teaching both at home and in the community, and interface with various therapists. All for minimum wage. In addition to the routine, many days were punctuated with 'behavioral problems' (which could run the

gamut from spitting indoors to overt physical aggression) and the related 'behavioral programs' I was to manage, document, and report.

Two particular instances stand out in relation to the topic of this study. In the first, I was 19 years old and living in Boulder, CO alternating shifts between delivering pizzas and being a DSP at a group home. On one sunny day upon arriving at the group home I was assigned to individually support a young man ('Jim', a pseudonym), Jim was perhaps 4-5 years older than I, had lived at this residence for a few months, and had been diagnosed with autism and schizophrenia. I had known Jim for a few weeks - comprising maybe 40 hours of shifts in the house. From my limited exposure Jim had presented as kind, quiet, constantly moving, and fascinated by the same pretty, pop-culture, females of the time as I. The instructions from the house supervisor were succinct: "Take him out, have a good time, but don't let him do anything dumb – especially with girls." In retrospect, my own personal knowledge at that time as to what qualified as 'dumb' in regards to girls was somewhat lacking but nonetheless filled with a mixture of debilitating anxiety and wild overconfidence. As staff at this house we had some cursory training in sexuality, disability, and rights but this was decidedly brief and more pro forma than any in-depth models of applied practice. There was no specific training as to history or concern in regards to Jim's particular situation. In any event, we went to my car and I asked Jim where he would like to go. He replied curtly with an exact address including the zip code and the brief statement of 'have a good time'. My (somewhat more extensive) training as a 'pizza delivery specialist' (PDS) allowed me to know the general location and quickest route. On the way there Jim was generally silent and staring out the window. About a half block from the address I recall feeling a little uneasy as the neighborhood was clearly only residential and Jim's usual knee bouncing had become

nearly a full body rocking. As we pulled up to the address Jim unbuckled, opened the door of the still moving vehicle, literally sprinted to the house, jumped over the stucco fence and ran around to the back yard. Slamming the car into park and yelling for Jim I exited and without much thought entered the property at much the same speed and manner as Jim. He was nowhere to be found. I called out repeatedly, rang the doorbell, honked my horn and sat anxiously in the car for quite a while before deciding to go back to the group home. Upon my arrival, ghost-faced and nauseated, I reported the event to the house supervisor. The response was intense and furious – "What do you mean he *just* ran!? Where the hell is he? Go back and find him! Shit – he probably went to Melanie's and he's got a restraining order!" My immediate (and 19-year-old egocentric) thought was "delivering pizza pays a lot more than this…". I drove around looking for Jim to no avail. Two hours later I went back to the house to find Jim sitting on the front stoop rocking and laughing. The police arrived a little while later and charged Jim with violating the restraining order. I was fired on the spot. After going back to New York City for the start of the new semester I left this brief tenure off of my resume and returned to my jobs as student, bicycle food delivery specialist, and DSP. Within a few months my job as a DSP ended when I refused to enact a behavior plan that called for removal of a television set any time a new resident (also a young man a few years older than I and diagnosed with autism) "became sexual". I believe my response was something to the effect of "He's always sexual – just like all of us, all the time". This, combined with my argument that the television seemed to be the only thing this young man enjoyed, led to the same 'released from duty' result as in Boulder.

Thus, in a relatively short period of time I had encountered both sides of the risk and rights coin. I had seen rights violated due to minor 'infractions' that I and my friends would

trump in 'severity' on any given Friday night. I had been asked to navigate a litany of risks with people I barely knew and guidance that seemed to consist of 'just don't screw it up'. I had received a paucity of formal training or coaching on either topic. Others made key decisions on 'programs' or 'restrictions' – unless something went wrong – in which case it was my fault. As I moved on from the DSP positions I decided again that I would do something to 'make a difference'. Maybe I could decide what was right and wrong. Maybe I could write the plans.

Experience as a Research Associate

During the years I spent in New York City I was an undergraduate at New York University majoring in psychology. As part of my studies, after my work as a DSP ended, I took an internship at a large, well-known emergency and inpatient psychiatric facility. While working in the psychiatric emergency room as well as inpatient psychiatric units I assisted in research projects concerned with presentation of various mental disorders both in the ER and on the inpatient wards. I recall feeling immediately more at ease in this context. The rules were clear, the doors were locked, and the interactions were scripted based upon structured tools. No complicated street crossing, no removal of items (the TVs were bolted down and behind plexiglass), and no cooking.

Following completion of this job I moved on to be a Research Associate in a project related to longitudinal presentation of mental illness in individuals who also had substance use disorders. As part of my duties I would travel to the location (jails, residencies, parks etc.) of the individuals who had volunteered to participate. Again, I felt very comfortable in this position. Not only was my role limited but I also got to be independent - out and about while working on a project intended to help. Once on location I would spend anywhere from

two to six hours going through the motions of a highly structured diagnostic interview. This interview covered all ranges of experience regarding possible symptoms of mental disorder including trauma, depression, suicidal ideation and so forth. Akin to my experiences in adolescence I found that people would tell me nearly anything with only minor prompts or encouragement. Once the interview was completed my next task was to write up a summary of the findings. The format of these summaries was set and followed a standard language. Over the mid to late 1990s I wrote hundreds of reports that referred to individual human beings as 'subject'. Not even '*a* subject' but simply 'subject'. A representative section may have read something like "Subject reports a 25 year history of polysubstance dependence and multiple physical traumas including sexual assault. Subject reports distress and impairment associated with these events." Often, for the sake of brevity, I would simply write 'S' instead of even finishing the word. This strikes me now as a way I might have been distancing my self from the person who had sat across from me for hours, answering a multitude of personal questions into a recorder, from an individual they had never met, wearing a badge from the Department of Mental Hygiene. They were not a person, telling their story. They were one of many *subjects ('Ss')* of a research protocol designed to improve how we categorize individuals into diagnostic labels. I was praised for my reports. They were disseminated as examples of how to do the final write-up. And now, I wish I could go back and shred them. In some (embarrassing) way, the dehumanizing aspect of cold clinical summaries was comfortable for me. I could rest on my laurels, confident that I was doing something of meaning. The research world was cozy and collegial. My primary goal, however, was to gain a license as a mental health counselor. To that end, in 1998, I moved to New Mexico after being accepted into the Master's program in Counselor Education.

Experience as a Mental Health Counselor

After moving to New Mexico in 1998 I began graduate studies in counselor education. After initial classes were completed (and again, while delivering pizzas to make ends meet), I began the process of practicum and internship. In these contexts I was seeing 'real people' with 'real problems' and I was there to be the helper. I was immediately drawn to take my internship at a local community agency that reportedly specialized in 'lost causes'. Truly, this was (and still is) an agency of last resort for many individuals who have been kicked out of or failed to complete programs at other agencies. In many ways I felt I was back to my roots. Talking to the people few others even noticed. I became somewhat notorious for working with individuals who had even burned through the other counselors at this agency and running the so-called impossible therapy groups for people with psychosis and intellectual difficulties (not necessarily ID but cognitive issues stemming from substance use or head trauma as adults). For several years I was happy and complacent – feeling as if I had come to the fore in my high school goals. The tide changed when a long-term client committed suicide by jumping in front of a tractor-trailer on the interstate. I had watched, and tried to help, as this man had experienced devastating symptoms of various physical ailments as well as persistent and severe symptoms of mental illness. I had visited with his landlord in a futile attempt to help him retain his apartment after he had been accused of indecent exposure on the grounds. I had gone with him to the Legal Aid offices, argued with psychiatrists about what I perceived as poor advocacy, signed for a hotel room, met for sessions in parking lots as he lived in his car and refused to go to shelters because he wanted to keep his cat. And then he was gone. Going back into session with other clients seemed impossible. *Subjects*, I thought, were a lot easier to deal with than *people*. In the midst of my

mental gymnastics about how to keep practicing in the shadow of such emotional turmoil a friend suggested that I seek work as a behavior support consultant (BSC) on New Mexico's Developmental Disabilities Waiver (DDW).

Experience as a Behavior Support Consultant

In 2002, after hearing about my experiences as a DSP, a coworker at the counseling agency told me that I *must* seek work as a BSC (known at the time as behavior therapists) on the DDW. There, she said, I could do what I hoped to years before – write the plans, make a difference. With a first child on the way, a more robust paycheck dangled in front of me, and having distaste for the intensity of community mental health, I took the leap. Within a few weeks I had a full caseload and a series of individuals with 'challenging behaviors' for whom I had some modicum of clinical power. I intended to 'use my powers for good'. At first, this seemed great – each person had a full team of interdisciplinary professionals attending to the multiple areas of medical or functional concern. I was not alone. Rapidly invested in this work, I left the agency, opened my own, and began hiring contractors. As the months went on, however, it became clear that I was, perhaps, much too surrounded by others.

Before relating the following scenarios it is important to note that the *vast* majority of teams I joined in the 12 years of work I did as a BSC were filled with intensely creative professionals who practiced with the highest degree of ethics and care for individual choice which resulted in meaningful change for the individuals we supported. This was, however, not always the case. For example, on multiple occasions a variation of the following scenario occurred. We would go around the team meeting table, presenting plans for how to address various areas framed as important to or for the individual receiving services. The physical therapist would present plans for how best to support a person with mobility issues. There

was no argument. The occupational therapist would present plans for accommodating a person's sensory preferences. There was no argument. This would continue around the table – the speech-language pathologist, the nurse, the job development specialist, and so forth with head nods and note taking all around. At some point I would present the plans for addressing what had been identified as a 'behavioral challenge'. Being who I had become through training and experience, I would invariably frame these issues from a quality of life and rights perspective before going down any further technical behavioral roads. Almost immediately the pens were put down, head movement went from up and down to side to side, and the 'suggestions' for punishment and control would come. Common refrains in these contexts were: "People don't learn without consequences"; "He's just being manipulative and we cannot tolerate that"; "What she needs to is just stop that behavior – why don't you focus on that?"; "Next time he does it we should take away his outings/TV/alone time/money/etc. [ad infinitum]." A particular time stands out when we were attempting, as a team, to determine how best to support a young man who had begun to masturbate in the common areas of his day program. One individual on the team suggested: "We should just lop them off [his testicles], that's what we'd do on the ranch if a bull was acting up. I mean, I know we can't, because of '*the state*', but I bet it would work." This was 2007. Others around the table laughed. I was dumbfounded. In the end, I was convincing enough to get the team on board with education, focused redirection, and a gradual shaping program that attenuated his public demonstrations without another mention of castration. In 2008, after literally cutting off a chain that had been placed around a person's refrigerator because 'he eats too much' I entered the follow-up team meeting, which, it turned out, was aimed at addressing *my* challenging behavior (i.e., the cutting of the chain and filing an abuse report).

"Who is feeding [the individual] with all this crap about his 'rights'?!" announced the

residential agency director as she entered the meeting. "That would be me," I volunteered.

This particular exchange ended with a follow-up meeting with the dreaded 'state' where my

position was thoroughly backed up and sanctions handed out. Determined to proceed further

I decided to apply for the doctoral program in Special Education at the University of New

Mexico. This decision was partially selfish (I've always wanted a Ph.D.) but also informed

by my desire to be a better support for people with ID, always seek to know more than I do

right now, and understand how to change systems. This was the decision that led to me

writing these words.

Experience as a Statewide Systems Director

In 2012, after heading a BSC agency for nearly a decade, I decided to make the leap

into public service and apply for my current job – Statewide Clinical Director in the New

Mexico Department of Health, Developmental Disabilities Support Division - Bureau of

Behavioral Support. In this position I, along with my co-workers, have oversight of the entire

system of behavioral services for individuals supported in the DDW. The accomplishments

listed below are not mine alone but are the result of the combined efforts of those who

worked in the department before me and those I am honored to work alongside now. I do not

list our accomplishments in order to receive praise but it is important to note that the paths I

have travelled have, I hope, led to some of these developments. In the two and a half years

since I began we have revamped the mandatory trainings for all BSCs and included much

more robust language in policies around human rights, least restrictive environments, and the

alternatives to punishment. We have ended the contracts of certain BSC agencies that had

repeatedly not adjusted practice to the positive behavior support model utilized in New

Mexico. We have increased our presence in technical assistance meetings with teams to the point that we regularly receive calls saying "This is what we've already done based upon that other case you consulted on." We have improved our system of sexuality support services in a litany of ways. Having been in private practice for so long, my energy at the state offices is often described as 'manic' or driven and I take that as a compliment (though the proper term is probably *hypomanic* as I am still, mostly, functional and focused).

From this position I have noticed there has been a marked increase in the inclusion of voices of people with ID in their team meetings. This is heartening as it was always something I would demand as a BSC – I often would not speak at the table until the individual was given opportunity and support to do so. Concurrent with this, I have also noticed the multitude of ways that DSPs are left out of the conversation. If present in meetings at all, DSPs will typically sit outside of the circle perhaps feeling intimidated by all the folks with letters after their names. If addressed, DSPs are typically simply asked, in a yes or no fashion, if they will take care of the various demands or recommendations proposed by the team. This is not always the case however. Certain agencies, as part of their general culture, provide and perhaps require that people employed as DSPs participate in interdisciplinary conversations regarding progress and planning for individuals with ID whom they support. Gaining their involvement is not as easy but I feel a strong connection to their positions and perspectives stemming from the stories told above. It is this, which drives my current work.

CHAPTER 4 METHODS

Overview

In the following sections I describe the research design and methodology I used to explore the primary research question: how do DSPs describe their experiences in working with individuals with ID and a history of pSCB? as well as underlying queries: (a) How do DSPs in the study sample define or describe behavior that may be of a sexualized, challenging nature?; and (b) how do DSPs conceptualize risk and rights when supporting individuals with ID and a history of pSCB? Specifically, I present rationales for selection of the naturalistic inquiry paradigm, use of semi-structured interview, and grounded theory methods of analysis. I further address approaches used for: (a) selection of research site and participants; (b) securing of informed consent; (c) data collection and analysis; and (d) addressing aspects of participant validation and trustworthiness.

Rationale for Research Design

Naturalist and Positivist Paradigms

Is truth an absolute? Can 'it' be located, examined, and defined? Or are there multiple, sometimes conflicting truth*s* whose discovery depends on context and perspective? Must it be one or the other? Might there be ways for these two perspectives to work in concert rather than conflict? These types of questions have dogged the human experience since the origins of modern philosophical thought (Howell, 2012) and led to significant divides in the ways we go about seeking answers (Lincoln & Guba, 1985). The unitary/multiple truths debate may be framed as a paradigmatic battle of positivism (unitary truth) *versus* naturalism (multiple truths) (Lincoln & Guba, 1985) and a stage is set for intellectual head butting. It is important to understand however, that it is not a matter of

which is 'right' or 'wrong' but how these base beliefs lead to formulation of questions one believes worthy of asking. In essence, the types of questions posed by a researcher are *contingent* on his or her paradigmatic stance (Creswell, 2013; Howell, 2012). From a positivist stance one may ask 'what is *the* answer?' From a naturalist stance one may ask 'what is *your* answer?' While it is tempting to see one's paradigm as superior than another's it is likely more accurate to see differing paradigms as complementary to the research process as a whole. In my own interpretation of these research practices I see positivist research as aiming to illuminate the numerical comparisons that may speak *for* all (or at least a statistical majority) while naturalist research aims to provide rich descriptions, narratives, and analyses that may speak *to* all by uncovering and exploring the individual truths available within the data. While readers of naturalist writings may not agree with the total of the participants' descriptions, they may find overlap that demonstrates a commonality of human experience. In one sense positivist research may aim to tell 'a story of numbers' while naturalist research aims to tell 'a number of stories'. At its base – this represents a difference in notions of what can be known (ontology) and how may it be revealed (epistemology; Howell, 2012; Lincoln & Guba, 1985; Willig, 2010). Positivist epistemology contends that research must be objective and "unbiased…without personal involvement or vested interests on the part of the researcher" (Willig, 2010, p. 3). This is in contrast to the naturalist stance that may contend that "research is dialogic: It is about being in a relationship" (Mayan, 2009, p. 25). This basic philosophical difference results in variation in what questions will be valued, how questions are posed, and what are judged to be acceptable methods of addressing research questions (Creswell, 2013). It is unproductive and divisive to frame one product as better or worse than

the other. They simply represent different answers to different questions that were born of different ways of seeing a complex world.

It may be pleasant to conceive our world of experience and belief as cleanly divided – this or that, white or black. The closer one looks, however, the more difficult it becomes to keep up this façade. All research methods may have portions or specific applications that stem from a naturalist paradigm. Likewise, all may contain portions and specific practice applications that may be conceptualized as branching out from a more positivist perspective. Such mixing of seemingly disparate elements has been referred to as pragmatism – or doing what works as demanded by the questions and conditions at hand (Creswell, 2013). For the purposes of brevity and maintenance of focus on the methods used in this project I will limit my exploration to naturalist applications. To that end, I utilize the synopsis of naturalism as proposed by Lincoln and Guba (1985):

- "realities are multiple, constructed, and holistic" (p. 37);
- There can be no separation of the "knower and the known" (p. 37). It is a reciprocal relationship wherein the actions of one influence and shape the responses of the other in a bidirectional fashion. In this regard cause and effect depend on perspective. The 'cause' from one stance may be seen as the 'effect' from another;
- It is inductive – hypotheses *"emerge from the process"* (p. 38, emphasis added) rather than the research being driven by *preordained theories of causation;*
- Values are an inescapable presence throughout the research and inquiry processes. From the choice of topic to determination of question to the

emergent theories and hypotheses and the interpretation of the data. At each

step the values of both researcher and participant are interwoven, ingrained,

and guiding forces (p. 38).

From the naturalist platform described above, the researcher attempts to access the

perspective of others in the arena. Such a stance demands attention at several levels that may

be informed by the researcher's weighted attention to the values and contextual variables that

s/he finds of greatest importance in the construction of reality (Creswell, 2013). Research

stemming from a naturalist perspective is commonly referred to as qualitative. As the vast

majority of literature in this area uses this term I will switch to it for the duration of the

manuscript.

Rationale for the Selection of Qualitative Inquiry

Hastings (2010) stated, "support staff have been relatively neglected as a focus for

research within [the ID] field [due to] a lack of attention to building a theoretical/conceptual

understanding of the role that support staff fulfill" (p. 207). He further contended,

"qualitative research might…be helpful to inform additional dimensions of relationships" (p.

209) that DSPs encounter in their work with people with ID. Simply put, as there is a paucity

of theory in this domain, there is little to examine from a positivist perspective. Instead, this

area of inquiry first requires "discovering what concepts and hypotheses are relevant" (Glaser

& Strauss, 1967, p. 2). Further, certain qualitative methods of investigation (e.g., grounded

theory – examined in detail below) may be well suited to "open up areas where there is

virtually no literature" (Glaser, 1998, p. 73). As described above, qualitative inquiry revolves

around inductive processes wherein the process of data collection and analysis may result in

generation of hypotheses. Being that the central research questions of this project involved

concepts currently under addressed in the research (Chapter Two) and therefore lacking in well-formed theory, qualitative methods are the best fit.

Rationale for the Selection of Semi-Structured Interview

While there are numerous methods of generating data for a research project, one of the most common, and presumed dominant, is the interview (Mayan, 2009). Some have proposed that we reside in "an interview society" (Atkinson & Silverman, 1997, p. 304) wherein this practice has become "a basic mode of inquiry" (Seidman, 2013, p. 8) and "the most feasible mechanism for obtaining information about individuals, groups, and organizations in a society characterized by individuation, diversity, and specialized role relations" (Fontana & Frey, 2005, p. 699). Underlining this aspect Seidman (2013) posited that an interview may be the most direct manner of accessing a participant's unique perspective and lived experiences.

Semi-structured formats may be one of the most prevalent variations of individual interview methods (Willig, 2010). This subtype involves the researcher having a 'skeleton' of basic questions or prompts that then may lead to more specific questions and elaborations. This specific method of interviewing may illuminate a depth of individualized information not present in many other forms of research (Seidman, 2013; Weiss, 1994). Further, a semi-structured approach provides for interviewer directed focus on specific topics pertinent to the research question(s) while allowing for participant elaboration and discussion of other related topics or concepts important from participant perspective(s) (Seidman, 2013).

The intent of this project revolved around accessing a depth of lived experience and perspective of DSPs concerning specific aspects of their work with individuals with ID. In order to access data germane to the research questions while permitting for the elaboration

essential for inductive generation of theory I chose to use a semi-structured interview as the data collection method. The interview questions may be found in Appendix A.

<p style="text-align:center">**Methodology**</p>

Selection of a New Mexico-based Research Site

Due to the history and current service system described below individuals working as DSPs in New Mexico's Developmental Disability Waiver (DDW) operate in a largely unique atmosphere within contemporary systems of supports for people with ID in the United States. Specific aspects of these distinguishing features are described below.

In many ways New Mexico's path regarding systems of supports for people with ID has mirrored the history of America outlined in detail in Chapter One. Large residential institutions in New Mexico (i.e., Fort Stanton; Los Lunas Hospital and Training School) were created in the early twentieth Century and continued to be the primary residence and community for certain individuals with ID for several decades. Conditions in these facilities may have been much the same as in the institutions described in Chapter One with sexual expression being seen as a discrete behavioral problem and either repressed or punished (C. Heimerl, personal communication, December, 14, 2014). Lagging behind some other states in the path toward deinstitutionalization and normalization, New Mexico's facilities remained open until the late 1990s. The move to close these institutions was, in part, informed by a 1987 federal class action lawsuit (*Jackson v. Ft. Stanton*) against the New Mexico Department of Health (NMDOH), the Human Services Department, and the Division of Vocational Rehabilitation. Following trial "the federal court held that the defendants were violating the rights of the plaintiff class by discriminating against people with severe disabilities and subjecting them to institutional conditions which were unconstitutional in

eighteen discrete areas" (Rucker, 2015, p.1). According to Rucker (2015), initial attempts by the defendants to ameliorate the listed deficiencies were found to be inadequate and, in 1997, "the defendants agreed to implement a detailed *Plan of Action* to improve the infrastructure for the community-based system" (p. 2, emphasis in original). The 1997 Plan of Action covered a variety of concerns including employment, healthcare, and guardianship (Rucker, 2015). In relation to the focus of the present investigation there were specific stipulations regarding sexuality and related behavioral supports. These stipulations and the resultant services developed and initiated since have served to create in New Mexico a system of supports regarding sexuality and ID that is unique in the United States.

ID and Sexuality Services in New Mexico

According to the 2006 revision of the 1997 Plan of Action (DDSD, 2006), beginning in 1995 New Mexico's Developmental Disabilities Division (now called Developmental Disabilities Supports Division, DDSD) "established a plan to meet the sexuality needs of individuals who have been previously institutionalized and develop capability within the state to address individuals' sexuality needs" (p. 94). Among the initiatives established through these processes were: (a) Individual Person Centered Sexuality Assessments; (b) recommendations regarding interventions in situations of pSCB; (c) "provision of training and technical assistance to provider agencies; (d) limited treatment to individuals; and (e) technical assistance to generic service providers" (p. 94, serialization added). In addition to the above, in 2006 the state was tasked with "development and evaluation of a tool specific to assessing sexuality deviance;…and increased training initiatives for teams and practitioners throughout the state" (p. 94). Specifically, DDSD was directed to adopt a Sexuality Services Plan that included a clearly outlined process for "assessing risk,

evaluating needs, and planning, delivering, and monitoring supports to persons with sexually inappropriate or sexually offending behavior" (DDSD, 2006, p. 98). In 2006, as a response to this stipulation the New Mexico Department of Health contracted with James Haaven, a noted expert in sexual risk in persons with ID, to develop said system in fulfillment of the plan.

Per Haaven (personal communication, October 20, 2014) there was a clear decision that any sexual risk screening process would be: (a) longitudinal and dynamic in nature (as compared to a one-time static assessment); and (b) necessarily accompanied and complemented by an in depth sexuality and relationship curriculum available to individuals with ID supported on the Developmental Disabilities Waiver, related support staff, therapists, family members, and natural supports. By 2009 DDSD via the Office of Behavioral Services (now called and heretofore referred to as Bureau of Behavioral Support) had created a multi-pronged system that included: (a) mandatory eight hour training on Sexuality and Intellectual Disability for all DSPs, residential and day service coordinators, paid interdisciplinary team members, and DDSD personnel; (b) a 24-session (three distinct series of eight classes each) Friends and Relationships curriculum; (c) the Preliminary Risk Screening (PRS) service; and (d) ongoing individual-specific technical assistance in matters of possible sexual concern provided by licensed clinicians within BBS. All of these services are described in detail below. Initially, these services were funded under a recurring contract out of State General Funds. In 2012, with the re-application to the federal Center for Medicaid Services, New Mexico's Developmental Disabilities Waiver system was approved to provide Socialization and Sexuality classes as well as the Preliminary Risk Screening services as part of the

available package of funded waiver services (DDSD, 2012) and thus eligible for federal matching dollars.

Preliminary risk screening and consultation (PRSC) related to possibly sexualized challenging behavior. The PRSC process "is part of a continuum of behavior support services…that promote community safety and reduce the impact of interfering behaviors that compromise quality of life" (DDSD, 2012, p. 225). Via a structured risk screening process, PRSC is designed to provide: "(a) identification of individual level and type of risk for inappropriate sexual behavior, and strategies for risk management under the least restrictive supervision conditions; and (b) technical assistance related to the management of risk" (p. 225). Any member of an individual's support team may make a referral to the PRSC service. Following initial screening by a Bureau of Behavioral Support staff member, the individual and his or her team may be scheduled to meet with one of the PRS consultants.

In essence, PRSC is a large group meeting facilitated by a contracted provider deemed qualified (i.e., independently licensed in a mental health related field, extensive didactic and field training/supervision, ongoing external secondary consultation) under the same service standards. The facilitator, using the ARMIDILO-S (largely created in New Mexico; see Chapter One for further description) interviews all participating team members or other concerned parties regarding static and dynamic factors related to sexual risk for people with ID. Particular focus is paid on ensuring the presence and participation of as many DSPs as possible. While screening for potential risk to the individual or others is the main focus of a PRSC session, the entire process is informed by an educational tone and intent. Participants are provided information on specific indicators of risk, methods of attenuating

said risk, as well as acceptable practice in regards to restrictions or limitations involved in support plans for individuals with ID who receive services through the Developmental Disabilities Waiver.

Socialization and sexuality services. Over the first several years of PRSC system development the Bureau of Behavioral Support, in conjunction with externally contracted consultants, developed a curriculum designed to address the educational component of the system of supports. The current iteration of the classes is composed of three series of eight weeks each. Participants meet once a week, for two hours in a classroom setting. Bureau of Behavioral Support contracted providers who have met a set of minimum requirements facilitate the classes. Topics of these classes include but are not limited to: (a) differences between friends, strangers, and acquaintances; (b) techniques and skills for arranging social connections; (c) basic anatomy and physiology; (d) pregnancy and fetal development; (e) consideration of social boundaries; (f) different types of intimate or sexual relationships; (g) mechanics of sexual intercourse; (h) safer sex practices; and (i) sexually transmitted infections or disease. Generally, the further one progresses into the series, the more detailed and explicit the provided curriculum. Like PRSC above, these classes are now a part of the Developmental Disabilities Waiver freedom of choice package of services, may be included in an individual's annual budget, and eligible for federal matching dollars. The vast majority of participants are accompanied and supported by DSPs and/or family members. Any waiver participant is eligible to become a student in these classes though the decision to enroll must be enacted by the individual or his/her legal guardian.

Sexuality training for providers. As part of the sexuality services outlined in the 2006 Plan of Action, the Bureau of Behavioral Supports created a one-day training on the

topics of sexuality and ID. This no-cost, six-hour training covers topics of general definitions of sexuality, gender identification, a brief history of the role of sexuality in support systems for people with ID, ethics and human rights, and case vignettes for small group examination and presentation. This training is required for all individuals working in paid positions on the Developmental Disabilities Waiver including DSPs. Sessions of the training are scheduled as needed but at least 12 times a year and offered in all regions of the state. Repeated attendance is allowed and encouraged. To date, the classes have hosted over 1000 participants (R. Smith, personal communication, March 2, 2015).

Individual-specific technical assistance. As part of DDSD, the Bureau of Behavioral Supports currently employs five full time Regional Behavior Specialists who are locally stationed in each of the five service regions around the state. Each Regional Behavior Specialist is required to be a licensed provider of behavioral health services (i.e., mental health counseling; social work) and receive pre-service or ongoing training in sexuality, intellectual disability, human rights, risk management, and a multitude of aspects concerning positive behavior support. These trainings are provided by external consultants and/or DDSD staff who have particular expertise in the subject area. In many cases Regional Behavior Specialists have gone on to become trainers in one or more of these subjects. The Regional Behavior Specialists are supervised by the Bureau of Behavioral Support Statewide Clinical Director (position currently held by author). All Regional Behavior Specialists and the Clinical Director take part in, and help facilitate, the PRSC sessions in their respective regions. As part of their many duties, this team responds to requests for assistance in situations involving individuals with ID, which may have a presumed or actual sexual component. The content of this assistance can involve agency or team specific training on

risk, sexuality, and/or human rights, assistance in behavioral planning and interventions, and sometimes detailed mentoring of the licensed behavior support providers including observation in individual residences and coaching of DSPs. In certain cases the Bureau of Behavioral Support may recommend or require removal of restrictive practices seen as unjustified by data or clinical judgment of DDSD and external consultants. In other situations the Bureau of Behavioral Support may recommend a consideration of increased support (e.g., lower staff-to-client ratio, environmental modification) when individual risk appears to exceed the current practice. In all cases, the assistance is available longitudinally and intended to be educational, rather than regulatory, in nature. While numbers regarding sexuality specific technical assistance are unavailable, in 2014 approximately 200 teams received support ranging in frequency and duration from one instance lasting 15 minutes to one hour to multiple iterations combining to 40+ hours over the course of the year.

Together, New Mexico's waiver funded educational, screening, and technical assistance services, as outlined above, create a statewide matrix of support unique in the United States (J. Thorne-Lehman, personal communication, October 24, 2014; J. Haaven, personal communication, October 23, 2014). This system has combined many aspects of established and emergent practices, which have stemmed directly from providers and consultants who have been key in the development of sexuality and behavioral services for people with ID since the 1980s. In the past six years, education and ongoing support of therapists and DSPs regarding individuals with ID and pSCB has reached all corners of the state and all provider agencies. As the DSPs working in New Mexico's Developmental Disability Waiver system remain at the crux of how rights, risk, and sexuality are balanced on a day-to-day basis, it is essential to understand how these men and women experience

their work and conceptualize this complicated topic. This is especially germane considering the multitude of changes that have occurred in this system over the past two decades.

In addition, I have an extensive history of experience in the system of supports for people with ID in New Mexico including work as an independently licensed clinical mental health counselor, Behavior Support Consultant, Agency Director of BSC services, and as the current Statewide Clinical Director of the New Mexico Department of Health, Developmental Disabilities Support Division's Bureau of Behavioral Support. In these positions I have designed and conducted multiple trainings for DSPs regarding positive behavior support programs for individuals with ID and pSCB. I have also been trained on the ARMIDILO-S and facilitated numerous PRSC sessions across the various geographic and cultural regions of the state.

In summary, due to the reasons outlined above, I conducted this study in New Mexico and involved participants who have worked, or currently are working, as DSPs in support of individuals with ID and an alleged history of pSCB.

Specific Site Selection and Purposive Sampling

In general, qualitative research endeavors are *not* aimed at "representing a population or increasing the statistical generalizability of…results" (Charmaz, 2006, p. 101). Therefore, the method of sampling participants may be more focused and directed than perhaps wider known random sampling methods. Denzin and Lincoln (1994) stated, "[m]any qualitative researchers employ…purposive, and not random, sampling methods. They seek out groups, settings, and individuals where…the processes being studied are most likely to occur" (p. 202). Willig (2010) described purposive sampling as a process wherein

participants are selected according to criteria of relevance to the research question.

This means that the group of participants are *homogenous* to the extent that they share

the experience of a particular condition, event or situation…which they are asked to

describe to the researcher. (p. 61)

Morse (2007) concurred, "the qualitative researcher must select participants to observe or

interview who know the information (or have had or are having the experience) in which [he

or she] is interested" (p. 232). Further, Morse (2007) cautions against attempts to sample that

aim for representation of the general population (i.e., demographics, culture) as these data

"will contribute variation due to *cultural differences"* (p. 232, italics in original).

Specifically, Morse (2007) contended, utilization of representative sampling results in

pooling of data from all cultural groups and therefore, "all cultural variation is lost in the

analysis" (p. 232). Cultural differences may be present in relation to a variety of factors

including language, geography, and religion. Taking a broad definition of culture as "the way

we do things around here" (Bower, 1996), I contend, due to the policies, practices, and

standard operating procedures that may be unique to each program, the providing agency

wherein a DSP works forms a cultural group. In the systems of supports for people with ID

the culture of the agency has been noted to be a factor in the manners by which direct

supports are provided and sustained (Brown, 2006). Gilbert, Cochrane, and Greenwell (2003)

referred to this as "organizational typology" (p. 781) and stressed the need for "social

policy…to be understood in local contexts" (p. 781). When utilizing a grounded theory

approach, if sampling includes representation of multiple cultures (i.e., in this study –

multiple provider agencies), each cultural group must be sampled to the point of saturation

(Morse, 2007). Such sampling to the point of saturation for each cultural group can quickly

become overwhelming and take the research away from the original intent (Morse, 2007). In addition, being that the topic of this study has not been explored in the literature to date, little is known of the phenomenon under examination. Per Morse (2007), only "[o]nce you understand what the phenomenon is that you are studying [is it then] appropriate to study the variations in meaning in different contexts and groups" (p. 232).

As the research aimed at initial exploration of a specific type of experience, a purposive sampling method that acknowledges the role of organizational typology was the best fit. Specifically, recruitment of participants involved outreach to one agency known to support individuals with ID and presence or history of pSCB. As the systems of supports have developed over the years in New Mexico certain provider agencies have taken on unofficial status as providers of specialized services. To further explicate, while all contracted agencies must serve and support any and all individuals allocated services on the Medicaid waiver program, at times, agencies may have a specialty interest or niche of support structure (e.g., ID concurrent with complicated medical conditions, family living services). In regards to the aims of this research, a handful of agencies have gained positive reputations for supporting individuals with ID and pSCB. Informal discussions with various individuals familiar with the NM DDW program (e.g., State Bureau Chiefs, outside consultants, contracted therapists) were unanimous in naming the study site agency as one of the best in the state for provision of services to individuals with ID and concurrent challenging behavioral patterns. In summary, targeted outreach and purposive sampling at this particular agency, with an established reputation, represented the best choice as "we, [who utilize grounded theory] seek the optimal, rather than the average, experience" (Morse, 2007, p. 234).

In alignment with the above, I recruited and sampled DSPs who worked at a single provider agency. This particular agency specializes in residential services, customized community support (i.e., day habilitation), and employment development for people with ID. While their aim of support has widened over recent years to include a broader demographic of people with ID, this agency has a history of particular expertise and experience in supporting individuals with ID and a history or presence of potential pSCB. The agency director, management staff, and many DSPs at this agency have been consistently involved in all of the state programs and special services described above. Further deep description of this agency follows.

The study site (a 501c3 non-profit corporation) opened in early 2001 as an agency providing services for people with ID via a contract with the state's DDW system. Within six months of opening the agency employed approximately 20 individuals working in DSP and management roles. Residential services were provided to roughly six to eight individuals with ID and located in four typical houses in a metropolitan community. Approximately eight to ten individuals with ID received day habilitation services. At the time of its opening and for several years following the agency retained a specific specialty in provision of services to individuals with a history of pSCB – specifically those with previous or current criminal justice involvement secondary to sexual boundary violations. Over recent years the agency has widened the service scope to focus less strictly upon support of individuals with a history of pSCB. Per the current Executive Director (personal communication, December 21, 2015) this decision was made in order to allow people in their program a greater diversity of social opportunities and a potentially less stigmatizing atmosphere.

As of 2015, the study site agency grew to include: (a) 11 community-based Supported Living houses (i.e. minimum of two but no more than four residents per house and provision of 24 hour staff presence) with 30 total residents; (b) a Customized In Home Supports program (CIHS; independent living) with 20 residents in 19 community-based apartments or houses; (c) a Customized Community Support program (CCS; this state's current terminology for a service similar to day habilitation) with 25-28 participants; and (d) an Employment Support program (i.e., job development and coaching) with 71 participants. Certain individuals may receive all types of services (residential, CCS, and Employment Support) through this agency. The current Executive Director is an independently licensed Clinical Social Worker with 16 years of experience in the field including several spent as a DSP. The Executive Director also works as a Behavior Support Consultant within the DDW and has extensive experience in the Preliminary Risk Screening Program as a trainee.

At the time of this writing the study site agency had 141 employees and gross revenue in 2014 of approximately $3.7 million. While agency records prevented a specific breakdown, data collected from the Administrative Director suggested that approximately 116 (82.2%) of the 141 employees work in positions that are consistent with the definition of DSP provided in Chapter One. Of these 116, 52% (n=60) are female and 48% (n=56) male. Data regarding overall range/mean age, educational history, and length of experience of DSPs at the agency were not available. The Supported Living portion of the agency includes approximately 48% (n=68) of the workforce with Employment Support (25%; n=35), CIHS (13%, n=35), and CCS (9%; n=8) occupying the balance. Certain individuals may work in DSP capacities across these services on a fill-in or as needed basis. In addition, certain employees may work in positions that could be considered 'middle management' (e.g., house

manager, program manager) but continue to work at least 50% of the time providing direct

support to individuals with ID. In addition to the employees and general agency management

personnel the study site also enlists a six person Board of Directors composed of

professionals from various disciplines (i.e., accounting, banking, public administration,

legal). Neither the Executive Director or any employees serve on the board. Consistent with

DDW standards the agency also includes a five member Human Rights Committee charged

with ongoing and as needed review and approval/denial of behavior support interventions

that may include restrictive or possible aversive practices.

Per the Executive and Administrative Directors (personal communications, December

21, 2015), specific to the culture of this agency, there is a particular focus on the retention,

support, professional development, and leadership skills of individuals in middle

management positions (e.g., program managers, house leads). In addition, those in middle

management positions at this agency receive a highly competitive salary, paid time off, and

are not required to be on-call during non-scheduled hours. Specific to DSPs, the Executive

and Administrative Directors stated that they have very rigorous hiring practices with a

significant focus on retention of quality staff. They estimated that following review of

application materials only 50% of applicants receive a face-to-face interview. Of these 50%

only 20-25% will be hired to a DSP position. The starting wage for DSPs at this agency is set

at the federal minimum ($7.25/hour at the time of this writing) but most start at $9.50/hour.

The starting wage may be higher if the individual has experience working with people with

ID. DSPs new to the agency are evaluated at 30, 60, and 90 days post hire with merit raises

dependent on evaluation outcome. In general, following annual and merit raises DSPs at this

agency receive a top wage of around $15/hour. All employees working over 30 hours per

week are eligible for $15,000 of life insurance and receive health insurance benefits for themselves and any dependents with 75% of premium paid by the agency. While there may be variation secondary to support needs at particular residences, weekday shifts at residential locations are, in general, 3:00pm-11:00pm and 11:00pm-9:00am. Weekend shifts can range from 8-14 hours. Any hours above 40 total for a week are paid at time and a half. The Administrative Director estimated that 620 hours of overtime are paid every two weeks with approximately 500 of these stemming from DSP work in the supported living services.

Participants

Participants in this investigation consisted of adults working in the role of DSP at the agency described above. I recruited twelve individuals to participate in the semi-structured interviews. Each interview was conducted individually. Following completion of the interview participants were asked to review transcripts for accuracy and potential clarification. In addition, participants were provided with summaries of the analyses for review and feedback to be integrated into this final analysis and discussion. Both the transcript and analysis reviews were entirely voluntary and not required for participation in the study.

Participant inclusion and exclusion criteria were:

(a) Over the age of 18 at time of interview;

(b) Fluent in spoken English;

(c) Employed as a DSP at the selected site at the time of interview;

(d) At least one year of work history as a DSP;

(e) Stated experience in working with at least one individual with ID and an alleged history of pSCB; and

(f) Provided informed consent to participate;

Participant exclusion criteria were:

(a) Less than one year of experience working as a DSP;

(b) History of work is limited to institutional settings (e.g., hospital, jail, intermediate

care facilities);

(c) Experience is limited to working with people without ID (e.g., people with

developmental disability only); or

(d) Not fluent in English;

Recruitment

Recruitment of participants involved written and verbal outreach to DSPs at the study

site. Written recruitment material included posting of flyers in common areas of the agency.

These flyers included a general statement about the research, inclusion criteria and a phone

number with 24-hour secure voice messaging as well as a dedicated and secure email address

created for the purposes of this research. Verbal outreach included brief presentation, by the

primary investigator, of research goals and methods at six of the regularly scheduled agency

'house meetings'. These meetings included DSPs and house managers for particular

residential locations and typically involve general management communication and review of

current events or concerns. With the permission of the agency director and house managers I

was allowed 10-20 minutes to introduce the general research goals and process, answer

questions, and provide investigator contact information for all attendees. At times, interested

parties approached me directly following the house meetings. In these cases I requested that

the individual call me at a later time to review further and potentially set a time and location

for the interview. In addition, certain participants, after completion of the interview, referred co-workers they thought might be interested to the research opportunity.

Once a potential participant initiated contact s/he was provided further verbal overview of the study and general aspects of participation. In each case I underlined the fact that participation in the study was completely voluntary. To my knowledge there was no implied or stated mandate from agency directors or managers regarding participation. The identity of individuals who choose to participate was not shared with any agency personnel. During this initial contact I also screened potential participants for information regarding inclusion and exclusion criteria as outlined above.

Recruitment efforts were ended after two consecutive verbal outreach sessions resulted in no new potential participants and the flyers had been in place for approximately four months. No additional efforts were made to recruit as the analyzed data revealed saturation across both breadth and depth of codes.

Informed Consent

The Executive Director (ED) and Board of Directors (BoD) of the study site agency were informed of the purpose and methods of the investigation. This agency does not have an internal review board or process for approval of research. As a substitute for an internal approval process the ED and BoD were provided a memo detailing the University of New Mexico Institutional Review Board's approval for this project. Following review of this memo, The ED and BoD choose to grant researcher access to employed DSPs.

Once a potential participant made contact and agreed to general participation, an appointment for the research data collection interview was made at a time and location of the participant's choosing. Locations included DSP's private residences and public locations that

provided a quiet atmosphere and relative privacy. Prior to collection of any demographic information or initiation of the interview I provided each individual with the informed consent document (Appendix B). This document was verbally reviewed in full with all potential participants. Specific attention was given to methods of confidentiality as well as the fact that any participant may end his or her participation at any time for any reason leading to destruction of all partial or completed documents or communications regarding or related to his or her participation. As explained to all participants, the sole exception to document destruction would be the 'voided' original informed consent document in order to document the process and timeline of such decisions. Without researcher presence, all participants were invited to take time to consider the decision to participate. No individuals chose to decline participation following review of informed consent. Following this consideration, signatures were secured on the informed consent document. A full version of the informed consent document was provided to all participants. Only once an individual choose to sign and submit the informed consent document was s/he provided with the Demographic and Experience Information Form (Appendix C) to complete and submit to the researcher prior to beginning the interview session.

Participant Demographics and Experience

At the start of the interview session each participant was provided the Demographic and Experience Information Form (Appendix C) to complete prior to initiation of the recorded interview. Due to the relatively small participant pool and overall community of providers these data were aggregated in order to protect the identity of individual participants. A summary of demographic data may be found in Table 1 and participant experience data may be found in Table 2.

Table 1: *Demographic Information*

Age Range (Mean)	Gender	Race	Ethnicity	Educational History
29-55 (41.2)	8 Female 4 Male	4 - African American	3 - Hispanic	3 - Only High School
		6 - Caucasian/ White	8 - Non-Hispanic	4 - Undergraduate Degree in Process
		1 - Caucasian/Navajo	1 - Chose Not to Specify	4 - Undergraduate Degree Complete
		1 - Chose Not to Specify		1 - Graduate Degree Complete

Demographics. Participants (n=12) were 66.6% Female (n=8) and 33.3% male (n=4) with an average age of 41.2 years (range: 29-55). Caucasian/White was endorsed for race by 50% of participants (n=6) with an additional 33.3% (n=4) endorsing African American, 1.3% (n=1) Caucasian/ Navajo, and 1.3% (n=1) who chose not to specify. Ethnicity was declared as Non-Hispanic by 66.6% (n=8), and Hispanic by 25% (n=3) of participants. One participant chose not to specify ethnicity. All participants reported educational history and included, 25% (n=3) with a High School Diploma alone, 33.3% (n=4) with undergraduate work in progress, 33.3% (n=4) with completed undergraduate degrees but no graduate degree, and 1.3% (n=1) with a completed graduate degree. Participants reported foci/majors of undergraduate work in disciplines of psychology, human services, sociology, criminology, family studies, linguistics, surgical tech, nursing, and 'clinical case work'.

Experience and training. Participants reported a range of experience as DSPs from 19-216 months (1.58-18.0 years) with a mean experience of 128 months (10.66 years). The combined DSP experience of all 12 participants equaled 127.6 years.

Table 2: *Participant Experience*

Months of Work as DSP: Range (Mean)	Person(s) with ID in Family?	Person(s) with ID as friend(s)?	Person with ID in Other Relationship?	Received Training Regarding ID?	Received Training Regarding Sexuality and ID?	Received Training Regarding Human Rights and ID?
19-216 (127.6)	N=4	N=1	N=3	N=8	N=8	N=10

Compensation of Participants

Individuals working as DSPs are often paid near to minimum wage and may work multiple jobs in order to meet financial needs. In other words, their time is valuable. As the interview process involved upwards of two hours to complete and was followed by non-obligatory review of transcripts and findings it was reasonable to compensate individuals for their commitment. I provided all participants who completed the interview process (n=12) a $20.00 gift card to a local business. I purchased these gift cards using personal monies. The cards were given to any participant who completed the initial interview. Provision of the cards was not contingent on the participant completing any of the additional reviews of transcripts or interpretations. As explained during the informed consent discussion, should a participant have decided to withdraw consent following completion of the interview, he or she would keep the gift card. No participants withdrew consent following completion of the recorded interview.

Data Sources and Collection Strategies

Interviews

I employed individual, semi-structured interviews to obtain personal, rich, and detailed descriptions from DSPs about their experiences in supporting individuals with ID who have a history or presence of pSCB. A total of 12 interviews were conducted.

The semi-structured interviews involved the use of an interview guide (Appendix A) which included both verbatim questions to be asked of all participants as well as general topics to be covered. Via this method, I acquired information/responses that were comparable between participants utilizing the technique of grounded theory (Glaser & Strauss, 1967) as presented below. As a grounded theory approach is non-linear (Saldaña, 2013), and may involve adjustment of research focus secondary to the uncovering of specific areas of interest generated by ongoing analysis of data. To that end, certain interview questions (i.e., possible follow-up questions) were included or excluded certain points in the research process (Charmaz, 2006). In addition to the questions from the interview guide participants were prompted to provide further detail via statements such as 'tell me more about that', 'I'd like to hear more about that', or 'how would you define [term used by participant]'.

The average length of the interviews was 81 minutes with a range of 47-113 minutes and a total time spent of 969 minutes (10h 9m). Each interview was completed in a single session with occasional breaks for reasons such as use of the bathroom or phone call taken by participant.

Recording

All interviews were digitally recorded utilizing an Olympus WS-822 GMT Voice Recorder and lapel clipped Olympus ME-52W Noise Cancelling Microphones for both participant and interviewer. Other than brief instances of unintelligible single words or phrases due to background noise in three of the recordings, there were no interruptions in the recordings.

Transcription

As noted by Jenks (2013), "transcribing spoken discourse is a highly complex task that requires making a number of different representational decisions that are inextricably tied to disciplinary and methodological issues" (p. 251). Rather than being an atheoretical process, transcription of spoken words may involve several decisions regarding level of detail (e.g., pauses, non-verbal actions), grammatical representation or correction, and description of context. In brief, "transcription work entails establishing and carrying out a plan to select and transcribe mainly those aspects of spoken discourse that address the theoretical requirements of the researcher, while adhering to the physical confines of the transcript" (Jenks, 2013, p. 254). Thus, manners of transcription represent theories of the researcher (Ochs, 1979) and are also "shaped by…personal biases and proclivities of the researcher" (Jenks, 2013, p. 254). In essence, researchers creating transcriptions must "find their own compromises between comprehensiveness and comprehensibility" (Niemants, 2012, p. 186) In the following sections I outline my methods of transcription.

Closed transcripts. I used a closed transcript for transferring participants' spoken words into a written format. In a closed transcript "[r]esearch questions are used to decide what aspects of spoken discourse will be transcribed" (Jenks, 2013, p. 253). Closed transcripts are less detailed than open transcripts, which may involve notation of micro level pauses, utterances and other detail (Jenks, 2013). My use of closed transcripts included notation of untimed pauses but not detailed paralinguistic features such as vocal tone, facial expression, rate of speech. Further detail on these aspects is described below.

Format. All transcripts followed the same formatting/structure rules of:

(a) Standardized header including the following information: Participant Identifier; Date of Interview; Date(s) of transcription session(s); Duration of transcription session(s);

(b) One-inch margins;

(b) Times New Roman font in 12-point size;

(b) Double-spaced;

(c) Each line numbered and followed by notation of who is speaking in the recorded verbal exchange;

(d) Line number and speaker notation each followed by one-half inch tab space;

(d) New lines started at each change in speaker;

For example:

1   Interviewer (I): Tell me about your experiences as a Direct Support Professional.

2   Participant 1 (P1): You mean like with people or at the agency?

3   I: Your experiences supporting people with intellectual disability.

4   P1: Oh like… [pause]

5   I: I'd like to hear more about that.

6   P1: OK. I guess I have a lot of experiences. All kinds of stuff happens. [laughs]

Representation. "Transcription work entails establishing and carrying out a plan to select and transcribe mainly those aspects of spoken discourse that address the theoretical requirements of the researcher, while adhering to the physical confines of the transcript" (Jenks, 2013, p. 255). As the recorded audio interview data will eventually be destroyed and unavailable to future readers of the completed manuscript, the created transcript and excerpts will be read as the primary source of data (Jenks, 2013). Ochs (1979) contended,

[a] transcript that is too detailed is difficult to follow and assess. A more useful transcript is a more selective one. Selectivity, then, is to be encouraged. But selectivity should not be random and implicit. Rather, the transcriber should be conscious of the filtering process (p. 44)

Thus, it is essential to clarify the decisions related to how participants' spoken words were represented. Within the larger construct of 'representation' in transcripts Jenks (2013) identified four areas that must be considered: readability, granularity, accuracy, and research agenda. Each of these are examined below in regards to this study.

Readability. The "comprehension of the intended audience" (Jenks, 2013, p. 255) was a primary goal of the finished transcripts for this study. Per Jenks (2013) a focus on readability intones the use of standard writing conventions rather than use of specialized notations related to phonetics and micro-analytic representation of paralinguistic features of the recorded interviews. To this end I used the script-like format as provided in the example above.

Granularity. Granularity refers to the level of detail represented in the transcription (Jenks, 2013). Represented details may include laughter, crying, tone, pitch, and duration among many other aspects of spoken language and verbal or non-verbal communication. Certain transcription methods may use highly specialized systems of notation when investigating particular phenomena of communicative events (Jenks, 2013). Per Jenks (2013) such specialized systems may negatively affect the readability of the transcripts. In this study I concluded that readability was of more import than granularity. To this end I included notations of laughter, crying, and pauses in conversation.

Accuracy. Per Jenks (2013) when constructing transcripts researchers must locate their efforts on a continuum between standardization and vernacularization. As the aim of this study is to capture the lived experience of DSPs I believe it is important to be as accurate as possible in reflecting what participants say in an interview as well as the specific words used. At several points, however, during the interview process participants asked that I not use their specific slang or manner of speaking as they felt this could be identifiable to certain potential readers. I had initially intended to use an approach more on the vernacularization end of the continuum, which aims to "represent talk as it is being spoken" (Jenks, 2013, p. 255). In deference to the wishes of participants I opted to err on the side of standardization. For example, should a participant have stated (per my hearing of the recording) "I wanna do better at my job", I wrote in the transcript "want to" rather than retaining the more vernacular "wanna". In relation to granularity above – I avoided including discrete phonetic notations as this would disrupt readability while also being outside of my current expertise.

Research Agenda. This study was concerned with a content-oriented analysis rather than interaction-oriented analysis. Due to this focus, there was less of a requirement for an intense level of detail in transcripts (Nikander, 2008). Specifically, in a content-oriented analysis the primary focus is on the words spoken rather than the prosodic details of tempo, volume, pitch, duration, and intonation (Niemants, 2012; Nikander, 2008). As such, the above stipulations regarding readability, granularity, and accuracy are in alignment with the research agenda. In conclusion, as outlined above, the primary focus of the transcripts was on linguistic and paralinguistic features, which "concern 'what is uttered', i.e. the words pronounced by different participants (including cases where they are inaudible or when the transcriber has difficulty in deciding between alternatives)" (Niemants, 2012, p. 170).

Completion of transcripts. I personally completed all transcripts in their entirety. The average length of time between interview completion and transcription was ten days with a range of 1-14 days. All transcripts were completed on the same day they were initiated. Transcriptions were initially completed in Microsoft Word 2013 for Mac and then transferred to the data management tool Dedoose for ongoing coding, analysis, and comparison. I spent a total of 55.5 hours completing the 12 transcripts (range of 1h 24m to 7h 17m; mean=4h 37.5m). On average 3.44 minutes were spent transcribing any 1 minute of recorded interview (range=2.65-4.46m).

Secondary check. Once transcriptions were entered into the word processing software outlined above, but prior to transfer to Dedoose, I listened to the recording while concurrently reading along with the initial transcript and checking for consistency or errors. These amended transcripts were saved under a different file name in order to track the alterations between documents should further analysis be required or sought regarding the development of the transcripts. Upon review, there were no substantive changes to transcripts between versions. Most changes consisted of correcting missed word order or inclusion of brief, single word exchanges.

Reflexivity related to transcribing. As noted by Jenks (2013) "transcripts are inextricably tied to personal interests, abilities, emotions, and experiences. In other words, a transcript is a reflection of the researcher who created it as well as the context in which it was created" (p. 253). Secondary to this, it is vital that researchers creating and using transcripts reflect on how the factors outlined by Jenks (2013) may have influenced the process. To this end I continually utilized portions of my reflexive journal to reflect on my experience in

transcription throughout the research process and how said experiences may have effected the representation or interpretation of the data.

Data Management and Security

As recommended by Ritchie (2003) all digital audio recordings of interviews were duplicated on to at least two local storage devices (i.e., notebook computer and desktop computer) within 24 hours of completion. In addition, each local storage device was automatically backed up to Dropbox, a secure and password protected cloud storage service. As portable digital recording devices are unable to be secured, the digital recording device was erased once the multiple forms of back up were complete and verified.

I utilized the web-based data management tool Dedoose (www.dedoose.com) to organize, apply codes to, and write analytic memos regarding data from the transcribed interviews. I also utilized the additional level of encryption available through Dedoose. I acknowledge, "such programs cannot *do* the analysis for the researcher…[and the best use of] computer programs [is] to facilitate the management of qualitative data (i.e., sifting and sorting) [while] the true essence of qualitative analysis is based in investigator-insight" (Morse, 2007, p. 233). Methods of data analysis utilized (e.g., coding, analytic memos) stemming from investigator insight are described below.

Any and all local machines, cloud based, or external storage devices were protected by encrypted passwords at multiple levels of interface including upon opening the operating system, upon opening individual files, upon accessing the internet, and upon signing into Dedoose.

Data Analysis

Grounded Theory

Grounded theory, which "is generally regarded as one of the first methodologically systematic approaches to qualitative inquiry" (Saldaña, 2013, p. 51), was engaged as the method of data analysis in this project. First described by Glaser and Strauss (1967), grounded theory is well suited to "open up areas where there is virtually no literature" (Glaser, 1998, p. 73) in order to access and analyze "the basic social processes that explain how people in the substantive area are continually resolving their main concern" (p. 117). Via a cyclical process of data collection, reflection, coding, and memo writing, a grounded theory approach may "ultimately lead to the development of a theory – a theory 'grounded' or rooted in the original data themselves" (Saldaña, 2013, p. 51). Since Glaser and Strauss' initial publication, the suggested processes of grounded theory have been adjusted, expanded, and altered by several authors (e.g., Birks & Mills, 2010; Bryant & Charmaz, 2007; Charmaz, 2006; Gibson & Hartman, 2013; Glaser, 1978; Glaser, 1998; Saldaña, 2011; Strauss & Corbin, 1997; Urquhart, 2012). Specific, sometimes differing, techniques of data organization and analysis (i.e., coding) from a grounded theory perspective have also been proposed (e.g., Glaser, 2005; Saldaña, 2013). For the purposes of the this research I primarily utilized aspects of grounded theory method and analysis as outlined by Charmaz (2006), and Saldaña (2013) and informed by markers of quality outlined by Strauss and Corbin (1997). Charmaz (2006) and Saldaña (2013) traced the development of described methods to a variety of other writings on the topic. Where applicable below, these other authors are cited as well. The specific steps in the utilized analytic process (i.e., collection, coding, constant

comparison, and analytic memo writing) are examined in detail below. A graphic

representation of the overall process from Saldaña (2013) may be found in Figure 1.
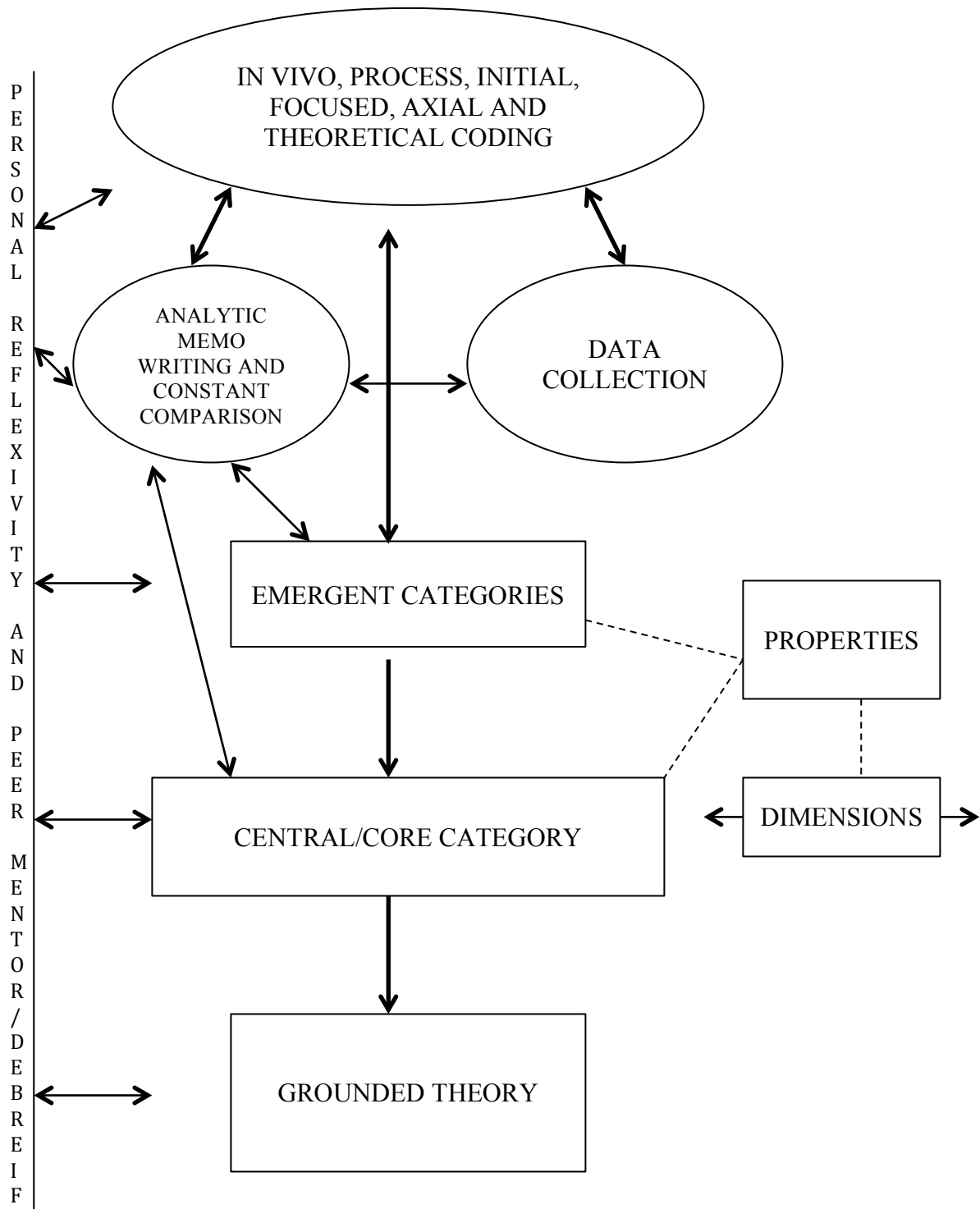
Figure 1: An elemental model for developing "classic" grounded theory. Adapted from Saldaña (2013, p. 53). Constant comparison, personal reflexivity, and peer mentor/debrief added.

Coding of data. In general, "grounded theory generates hypotheses from data and in no way tests theories found in other literature" (Glaser, 1998, p. 68). In order to accomplish this goal, "the process [of grounded theory] usually involves meticulous analytic attention by applying specific types of codes to data through a series of cumulative coding cycles" (Saldaña, 2013, p. 51). Per Charmaz (2006), "coding means categorizing segments of data with a short name that simultaneously summarizes and accounts for each piece of data…show[ing] how you select, separate and sort data to begin an analytic accounting" (p. 43). Saldaña (2013) specified "six particular methods [that] are considered part of grounded theory's coding canon" (p. 51). These methods, per Saldaña (2013), may be subdivided into processes that occur at the beginning of data analysis (i.e., First Cycle methods including Initial, In Vivo, and Process Coding) and those that take place once the research is far along (i.e., Second Cycle methods including Focused, Axial, and Theoretical Coding). Various authors may use differing terms for each of the coding methods described below. For purposes of consistency of terminology and approach, I defer to the terms used by Saldaña (2013) while providing additional explications of method, technique, or reasoning from other sources. Following Saldaña's (2013) example, I retain capitalization of these methods. Finally, it is important to note that "[g]rounded theory coding is flexible; if we wish, we can return to the data and make a fresh coding" (Charmaz, 2006, p. 71). In essence, the process of grounded theory is multifaceted and involves multiple steps that do not necessarily occur in a linear fashion (Saldaña, 2013) but "blur and intertwine continually, from the beginning of an investigation to its end" (Glaser & Strauss, 1967, p. 43). Therefore, the below should not be interpreted as a linear process wherein one method simply followed the next until

completion. Rather, this method involved a cyclical and recursive set of possible activities with multiple points of potential entry, exit, consideration, reflection, and re-entry (Figure 1).

First cycle coding methods. According to Charmaz (2006) initial coding of collected data is "the first analytic turn in [a] grounded theory journey…[and] requires us to stop and ask analytic questions of the data we have gathered" (p. 42). In these early stages, the data "is fractured or split…into individually coded segments" (Saldaña, 2013, p. 51) via a series of different coding methods described below.

Initial Coding. Saldaña (2013) described Initial Coding "as a starting point to provide the researcher with analytic leads for further exploration…[though] [a]ll proposed codes during this cycle are tentative and provisional" (p. 101). As this project utilized transcribed data, Initial Coding methods included line-by-line analysis as a first step. Per Charmaz (2006) "[l]ine-by-line coding means naming each line of your written data…[which] prompt[s] you to remain open to the data and see nuances in it" (p. 50). Saldaña (2013) specified, "such detailed coding is not always necessary, so sentence-by-sentence or even paragraph-by-paragraph coding is permissible" (p. 103). Initial attempts to engage line-by-line coding proved a bad match for these data. Participants tended to speak in monologues about particular topics following question or prompt and thus I utilized sentence-by-sentence and paragraph-by-paragraph coding. Overall, the method of careful Initial Coding helped to shed light on both implied and overt messages while remaining attentive to gradations of meaning (Charmaz, 2006). During this stage of coding, aspects of In Vivo and Process Coding (below) were also utilized (Charmaz, 2006; Saldaña, 2013).

In Vivo coding. In Vivo Coding identifies and utilizes "terms used by [the participants] themselves" (Strauss, 1987, p. 33) to begin the process of splitting the data into

segments. As these "specialized terms provide a useful analytic point of departure…and help to preserve participants' meanings of their views and actions in the coding itself" (Charmaz, 2006, p. 55), the process of In Vivo Coding may be useful in "studies that prioritize and honor the participant's voice" (Saldaña, 2013, p. 91). Charmaz (2006) identified three types of In Vivo codes: (a) "general terms that everyone 'knows'" (p. 55); (b) innovative or unique terms (neologisms) used by participants "that capture meanings or experience" (p. 55); and (c) "insider shorthand terms specific to a particular group that reflect their perspective" (p. 55). As participants were noted to use a variety of particular terms each of these types of In Vivo codes were used at points in the initial stages of coding. While In Vivo coding may be "a safe and secure method with which to begin…[one must also] be wary of overdependence on the strategy because it can limit your ability to transcend to more conceptual and theoretical levels of analysis and insight" (Saldaña, 2013, p. 95). In order to proceed along the path to grounded theory, further coding methods were applied.

Process Coding. Process Coding focuses on "gerunds ('-ing' words) exclusively to connote action in the data" (Saldaña, 2013, p. 96). According to Charmaz (2006) "we gain a strong sense of action and sequence with gerunds…[helping to] stay close to the data and, when possible, start from the words and actions [of participants]" (p. 49). I utilized the search function on Microsoft Word to screen each transcript for gerunds during Process Coding. I then assigned each found word to one of three categories: (a) actions of the participant DSPs; (b) actions of people with ID as described by the participants; and (c) actions of others involved with decision making processes (e.g., Interdisciplinary Team members, agency management) as described by the participants. Following this procedure I combined the lists from each transcript into three full lists representing the Process Coding results from the data

set as a whole. I copied and pasted these lists into an online word cloud generator that created

an image of all listed words wherein the frequency of the word/phrase in the list is positively

correlated with the size of the word in the image (i.e., a word cloud). These generated word

clouds and related discussion thereof may be found in Figures 2, 3, and 4 respectively.

    Second cycle coding methods. Saldaña (2013) stated,

> Second Cycle methods…both literally and metaphorically constantly compare,
>
> reorganize, or 'focus' the codes into categories, prioritize them to develop 'axis'
>
> categories around which others revolve, and synthesize them to formulate a central or
>
> core category that becomes the foundation for explication of a grounded theory. (p.
>
> 51-52)

Charmaz (2006) described these second cycle coding methods as an effort to "pinpoint and

develop the most salient categories in large batches of data" (p. 46). During this stage, I

utilized Focused and Theoretical Coding methods as described below.

    Focused Coding. According to Saldaña (2013), "Focused Coding is appropriate for

virtually all qualitative studies, but particularly for studies employing grounded theory

methodology, and the development of major categories or themes from the data" (p. 213). I

began Focused Coding of data after thorough exploration of the First Cycle methods

described above (Charmaz, 2006; Saldaña, 2013). This process differed from the above in

that there was a discrete focus on *conceptual* patterns in the data (Charmaz, 2006). In other

words, rather than a multitude of targeted, incident specific codes, I used Focused Coding to

look for larger 'umbrella' terms or concepts that covered or subsumed a wider swath of the

data. After identifying the most prevalent or seemingly significant codes from earlier analysis

Focused Coding may be used to check researcher preconceptions and determine "which

initial codes make the most analytic sense to categorize your data incisively and completely"
(Charmaz, 2006, p. 58). In another cyclical process, these endeavors may involve
"comparing data to data…[to] develop the focused code…Then we compare data to these
codes which helps refine them" (Charmaz, 2006, p. 60). Saldaña (2013) described Focused
Coding as "a streamlined adaptation of classic grounded theory's Axial Coding" (p. 213).
During second cycle coding of transcripts I used Focused Coding methods as described
above to begin to group the data into larger 'umbrella' or 'parent' categories. For example,
initial coding revealed several different types of pSCB encountered by participants. Each of
these types were assigned a unique code. During Second Cycle review I began to 'parent'
these various codes under the code 'pSCB: Types'. Similar processes were used to group
data regarding General Experience, Frustrations, pSCB: Etiology, and pSCB: Response
among many others.

    Theoretical Coding. According to Saldaña (2013), "Theoretical Coding is appropriate
as the culminating step toward achieving grounded theory" (p. 224). The process of
Theoretical Coding involves a transition of focus from discrete or specific categories to
formation and examination of relationships between categories (Charmaz, 2006) culminating
in a "central or core category…phrased as an abstract concept" (Saldaña, 2013, p. 227).
Saldaña (2013) connected this to Strauss and Corbin's (1998) statement that the central
category must "explain variation as well as the main point made by the data" (p. 147). In
other words, through the process of Theoretical Coding, the researcher moves from contained
and separated categories to larger hypotheses that may ultimately form the foundational or
grounded theories of the project as a whole (Glaser, 1978). At this stage in a grounded theory
project one must "[m]ake certain that your analytic memos and final report…[serve to]

overtly name the category and state the theory in one sentence with an accompanying narrative" (Saldaña, 2013, p. 226). While providing more perspective on the interrelated microcosm of the data within the study, Theoretical Coding also may move the analysis to the macrocosm of potentially transferrable theory (Charmaz, 2006).

As the data developed in digital format as well as my thinking I began to create more theoretical codes that appeared to encapsulate the essence of participants' overall statements. What began as a catch-all category for 'frustrations' and 'feeling confused' evolved into the overall theoretical concept of 'Being Between' with 32 distinct child codes of varying presence in the data. These are examined in detail in Chapter 6.

Analytic Memo writing. Memo writing is an essential and reflective process of grounded theory (Saldaña, 2013) that "keeps you [the researcher] involved in the analysis and helps…to increase the level of abstraction of your ideas" (p. 72). The process of memo writing occurs throughout the entirety coding and the research project as a whole. Thus, it represents the underlying work of analysis leading to data driven theory development (Charmaz, 2006). It is, from Charmaz's perspective "the pivotal intermediate step between data collection and writing drafts" (p. 72). Saldaña (2013) compared analytic memo writing "to researcher journal entries or blogs…[which involve] private and personal musings before, during, and about the entire enterprise as a question-raising, puzzle-piecing, connection-making, strategy-building, problem-solving, answer-generating, rising-above-the-data heuristic" (p. 41).

For the purposes of this project, and in line with Saldaña, 2013, I utilized the memo tool in Dedoose to write analytic memos regarding development and definition of specific codes, musings about sections of data, emergent patterns, relationships between participant

statements, larger theory development, potential related literature, and potential avenues of further research. As the project moved back and forth from data collection to coding, these memos helped me remain "actively engaged in [the] material…develop ideas, and fine tune…subsequent data gathering" (Charmaz, 2006). The material from these memos forms the basis of my analyses in Chapters 5 and 6.

    Constant comparison. According to Charmaz (2006), "[t]he grounded theory method depends on using constant comparative methods *and* your engagement" (p. 178, italics in original). While focused memo writing (described above) can serve to increase engagement, procedures of continuous evaluation of data from a wider angle may "advance…conceptual understanding…of analytic properties of your categories and then begin to treat these properties to rigorous scrutiny" (Charmaz, 2006, p. 179). Ongoing comparisons may be made within and between newly collected data and existent codes, as well as between codes, emergent theories, and aspects of reviewed literature. Per Glaser (1998), "[h]owever accurate or inaccurate the literature data might be, it will be constantly corrected, put in perspective and proportioned in relevance by the constant comparative method" (Glaser, 1998, p. 72). As explicated in the introduction to Chapter Two, "in order to prevent the preconceiving, grabbing effects of the literature search the researcher should turn his review into data collection to be constantly compared" (Glaser, 1998, p. 72). Glaser (1998) recommended that a review of the related research be completed only *after* data collection. Institutional requirements surrounding this research prevented such ordering.

    A constant comparison method was embedded within my coding and analytic memo writing processes described above. As the coding process neared its end, I paid specific attention to comparing emergent theory to related research as compiled in Chapter Two of

this manuscript. In addition, as theoretical codes developed I explored potentially informative

literature regarding general personality psychology and the concept of 'moral distress'

present in nursing research.

Credibility

Interpretive materials may be evaluated by their ability to illuminate a phenomenon as

lived experience. Such materials should be based on thickly contextualized materials that are

historical, relational, and provide clarity of process (Creswell, 2013). The core of these

materials is composed of "personal-experience stories that subjects tell one another" (Denzin,

2009, p. 109). In short, qualitative research summaries are not brief. Via the filling of pages

qualitative research may paint a picture of both breadth and depth. Such intensive levels of

detail may help readers to trust the data. Lincoln and Guba (1985) discussed this factor as

credibility. In relation to the common positivist term of 'validity' (measuring what one

intends to measure), qualitative research must aim to establish credibility. A credible project

is one that provides readers a sense of trustworthiness and dependability (Lincoln & Guba,

1985). I used the following techniques to establish the credibility of this project.

Rich Description

According to Charmaz (2006), "[r]esearchers generate strong grounded theories with

rich data…[that are] detailed, focused, and full" (p. 14). Engagement in these efforts

translates in to 'thick' descriptions (Geertz, 1973) that "get beneath the surface of social and

subjective life" (Charmaz, 2006, p. 13). Davidsen (2013) concurred, "the aim is to see things

in their appearance [via the use of] rich descriptions or narratives that illuminate the lived

world" (p. 320). In order to achieve this marker of credibility I compiled and provided

detailed descriptions of both participants and interviews in the sections above. All interviews

were transcribed according to the methods described above. In addition I recorded information regarding dates, times, location, duration, and environmental circumstances of all interviews potentially allowing for additional "revealing data" (Charmaz, p. 70).

While a thorough report on all of these factors may have increased certain aspects of credibility in this project, concerns about ensuring participant confidentiality limited this portion of the report. While I had originally planned on spending significant space describing detailed aspects of participants, as the research progressed it became clear that to do so would jeopardize their trust. Specifically, I conducted this research in a service system that, as a whole, is relatively small. As the participants were all from a single provider agency it is increasingly likely that individual participants could be identified should a great deal of individualized demographic or other descriptions be reported. Further, in several instances during interviews participants asked questions regarding the anonymity of the data and if their statements would be connected to their demographic information. Lastly, during interviews, transcription, and coding I found it striking how candid and forthright the participants were with the information and opinions they provided. It felt, at several points, that participants were 'going out on a limb' and disclosing stories and viewpoints of a deeply personal nature. Due to these factors, I chose to limit the participant descriptions to the aggregated demographic and experience information provided earlier in this chapter.

Investigator Triangulation via Critical Friend

Operating as an island is unacceptable in qualitative research. With the potentially overwhelming load of data collection, constant personal reflection, efforts to obtain multiple sources, and overall organization, the researcher attempting these endeavors must be part of a community. By accessing the knowledge and separate view of a well-trained peer a

researcher can become "fully aware of his or her posture and process…as they pertain to substantive, methodological, legal, ethical or any other relevant matters" (Lincoln & Guba, 1985, p. 308). For these reasons I enlisted a colleague of equitable experience in qualitative research to act as a conduit for exploration of data analysis and interpretation. In addition, the use of a critical friend aided in my process of Analytic Memo development and the resultant course of coding strategies described above. Further use and benefits of the critical friend process are examined below in the section addressing subjectivity.

External Auditors

Similar to the process of peer mentoring described above I engaged in regular consultation with my dissertation committee chair during data collection and initial analysis. This process differed from peer debriefing in that: (a) members of the committee have significantly more experience in conducting or consulting on similar projects; and (b) there is a power differential implicit within the relationship between candidate and committee.

Member Checking

The data and interpretations that are presented to readers "should be given in the language, feelings, emotions, and actions of the people studied" (Denzin, 2009, p. 109). While careful transcription may portray the verbatim words utilized, through application of theory the researcher may make leaps of interpretation. In order to further enhance the quality of qualitative research an investigator must engage the direct feedback and opinions of participants regarding these interpretations. Lincoln and Guba (1985) characterized this process as "the most crucial technique for establishing credibility" (p. 314) and evidence of must be sought throughout the research process as a whole. Member checking may be further

detailed by the participants' review of near-final drafts of the written report (Lincoln & Guba, 1985).

In order to achieve/ensure credibility of interpretation I utilized a member checking process that involved: (a) verbal summations of participant statements (e.g., 'It sounds like you are saying that…') during interview sessions; (b) provision of full transcripts for review and comment prior to coding or analysis; (c) provision of a brief summary of findings (e.g., codes and/or categories with representative quotes from transcripts) to each participant via US mail including a non-compulsory comment sheet and self-addressed stamped envelope as well as instructions for how the participant may submit comments via email, fax, or telephone contact; (d) non-compulsory verbal and/or written review of identified themes with each participant following initial and ongoing coding of interview data; and (e) provision of draft interpretation and conclusion sections of the manuscript to all participants for voluntary review and feedback. Participant responses to these efforts were utilized to further examine and hone the interpretive sections of the project.

Ethical Considerations

All investigations contain a variety of potential ethical conundrums involving areas such as the relationship of investigator to participants, potential for harm, and protection of confidential information among others. In the following sections I describe the particular ethical situations that may have been inherent within the study along with potential manners by which I hoped to manage or mitigate the potential effect(s) of these situations.

Explanation of my role as academic researcher versus professional role. As described above, at the time of this research I was employed by the New Mexico Department of Health as the Statewide Clinical Director for the Bureau of Behavioral Support. In this

position I provided oversight to the practice of individuals working as contracted Behavior Support Consultants in the Developmental Disabilities Waiver system. In addition, I was partly responsible for provision of technical assistance to interdisciplinary teams who requested support for behavioral concerns that have challenged their process of support for individuals with ID. At times, this involved direct training of individuals working as DSPs. As such, I have had extensive contact with nearly every agency in the state and literally hundreds of DSPs received trainings conducted by one of my co-workers or myself. Although I was employed by the New Mexico Department of Health, I had no direct oversight or supervisory capacity in relation to the work of DSPs. Due to the nature of New Mexico's Developmental Disability Waiver system, all DSPs work in independently contracted agencies that are overseen by Department of Health offices functionally or hierarchically separate from my own. Nonetheless, this division of oversight might have been unclear to participants without explicit explanation. Further, as many of the participants may have known of my position with the Department of Health there may have been some confusion regarding in what capacity I conducted the study. In brief, I conducted no part of this study as part of my duties with the Department of Health and I used no Department of Health resources in the completion of this study. I conducted this study entirely within my role as a doctoral candidate at the University of New Mexico. I provided explanation to all potential participants regarding the division between my role with the department and my role as a doctoral candidate. I provided such explanation both in the informed consent document and reviewed verbally with all participants prior to initiation of the research interviews.

Duty to report suspected abuse, neglect, exploitation. Regardless of within what professional or academic capacity I was conducting this research, I was a Licensed Professional Clinical Counselor (LPCC) at the time. One of my ethical obligations as a LPCC includes a positive duty to report any suspected abuse, neglect, or exploitation of individuals less than 18 or who "lack the capacity to give voluntary consent" regardless of age (American Counseling Association, 2014, p. 7). Certain individuals with ID may be included in this definition. As an essential part of participation in the study, respondents were asked to speak of their experiences working with individuals with ID. At times, this included speaking of incidents or circumstances involving specific individuals in residential or community settings. Should information have been revealed that led to suspicion of abuse, neglect, or exploitation of an identifiable individual with ID, I was ethically obligated to report to the appropriate investigating agency (e.g., Adult Protective Services, Department of Health Improvement). As participants related detailed stories of their experiences, individuals with ID referenced in these stories may be identifiable even when not referred to by name or location. My obligation to report was outlined in the informed consent document that was provided to, and verbally reviewed with, potential participants prior to initiation of any data collection (i.e., demographics, recorded interview). Nonetheless, despite best efforts at initial and ongoing informed consent, participants may have been intimidated or uneasy with this aspect of the process due to the sometimes very sensitive nature of supporting individuals with ID and pSCB. This was an inescapable portion of study in this topic regardless of geographic location or my disposition as a Department of Health employee or doctoral candidate. While licensed, my positive duty to report applies to the whole of the United States regardless of my specific job or job title.

Protection of identity of individuals described by participants. In order to protect the identity of individuals with ID who may be described by study participants during interview responses I altered certain details of these descriptions (i.e., location, time, physical descriptions). This was done in a manner that protected identity without compromising essential clinical or other aspects relevant to the participant's narrative and related data coding or analysis.

Protection of identity of participants. As this study involved a single location the protection of identity of individual participants was essential. Methods of electronic security of files are outlined above. In an effort to protect the identity of participants in the final written document I engaged the following steps:

(a) I aggregated all reported demographic data in this final written report;

(b) I did not include discrete descriptions of any participant in relation to his or her quoted material;

(c) Demographic data was not directly connected to individual participants;

(d) Rather than using pseudonyms, all quotes utilized in the final written document are preceded with the generic "A participant said…" (or similar/equivalent);

Protection of identity of the participating agency. As this study took place within a relatively small community of providers, the identity of the agency may be recognizable depending on the amount of detail provided. As outlined in earlier sections of this chapter, high quality qualitative research typically involves provision of rich detail and context. I contend however, that ethical considerations of privacy and confidentiality outweigh the recommendation for intensely rich detail. Due to this matrix of considerations I first gathered sufficient information to fully describe the location and context of the agency from which the

participants were recruited. I then provided drafts of the written summary of this information

to the agency chief executive officer for review. I included said description in the final

written report only once all parties agreed to the content.

Acknowledgement and management of power within this relationship. In a

frequently cited article, Kvale (2006) described the qualitative interview process as initially

driven by an "attempt to understand the world from the subjects' points of view and to unfold

the meaning of their lived world…[as] interviewers enter into authentic personal

relationships with their subjects" (p. 481). Tracing the history of this interview method Kvale

contended that the dyadic process of naturalist interview methods resulted from a move away

from the alienating, sometimes manipulative aspects of research that dominated the 1960s

and 1970s. Kvale went on to point out that the framing of naturalist-style interviews as

egalitarian has come under repeated scrutiny though "the power dynamics...and potential

oppressive use of interview-produced knowledge, tend to be left out in literature on

qualitative research" (p. 483). Kvale (2006) further specified that despite inherent

shortcomings,

> the use of power in interviewing to produce knowledge is a valuable and legitimate
>
> way of conducting research. With interview knowledge jointly constructed by
>
> interviewer and interviewee, overlooking the complex power dynamics of the social
>
> construction process may, however, seriously impair the validity of the knowledge
>
> constructed. (p. 485-486)

In relation to these dynamics Våhåsantanen and Saarinen (2012) presented an analysis of a

research method that attempts to address this dearth of attention to the role of power in

qualitative interviewing. The role of power between researcher and participants, in

Våhåsantanen and Saarinen's view, may be directly addressed and potentially used during an interview process. By explicitly making this an embedded feature of discussion, regardless of the general topic, there may come "an understanding of how the actions of others are interpreted *during* the interview, and how these interpretations shape the parties' activities and power relations" (Våhåsantanen & Saarinen, p. 508).

There are inherent power differentials in the research method I engaged. I was the investigator. In this role I decided on and asked the questions, recorded the responses, and parsed the data toward conclusions. The participants were questioned; their words, dissected. Further, at the time of the research I worked for 'The State'. While this research was not conducted as part of my work with the Department of Health, my professional role was well known in this relatively small community of supports for people with ID. In short, my professional position could have been a source of discomfort for certain participants. In order to acknowledge, and potentially attenuate, some of this disparity I: (a) clearly outlined the role from which I was conducting this research (i.e., doctoral student) during the informed consent review process; (b) carefully reviewed the voluntary nature of participation including the choice all participants had to withdraw at any time without penalty; (c) clearly delineated the aspects of mandatory reporting (e.g., in cases of potential abuse, neglect, exploitation of a person with ID) that may be involved in the research; and (d) included a question (i.e., Appendix A – Question 16) regarding this difference in roles between interviewer and participant. In the analyses sections of the final manuscript I integrated findings and thoughts on these power differentials in relation to their effect on the research process in this study.

Subjectivity and Bias

At the foundational level of any inquiry, the determination of subject is informed by the researcher's history, training, and preference. It is s/he who decides whose portrait to take, what paradigmatic camera to use, what perspective lens to apply, which filters of theory to snap on, and how to manipulate the dials of method. Further, the developed image ends in the researcher's hands and is distributed out en masse as s/he points out the most interesting details from an inherently biased perspective. As Jansen and Peshkin (1992) stated, these "choices equal subjectivity at work" (p. 721). Subjectivity, from a *positivist* position (i.e., traditional quantitative research) may be said to add an inescapable element of 'corruption' to the original data of the participant's pure emic experience, their phenomenological essence (Jansen & Peshkin, 1992). This is analogous to statistical 'noise' in quantitatively analyzed data. Conversely, subjectivity is considered 'a given' in qualitative research as "all texts are biased, reflecting the play of class, gender, race, ethnicity, and culture, suggesting that so-called objective interpretations are impossible" (Denzin, 2009, p. 100). Lincoln and Guba (1985) recognized this as a basic tenet of naturalistic research in that "all inquiry is value bound" (p. 38) from moment of instigation through interpretation and presentation. Per Morse (2007),

> excellent qualitative inquiry is inherently biased…it has been deliberately sought and selected. This bias is essential if we are going to do good work and this bias is not something that impairs the rigor of research. In qualitative inquiry… researchers seek the best examples of whatever it is that they are studying. (p. 234)

The anodyne to this influence is not attempts to *eliminate* but ongoing efforts to *elucidate* the subjective factors that inform inquiry (Charmaz, 2006; Jansen & Peshkin, 1992; Hays &

Singh, 2012). As Denzin (2009) argued, "the moral biases that organize the research should be made evident to the reader" (p. 109). This load of value-based acknowledgement is not a threat to research but "an integral aspect that…should be viewed in a positive light" (Hays & Singh, p. 145) and "tapped to illuminate the phenomenon under investigation"(Gough & Madill, 2012, p. 382). By integrating the subjective viewpoints of both participant and investigator a holistic picture of interaction may be developed as to "how self and subject have intersected and with what effects" (Jansen & Peshkin, 1992, p. 717). Thus, the final picture may be one of *inter-subjectivity* wherein the previously hidden of both worlds is laid bare in concert rather than conflict (Gough & Madill, 2012). For the purposes of this investigation methods of reflexivity and peer review were used as methods of examining subjectivity. Further, a detailed exploration of my stance as a researcher which examines my personal and professional experiences and possible biases is included in Chapter 3.

Reflexivity

Throughout a qualitative research project practitioners are encouraged to keep a careful journal-based record of their experiences, thoughts, decisions, confusions and so forth (Denzin, 2009; Hays & Singh, 2012; Lincoln & Guba, 1985; Merriam, 2009; Silverman, 2005; Willig, 2010). This process is often referred to as reflexivity and "might be thought of as providing the same kind of data about the *human* instrument that is often provided about the paper-and-pencil or brass instruments used in conventional studies" (Lincoln & Guba, 1985, p. 327, italics in original). According to Lincoln and Guba the reflexive journal should contain both objective (e.g., logistics) and subjective (e.g., values and interests) explorations while also documenting methodological considerations. The process of Analytic Memo writing, contained within the grounded theory method described above, served the purpose of

logistical and technically focused reflection pertaining to theory development. A more

reflexive journal that includes my inner experiences and emotional responses during the

research process may aid in identifying blind spots, areas in need of further clarification, and

reduce the risk of becoming "preoccupied with theory verification" (Denzin, 2009, p. 106).

When included in the written report "such clarification allows the reader to better understand

how the individual researcher might have arrived at the particular interpretation of the data"

(Merriam, 2009, p. 219). Much as keeping lists may help one remember what needs to be

done, careful efforts at reflexivity may help a researcher remember what s/he has done and

why.

Throughout proposal, recruitment, data collection and analysis I have kept a personal

journal reflecting my inner and outer experiences during this hectic time. Portions of these

reflections are included in Chapter 6 following the data analysis.

Peer Debriefing

More than just a 'fact-check', the peer mentoring process (described above) may also

examine the affective aspect of conducting research (Hays & Singh, 2012; Lincoln & Guba,

1985). After all of the self-searching and management of relationships in sometimes charged

situations a researcher would have to be robotic to avoid the potential for emotional bias.

Similar to the critical friend process described above, peer debriefing was utilized to examine

more personal, less technical, aspects of my experiences during this project.

Summary

Utilizing data gathered from individual interviews I used techniques of grounded

theory to explore the experiences of DSPs who work with individuals with ID and a history

or presence of pSCB. The research was conducted in New Mexico through the University of

New Mexico. It included recorded and transcribed interviews, collection of demographic information, researcher reflective analytic memos. All University practices for informed consent and research protocol approval were observed and no research was conducted prior to approval of the IRB and related agencies. In order to assure credibility of the research, multiple sources, member checking, critical friend, and external audit procedures were used to improve clarification of gathered data and related interpretations or analyses. Subjectivity was examined via personal reflexive journaling and peer debriefing. Aspects of Foucaultian analysis were utilized in theoretical examinations.

A Selected Excerpt from Each of the 12 Interviews

"They see clients. I see people."

"You have to put all your biases and all that stuff aside. And you have to focus on that person."

"Some of them are from institutions or they've had sexual abuse back grounds and they're just acting out what was done to them and I get it you know. It doesn't make it right. But I have empathy".

"I guess that's what our job is. It's to educate them in every aspect of life."

"It's your job to almost play every single role. To keep everybody safe."

"There's always that really fine line of what's quote unquote appropriate…We walk that boundary. It's a tightrope. Just do your best."

"You can't expect people to do some of the stuff that we do and put them in positions of direct care when you pay them shit".

"It's a lot going on. I'm not emotionally but I'm mentally drained when I go home."

"I wish the system would listen to us more. I wish they would take what we say and believe that what we say is worth listening to."

"Everybody has the right to be in a relationship. Everybody has the right to a healthy relationship. Everybody has the right to not be assaulted."

"You can't deprive them of life. But you can teach them – try to teach them about what they are feeling and how to deal with the feelings".

"I think we actually elevate peoples' risk by taking rights away."

CHAPTER 5 FINDINGS

Overview

This chapter summarizes the findings of a series of semi-structured interviews

conducted in the Summer and Fall of 2015. All 12 participants had at least one year of

experience working in the role of Direct Support Professional (DSP) in residential and/or

general community settings for individuals with ID and a history of possibly Sexualized

Challenging Behavior (pSCB). The purpose of this study was to investigate the lived

experience of DSPs who provide support to individuals with ID and a history of pSCB. The

primary research question of this study was:

1. How do DSPs describe their experiences in working with individuals with ID and a

history of pSCB?

Underlying queries to this topic were:

1. How do DSPs in the study sample define or describe behavior that may be of a

sexualized, challenging nature?; and

2. How do DSPs conceptualize risk and rights when supporting individuals with ID

and a history of pSCB?

Data collection resulted in transcripts of recorded interviews. The semi-structured

interview for each participant utilized questions developed in advance and approved by the

Institutional Review Board of the University of New Mexico (see Appendix A – Interview

Guide). While many of the interview questions related directly to the above research

questions several involved a more broad approach to investigating the participants'

experiences in supporting people with ID. This approach was utilized in order to: (a) acquire

a more holistic picture of participant experiences; and (b) provide an opportunity for

participants to 'warm up' to the interview process before proceeding to topics of possibly increased emotional or personal content.

This chapter is divided into three sections. Specifically, I present the findings in line with Corbin and Strauss' (1990) conceptual organizing scheme of Conditions, Actions/Interactions, and Consequences. Per Corbin and Strauss (1990),

[i]n grounded theory representativeness of concepts, not of people, is crucial. The aim is to build a theoretical explanation by specifying phenomena in terms of conditions that give rise to them, how they are expressed through action/interaction, the consequences that result from them, and variations of these qualifiers (p. 9).

In each of these three sections the data are presented in relation to codes I derived via the Focused Coding process described in Chapter 4 with use of extensive quotes and minimal analysis.

In all sections I use extensive excerpts (infrequently repeated; all italicized) from the 12 interview transcripts in an attempt to maximize representation of the voices of the men and women who shared their stories. In all excerpts, if a conversational exchange between myself and the participant occurred, it is denoted by a 'P:' for participant and an 'I:' for the interviewer. In consideration of protecting the confidentiality of participants, I have, except when excerpts from the same transcript directly follow each other, chosen to not connect excerpts to individual participants by either pseudonym or identification number. Instead, I use the general 'a participant said…' or similar. Where directly relevant to the discussion or analysis, and/or when phrasing demands, this is minimally more specified as 'a female…' or 'a male participant said…' Unless expressly indicated, all excerpts in subsections are from different participants.

In this chapter, I have also greatly limited the use of any comparative analyses to research literature, theory, or my own perspective. I took this approach in order to remain as faithful to the data as possible and allow readers to 'hear' the story/stories with as little interference as possible. Of course, my (hopefully minimized) voice and choices remain inescapably embedded throughout as a part of coding and positioning of the selected excerpts. In parts of Chapter Six (Discussion) which includes 'Arrival at a Grounded Theory' the presence of my voice is, naturally, more ingrained as this represents, in essence, my story of their stories. Further analyses of the data in juxtaposition with the history presented in Chapter One, reviewed literature from Chapter Two, potentially related literature from other fields, and through a theoretical lens stemming from the works of Foucault may be also found in Chapter 6 along with a discussion of my personal experience in conducting the research, limitations of this study, and areas of possible further investigation.

It should be noted that all participants have worked with a variety of individuals with ID who receive supports across a wide range of activities and settings. Certain of these individuals may have histories of pSCB; many do not. While the research questions repeated above were focused on specific concepts of work with people with ID and pSCB it is necessary to situate this particular part of the work within the context of the participants' larger work life. Thus, in each section I address the holistic, inclusive, and varied experiences of participant DSPs in their day-to-day work. I address the specific manners by which participants described how they understand envision, and enact supports for people with ID and pSCB as part of this larger context.

Conditions

In this section I provide examples and explanations of how participants described the various conditions in which they operate as DSPs. These conditions include concepts such as general experience and job duties, participants' statements about the best and worst parts of their work, different types of challenges faced, how decisions are made, and how certain terms are defined and delineated. Each subsection in this and later sections stemmed from conceptual codes and related memos I generated during Focused Coding methods (Chapter 4) and include representative excerpts (italicized) from transcribed interviews. As this area 'sets the stage' for the resultant actions/interactions and outcomes, I have aimed to provide a high level of rich detail via thorough representation of all categories (properties and dimensions) and sometimes lengthy representative excerpts from multiple participants.

General Experience in the Role of DSP

As an introduction to the interview participants were asked to summarize their general experience of their work in direct support of people with ID regardless of the presence of pSCB. Overall, participants described the job as one of constant adaptation to a spectrum of events and emotions with the overarching aim of impacting the lives of people with ID. This subsection is divided into groups based upon themes I generated and found common to participant responses.

The unexpected and a wide spectrum of emotions. Participants spoke about the range of events and emotional content they have encountered in work as DSPs. Summing this up, one participant stated:

Exactly what I tell people about my job, I don't explain specifics, but I kind of say

every day is an adventure. I say some days it's the best job in the world. You have fun,

you play. Some days it doesn't even seem like work. Other days it's the worst job you

can ever think of all the way up to the point of having someone try and kill you. And

so that's how I describe it. It's kind of everything. It's kind of both ends of the

spectrum. It's the best and it can be the worst.

Along the same lines, another participant replied:

Everyday is different you know? Some days are better than others just depending on

the client's mood. You know if they are in a great mood, its probably going to be a

great day. We're going to go out and do exciting things. There's days where they

could be in a bad mood and they just take it out on you. You've kind of got to deal

with it. Work with them to de-escalate their behaviors and to...get back into a better

space so they can have a better day. It's interesting because not everybody is the

same you know?

Continuing this theme, and expanding it to include a feeling of the vigilance that may be

required, another DSP summed her experience up as follows:

It's interesting. It's, you never, I always say 'there's never a dull day…', there's

always something going on. Like, the individual could be having a perfectly fine day

and then something could set them off that you don't even, wouldn't even bother you.

And it could just ruin their day. They could start acting out. Start yelling, throwing

things. You are always on your toes. You always have to be on your guard. You hope

for the best but you always prepare for the worst in this line of work.

Similarly, another participant related the perspective a long career in this field has yielded:

So, the more I work with individuals, nothing surprises me anymore. So much has

happened in the 18 years I've been in the field that I don't think anything could

possibly surprise me at this point you know [laughs]. I, my mentality is, I go in and I prepare for the unexpected. Everyday. And we just deal with it as it comes up.

A further participant provided the parallel statement that,

You never know how your day is going to go. This is why I love my job. Most people would hate this. But, for me, you never know what the hell you're going to do that day… you never know – that's part of the job. It's absolutely part of the job – you don't know how your day is going to go. You can hope for the best but you're working with humans. Humans are unpredictable.

In these respects, the qualities of the unexpected, for this participant were part of the ongoing attraction of the work as a DSP while 'working with humans' was presented as the reason the job of DSPs contains such variability. A similar sentiment regarding the sometimes unpredictable, 'human' aspect of the experience was voiced by a participant who said:

The first word that comes to mind is 'interesting'. Each person, each individual has their own personality even though a lot of people want to throw them all into this big bundle, each is just like us. We each have our own personalities and so do they.

Another participant mirrored,

It's kind of stressful, to be honest. Um, well because you're like dealing with people so, in general, that's stressful…They're not machines, not something you can control. So, that's stressful. It also is rewarding, because you learn different things about yourself and other people.

This 'stressful' aspect of the nature of the work was further addressed by a participant who explained,

Well, I guess, because you're involved in another human beings life. It's not like working at Wal Mart where if you make a mistake it's not really a big deal. If you make a mistake or a pretty huge mistake working with someone's life – that could turn out to be a big deal. So you have to be on top of your toes. You need to be with it at all times. Just on top of everything.

Making a difference and enjoying it. Regardless of the necessary vigilance, potential for the unexpected, and related stress participants were often optimistic about the job. Specifically, the concepts of making a difference or having an impact were common.

Actually, it's one of the better jobs that I've had. Where else in the world do you get paid to actually go out in the community to take the guys out to go out bowling, the movies, go play basketball on the courts. Things like that. It's really interesting. It's really exciting because you're working with human beings and each human being is different and it's pretty cool to get to know them and their personalities. To bond with them in that way and to gain that trust because they know that you are there to help them. So I, I think that's what brought me into the field and what's kept me in the field. It's really a good feeling to know that you made a difference in someone's life.

Another participant made a similar comparison to the difference between working as a DSP and previous types of employment as evidenced in the following exchange:

I: You said that it's different than those…

P: Soul sucking jobs? Yeah. It's different. You're not just working, it's more rewarding. It's not tangible, like 'hey I can touch it' and you're not making the most money in the world. Like working [in another healthcare setting] like I used to – the kind of money I made there and everything else, the wonderful benefits. I don't get

that but I do get the benefit of knowing that I've helped someone in the day. And

generally when I feel that I've helped them I feel like I have taken them into account.

Not just looked at their plan and been like 'hey, this is how they are supposed to

behave, and do this, don't do that'. That's how I feel like I've helped.

The effect that DSPs have in improving the lives of people with ID was again cited as a key

part of the experience as exemplified in the following excerpt:

I really enjoy it. I love seeing the happiness when they are having a good day and

they get to do things that they weren't able to do before because there hasn't been

staff, shortage of staff, or there were staff and they just didn't care so the clients just

sat there.

As a corollary to this one participant envisioned the job as having a positive effect in her own

life:

As far as my experience – it's been an adventure for me. I've worked with all sorts of

individuals. I've worked with some very difficult ones. It's helped me. It's taught me a

lot that I didn't know. I got into this business not knowing anything and I fit right in.

Positivity in the face of challenges was also reflected by another participant who stated,

Most days I'm in a great mood. I love going to work. Actually all days to be honest

with you. With the company I'm with now. They need someone to care. And I care.

It's hard not to care. It doesn't matter how challenging a day a client is having. Even

on their worst days I still care. And I know it's not personal. And I don't take it

personal.

The experience of supporting people with ID and pSCB. When the aspect of

supporting people with pSCB was considered, the participants' descriptions of their work

revolved more directly around the concepts of vigilance and being constantly aware. As one

participant put it,

> *You need to be aware of your surroundings at all times. A lot of people say this is an*
>
> *easy job. And it is an easy job but you've got to be on top of everything. You need to*
>
> *be aware of your surroundings. You need to know what they are doing. It is easy but*
>
> *you've just got to be focused is all. You've definitely got to be focused and be aware*
>
> *of what is going on at all times.*

More succinctly, one participant stated, *"you just have to be really really really aware of*

what's going on around you [laughs]".

For another participant the effort toward attentiveness was paired with a quality of confusion

about what actions might be taken:

> *You are literally on guard like the whole entire shift. You are thinking ahead like*
>
> *'with this person, if a little kid walks by – what am I going to do?' 'If somebody*
>
> *comes up to them to hug him – what am I going to do? What am I going to say to*
>
> *them?' And you don't want to be like 'oh no don't do that – this person is a sex*
>
> *offender'. You don't want to because they don't need to know.*

For one participant this endeavor to remain constantly aware branched into all of the various

settings:

> *You have to be really careful because some individuals will inappropriately touch*
>
> *other individuals so, not only making sure that these guys are safe in the community*
>
> *and the community is safe around them but then you have to also be careful about in*
>
> *the programs or in the homes in particular about everybody respecting each others*

boundaries and space and what are appropriate relationships and how to have a

healthy relationship.

In addition, as related by another participant, this level of vigilance may include a high level

of attention to the histories of people receiving support:

I always keep in the back of my mind of you know all the information that you've been

given about an individual up front in the positive behavior support training and you

know all of their historical information, I always keep it in the back of my mind but I

don't always assume that it has something to do with the present day.

The added aspect of intense attention to history, surroundings, and actions was connected to

feelings of being depleted at the conclusion of a shift. For example,

 Depending on the person it can be really, I don't even know how to explain it.

Draining. It can be really draining and exhausting. Some people can be really

emotionally demanding not so much like physically, so at the end of the day you can

be really filled emotionally and drained.

Another participant voiced a similar experience:

I'm not emotionally but I'm mentally drained when I go home. To the point where my

girlfriend might ask 'what do you want for dinner?' and I'm like 'I don't care'

because I don't feel like thinking.

Job Duties

The code Job Duties was initially intended to apply to statements of participants

regarding objective or concrete work duties that compose part of the work of DSPs - the 'nuts

and bolts' in the daily work of DSPs who support people with ID in community-based

residential and other settings. As coding developed, however, it became apparent that the

participants had a difficult time pinning down a proverbial 'laundry list' of tasks/duties.

Instead, descriptions of duties tended to evolve into more global concepts of their work as

DSPs and the highly individualized ways this may develop. More specific aspects of the

actions/interactions participants described as part of their work are examined later in the

second main section of this chapter – Actions and Interactions.

Speaking about what a typical day of work as a DSP might entail, one participant

stated:

> *I'm told I need to work here and I pick that person up and we talk about what they*
>
> *want to do for the day and I take them where they need to go whether it's Special*
>
> *Olympics or they just want to go back to the house and I usually help them prepare*
>
> *dinner and if they want to watch TV or whatever and I make sure to follow their*
>
> *plans. A lot of them have chore lists. Make sure they do their chores, hang our with*
>
> *them and they pretty much do whatever they want to do and they go to bed and I write*
>
> *my notes is how that works.*

Similarly, another participant said:

> *I've worked with…people with intellectual disabilities for about 10 years…Five days*
>
> *a week, seven days a week. Sometimes helping them with their day to day routines*
>
> *i.e., personal hygiene, med assistance, feeding, bathing, transporting them to*
>
> *appointments, day hab or staying with them at home because the don't have day hab,*
>
> *they don't work.*

Overall, participants tended to describe work as a DSP as having an 'all encompassing'

quality that was hard to pin down to specific or predictable tasks. One participant stated,

Generally, when you try to describe what you're doing it's not that easy so I basically

have told people that I've done everything from wiping peoples' rear ends to driving

people around and looking for school, work, education. I've helped in more aspects

of people's lives than I ever expected to.

While a variety of particular tasks may be part of a workday for these DSPs one participant

summed up a more individual focused perspective:

This is their 8 hours, what ever they want to do in these 8 hours, that's what you do.

They want to go over and sit in the corner and they want you to stand there or be in

that specific spot for that time – that's what you do. Whatever works for them. This is

their 8 hours. It's got nothing to do with what you want, what you think, the way you

want it done, this has absolutely nothing to do with you. This is their world.

From a more didactic perspective a theme of being an educator emerged in several

interviews. For example, one participant stated,

I guess that's what our job is. It's to educate them in every aspect of life. Educate

them how to cook, how to clean, how to keep their house clean, how to shower

correctly, how to smell good, how to look good, how to dress. And I guess that also

falls into showing them how to interact in public in the right way and how to interact

with a potential partner in the right way.

I: That's a big range of responsibilities.

P: It is man. Like I told you at the beginning – it's dealing with humans. It's not

working at Wal Mart man [laughs]. We are dealing with human lives and that's a

very huge responsibility. Not many people can do it and pull it off.

Similarly, another participant summed up the job as follows:

I'm here to support you, I'm going to teach you how to cook something. I'm going to

help you clean. I'm going to take you places. I'm going to, I can be an emotional

support – if you are having a hard day, let's talk about it, try to figure out what's

going on together. Let's learn how to effectively communicate. Let's go to

relationship class and you can learn how to have a healthy relationship.

In essence, as related by these participants, nearly all facets of supporting another person's

life - from cooking, to cleaning, transportation, hygiene, medication protocols, relationship

coaching, emotional support, and management of various interactions - may be contained in

the day-to-day work of DSPs. Or, as one participant summed up, *"It's your job to play*

almost every single role".

What are the Best Parts of the Job?

Participants were asked to describe what they believed to be the best part of work in

direct support of people with ID. Again, this question was not aimed specifically towards the

work with people with histories of pSCB but, instead, to the overall work as a DSP.

Seeing change and making a difference. Similar to the general experiences

examined above, many participants described the aspects of 'making a difference' or 'seeing

change' as rewarding aspects. For example, one participant described the best part of the job

as:

Probably working with the guys. Working with all the staff as the team, having the

common goal of giving them a better quality of life. The clients. That's always good.

In my belief from working in this field is that they've probably seen a lot of abuse and

a lot of garbage in their time and then they come to these group homes and it's up to

us to give them that better quality of life. Have them enjoy their life. Help them do

things they enjoy doing. What's meaningful to them? Get them out there and do it.

That's really cool. To be a part of that and to have them get in a situation in their life

where you can actually do that for them.

Similarly, as another participant described, *"The best part of my job is seeing them succeed in something they want to do…seeing people get to do things in their lives that they were told…that they couldn't do and watching them succeed in that. That's rewarding".* Another participant used a specific example of seeing change and growth to sum up her opinion of the best part of the work as a DSP:

To see him grow. Eventually he got married and he got out of the company. That was

something he was looking forward to and he didn't think he would be able to do it.

But he was able to do it. It made me feel like we did something right. We weren't

there to keep him behind. We were trying to let him grow. And as far as where I'm

working right now? I think that's our goal. To get people to actually grow. You never

know how long this kind of stuff is going to last. How long this type of business is

going to last. So, it's going to last some unknown time because the rich can afford it

but not the poor. So, you need to be able to get people to cook their own food, take

their own meds, wash their own clothes. When you are able to do that, that's a big

plus.

This theme of moving towards independence being the best part of the job was echoed further by a participant who stated, *"[w]hen somebody learns a new skill that they actually do on their own. Or they're doing something and you don't even have to prompt them to do. Or they've succeeded in doing something that they've always wanted to do".* As another participant related in the following excerpt, while having an individual they support

acknowledge the assistance may be rewarding, it is seeing the growth or change itself that is the best part of the job:

 Well, every once in a while you'll get someone – a guy you provide for – say 'thank you' and actually you might feel like they really mean it instead of something more superficial. Which makes you feel really good you know? Or even if not a thank you – if you've been hard at work trying to teach them something - whether it's to read or count or budget their monies in a better way - and they actually take that as part of their life. Something you actually taught them and they start to use it on a daily regimen. That's like a thank you to me just the fact that they actually listened and were able to apply that to their own lives. That's great. That's positive of course.

Relationships and a long term view. The above theme was expanded by several participants to include aspects of extended involvement and development of trusting relationships. As stated by a participant, the best part of the work as a DSP is "*[s]eeing progress which sometimes takes years*" and thus stressed the long-term commitment that may be a necessary component to realizing these changes. This was further echoed by another participant who related,

To see people be able to do things on their own without you help like 'I got it! I can do it!' When you first meet people they aren't like that. But a couple of years down the street its like 'I can do it, I can fix my own dinner without help!' Then you know you did something right. You helped this person excel in life. To me, that's the best thing ever. When you see somebody actually doing something. And we're not keeping them back and they don't feel like we are keeping them back.

In the words of another participant, perhaps part of this longitudinal aspect includes the development of a trusting and supportive relationship:

> *In direct support I think the best part of the job is just um, honestly, it's having that relationship where they can talk with you and you can talk with them and they can come to you and tell you 'here's what I want to do with my life' and you can help them make that happen…I still like, this is really cheesy, but I still get really teary eyed every time they get a job.*

This was also reflected in another participant's summation of the best part of the job as,

> *Bond[ing] with them in that way and to gain that trust because they know that you are there to help them. So I, I think that's what brought me into the field and what's kept me in the field. It's really a good feeling to know that you made a difference in someone's life.*

For another participant, this aspect of developing relationships was more global and included comparison to aspects of a friendship:

> *The best part is getting to have fun. Getting to hang out with people. Like I said, on a really good day you could be in the park playing football, you could go to the movies, you could be having a barbeque, you could be doing something simple like hanging around and watching a football game with somebody. It's you know, kind of like hanging out with friends sometimes you know? Which is good stuff.*

Similar sentiments of the relationship between DSPs and the people they support being seen as akin to family or friends and how this may relate to some resultant frustrations, conflicts or confusion are explored in later parts of this and the next chapter.

In summary, the participant DSPs reported that the best part of their work was related to a sense of developing relationships seeing change or achievement over the long term which, in the words of one, can result in a sense of,

>*Fulfillment. I am completely fulfilled. I go to sleep every night knowing that they have a job, and are keeping their job partly because of me. Because I am helping them and I am helping them succeed in a way. Because there are some clients that wouldn't have a job if they didn't have a job coach. And I, it's just getting to know them. They are really great people. They're awesome and it's total fulfillment.*

What are the Worst Parts of the Job?

In corollary to the above, participants were also asked to describe what parts of the job as a DSP were 'the worst'. While dealing with the death of individuals with ID, and aspects of personal care were mentioned by single participants, more prevalent themes in this area revolved around encountering acts of physical aggression, knowing of abuse or harm committed on or by a person they support, and feelings of powerlessness or inability to help.

Dealing with harm to self or others. Many participants related that the aspect of the job which involves physical, possibly aggressive or destructive actions by people with ID was 'the worst' part of their experience. For example, a participant said, "*dealing with their behavioral issues where they attack other clients or attack staff or destroy property"* was one of the less favored parts of his work. Putting it more bluntly, another participant stated,

>*I don't like the physical stuff. When they put you in a house with somebody that's physical. I don't like to be bit on. I don't like to be spit on. And I've worked with people who spit and bite. It's hard to talk them down. Once they get into that mode*

and you can't talk them down there's noting you can do. That's the part I hate. I hate the physical parts. I will do it, don't get me wrong, but I don't like it.

Using examples of events that are possibly more dangerous another participant labeled the biggest challenge in DSP work as,

Impulsiveness. Once again – not knowing how to deal with that. Impulsiveness where you are driving and they want to grab the wheel because they're mad at you because you are redirecting them not to curse out the window or spit out the window because there are other cars coming by and they might get upset and try to jump out of the car while you are driving or grab the steering wheel which is effecting everyone in the car's life as well as everyone else around. Yeah – the danger. The violence.

Another participant related similar sentiments and expanded this to include aspects of persistent low mood or possible symptoms of mental health conditions:

The worst part of the job. Well I've had some pretty crazy experiences. Like I mentioned before I've been all the way to the point of literally having someone try and murder me. Or being in a situation where someone is trying to harm themselves or kill themselves and I've got to jump in and try and intervene with that without thinking in regard to my safety. Kind of just letting all that go and putting myself there for the individual. The hardest parts are seeing anybody being hurt or hurting themselves or just someone who is constantly unhappy and not only seeing them in that state and trying to cheer them up but sometimes you're around that so often it just brings you down. Just really hard to be around.

In relation to the above, while the possibly physically harmful events may be difficult to encounter, the sometimes required physical response was more troubling for one participant who reported:

> *You might have to use Handle with Care* [a de-escalation and physical intervention system approved for use in this state] *or any of the other restraints they teach you at whatever agency you may be at. And that's never fun to have to do that. That's one of the things I hate most about the job is when you have to actually deescalate a behavior by having to restrain them for what ever reason – if they are hurting somebody or themselves.*

Knowing or hearing about past abuse. While physically challenging events were clearly an area of concern for many participants, others stated that more emotional aspects related to the histories of people they support were the most difficult. For example, a participant stated, "*the hardest part for me is dealing with those that were taken advantage of. That's the hardest part for me. Because it's hard to imagine that someone could be so cruel and so, that part is really hard for me*".

Expanding on this, another participant related,

> *Some of the hardest parts are learning the histories of some of the individuals I work with. That's really rough. Getting past things that not only have happened to them but trying to look past things that they have done and just trying to keep a regular relationship with some people just knowing what you know.*

In this way, the presence of certain types of pSCB (e.g., when possibly violent and directed at others), appeared to add an additional dimension to the challenges faced by these DSPs. For one participant, this aspect took a more central role in the statement : "*[t]he worst part is*

when you work with the sexual predators. That is the worst part ever. I hate it. I hate it. I

have a client and I want to say it's his fault but it's not his fault". On a similar note, another

participant also attenuated their displeasure for "*[d]ealing with some of the* [sexual] *issues*

that they have" by framing in terms of prior mistreatment in that,

> *"[I] know that they can't, that they can't help it in a way. It's just their way of*
>
> *thinking because of some of the things that have happened to them in the past have*
>
> *made them they way they are today. And it's not even their fault. It's just, some of*
>
> *them were just brought up this way and it's all that they know. And that's some of the*
>
> *hardest things – just knowing that they have been dealt a really bad hand. And this is*
>
> *all they know and they honestly don't know any better.*

From a more general perspective regarding the difficulty of working with some individuals, a

participant stated,

> *I think it's always inherently challenging for people when they have to work with*
>
> *people that they genuinely do not like. And that's the bottom line, no one is capable of*
>
> *liking everyone and I think, when there's a real personality clash that becomes really*
>
> *challenging.*

Feeling like you can't help. In addition to the above, and related to the preceding

'Best Parts' section, there was a theme of not being able to help that emerged as one of the

'worst parts' of work as a DSP. For one participant this was defined as,

> *Letting your client down. Pretty much. When you said you were going to do*
>
> *something but then you don't end up doing something. Or, um, you can't fulfill your*
>
> *end of a promise that you made for them or you feel like you let them down…You've*
>
> *done everything you possibly can and you still can't help them.*

For another, this difficulty in the work stemmed from the supervision and restriction

requirements mandated (presumably by a treatment team and/or the provider agency) for a

particular individual:

> *Well, for me, I think some of the worst jobs in direct support are like* [individual's
>
> initials] *from day hab who, at first, when he was going there* [due to concerns related
>
> to adjudicated sexual crimes] *he was never allowed out. So, it felt like we were in a*
>
> *penal system instead of working as a, with some one who could move on in their life*
>
> *or be in the community and over time even though I don't prefer to work with him,*
>
> *he's grown to be able to do certain things.*
>
> I*: So as far as the worst part of the job it sounded like you were talking about when*
>
> *you have to um, in your words, treat people 'like they're in a penal colony'.*
>
> *P: Yeah, like a penal system where you're kind of like "no, you can't do this",*
>
> *keeping them from going out. The most they get to go out was like the ride from home*
>
> *to the day program where I was working. That was hard.*

Similarly, another participant related the difficulty of seeing restrictions placed on a

relationship between a male and female in her support as she stated,

> *I just keep going back to these two individuals. Their teams are keeping them apart.*
>
> *Which, man, the more you say no to someone the more they want it right? It's been a*
>
> *year now and they haven't seen each other. I mean really… And they're still, they*
>
> *haven't seen each other in a really intimate, other than at* [a local community dance],
>
> *a wave, in probably in almost a year and they're still calling each other fiancée. So I*
>
> *mean it's really interesting, and now a year later the teams have decided maybe we*
>
> *should let them have a date, a year later. I don't know it almost seems like a right that*

was taken away. I mean I don't know. They substantiate the reasoning on the girl's

side - which I didn't agree with. They [the individuals with ID] *were taking all the*

right steps and doing all the right stuff but what are you going to do?

From the above it is evident that these DSPs work in a highly dynamic environment

with a strong commitment towards effecting change and seeing growth despite some of the

intense challenges faced both from individuals they support and the systems within which the

work occurs. In most cases, the additional variable of working with people with pSCB adds

additional complications. As intoned in the last excerpt, *"but what are you going to do?",*

these passions may at times be attenuated by a sense of powerlessness to effect the change so

important to their experience of the work. As the following sections develop I will provide

further attention to this aspect of frustration and conflict. Presently, however, I will move to

providing further detail as to the conditions surrounding or embedded within the work life of

these DSPs.

Types of Challenging Behavior

In addition to the highly varied and hard to describe set of job duties, participants

were asked to speak about the different types of general 'challenging behavior' they have

encountered while working as DSPs with people with ID. While at times I prompted for

further detail, I provided no definition or 'set up' of the term 'challenging behavior' to any

participant. As with the preceding sections, this section is meant to provide a wide

perspective regarding the conditions in which DSPs operate. Specific exploration of the

range of pSCB also follows.

Overall, 25 distinct patterns of behavior described as challenging were reported by

participants. The most frequently cited types of events involved: (a) verbal or physical

aggression (either directed towards DSPs or others in residences/community); (b) self injurious behavior; (c) elopement (i.e., when a person receiving supports intentionally leaves the presence of a DSP and such action is unsafe due to skill deficits or other safety related behavioral concerns); and (d) shoplifting/stealing. Representative examples in these domains included the following statement by a participant: *"I've had things thrown at me, I've been bit, I've been spit at, I've had to restrain individuals that were going to harm themselves or others"*. Another participant reported that, of the individuals he has supported, one *"would destroy his house. He would throw things into the toilet. Just anything he could find to try and clog it up. Put holes in the wall, doors."* While another, *"would go to his room and he'd try to be sneaky and get his thumbs or hands and just keep banging against the dresser trying to pull out his nails."* And a third individual *"would try to run out in the street to get hit by cars"*. In a similar description, another participant reported,

> *I've had lots of issues with people trying to hurt themselves. There was a specific time where I had an individual jump into oncoming traffic and I jumped in with him. That was a very scary situation. We were able to turn him around and did a bunch of turns and he almost got his. I was able to get him to the median and then have to restrain him in the middle of the road.*

This same participant also stated,

> *I've dealt with people who are cutters. People who try to strangle themselves. I've had people stab themselves. I've prevented a guy from shoving a piece of broken glass in his throat. Many, many times they have tried to hurt themselves. I've worked in situations where two individuals were trying to constantly trying to hurt each other. Constantly breaking up fights.*

Another participant related an equally intense recollection of several challenging events including,

> *People trying to commit suicide on several occasions. Walked in and they were trying to hang themselves and I walked in and had to redirect and undo nooses. People running in the street and I have to push them out of the way of a car. People trying to injure me. Getting cussed at by the guy that I am trying to save and spit at and bit. All while trying to save them from oncoming traffic [laughs]. Yeah, so, a lot of stuff.*

Less frequently cited concerns in this domain included a variety of events including property destruction, problematic use of alcohol or other drugs, smearing feces, and making accusations against DSPs. Participants also related encountering more discretely psychiatric events including paranoid delusions, psychogenic seizures, and persistent depression.

Diverging somewhat from traditional definitions of 'challenging behavior' (e.g., Emerson, 2001), participants also spoke about difficulty communicating with people who choose not to/cannot speak, concerns about individuals aspirating on food or drink, complicated medical conditions, having to address situations wherein people they support are seen as gullible and may get exploited in the community, and instances where their efforts as DSPs seem to fall short. In these ways, participants' definitions or schemas of what may be included under the term 'challenging behavior' is more wide-ranging and inclusive. As one participant put it, despite the litany of events described above, "*[c]hallenging to me is constantly constantly constantly trying to help somebody who is not willing to be helped or is not willing to accept the help or just does not show any sign at all of being helped. That's very challenging*".

Types of pSCB

Specifically to the aims of this research participants were asked to describe the different types of pSCB they have experienced during work as DSPs. In the course of all interviews I put no boundary on what may or may not be considered as sexual in nature and instead left the question open to participants' interpretation. Later in this section I describe how participants identified whether or not certain actions of people with ID were sexual.

Overall, 33 codes developed to encompass the range of pSCB described by participants. The categories that demonstrated the greatest depth of response included: (a) actions directed toward DSPs (female and male); (b) actions directed toward children; (c) masturbation (in public or private); (d) assenting or consensual intercourse between people with ID; and (e) exposure in public. I address these categories in detail below. Following this, I delineate and provide brief examples of event categories less frequently reported by participants, explore how frequently participants stated they encounter these types of events, and examine certain terms used by participants.

It is possible, if not likely, that certain participants may have been speaking of the same individual(s) or events as other participants in different excerpts but from slightly different interpretations or levels of involvement. It was not within the intent or scope of this study to particularly identify or delineate events at the individual level.

Actions directed towards female DSPs. While every participant described events wherein the actions of people with ID were directed at themselves and interpreted as sexual, female DSPs had much more repeated, vivid, and personally directed accounts. For these reasons I have provided this distinct section, based on a code that developed early in the process, to present these findings.

In a representative statement, one participant related,

I've had some people who developed crushes. Of course that comes with the territory, you work really closely with people and then they start trying to come on to you and that can be difficult to redirect but I'm really, I'm pretty clear on that. I don't really have a problem redirecting that.

More specifically, this participant stated that

Most recently there is one individual who, but I think it's kind of an ongoing crush, but when I worked with him in a different arena, not in the program I'm in now but same agency, different program, um, he's was working on how to read, write, things like that and because I came from an teaching background they felt that I was probably really strong at being able to help him further develop those skills because he had them, and then he had an accident that caused a traumatic brain injury so he's relearning a lot of um, so he and I worked together really closely of course, you now sitting down doing math problems and reading and writing and writing paragraphs and learning how to do all those kind of things and he just kind of randomly started saying 'I love you' and 'let's go to dinner' and he was actually not super inappropriate in how he went about it.

Relating a similar experience another participant said, *"I guess you know being approached to go on a date with or be their girlfriend, you know, those invitations"*.

Other participants described encountering events where males receiving supports were "*staring at my boobs in a sexual way. Constant redirection with that"*. and "*hav[ing] to redirect people about inappropriate comments about boobs"*. Another participant described a representative event in this arena:

> *[w]ith one particular gentleman, he thought I didn't hear him, and he said something about my breasts and I really don't remember exactly what it was and I said 'excuse me, what did you say?' he got that cue, that he did something wrong, and he said 'oh, I didn't say anything'. 'Yeah you did, what did you say?' "no, no, no, no, I didn't say nothing, what's wrong with you I didn't say nothing'; 'ok' and it was something he's never said again.*

In several instances, participants described these possibly sexual approaches as having a more detailed intensity. For example, one individual who had reported being 'hit on' above continued on to describe a more specific event involving,

> *one individual – I don't work with him directly, I see him at day hab and he has a thing for me and he would tell other staff some pretty explicit things he'd like to do with me. And um – it got like, he hasn't taken any action so it's sort of let go. Um – I don't feel threatened by him in any way.*

Similarly, another participant recalled one individual who

> *talks about it all the time. Um, he always is inviting me to go to bed with him. He's always inviting me to touch him. He's always wanting me to do things…It's harmless.*

For one participant these sexual advances involved a male who

> *would, pretend that he didn't know how to shower himself and then he would call you into the bathroom and he would be masturbating like when you were standing there trying to shower him.*

Recalling the first time she encountered a similar event a participant stated,

> *It was probably the first month I started working. I went down into day hab and I was working with an individual who cleans the day hab so it was just me and him. And*

keeping in mind – this was the first time I've ever done this line of work. I was

trained. I did everything…So we went to go throw out the trash and we were walking

back to the car [and a coworker] *says 'I don't know if you know this but this*

individual kept getting closer and closer and closer to you. He started to walk next to

you and then he was behind you and I could see him checking you out and I just want

you to know – he is grooming you. Next he's going to try and hug you.' And the next

day he tried to hug me and it was – it's these little things where you don't even pick

up on it. But now that I'm aware it, I totally see it every time. But for somebody who

is new – if you didn't, if you weren't on your guard all the time then you never know

what is going to happen.

This same participant also related an event wherein,

I once had a client say that he wanted to decapitate me and put his head on my body.

And that was just like – it came completely out of nowhere. We were just having a

normal conversation and he turned and said that. And it was like 'what!?'. I told him

that was inappropriate, that it made me uncomfortable, it is inappropriate. I told him

'you know I'm going to have to talk to your team about this. I'm going to write an

incident report.' And after the fact, like the next day, he was like, 'I know that was

wrong. I understand and I'm sorry'. So, there's certain things like 'why would you

say that?' Like it came out of nowhere.

At times, these advances are of such intensity that one participant reported,

I'll be honest with you, there's some individuals we've had in our agency where I

couldn't work with them period because they were so, it just wasn't, not only do they

attack males but they would certainly, and one even expressed how he would like to

rape me so it was like not ever am I going to be put in that situation where I would

work with that person

Male participants reiterated similar stories such as a particular individual

"who…if female staff were combing his hair for him, getting ready for day hab, and

he just reached and groped her. He did that a lot in public or the day hab. Just walk

over and out of nowhere and grope…he would grab her breast area, he would grab

her buttocks, grab her front. Things like that. That's what I'm talking about when

he's groping".

From a more general perspective, another male participant described how certain

individuals with ID will "*try frontal hugs. Some have even tried to frontal hug with a kiss on*

the cheek".

Actions directed toward male DSPs. Male participants, as provided briefly above,

also spoke about actions directed at female co-workers. As a whole, however, they

volunteered decidedly fewer examples of times pSCB was pointedly or distinctly directed

towards their own bodies. Similar to the stories above one male participant reported,

I've known individuals that have made it clear that they've had crushes on me

personally but no I've never had anyone violate my space, my boundaries. I've had

individuals attempt to give me hugs or maybe try to see what they could get a way

with".

Later, this same participant somewhat amended the above statement telling of a single

incident when he

had an individual get aroused in restraint. Literally. Boner. Humped me in a

restraint. And was humping so hard that anytime we would try to let go he'd start just

swinging and kicking. So we had to start again. And he'd start again. And right here,

in my back, boner.

Another participant encountered a situation with an individual who used epithets regarding

sexual orientation. Specifically, he reported that,

I had one individual who, well, I'm gay, and his favorite thing was to go either

"that's gay" or "that's gangster" and it was offensive to me and we talked about it

though and worked through it and the last time I worked with him he was not using

the word 'gay' anymore to be an insulting or pejorative term. So, at least not around

me [laughs] I would just go to ask him "I don't do that. What makes that gay?"

Finally, another male participant spoke of his caution and general avoidance of working with

females with ID due to fear of being accused of sexual wrongdoing. He stated

Well, I've only worked with one female, which I really didn't want to do because of

the accusation part of it. It was one on one. Which I really didn't understand –

definitely should not be that. Even cops use that. If there is not a female officer

present you can't really pat down a female suspect. Same difference. They could make

a pass at you and you say 'that's inappropriate'. They could get their feelings hurt

and a lot of the [people we support] *are super manipulative and they could turn that*

into 'he tried to make a pass at me and I told him no and he got hurt and wouldn't

take me anywhere that night' but the real reason you didn't want to take them

anywhere is that you did not want them in the car by yourself.

I: Has that ever happened to you?

P: Yes. And just because of the fact – well, I lucked out because this one lady client

had actually made a lot of accusations against male staff on many occasions.

Unfortunately many of them were true. So it was kind of hard to believe or not

believe.

Actions or interests involving children. Stories of supporting people with ID who

have a history or current interest in sexual contact with children were prevalent in many of

the participants' discussions of times they have encountered pSCB. While the term 'child'

may be legally defined in the United States as anyone under the age of 18, the entirety of

participant anecdotes in this area involved interests involving individuals of pubescent or

prepubescent age.

From a general perspective, one participant described how these types of concerns

may be present in the histories of certain individuals who receive supports through he study

site agency stating, "*I've heard a lot of the clients when they were younger, being involved*

with small children and stuff. Some of the clients I've dealt with now have that in their past,

that they've dealt with young children and what not". Another participant echoed this

summation and brought it more towards current or ongoing concerns with certain individuals:

We do have some individuals who will probably have lifelong fixations with children.

And that usually is pretty evident by like a recurring pattern of behavior where they

have had multiple instances over a long period of time…where they've tried to do

things or just an ongoing fixation with children is noticeable. They're downloading

child porn, they're storing pictures of children in their room and the staff finds them.

This was further reiterated by another participant who stated, "*I've been in situations where I*

have been with certain individuals who have issues with children and you can see that they

are proudly displaying their excitement".

Tightening this perspective, several participants provided examples of the child-focused sexual interests or histories of specific individuals whom they support. As stated by one participant,

> One gentleman has an absolute fascination with toddlers…he will tell you himself that he's a danger. He will tell you himself that he is an unsafe person. And, it's concerning because in the instances that he has gotten away and offended he's done it quick. You know, staff turn their head to talk to somebody, and he's gone.

Another participant briefly described working with an individual who has an alleged history of *"tying up little girls and gluing their eyelids shut"*. A different participant described an individual receiving supports who "*has an attraction for babies so he'll cut out pictures* [or] *when you're in public you have to make sure to watch him because he will stare inappropriately"*. Likewise, a third participant described an individual

> who really really likes younger females. And he works in [an entertainment facility]. It's really hard because people come in with their kids all the time and so really you just have to keep an eye on him and make sure he's not being inappropriate.

At times, support of individuals with these types of interests or preferences may involve intense actions while out in the community. For example, a participant recounted an incident in which,

> [o]ne time we took [this individual] to [a large retail store] and he saw some kids and got excited. The worst thing was that he wanted to touch the kids. Then he got frustrated and went in the bathroom and took off all his clothes in the bathroom. The security got called and came to get us. We heard a big old commotion and he's in the bathroom masturbating because he got excited when he saw these kids…and said 'I

want to be with the kids'. And I asked him 'what do you mean 'be with the kids' and

he said 'I want to fuck the kids'.

The above excerpts reveal some of the intense considerations and situations faced by these DSPs when supporting people with ID and a history of pSCB. From difficult pasts to sometimes troubling current preferences for and interests in children these participants spoke about attempting to navigate the lives of people many might consider beyond help. As imparted below, however, these types of concerns are merely one part of the overall conditions within which the work of these DSPs takes place.

Masturbation or exposure. When asked about times they have encountered pSCB participants also spoke about incidents involving individuals with ID who have histories of masturbation in ways that may cause physical harm such as "*masturbat*[ing] *so much that they have rubbed themselves raw*" or, an individual who, "*when he's stressed out, or when he's upset he will take his feces and he will smear it all over the bathroom or he'll masturbate with it*".

More frequently, participants spoke of individuals with ID masturbating or exposing genital areas in various socially 'inappropriate' (defined by participants in a following section) locations or situations. One participant stated that he has worked with "*people who would pull their genitals out and masturbate in front of anyone who's there. Especially when you are in public is quite a hard thing to deal with*". As in the above sections, most participants tended to use particular examples they have encountered or been privy to in describing these events. For example, a participant spoke of

a gentleman I used to work with, he has a history of doing this but he's never done it

any where when he's with me so I don't really keep it very strongly in the back of my

mind but he has a history of you know, taking his pants off or whipping it out or going

around to neighbors when he's knocked on the door naked. Things like that.

In a similar vein, another participant related that *"[w]e had one client that would go into the*

community, to the store to go grocery shopping or clothes shopping and he would just get a,

pull his pants down, urinate in public or he would just start masturbating".

In another example of this occurring in a public/community location a different participant

stated,

> *I've had quite a bit of that. Like might get mad or sexually frustrated like at the*
>
> *casino. Might pull down their pants and start jacking off right there on the*
>
> *spot…Most of the time it's in casinos – something like that – grown up settings. It*
>
> *happened to me at* [a local hospital] *before. Pulled down the pants. But, that's more*
>
> *trying to get to the staff then anything. Trying to test the staff's limits. See what they*
>
> *will do. What they can get away with. Like I said – I've got two teenagers so I've kind*
>
> *of been through that already. I've got a little experience in that field. [laughs]*.

This category of pSCB was also noted to occur in residential locations as related by one

participant who stated, *"[w]e do have one gentleman who I think masturbates into towels and*

puts them back on the shelf at his house" and another who described an individual who

"would pretend that he didn't know how to shower himself and then he would call you into

the bathroom and he would be masturbating like when you were standing there trying to

shower him". Likewise, a further participant discussed an example of an individual who

> *P: liked to expose himself in his room because right across was a lady and her*
>
> *daughter. So he'd open up his windows, get undressed, and start masturbating.*

I: So the lady and her daughter were in another house and he would start masturbating?

P: Well, if they were on the deck they could see this. Finally they called us, told us, '[individual's name] better stop doing that or I'm calling the cops'

Assenting or consensual sexual acts. In this category participants related anecdotes of times when people with ID were presumably engaged in discrete sexual acts (i.e., oral sex or intercourse) with another person. In these excerpts the legal guardianship status of involved individuals, while intoned at times, was uncertain and not discussed with participants. Nonetheless, in these stories the participants seem to be framed as willing participants (i.e., assenting) even if, at times, all individuals may not have held full legal rights to decisions (i.e., consenting) due to guardianship status. In many of the excerpts below it is evident that the participants framed these speculated or actual events as problematic mostly due to the location(s) in which they occurred rather than specifically due to the nature of the sexual interactions themselves.

Speaking of working as a DSP in residential and day program locations one participant stated, *"there's always the bathroom issue of making sure they don't go in together and have sex, give blowjobs, or have somebody do something for them in the bathroom".* Another participant similarly related,

P: I guess a lot of clients now will do stuff in the bathroom, things like that. You know, like oral sex.

I: Do things with?

P: Other clients. Yeah.

And again, a third participant reiterated, *"[y]ou get some people who, they see an opportunity to sneak off to the restroom with a person or go do this or that type of thing"*. Speaking of the difficulty in remaining aware of these type of possible events one participant stated,

> [t]*here's been incidents where it's happened right under my nose. Literally, and I didn't even know it. I've had clients you know, um, have oral sex with each other right in front of me and I didn't even know which was a trip to me. It really opened my eyes.*

From a more incident specific perspective this same participant stated,

> *P: I was working in the day hab and we had one guy sneak into a bathroom with another guy. So, not that that was the worst thing that could've happened. They were both consenting adults but that was the first experience that I had with something that was…*
>
> *I: Concerning and sexual?*
>
> *P: Something that was sexually related that should not have been happening in the setting it was happening in.*

In the above scenarios participants were speaking of events that occurred or might have occurred at group day program locations. Another participant spoke of analogous events in residential locations such as,

> *guys sneaking into each others' rooms. That's more on a consent basis. Of course, there's rules for every group home or agency and that is definitely not supposed to happen. It is within their rights and it's a thin line between their individual human rights and what is appropriate and what's not.*

This sense of the division between rights and 'appropriate' was repeated by another participant speaking of an

> *incident that happened, I wasn't there, but the backyard where he had somebody give*
>
> *him a blowjob. You know it's, I don't feel that those are necessarily inappropriate*
>
> *and I don't feel that anyone was in danger from those, except for that they were in an*
>
> *inappropriate place and maybe legally inappropriate...*[because] *if someone sees you*
>
> *having sex outside that might be legally inappropriate. Like indecent exposure at the*
>
> *most. I don't think that's the worst thing.*

Relating a sense of the underlying conflict in these types of situations this same participant expanded

> *P: I'd feel hard pressed to feel guilty, guilty like, like I feel no guilt over what*
>
> *happened. I would never let it happen if I were there but you know yeah… ugh. It*
>
> *happened, let's try not to let this happen again but I do remember when that*
>
> *happened like 4 years ago?*
>
> *I: When what happened?*
>
> *P: Between [names two male individuals] and outside in the backyard. I don't*
>
> *remember who gave who a blowjob but to me I felt like part of that was a bit*
>
> *overblown.*
>
> *I: What part?*
>
> *P: The team reaction for the most part about [one individual] and some of his issues*
>
> *and [the other individual] was just looking to be happy in the moment. And I don't*
>
> *feel guilty for him having his moments. That kind of thing. I feel guilty if I don't catch*
>
> *things and I try to make it better, less dangerous, and some things like that. I know*

that I won't let it happen again, I'll try to learn from it but I don't have the emotional attachment in my head like 'I feel guilty about that' I'm more like 'Good for you, you found a way around the system. You got what you wanted. We're going to try not to let that happen again because of x, y, z' which I still don't understand but…

Later in this same interview the participant related another example of a person with ID engaging in sexual intercourse framed as problematic due to location rather than the act itself and perhaps provided impetus due to factors outside of his control:

As far as like an individual like, ok [individual's initials] *having sex with her boyfriend on the couch and at the time, everyone on her team said 'no, no no' like they can't have sex and she just took matters in her own hands and that's what happened. Totally inappropriate place. I think letting them do something behind closed doors would have been better. She's an adult who is in her mid 20s and he's maybe two years older than that. Maybe three? Not letting them have an intimate moment led to them doing something on the couch that had to be cleaned up in a very different way. There were no couch covers at that point [laughs].*

This participant's sense of confusion, and intonation that other parties' (e.g., guardian, parent, interdisciplinary team members) decisions regarding limitations or restrictions have a possible causal role in some of the etiologies of pSCB was reflected in many of the other interviews. It is further explored in later sections. From another angle, it is notable that these types of actions (i.e., consensual or no clear harm to self or others) were mentioned by participants when discussing pSCB. As with 'types of challenging behavior' above it appears that these DSPs may have a slightly wider definition of the term pSCB. Again, the events are not framed as challenging in and of themselves but were, perhaps, discussed by participants

under topic of pSCB due to the challenges these actions pose for DSPs in regards to duties or required responses. This too is explored in depth in a section of the following chapter – Arrival at a Grounded Theory.

Other types of pSCB. In addition to the above, participants spoke directly but with less frequency about supporting people with ID and a history of experiencing/engaging in or current interest involving:

(a) cross-dressing:

> *he would dress up like a woman. And the company required me to take him out. So, at this time, the world wasn't so giving toward that. So it was like gay-bashing and stuff like that. They had me working with him because they thought I was a tough one. We were walking down the street and someone threw a soda at us so it was like and they called us 'gay' and stuff like that;* Or,

(b) peeping: *"I known of guys who are peeping toms who like to get out, pop up in bushes, look in windows";* Or,

(c) entering other's homes for possibly sexual purposes: *"I've known people to walk into strangers homes naked or otherwise".* Or,

(d) bestiality:

> *there's other clients who have desires towards animals. And, well, there's animals and dogs coming in our agency all the time. People bring their dogs to work. So, it's just making boundaries where it's like 'you can't take your dogs downstairs. You keep it in your office';*

and likewise from another participant, *"a certain client when I was at a different agency. He would come out naked. He would talk about wanting to have sex with pigs";* Or,

(e) incest:

> *I have a client and I want to say it's his fault but it's not his fault. He was molested by his mom who had all these personalities. First she was the mom and next she was the friend. Then she was the girlfriend and then she was the sister. When she was the girlfriend it was up to us to step in to try to stop it;* Or,

(f) 'hands-on', non-consensual, actions against other people with or without ID:

> *We had a gentleman when I was at the first agency that I was at who was very sneaky about this but they had transport vans and he would attempt to take advantage of people in transport vans, you know try to take his hand and stick it down the pants, lower functioning people than him usually.*

And the similar from another participant, *"[t]here's been a couple of situations with some of the people that we have who have, I wouldn't say assaulted their roommates but taken advantage of them because they are vulnerable in that situation"*. Or, the more severe examples provided by other participants of one individual with ID who *"raped somebody 15 years ago"* and another in which the participant stated, *"I've worked with people who can't even go in public restrooms because of assaulting people in restrooms in years past"*.

  pSCB in females with ID. Other than the excerpts regarding (a) the young woman having intercourse on the couch at her home; and (b) the worry one participant expressed over potential accusations, the overwhelming majority of the above stories and generalities regarding pSCB and individuals with ID related by participants involved males with ID as the primary actors. The following excerpts represent the remaining totality of incidents of pSCB participants spoke of wherein a female with ID was the actor or target of interventions. Representative of this lower frequency pattern one participant summed up that, *"we work*

with female clients but they have their own behavioral issues going on. They really don't go groping I don't think. I can't recall an instance where a female client would go groping a male staff member.

In regards to masturbation, a participant described how *"[o]ne female client was caught in bed pleasuring her self. But you know, that's her right. She's in her bedroom, it's in private but they made a big deal out of it".* In this regard, the problematizing of the situation appears to be attributed to the views of others rather than the DSP his or her self. Another participant spoke, with a degree of dry sarcasm, of a somewhat similar situation involving a woman who was identified as,

> *P:…'hypersexualized' [finger quotes]…*
>
> *I: What does that mean – to be hypersexualized? Where does that come from?*
>
> *P: I don't know if she was every like totally diagnosed with that but with her everything can be sexual supposedly. So, she looks at everything like 'I'm going to touch myself because of this' or all sorts of different things. She's kind of, for me, by layman's terms I would say just being more sexual, or doing more sexual things than what is quote unquote considered normally acceptable.*
>
> *I: What is 'normally acceptable'?*
>
> *P: Apparently people aren't supposed to masturbate, Jason.*

Regarding public exposure, one participant spoke of a

> *lady who for whatever reason went into this phase of, she lived in a home on her own and had some unsupported time, and she got to where she would do this with staff. She would call people randomly - firemen, policemen and when they got to the house*

she would be posed there completely naked in the doorway or on the couch or

something along those lines

Lastly, regarding sexual intercourse, a participant described supporting a

very healthy young woman and she wants to pursue a sexual relationship with her

boyfriend and she needs to know, to understand that there are steps that, how to be

safe when having sex. And she's taken all the classes, the sexuality classes and

getting tested and all that stuff and we are trying to facilitate – we aren't trying to

facilitate her having sex – but helping her get ready emotionally for when she has a

sexual physical relationship with her boyfriend. But other than that, female clients

aren't as, I've never come across any…of a woman who would blatantly try to

masturbate in front of staff or anything like that.

In summary of the above section regarding types of pSCB, the DSPs who participated

in this study told of events of a possibly sexual and concerning nature that ranged from

verbal approaches to assenting/consensual physical contact, to potentially or actually harmful

or illegal actions directed towards self or others. In later sections, I examine the ways in

which these participants envision and enact supports in what they see as a sometimes

confusing or conflicted atmosphere with a multitude of invested parties.

Frequency of pSCB

The types of events described above are of a wide range and involve a multitude of

different individuals in diverse locations or activities. Participants were asked to estimate

how often they encounter incidents of pSCB *in general* during the course of their work as

DSPs. Therefore, the following estimates by participants mostly represent the frequency of

overall occurrence rather than frequencies broken down by distinct subcategories.

Speaking about being 'hit on' or sexually approached by an individual receiving supports one participant stated, *"I encounter it I'd say, at least once a week"*. This same participant, when describing a time she supported a particular individual, related, *"he really thought that we were going to be bed mates. I mean he was convinced. So it was like every day for a long time"*. In less specific terms, a different participant estimated the frequency of pSCB events as occurring *"several times a week"* while another placed it at *"2-5 times a month. Easy"*. A third placed the estimate as *"at least 3 times a week or more. 5 times a week? The staring, the touching during transport"* . From a more personally directed perspective another participant explained

> *Um, lately? Not very often. In the beginning and maybe it was because I was new, I saw it a lot. There was just like 'Whoa! Boundaries!' And well, I've also had the same clients for almost a year and so in the beginning I think they were testing me like 'Let me see how far I can get with her' and then once I made the boundary of 'No, that's not ok' they know now that 'If I try and hug her she's going to tell me 'no' or she will get mad, she will say something'. They know now not to even try it. So I think that it hasn't happened in a long time. But in the beginning it happened quite a bit because they test you. They are going to see how far you can get.*

Describing the environmental considerations that perhaps effect these frequencies a participant stated, *"[w]ith the agency I'm at it's almost daily with the guys that we have there. There's always something going on with one of them. I get notified everyday of something or I would say at least every other day with some of them"*. This participant explained further that,

we have a day program downstairs that has 30 individuals that the entire, almost the

entire clientele has sexual behavior concerns and that's why they're at that particular

program. I think that we're kind of notorious for specializing in that so, um, you know

there's always that kind of thing there and it's almost like it carries over to other

arenas because a lot of them are in multiple programs in that agency so there's a lot

of cross referencing with each other like 'ok, this individual is doing this'; or 'this

happened, these two snuck off to the bathroom and did this'; or you know, it's kind of

an ongoing thing there.

Providing a longer-term perspective about the agency-specific variables, another participant explained,

[i]n this agency, for an average, I think it's gotten much less. A lot of the guys that we

work with, with those issues, have been with us for years and years and years and

years and really have shown progress. If not progress, they've been prevented and

they've really kind of settled into that. But on a day to day, I mean I would say that it

probably happens several times a week. Someone's trying to get away with

something.

Speaking of the specific experience of supporting people in the day program setting another participant estimated,

P: Out in the community each time, at least once. But not the whole time.

I: Once every?

P: Outing

I: Once every outing…

P: But not like, there's a mild thing but you can catch it early if you are aware. So one of them, if we're like driving in the morning we make sure not to go by schools and stuff because that's the way they do it but, um, I wouldn't say its all that often to be honest but like you know, if you have a behavior during the day or just behavior where they're staring and doing the looking, some of them have grabbed themselves. That kind of inappropriateness.

Likewise, another participant stated that frequency *"depends on the situation. It may not happen that much depending on what you are doing or it may happen a lot"*

Terms used by Participants

In the above sections participants utilized a variety of terms to describe events, actions, and concepts related to pSCB in people with ID. Selected terms (i.e., grooming, pedophile/ predator, deviant, and appropriate/inappropriate) are examined below in relation to how they were understood, delineated, or defined by participants.

Grooming. The term 'grooming' was invoked several times when participants were describing particular individuals or types of pSCB events. When used, participants were asked what they meant or how they might describe the action of 'grooming'. One participant provided the following explanation:

I think that a lot of them are groomers, which means that they are looking to see how far they can get before they actually make the advance. So they are going to come as close to you as possible. The next time they are going to hug you. The next time they are going to accidentally – quotations, 'accidentally' rub their hand against you. And it's just – well, with some of the clients, if you don't set that boundary- they will do that. So I think that's what grooming is.

Other participants provided some further examples of what they saw as 'grooming'. For example one participant said, *"[s]ome guys even go as far as older guys like late 30s, 40's wearing a Dr. Seuss hat or badges – 'I'm a cop, I'm a fireman, look at this.' They touch the badge, the guy tries to grab the hand, grab something else".* Speaking of a similar set of events, another participant stated, *"[y]ou get people who buy candy and balloons, whatever for the kids – just so they can get close to them. Or have a conversation that the kid wants to have".* One participant was less clear on how to describe the term, stating, *"[t]he whole grooming thing. I mean I know the word, I know what it means, but what are the specifics that it looks like? I would like to know – those are the people that we serve".*

Deviant. The term 'deviant' was used to describe certain actions of individuals with ID as well as to describe overall qualities of individuals. One participant connected this term to a loosely psychiatric quality:

> P:…unless you're a bona fide deviant, there's a better way.
>
> I: What does a bona fide deviant mean?
>
> P: They talk about it when they're having court. When this person is just pathological.

This was vaguely echoed by another participant who stated,

> Deviant to me is essentially not giving a shit. Knowing that what you are doing is wrong and not caring. You don't care if it hurts somebody, you don't care about their feelings, you don't care if you damage somebody. Very selfish. Very – all about you.

Another participant related the term 'deviant' to a legal standard:

> Deviant means unlawful. Something that's not legal. If you are over 21 and you are having – or is it over 18? Depends on the state. If you are over 18 and you are having

sex with someone under 18 or you are trying to, or you keep trying or even younger –

it's illegal. Oh no, no, no. No pedophilia. That's illegal

I: So deviant is connected to legality?

P: Legality yes.

Loose ideas of social norms or rules were used by additional participant in the statement, *"Inappropriate would mean deviant, manipulative, you know when they are doing something they are not supposed to be doing. Which a lot of them do. You know, in public. Public stuff. Age inappropriate stuff"*. Lastly, one participant seemed to couch this as a term of questionable validity stating, *"they act out and do these deviant, so called deviant behaviors"*.

Pedophile or sexual predator. These terms, while less explored in the interviews, were connected in the statements of those who did speak to the definitions. For one participant the connection was fairly direct:

To me a sexual predator…is the one who likes the kids…A sexual predator is someone who lusts after children. You've got some that lust after grown ups but being in this field I haven't seen any. Everyone I've seen lusts after children…So those people to me are sexual predators. You know you are a grown man. You know this is a kid. What business do you have lusting after a kid? What business do you have going after that kid? So therefore – you are a predator.

Another participant also drew a connection between the terms stating, "[f]*or 'pedophile' it's, for me, I define it as anyone who focuses sexual attention towards children. Anyone who is pubescent or below…So, I mean obviously they are adults but they're predators. They focus*

their sexual attention towards children". A third and final participant used an example of a potential sexual advance toward a child to explicate the term 'sexual predator'

> *A lot of the guys have sexual predator type behaviors and will go after it if the opportunity arises….For example – I'm in the bathroom and I turn around to wash my hands and they turned around and snuck under the stall into the next stall that a kid was in?*

> *Appropriate/Inappropriate.* Perhaps the most commonly referenced set of terms in this set of interviews were variations on the words 'appropriate' and its corollary, 'inappropriate'. These terms and variants thereof were used to describe particular choices made by people with ID as well as to describe a common aim of their work as DSPs involving incidents of pSCB. In regards to the intent of the work one participant stated *"The trick is, teaching them what is appropriate, what isn't appropriate. That's the really hard part of it".* Congruently, another participant stated, *"[t]he job would be to encourage safety, privacy. Always teaching. Always being supportive and encouraging the appropriateness of whatever is going on".* Expanding on this theme, a different participant referenced teaching notions of personal space and consent as part of the appropriate/inappropriate continuum:

> *when I say appropriate I also mean boundaries. Each person has boundaries. Like when you, are you violating their space? Are you touching without consent? These are not, these are things I teach them 'this is not appropriate'; 'this is not acceptable; 'everybody has their boundaries'.*

In the following exchange a this same participant further connected the terms to a legal standard regarding general sexual relationships:

I: ...So some words come up a fair amount. Appropriate and inappropriate. What, um, talk more about that. How do you conceptualize that?

P: What's appropriate?

I: Yeah, how do you define that?

P: Ok uh, so if you are 23 years old, 'appropriate' would be a 23 year old. Not a 6 month old baby. Appropriate ok? By law standards.

I: So there's like a legal standard.

P: A legal standard absolutely. We do go by legal standards. There's like quite a few individuals who have attraction to 'pubescent', I can't even say that word [laughs], pre-teens?

I: prepubescent?

P: yeah...Children, ok, obviously the legal age I'd have to say would be 18. These guys are all over 18 so let's stick to 18. Whether it's a male, female, I'm not even caring about that. I want you to be able to date someone your own age and date where they are accepting of dating you.

When asked to describe how she knows if a particular event falls in the range of 'appropriate' or inappropriate' this participant stated,

anytime it makes me feel uncomfortable and it's sexually in the wrong direction um, I'm a female so you know, anything sexual and offensive or inappropriate, any comments to do with a woman's body or even a man's body and something I know that person wouldn't agree to. When it makes me feel uncomfortable that's when I'm like 'ok that's...' and I'm not very quick to be like 'that's inappropriate. You don't

discuss that. You don't talk to me about it either. It is not appropriate to talk to

someone that way'.

The notion that 'inappropriate' may be quantified by an action's effect on others' comfort was echoed in the following exchanges with two different participants:

I: So how do you know if something is appropriate or inappropriate?

P: By, I feel that if you know that it's going to make somebody uncomfortable, or if

you know that, and it sucks to say, but by society's standards, if that is not ok then

you probably shouldn't be doing it or saying it. And it's, I'm sure everybody thinks

weird things – but you shouldn't act on them.

And,

P: Inappropriate is looking at someone and making them feel uncomfortable. That's

not appropriate. 'Would you look at your mom like that?'; 'No'; 'Then don't look at

me like that – it makes me feel uncomfortable'…Appropriate is, is, coming up to

someone 'Hi', shaking hands, looking at the eyes, not looking at the chest, not

standing too close because people have space…Appropriateness is when you want

some alone time – you do it in your room.

I: Alone time meaning?

P: Touching yourself. You don't do it in the car during transport. You don't do it in

the room at day hab. You don't do it at a restaurant. If you are starting to have those

feelings then you need to let staff know and then you boogie on home. [laughs].

Consistent with some of the above, another participant also connected the terms to an age-based or behavioral standard framed as part of her duties to notice and encourage or discourage:

> *And so when you see them exhibit it I think that's something you should say – 'this is appropriate, this is a good thing to pursue, you know talking to people who are in your age range and talking appropriately with them and asking them how their day is instead of you know, pulling your pants down and showing them [laughs] something they don't want to see. So you know, that's probably the biggest challenge is the ascertaining of 'ok, where are they being appropriate and where might they be scoping out, being predatory, or something along those lines.*

Also referencing specific types of behavior, participants provided further ideas on their operational definitions of appropriate/inappropriate. One participant stated, *"he's made a couple of comments like that* [about breasts] *and I've had to be like 'That's not appropriate'"*. Another participant was more concrete when she stated, *"taking feces out of a diaper and rubbing it on your penis is not appropriate sexual behavior"*. Stating, *"[i]nappropriate is definitely something ending in a negative outcome... ,* a further participant implied that one must gauge the possible adverse results of a behavior in order to determine where it lays on the spectrum. Expanding on this theme, another participant demarcated appropriate/inappropriate in reference to the possible harm of a particular behavior, location thereof, and any applicable legal standards:

> *But, there's always the bathroom issue of making sure they don't go in together and have sex, give blowjobs, or have somebody do something for them in the bathroom. The incident that happened, I wasn't there but the backyard where he has somebody give him a blowjob. You know it's, I don't feel that those are necessarily inappropriate and I don't feel that anyone was in danger from those, except for that they were in an inappropriate place and maybe legally inappropriate.*

From a more global stance one participant stated,

> *appropriate is everyone has sexual feelings. Everyone has those feelings. Everyone has the need to feel sex, to feel love. Appropriate would be – you go into your bedroom with the door shut locked, windows closed, curtains drawn, very private thing. Appropriate is talking about your feelings with somebody,…asking the questions. Inappropriate would mean deviant, manipulative, you know when they are doing something they are not supposed to be doing…You know, in public. Public stuff. Age inappropriate stuff.*

The above characterizations of appropriate and inappropriate appear wide-ranging in that they are grounded in variable concepts such as personal space, social comfort and conduct, and harm while concurrently addressing more concrete notions of legal statute. As evidenced above and in following sections these concepts appear to inform many aspects of these DSPs work with people with ID and concurrent pSCB. Encouraging the 'appropriate' and preventing or addressing the 'inappropriate' are central aspects of the actions and interactions described by these DSPs in the next main section. Who these DSPs see as making decisions about what related actions to take and when, is presented later in this section.

How Can You Tell if a Behavior is Sexual or Not?

Notions of inappropriate and appropriate may, at times, have far-reaching connotations regarding the actions of people with ID and pSCB. Similarly, how one might tell if a certain behavior is sexual or not may also rely on a far-reaching set of references and standards. To explore this concept, all participants were asked to provide thoughts on how they gauge the possible sexual intent/content of the behaviors of people with ID.

You can't or it's hard to tell. Initial responses to this query often involved statements of the trouble in knowing if an action by a person with ID has a sexual connotation or component. For one participant this 'not knowing' was perhaps less important than the possible outcomes of the action regardless of sexual intent. Specifically, this participant said,

the interesting thing to me is you can honestly never say that for sure something is sexual or not. Only that person knows that…The only thing you can do is kind of monitor for both the safety of that individual and anyone they might come into contact with

Expanding on these thoughts, this same participant went on to say,

you can never make the determination if something is sexual or not. Only that individual knows if it's sexual in nature. Now, they may tell you and if they choose to tell you then you might have some idea but even then I think it's, until we have the ability to read minds we're never going to know 100%, to be certain if something is sexual or not. You now and there have been some where I've honestly questioned like 'maybe they just have a fascination with things they think are pretty'

From the above, it seems that this participant was willing to consider other interpretations of actions that may have been framed as 'sexual' for certain individuals. In a more lengthy exchange, another participant expressed similar thoughts regarding types of behavior that could, at first glance, be seen as 'clearly sexual':

P: To me, I don't think there's a sexualness to masturbating in public. I think there's a shock to it like getting himself out of an uncomfortable situation.

I: So how do you tell that?

P: How do I tell that? How does anyone tell that? Well, I mean there's the stuff I know from sexuality classes and knowing about rape and going to women's groups and things like that I know that rape can be about power and things like that. Not necessarily sexuality. I guess, the gratification factor of it. If they are happy and they are enjoying it physically. There's physical intimacy like getting physically intimate with another person or they are just enjoying themselves, their time with themselves I...I don't know why we just associate it with certain parts but yeah of course, there's parts, touching parts

I: certain parts

P: Yeah, I think that's a good hard boundary for it. For how we all think about it generally. For me, I think that you know, everyone adjusts a part now and then. They should be allowed to because it's not comfortable through the day but if they are doing it a lot in a row or at a certain time, is that sexual? I don't know.

I: So the other end of it you were saying about the guy who was masturbating in the dentist office, he was touching

P: himself

I: but that you thought wasn't

P: I didn't think it was [sexual] *but I think he was doing more like "I'm uncomfortable in this situation and this is something that will get me out of here because you'll remove me from this place" Which, it did get him out of the space that he was immediately in but it didn't get him out of the appointment. We got him into a space more quiet and by himself which I think helped with calming him down but he was still upset. No one likes the dentist [laughs].*

A further participant added to this line of thought and the difficulty of not being sure stating, "[t]*here's grey areas. Yeah. It's hard. It's hard. Especially when you are working with a client that is not very verbal. It's frustrating to not understand. To not be able to know, to help them".* Lastly, another participant also expressed his difficulty in knowing how to determine the possible sexual aspect of certain behaviors and implied that there may be an intuitive aspect:

> P: *How do I know when it's sexual or not?*
>
> I: *yeah*
>
> P: *[sighs] You would think that's a pretty straight forward answer to that question. Um, I guess it's just that feeling you get you know?*

Sometimes you just know. As intoned in the preceding excerpt, a theme of 'gut' or particularly elusive feeling was related by several participants when speaking about the possible sexual intent/content of individual behavior. As put by one participant, *"It's just a general uneasiness you get from him sometimes. I wish I knew how to explain better".* Likewise, in the following exchange, another participant related the use of personal emotional reaction as a type of 'sexual barometer':

> P: *"It's a tough one because I don't know – I know when it is sexual…It's like a creepy, ick factor…I don't know if it would be sexual on their end, but to me it feels sexual and inappropriate. It's just…*
>
> I: *So, your reaction is a gauge for that?*
>
> P: *Yeah. Touching them, most of the time, unless it's like a tap on the shoulder like that* [lightly taps own shoulder with fingertips]. *A general "Hey!' something's going on" would feel inappropriate for me.*

Expanding this somewhat, a different participant implied that information received through individual trainings in conjunction with assessment of environmental variables may add to (or possibly inform?) the instinctual interpretation of a person's sexual intent: "*A lot of it is just your personal instinct and the training that you've had on that person. So, um, its just it's just how you feel at the time or what's going on, what's around you and what they are doing*". Similarly, in the following exchange, another participant wove together a combined picture involving instinct, and individual history with the additional aspect of attending to the qualities of a person's body language:

I: So how do you know if that has a sexual component or not? How do you make that call?

P: Well, I mean first of all you know the histories of the individuals you are working with. You know what they do if you've spent any time with them. There's always that gut feeling with it.

I: What is that feeling?

P: You just have that gut. Like 'I know what you're doing. I know what you're up to. I can tell something is brewing in your eyes. I know you're not hearing me as I'm talking to you right now because you're staring in that direction and I know what's over there'. It's just about knowing.

I: And the 'something's brewing in your eyes' – what does that mean to you?

P: To me? You know, you get to know somebody. You know where their focus is at. You can just tell that their wheels are spinning. It's not always noticeable obviously. Yeah. I don't know.

Eyes, body language, focus, and gravitation. In continuation of the above, the factors of an individual's eyes/gaze, and physical movements were discussed by several participants. As related by one participant, *"[f]or me the eyes tell everything. It tells you where their focus is. It shows the light or it shows the dark. I don't know how to explain that".* Another participant also seemed to home in on the qualities of a person's eye contact and/or movement as a method of assessing possible sexual intent:

> *P: Like if a kid passes by. You can just see that they get excited. Or the look in their eyes. They like perk up. It's just, It's body language.*
>
> *I: What do you mean by the look in their eyes?*
>
> *P: Their eyes will just literally spark. Their eyes will get big and their shoulders pop up and it just like 'ok, I've got to get them out of this situation'.*

The observed qualities of an individual's eye contact was again reiterated in the following exchange with a different participant:

> *P: It's like a long stare where he's gawking and you feel like there might be some drool [laughs]. It's almost like, clearly not normal glancing. It's not the eye contact you make with someone. It's glaring at them like this, and staring at the kid like it's a dessert. That's the best way to describe it. I mean I showed you but you can't really hear that [laughs].*
>
> *I: Actually I wrote that down - 'opens eyes wide and moves head forward'.*

Complementary to the above, another participant connected the quality of eye gaze to a loose sense of social norms:

> *holding the gaze longer than would be socially normal you know, not that there is 'normal' [finger quotes], but with, with staring or watching things in the community, I*

don't know how to explain it but the intensity of a stare and how long you're looking at something and you know – are they breaking away or are they willing to or if you break into the line of vision are they trying to get around you and continue looking at what they're looking at?

Similar description was offered by another participant who stated, "*For me, it's this really odd vacant look in their eyes when it happens. You know their focus is there and it's like they're not in their head kind of thing*". This same participant went on to give an example involving the quality of eyes and movements of a particular individual with whom he has worked:

Watching certain people come around, he does have focus and it's kind of really creepy. So to, if you see him kind of focus or stare in a certain direction, especially when I first started working, I don't know how long he'd been in [this region of the country] *at this point but he would just blatantly stare…I mean there was staring but there was physical presence too. I mean he was staring but he tried to start to walk towards them* [children]*, he just gravitated towards them. It was really not the funnest thing to do to walk him outside and say 'hey we've got to get going now, you can't do that'. That was kind of creepy. Watching him and seeing him creep up.*

Attempting to describe this in another individual, this same participant described it as:

P: *it's obvious that he's got this physically intense, visual gaze focus that is straight on the object that he's looking at.*

I: *The object being?*

P: *An infant.*

For some participants, while observed qualities of gaze and body language remained prominent factors in interpretation, were percolated through the knowledge of a person's past actions

> *Depends on who I'm with. If I'm with a client who I know does not like kids then I*
> *don't look for the slobbering. The hand motions. The eyes back and forth. I don't have*
> *to worry about that. But if you are with someone who you know likes kids they'll look*
> *back and forth to see if you notice them looking. So you'll see a lot of this [looks back*
> *and forth rapidly] the back and forth looking.*

The potentially strong influence of history as implied in several of the above excerpts is further explored below.

The influence of history and training. Regardless of the general uncertainty and reliance on gaze, body language, focus, or 'gut feelings', many of the above examples intone that the sexual history of individuals often plays a key role in the determination of sexual intent.

As framed by one participant, "*it's difficult to distinguish between what's a sexual behavior and what is not because we know their sexual history*". In this excerpt, the participant appears to imply that the knowledge of a person's previous actions may add a level of bias to interpretations of this individual's actions. This was reiterated by another participant who stated, "*I think they are labeled sexual based on their history – contact with minors or what have you. Sexual offenses. Anything they do from then on out is labeled as sexual*". According to another participant, knowledge of previous patterns or actions was implied to be essential in the determination of sexual intent: "*Knowing their history? Absolutely. Knowing what their behaviors are, what they've done in the past. Knowing what they've said*

in conversation if they are willing to talk about their stuff. What they have done. You kind of know what you're looking for". This line of reasoning was repeated by another participant who stated, "*it might be hard to tell at times until you actually know the client really well and you know their history and background I guess*".

In the following excerpt, a further participant seemed to express a degree of frustration with how these history effects may influence the quality of supports:

> *To me what's really really challenging with individuals with sexual behavior issues or concerns I guess we should say, is um, I think that there's a tendency to over do it where anything and everything they do can be misconstrued as doing something inappropriate when it's not always.*

This same participant expanded on this in a later section of the interview explaining,

> *There are a lot of people who have sexual behaviors with children at that particular agency and I do think some people take it to far like if they happen to glance at a child who is in the range of their vision then suddenly everyone is freaking out but I think there's a vast difference between that and if they actually go over or stare or kind of fixate on something.*

In summary, the factors of instinct and attention to body language, as influenced or informed by historical actions, descriptions, and labels, appear to serve as a type of algorithm in these participants' interpretations of what they (or others) may or may not consider sexual in the people with ID whom they support. As revealed in later parts of this chapter, the tension between current actions/responses and historical interpretations is a prevalent outcome for these participants. Before moving on to discussion of the stated

actions/interactions of these participants one further aspect of conditions remains to be addressed.

Who Decides What to do in Situations Involving General Sexuality and/or pSCB?

In the mix of job duties and experiences, sexual considerations, and other factors addressed above, there are sometimes a litany of other invested parties whom participants portrayed as having a high degree of influence over long and short term responses to situations involving sexual rights and pSCB. As presented below, during this section of the interviews many participants also spoke about conflicts involving rights, restrictions, and the general structure of supports in this particular system.

For one participant, as related in the following excerpt, primary or initial actions regarding perceived issues of safety were in the domain of DSP decisions. Following that, however, a range of individuals were listed as involved:

> *P: Well, we try to get more on the safety you know? If someone is pushing themselves on somebody or what not, we get that person to safety and we start calling the team right away. We call the guardian. We call the behavior therapist. We call the service coordinator….We call the cops if they tell us to do that…I just start making the calls and, if they tell me, I might tell them to call someone else like call the crisis team, the cops. I'll just follow the directives of my superiors of what needs to be done next. But first, yeah, first and foremost get that person to safety, keep them from harm's way and call and let them know this is what's going on.*

Another participant reflected,

> *There are certain people with plans where they can't have pornography etcetera and there are reasons for that and there's the human rights committee who can decide whether that's acceptable or not*

A different participant stated that after these initial calls or reports regarding incidents of concern, the various involved parties may direct responses and actions that do not necessarily include the input of DSPs:

> *P: Not always necessarily, but sometimes, the team will be like "ohh, we want to protect them" I don't necessarily think that's helpful but again, as a staff you can't really make those calls. It's the team's call so…*
>
> *I: Talk some more about that*
>
> *P: The team makes the decision. So, you report the incident and the case manager, the guardian, every one like that, will have their say in it and usually staff don't have a say. They just report it. They,* [DSPs], *don't have a say in what should happen.*

While the above participants focused on the concrete actions involved in decision making, others took this line of inquiry down a more philosophical path involving rights and restrictions. For example, in the words of another participant, these externally driven decisions may include directives that conflict with her personal perspective:

> *They pretty much have the same rights as everybody else. And I say 'pretty much' because that's not always true. Because people like to take certain things away from them. They have all the rights that everybody else has but then when you get down to like the behavior therapist, the guardians, the OTs, people on their team, then their rights get stripped away. So, they don't have all the rights that anyone else would have.*

Another participant echoed the above sentiment:

> *I do see a lot of teams get into, and I'm not negating this but, they get into the 'oh but the more they have sex, the more they fixate on sex' but, that's who they are. If they are not going out and doing things that aren't ok to do, they're not going out and forcing anybody to do anything, they're not pursuing underage people, or you know, people with significant low functioning ability that would not even know what they are doing, then, I know it's kind of a grey area for some people, but I feel like we take way too much control over them doing things that adults should do. You know, um, because the bottom line is, if two people are adults and they choose to enter into a relationship with each other whether its romantic, whether it's sexual, whatever it is, if nobody is being hurt in the process then that's a basic right they should have to pursue. You know, and in a lot of cases I feel like it isn't…And like I said, a lot of the time the biggest barrier to that is the IDT team. Um, because, they just have that tendency to treat them like children like 'well you now they cried and yelled at each other the last time they dated, therefore they shouldn't date'. Who the hell doesn't cry and yell at each other sometimes in relationships? You know, it's ridiculous. Um, so, I'm sorry, [laughs] it's just utterly ridiculous because it's like the whole point is to get them to stop doing these things that they're not supposed to do and encourage them to do the things that are appropriate and when they want to do the things that are appropriate – you don't let them! So, we revert back to here…Who would tolerate 15 people sitting around a table telling you how you can go on a date?*

Another participant related a similar stance and provided his thoughts regarding possible reasons behind seemingly cautious measures and the hierarchy of invested/involved parties:

P: I don't have to get consent from anybody if I want to have sex with somebody. I

don't have to tell any one if I want to go out with somebody. It's unfortunate that they

have to go through all these little loopholes in order to have a relationship. That's

probably one thing that hasn't changed too much.

I: Why do you think that is? Why are there all those steps?

P: Just everyone covering their bases.

I: What does that mean?

P: Just everyone covering their bases so they don't get in trouble.

I: Who gets in trouble?

P: The whole team.

I: From who?

P: The state.

I: And I'm not looking for anything or anybody in specific just – so you said the

state?

P: Yeah – by the state, by the maybe behavior therapist, maybe the director of the

company. I mean if you consent to all this stuff without going through the proper

steps some one will get in trouble for it. So you've got to go through the proper

guidelines. Which, you know, it's not fair to them [people with ID].

Two participants located guidelines for decision-making as being in 'the plan' as

derived by an individual's Behavior Support Consultant (BSC; sometimes referred to as

behavior therapist). A description of the BSC role in this region's system of supports may be

found in Chapter Four.

When discussing general sexually-related decisions in the lives of people with ID one participant stated,

> P: Hey you know – if they are able to. If it's in their plan. But who decides their plan?
>
> I: So that's the next question – what's up with that?
>
> P: The behavior support consultant. Now you get direct support staff that are with him 5-7 days a week but you [the BSC] get to run the show and are not taking any suggestions from the panel? You know what I mean? Now, if you can't get direct support staff to be on board with the plan that you make – you'll have an issue. So, if the BSC feels like 'Nah – I don't think they are ready. The ADLs [activities of daily living] and their hygiene is bad. Blah Blah' and they go ahead and make a judgment call instead of letting them try and fail. Maybe they are being a little over protective. Maybe not. It's kind of hard if you are not with them all the time. It gets lost in the shuffle sometimes.

As with excerpts earlier in this section, the above participant's statement included elements of conflicted perspectives. Similarly, another participant dryly quipped,

> P: You have the right to follow your plan.
>
> I: What do you mean by that?
>
> P: It means that you have the right to do what I've drawn out that you are allowed to do.
>
> I: And who does that? Who are the people who make those, those
>
> P: Usually the behavior therapists do that. Of course you have a team of individuals who discuss it but it's usually the behavior therapist that draws that, these guidelines out.

Lastly, a participant connected decisions regarding the sexuality of people with ID to larger

social norms:

> *I mean societally we try to push for 'hey, let's have a happy relationship before you*
>
> *do this, let's do this' which is what the friends and relationship classes and yeah we*
>
> *know this is the model for stability but guess what – we know many 20, 20 year olds,*
>
> *late early 20s even high school students, when I was in high school myself, who are*
>
> *doing their inappropriate things and that was their norm as far as that kind of model*
>
> *of 'yeah no, sex before marriage but whatever'. So, I don't know, I think they* [people
>
> with ID] *are robbed of sexual experience in that sense. They are not supposed to have*
>
> *it some of them ever. And I think there is an over-worry of them obsessing over it I*
>
> *guess, I don't know what it is exactly. Therapists surmise that some of them can't do*
>
> *this other than maybe there's some ramification or some lawsuit that's happened*
>
> *where 'you let my child have sex!' or you know, they're adults to a degree. I mean I*
>
> *know they have guardians but does that mean, a lot of them have guardians, but does*
>
> *having a guardian mean that you are not going to need to masturbate or do what you*
>
> *need to do? I find it weird. I've seen in sexuality classes that I've taken in academia*
>
> *that people who don't do those things are kind of crazy. [laughs] So, why are you*
>
> *robbing a full life from someone?*

Actions and Interactions

In the preceding section many (but certainly not all) of the general conditions of the

job of participant DSPs were described. Within these complex conditions, interactions occur,

decisions are made, and responses are enacted. In the following section I provide a

breakdown of how participants described actions and interactions that, for them, characterize

some of the dynamic aspects of their work. In keeping with the specific aims of this study, I focus specifically on these actions and interactions as related by participants in relation to sexuality and pSCB. As a corollary to this section the word clouds generated from Process Coding of gerunds used by participants may be found in Figures 2, 3, and 4 respectively.

Figure 2: Word cloud generated from Process Coding of participant descriptions of their own actions. The larger the font size, the more frequently the word appeared in participant statements. The word 'working' was removed from the list.

Figure 3: Word cloud generated from Process Coding of participants' words regarding actions of people with ID and pSCB whom they support. The larger the font size, the more frequently the word appeared in participant statements.

Figure 4: Word cloud generated from Process Coding of participant statements regarding the actions of other parties involved in support of people with ID and pSCB. The larger the font size, the more frequently the word appeared in participant statements.

Setting and Keeping 'Boundaries'

The concept of 'boundaries' was prevalent in participant statements regarding several aspects of their actions/reactions to pSCB. In the words of one participant, the term 'boundaries' involved *"be*[ing] *direct, concrete".* Another participant reflected a similar action saying, *"[y]ou need to make it very black and white". .* A further participant defined boundaries as having elements of *"legal constructs, legal boundaries* [or]…*sexual boundaries like 'why are you having sex in the backyard where people can see" or getting a blow job in the backyard or giving one where people can see you. That's inappropriate and maybe legally too".* This was expanded to wider considerations by another participant in the following exchange:

I: And I know my definition but what do you mean by 'firm boundaries', how do we define that?

P: I guess, being very clear. Being very stern. I just think knowing… I don't know how to describe it. Just knowing how to act, how to be professional. Just knowing how to not give someone the wrong idea I guess. Just being support. I don't think I've ever thought about how. I think if I were to tell somebody, if I were to train somebody – it's basically, I don't know, just be aware of your surroundings.

For several participants the notion of 'setting boundaries' was primarily connected to their own personal space and knowledge of the individual with whom they are working. For example:

Boundaries, um boundaries are – there's a limit. There's a point in my comfort zone that you cannot pass. I don't like people that stand right in front of me and are face talkers. I need you right there – to see all of you. I need to plan my escape route. Depending on the client you are serving. If they are not physically a threat to you and they want that closeness then…it all depends on the clients you are working with.

In reference to a specific event, another participant described:

I didn't even see him right there. I was talking to someone and I was like "What!? What are you doing? How did you move so fast?" [laughs] I was a little stunned because I was talking and like 'Whoop, right there'. I would tell him "Hey, boundaries, please respect my space and move back".

Other participants extended this to include setting limitations regarding personal interactions. For example, one participant described how she might respond to certain approaches:

'It's ok for you to talk to me, ask me how my day was, that kind of thing. It's not ok to ask me out to dinner or to say 'Can I take you on a date sometime?' That kind of thing. That's not ok with me.

Similarly, another participant stated,

I've realized that you have to set boundaries right away. Like if you don't set boundaries, things could get out of control really fast. You have to let the individual know that you are there to support them at their job and that's the role. You don't want to make, you can be friendly with them but you don't want to make friends with them. Because I don't think they fully understand if you don't make that line clear. They don't see the difference between a friend and somebody who is there to help you work. So, I've found that as long as you set clear, firm boundaries you don't really have that problem. It's easier if they start getting off course and talking about things that are inappropriate. You just tell them that 'you should not be talking about that at work. You should not be showing that behavior or acting that way' and they usually stop.

Hugging between DSPs and individuals with ID and pSCB was referenced as a particular element of setting boundaries of personal space and conduct. One participant said,

I've learned with the men that I can't hug them that way – there was one that I hugged every time that I saw him and then I started to learn some things, working there, that I can't hug him that way and furthermore, don't hug any of them that way. Full frontal hug with this one particular guy and its not that I picked him out of the crowd or anything its just that 'hey, I missed you, how've you been' sort of thing. And then I was told that it's this [indicates breasts]. *They're not feeling this* [indicates

hug]. *They're feeling this* [indicates breasts] *and then that will lead to other things. So I had to learn, and it disappoints this guy, because that's what he's used to with me. And you can see it in his face when he goes to hug me and I do this* [indicates fist bump].

Similarly, another participant stated, "*that is like a big boundary for me. I don't touch these guys. I don't hug on them. I don't – that's just not the work relationship we have*". A third participant reported, "*I've had individuals attempt to give me hugs or maybe try to see what they could get a way with. But no. I've got very, very firm boundaries. I've made it very clear*"

    Demarcation of 'boundaries' also appeared to define participant actions in community and residential environments. According to one participant, "*sometimes you do have to make it that cut and dry and that's the boundary line 'I'm seeing this and it's time for us to go'*".

This was furthered by another participant to include actions of pre-emptive or preventative intent:

> *It's making boundaries and knowing your surroundings. Instead of driving by on the route to take them to day hab or to their work – instead of passing by an elementary school, go a couple of blocks around it. It's just keeping them – don't put them in a situation that they don't need to be in. And it's just making those extra efforts that I feel is keeping the community safe and keeping the individual safe as well.*

Complementary to the above, a third participant intoned preventative actions wherein, "*you have to also be careful about in the programs or, in the homes in particular, about everybody respecting each others boundaries and space*".

Lastly, as introduced here and expanded in the following section, concepts of 'boundaries' were included in participant definitions of the intentions of their work as DSPs. For example, one participant stated, *"I mean there's going to be that little blur but you always just have to teach them consent and boundaries"*. Another, described this as, *"I am here to guide you teach you and that's it period"*.

Teaching and Guiding

A theme of teaching and/or guiding was present in many of the participants' statements regarding central aspects of their interactions with people with ID and pSCB. As related by one participant,

> *Teaching people life sills is very meaningful to me. Very rarely do I solely just job coach or just take them on an outing, there's like millions of little opportunities every day to reinforce a good life skill that might get this person further down the road.*

Another participant appeared to arrive at this conclusion during the interview as he stated, *"I've never considered myself as an educator or a coach but I guess that's what our job is. It's to educate them in every aspect of life"*. A further participant provided the following summation of the types of skills that may be taught by a DSP: "*how they interact with society doing things like going to get a soda from the gas station or buying shoes, or going to school like how do you get help going to class and finish your GED or what ever you do.*

In regard to sexuality and pSCB specifically, another participant reflected that teaching could include aspects of appropriate/inappropriate as discussed earlier:

> *I: So you personally, what do you think should be done by a direct support staff when they are with a person with intellectual disability who is having kind of an*

appropriate sexual moment or action or something like that? What do you think the

job might be there?

P: The job would be to encourage safety, privacy. Always teaching. Always being

supportive and encouraging the appropriateness of whatever is going on.

I: And then on the other end when working in direct support and maybe something

sexual and inappropriate is going on – what do you think should be done in those

situations?

P: Again – depending on the level of inappropriateness and where it's at, is putting a

stop to it. But there's also the education factor. The teaching. Always encouraging the

appropriateness even when it's inappropriate.

In a similar statement from another participant, this aspect of education/teaching was also

applicable to an individual who had allegedly demonstrated a history of crossing physical

and consensual boundaries:

We educate. Because education is a thing for anybody to have. To get anywhere. We

educate him on what's right and what's wrong. And pretty soon if we keep it up and

keep it up – we are going to change his way of thinking. So therefore – maybe he can

be with Sally and not hurt Sally, and not tie her up and what ever she does not want

to do. And maybe he can take 'no' as 'no'.

This same participant went on later to express a wider perspective on this same topic:

If they make a bad decision you should go back to educate some more. You don't just

get mad about their bad decisions. Nobody gets mad about your bad decisions. You

might go to jail or something like that because of your bad decision but with them I

think we should talk to them about what happened, why it happened, how it should

have happened, and make sure it does not happen again…I think they have a right to

know. They have a right for us to teach them like they have some sense.

Aspects of teaching respect toward women specifically was central to many participants'

reported actions in this domain. One female participant put this quite directly, stating, *"I*

think my responsibility as direct support is to show them how to, as much as I possibly can,

show them how to treat a woman. As much as I possibly can. Some will get it, some won't".

This was reiterated by another female participant through a specific example:

I try to like teach people how to respect each other, how to appropriately talk to

someone. So, say for example, 'Oh, you have nice boobs', That's not an appropriate

conversation, that makes people uncomfortable so when I'm hanging out with the

individual and I'm working with them I always try to you know [say something like]

'respect the person you are talking to and don't say something that is offensive and

uncomfortable' you know?

For one male participant, teaching included aspects of interactions in the community. In

describing follow up to a potentially uncomfortable event in a public location he stated,

It's a learning process like when we are in the van on the way back like 'hey, you

know' and I always try to make them answer the question. It's always a question

more than a statement like 'do you see anything you did wrong? Do you think you

could have done something better in this outing?'; 'Yeah, I probably shouldn't have

stared at that girl like I did but she was so fine'; 'Yeah I understand'; 'In my situation

I'll see beautiful women everyday. I'll look at them and try not to stare for more than

one second, maybe two, and then you imprint that picture in your head and you get to

keep that all day if you like. But they didn't notice it and you have the picture in your

head. She didn't notice it and you have the picture in your head. Might last all day. Might last two days whatever until you see some one else that's just as cute or cuter. But you didn't show disrespect – you got to look and that's it.' Maybe you should have just looked instead of staring and kept moving right?'; 'Yeah, I'll try that next time'.

This same participant continued on to provide another example wherein,

A lot of the guys can't tell the difference between a teenager and a grown woman so I'm always taking opportunities to, like we are passing by a school and they are staring so I'm like, 'Hey, if we are by a school, if you are rolling by a school' and I might have 3 or 4 guys with me – a learning opportunity – 'hey guys if you are ever by a high school or middle school and you see girls with backpacks – probably not a good idea to talk to them because they are under age. Now, if you are by a college and you see that you might have a little more chance of being appropriate because they are, they should be, over age'.

Another participant reflected on the efficacy of these actions and stated,

I think that talking actually does a lot more than people give it credit for. You overhear something being said that is out of line or isn't correct – that's a conversation that you can have. Everything is an opportunity for coaching. Um, you know or guidance, something along those lines. You can say 'you know what..' and I've had guys I do talk really straight to like 'you know what, women absolutely hate when people say things like that' or you know that type of thing… There's a lot of room for guidance and a lot of times it is as simple as explaining 'this is not the way you go about things'.

Similar thoughts were expressed by another participant in regard to same-sex relationships:

> *I've got a client I'm working with now and he wants nothing more than to have a boyfriend. That's all he wants. And I asked him, "What's a boyfriend to you?"; "To do things with, to have sex with, to go out and have fun". And I explained to him that you can't just force it – you can't force yourself on people. It's got to come naturally. When you meet someone, don't force yourself on them. It's got to come naturally. That's always the advice I give to them. That way he doesn't get himself in trouble because once he gets excited or over stimulated he doesn't always think with the right head. [laughs]*

From the above it is evident that these DSPs conceptualize teaching, educating, or guiding as wide-reaching parts of their job when working with people with ID and pSCB. Used as a type of support, preventive action, or corrective reaction, these reported efforts toward teaching include aspects of appropriate/inappropriate, current aspects of social boundaries, and legal constructs as well as general life skills. As examined below, the potential success of some of these endeavors were framed as reliant upon the creation of relationships between the DSPs and the people they support.

Knowing Individuals and Developing Relationships

The importance of cultivation of individual-specific knowledge and creation of relationships with people with ID and pSCB was repeated by several participants. Specifically, participants related that, through a series of interactions, sometimes over years, their abilities to assist, and possibly intervene, were improved. As told by one participant, *"a lot of it is talking, developing that rapport where people will respect what you have to say in the first place"*. This relationship building was a framed positively by another participant

who stated, *"it's pretty cool to get to know them and their personalities. To bond with them in that way and to gain that trust because they know that you are there to help them"*. . As told by another participant in the following excerpt, ability to build relationships with people in these circumstances has changed over time:

> *At first it was really different to me because when I first started doing it like ten years ago I just needed a job and so, I didn't really know much about anything. I mean I went to school with people in high school with disabilities but I didn't really, never really associated with people with disabilities because usually they were in different classes than me. So, when I started it was really weird. I did all this paperwork and they just kind of threw me in with a manager and he described the person I was going to work with and he was like "Ok, have the BSC training here you go!" So it was like, I didn't know. At first it was a little terrifying and I'll be honest, I didn't really want to work with people with that kind of, not so much really just disabilities, but the ones who focused on sexual stuff. So, I was really actually nervous and kind of uncomfortable and kind of I would say prejudiced against because I just had this one viewpoint of people who committed sexual crimes and I didn't really understand everything behind it. I just had this one viewpoint and I was like 'I really need the money but I don't really want to do this'. But then you build relationships with them so today, it's like second nature I don't even know how to tell you how I work with people with intellectual disability because I don't see them that way anymore.*

This same participant later expanded on how long term relationships are part of this equation stating,

There are some that I've worked with for years that will give some new staff a really

hard time but they won't give me a hard time and it's such second nature that I've

worked with them for like ten years that they know me well enough that they are

comfortable enough and I'm comfortable enough

At times, for one participant, gaining more in depth or personal knowledge of individuals

with ID and pSCB appeared to be a possible barrier to relationship development

Some of the hardest parts are learning the histories of some of the individuals I work

with. That's really rough. Getting past things that not only have happened to them but

trying to look past things that they have done and just trying to keep a regular

relationship with some people just knowing what you know.

For another, the depth of knowledge and relationship with a particular person appears to have

allowed a greater range of possibility in the individual's life.

Taking [an individual with specific, possibly sexual, interest in children] *to go see* [a

movie]*, and you wouldn't think that there'd be nothing but children in there and then*

there's nothing but children in there. And weird, like he's on a date, with his

girlfriend and your call is to let him watch this movie with his girlfriend or you guys

find a different movie. So, I chose to let him watch the movie with his girlfriend while

his prime targets were sitting right next to me and he's sitting on this side [indicates

other side of body]...I kind of felt like I could handle the situation if it turned west and

most of the other direct care staff would have been just like, 'no this is not happening,

we are not going in the movie theater, we need to pick a different movie, But knowing

[this individual] *the way I do, I put what he wants before my comfort level and did my*

job.

Another participant spoke about how being very familiar with individuals with ID and pSCB

is a part of risk management:

> *I think though the biggest key to managing risk is keeping an eye on people's*
>
> *agitation level. Just watching their body language. Are they starting to appear that*
>
> *they are more agitated then usual, or are they starting to fidget more, or whatever*
>
> *their particular quirks may be that show that they're not in a mellow zone*

Further, when intervention such as 'redirection' (as defined by a participant in the excerpt

below) is utilized, detailed knowledge of a person's preferences or interests was essential:

> *It means getting their attention away from whatever they may be focusing on that's*
>
> *not necessarily appropriate. And usually it means directing them towards something*
>
> *that is a personality trait of theirs whether it's humor or games that some of them like*
>
> *to do. It's knowing who you're working with. That helps. If you don't know them,*
>
> *what they like to do and stuff, it doesn't always work. It doesn't work well for them or*
>
> *you [laughs.] You can redirect them all the time but not successfully.*

Many participants mentioned receiving training on support plans and reading files played a

role in becoming more familiar with people whom they support. For one participant the

information received in trainings was secondary to what he saw as necessary information for

relationship building and provision of direct supports:

> *I want to say that – as far as trainings, the trainings that we do, I do not take as*
>
> *personal guidance tools. I hear it and then I dissect personally. You get the worst-*
>
> *case scenarios as far as everything they have done since they were in custody. Why*
>
> *does he do this? Why did he do that? What set him off? Were his parents around?*
>
> *Were his parents involved in his life? Is he alone in his life? Does he have any*

natural supports? Those are the questions that I ask pertaining to the person rather than what they did.

Comparison to relationships with children, family, or friends. For many participants, the particular nature of these relationships was difficult to pin down. Specifically, metaphors regarding similarity to parenting, family relations, and friendship were prevalent. These comparisons were, however, often internally qualified by participants with contrasting or opposing statements. These comparisons are briefly explored here. A more thorough discussion on this topic is presented in the final section of this chapter, "Arrival at a Grounded Theory".

Parent/Child Relationships. Several participants utilized abated metaphors or similes to explain experiences of the job and resultant relationships. As one participant explained,

Kind of the same way you know – you take your kids out. The risk is there. You don't want your kids running off. You don't want them getting lost in Wal Mart. You don't want them running into the street. Those are the kind of things you as a parent kind of keep your eye on. Protect them the best way you know how. You teach and you watch.

Another participant voiced a similar comparison:

This may sound odd, but the people that I know that are some of the best direct support staff are usually somewhat parental in their type of approach like you know 'I care a great deal what happens to you and I'm going to do this this and this to help ensure your success but at the end of the day I'm going to tell you when you're out of line and be very clear on you know – this is not ok. You can choose to do it but I'm just telling you right now, it's not going to get you where you want to be in life.

This same participant later qualified, "*I hate to put it like this, but it's kind of like with a child". .* A different participant offered and then attenuated, a similar, positive sense of being a parent-like figure while working as a DSP:

> *I bring something to the table. A motherly thing. A motherly type attitude. Not a smothering mother but caring, nurturing. A lot of them look for that. They trust me…I'm not there to be their best friend you know? It's like being a parent – you've got to…Well, it's not like being a parent. It can be but I don't' want to – you have to, to establish boundaries in a way that they know you care about them and are there to care for them.*

A further participant described an intrapersonal conflict related to this sense of parental relationship:

> *I mean they can have sex but I, I even fall into that category of not wanting them to do it. I do. Like* [a particular individual] *is getting to the point where he's getting ready to potentially have sex with his girlfriend and to me it's like 'No! he can't, he can't have sex with his girlfriend! No." Because, you know, he's like my kid [laughs]. But I have to put that aside because like 'no, why can't he? Because I don't want him to?' No. I can't do that. You've got to put your own personal stuff aside and let your, not child, but the client you've developed a relationship with, go have sex. And you're going 'I'm going to try and not freak out at this moment'. Yeah.*

On a similar line, another participant expressed,

> *I'm actually more of an advocate though. I will say that. I get really offended and I get like "God, why are they talking about people I care about that way?' You know, it's kind of like children, I don't have children, but kind of like a mother would be with her children, I get really offended and really defensive…I mean they have rights*

too. I don't know. People with disabilities are not children. They're not children.

They are humans. A lot of people want to treat them like children.

Finally, another participant expressed frustration related to these sometimes confusing roles and rules:

It's either like we treat them like kids or we treat them like grown ups. Which one is it? So, I want to know myself. Which one are we supposed to do? On one had you want us to treat them like 'oh you know better' and on the other it's like 'oh, you poor thing'. No. It's got to be either or…You can't keep this man a kid all of his life and that's what we do. Because his grandpa says 'no' we have to keep him a kid all his life. And I think that's wrong.

Friend-like relationships. Similar to the above, participants also offered qualified 'friendship' comparisons of relationships between DSPs and the people they support. For one participant the line appeared to be more clear than for others: "*I just reminded them you know what my role is and that I am paid. I'm not your friend. I am here to work with you at your work and that's it*". According to one participant the division was less clear: "*It's you know, kind of like hanging out with friends sometimes…Which is good stuff*". Later, reflecting on how a 'friend-like' relationship may be seen as 'wrong' by others, this same participant stated,

It confuses the shit out of direct care. Because here we are on the front lines. Being with somebody 8, 10, 12 hours, 14 hours a day trying to gain trust, trying to make some kind of relationship – who we have to be very clear with – 'this is not a friendship because I am being paid to be with you. No, you can't call me when I go home because I'm off the clock'. So we have these fine lines drawn for us about how

we do things and how we create these relationships and how we gain trust to be able

to help and to educate

A similar sense was related by another participant:

And so you have to get to know your individuals which also is a hard line because

getting to know them can get confused with being their friend. It's a very very fine

line between 'I'm not your friend – I'm your support staff'. But, you have to get to

know the individuals that you work with. If you don't then you're not going to know

their personality or 'this might set them off because, if I say this, this might make

them angry'. It's kind of unfortunate because people are so strongly discouraged

from letting them think of you as a friend and that kind of thing. And really, in most

cases, it's the only friends they really have. It's the only people they see regularly. It's

the only people who inquire about their well-being regularly

Similar to the above, another participant stated, "*I think there is a really fine line between*

being a support staff and being a friend".

Preventing pSCB

Many of the actions and interactions discussed by participants revolved around

techniques intended to avoid or prevent pSCB in people they support. As examined above,

setting/teaching boundaries and creating relationships were portrayed as key aspects in these

endeavors. What follows is an examination of other specific actions described by participants

in this domain.

Being aware and constant vigilance. As related in the above section regarding the

general experience of supporting people with ID, mindfulness of situation and surroundings

appears to be a central aspect in prevention of pSCB. For one participant, this sentiment was

directly connected to a sense of protection: *"reoffenders, require lots of monitoring and that's what my role is. I'm out there to monitor so the community is safe".* Another participant expressed the pervasiveness of these efforts stating,

> *you are literally on guard like the whole entire shift. You are thinking ahead like 'with this person, if a little kid walks by – what am I going to do?'; 'If somebody comes up to them to hug him – what am I going to do? What am I going to say to them?'…It's being aware of the situation before he is aware of the situation."*

This was reiterated by a further participant who expanded on how this can become more complex due to ratios of staff support:

> *You've definitely got to be at least 2-3 moves ahead…You definitely have to be paying attention to your surroundings, where you are at, the state of emotion your guys are in and then for the most part its usually 3-4 to one staff and they all have their different issues.*

The mental efforts required to enact such vigilance were expressed by another participant:

> *You need to be aware of your surroundings at all times. A lot of people say this is an easy job. And it is an easy job but you've got to be on top of everything. You need to be aware of your surroundings. You need to know what they are doing. It is easy but you've just got to be focused is all. You've definitely got to be focused and be aware of what is going on at all times. Even in the house you've got to be aware.*

Endeavors of awareness were framed by another participant as *"[T]he biggest challenge. The ascertaining of 'ok, where are they being appropriate and where might they be scoping out, being predatory, or something along those lines".* An additional participant described that her style of support has changed since working with people with certain types of pSCB:

My heightened awareness. My guard. My observation. I'm on high alert now.

Especially at the house I'm at now.

I: Why so?

P: Because there are opportunists in that house that are attracted to underage

people. So, we have to make sure.

A different participant provided the following situation specific example of these efforts:

P: So I'm not even watching the movie because I can't be watching the movie I have

to be watching him and his mannerisms and who he's touching yeah.

I: That's a lot to absorb.

P: Yeah. I left drenched [laughs] from the movie theater because usually you can

chill and relax but my mind was not anywhere near the screen. It's 'What is he

doing? What is he looking at?' You know? Yeah.

A final participant expressed a level of discomfort related to how constant monitoring may impede on individuals' general autonomy:

You always want to be really hypervigilant sometimes. Especially like when you first

start working. It just sets the territory. Hypervigilance like, 'they are not going to do

anything'. And that works for some people but…the boundary I see with most people

it's kind of a feeling, you feel like you're taking away their ability to be independent,

make certain decisions. They may not always make the healthiest decisions but if you

look at society in general, in [this state] in general, you look at ourselves, we are not

the least obese state in the world, we're not the most educated, whatever. There's a

lot of things. What's wrong with letting someone live an average life? In some ways.

Education of people with ID and pSCB. In addition to the above, participants spoke about offering education regarding relationships, sexuality, and boundaries as a preventative intervention. As one participant explained, educational ventures may include, "*Exploring different ways that they can be sexual through educating and not judging them when they make a mistake or what we perceive as a mistake*". Another participant related that education can extend to topics about intimate relationships such as,

> *How to start one, how to be in one, how do you conduct yourself, what does it look like to have sex, what are the steps to having sex, you know all of that. I think some of them are clueless. I mean some of them maybe can't even comprehend what you're, you know the simple stuff, but I would offer it.*

For another participant education was a described as a better option than interventions offered by other involved parties such as,

> *When the team's just like "We are going to limit it." But you miss out on the huge opportunity to educate on how to communicate effectively and have a good relationship... There is that whole gap that you take away.*

Avoid or remove from locations. In addition to the above, several participants described how they might make preemptive decisions regarding specific environments in order to avoid possible concerning outcomes. As stated by one participant,

> *"We don't do things around little kids. We keep it so they won't get over stimulated by that fact. And if we see someone in line with a kid or something and he starts to look we just go, we remove him from the situation.*

This was reiterated by another participant using more 'behavioral' terms: "*I would try to avoid triggers. As much as possible. You can't totally rule them out but I would try not to purposely put triggers in front of them*".

Further, another participant portrayed these efforts as a manner of protecting individuals with ID from potential negative outcomes:

> *Keeping them out of situations that they shouldn't be in. I think that's our job because a lot of time they don't see 'If I work here, this might happen'. They don't see the future. They just see – 'hey, if I work here I get money'.*

Lastly, a different participant described a specific avoidance technique aimed at safeguarding others in the community and why this might be difficult for DSPs of differing genders:

> *There's the bathroom situation I told you about where if they have to use the bathroom we have to leave* [the community location] *or a male works with them if they are on shift….for a female it's really hard because you have to make sure that he goes to the bathroom before or if he needs to use the restroom we have to leave because I cannot follow him into the restroom and if a kid was to follow him into the restroom there's a chance he could assault or something so it's protecting other people too in the community*

Responding to pSCB

At times, despite the actions described above, DSPs must respond to incidents of pSCB of varying types (as described in Conditions above). These responses can, per participant statements, involve a myriad of potential actions dependent on factors such as the history of the individual, particular directions from trainings or plans, and the specific nature of the behavioral concern. Where one draws the line between prevention and intervention

depends upon what is considered 'an event' versus 'a potential event'. Therefore, there are areas of crossover between the actions/interactions in this and the preceding section 'Prevention of pSCB'.

Confront directly. When individuals with ID engage in certain actions a common response, according to these participants, may be to plainly address the situation, and possible consequences, as soon as it occurs. For female participants, these types of actions/interactions were often related to possible sexual advances or comments. For example, one female participant reported that after a possibly sexual comment was directed at her she "*told him that was inappropriate, that it made me uncomfortable, it is inappropriate. I told him 'You know I'm going to have to talk to your team about this. I'm going to write an incident report'".* Similarly, another female participant described these face-to-face directives as a primary intervention:

> *I'm first to set my boundaries. 'Don't touch me. This is my space, that's your space, there's a nice bubble here' if they say something inappropriate I'm very quick to redirect "That's offensive, we don't talk about things like that here. That's not appropriate'. And I think that's really important that I do that because other than that, letting, not saying those things to someone will let those problems start.*

For male participants, immediate confrontation of pSCB was mostly related to actions directed at others in the community. For example, one participant described a specific incident wherein, "*it's like 'hey you need to get off that bed and get dressed because they're going to call the cops'. Because he's smart enough to know that he doesn't want the cops there so he gets off the bed".* Speaking of a different incident, another participant related, "*It*

was really not the funnest thing to do to walk him outside and say 'hey we've got to get going now, you can't do that'.

Redirection. At times, instead of candidly addressing the area of concern, participants described the use of interventions intended to get individuals' attention away from certain situations or interactions. One participant described her frequent use of this technique in particular circumstances:

> *Actually, when I walk in that day program there's probably like 10 of them who will [laughs] who will try to come up and talk and it's more a matter of just trying to redirect it away you know with humor. I redirect with humor a lot. 'Oh we miss you!, I miss you! I wish you were here! Let's go do this!' and it's like 'No, I don't know why you miss me, I don't even go anywhere. You see me every day [laughs]' Um, but, that's kind of, with a couple of them it's kind of an ongoing boundary.*

Another participant, in the following exchange recounted how efforts of close observation, direction, and redirection may be used in conjunction:

> *P: Like* [a particular individual], *he's saying he's not doing something because he's trained himself to say that but it's obvious that he's got this physically intense, visual gaze focus that is straight on the object that he's looking at.*
>
> *I: The object being?*
>
> *P: An infant.*
>
> *I: An infant ok.*
>
> *P: An infant and it's kind of like "ok, what are you doing?" so you, I mean, we call it 'redirect' that's like our favorite word [laughs]. There's the "Hey,* [name], *let's finish checking out. You want to go have what you just bought right?"*

This was echoed by another participant who stated,

> *If it's just a glance, everyone glances around them to see what's around them but, if they are staring and you see that they are staring for more than a few seconds – 'Hey man, what are you staring at? You staring at that kid?" And more often than not they'll be honest with you – "Yeah, I was seeing what they were doing"; "Well, let's go over here and do this. Let's go to another area of the park. Let's go to another area of the store. Let's get away from this." And I don't tell them why we are doing it but it's basically just to redirect them so that nothing does happen.*

Physical intervention. Participants also described various specific techniques of using physical presence or interaction in response to pSCB.

Blocking or body blocking. One participant used and then defined the term 'body blocking' to describe a certain type of intervention in tandem with redirection as described above:

> *P: Body blocking*
>
> *I: What does that mean?*
>
> *P: When I put my self in between who ever they are targeting and the guy we provide for. I might get a little push or a nudge or maybe a sock because I am preventing them and I'm in their line of sight of what they are trying to target. If it gets that rough then we are leaving. No questions like 'oh let's go – I've got to go to the store or I forgot something – get in the van let's go, let's take a ride and oh – now we are day hab – I forgot.'... So I really try to stay diligent and not – I'll use myself to body block. If we are in the mall and I feel like they are going towards someone to try to*

touch them inappropriately – I'll put myself in between they guy or the girl and who ever it is in the community that they are targeting.

This was reiterated by another participant who described,

You've got to get into their line of vision and talk to them about something else…Are they breaking away or are they willing to or if you break into the line of vision are they trying to get around you and continue looking at what they're looking at?

For another participant, efforts of blocking a person's line of sight seemed to be a common occurrence during the course of work as a DSP or, as he stated, "*I've never been more of a door in my life than I have now in this field [laughs]. Like 'hello, you can't look through me, I am a wall'. Thank god for my size because I am taller than most of you! [laughs]*
As described by a further participant, 'blocking' may also be utilized to address certain actions directed at other DSPs: "*But he used to just, the staff would be sitting there blocking and he would reach his head around [laughs] and go all the way around just to see me.*

Separation or removal from locations. In certain circumstances participants reported that any or all of the above efforts, depending on perceived efficacy, may be followed by or accompanied with, directed removal from location or separation of individuals. As related by one participant, "*sometimes you do have to make it that cut and dry and that's the boundary line 'I'm seeing this and it's time for us to go'*". Another participant stated, "*we just go, we remove him from the situation*". A further participant specified, "*I've been in situations where I have been with certain individuals who have issues with children and you can see that they are proudly displaying their excitement. An erection in public. That I've had to remove. Yeah*". This same participant also described situations wherein unwanted, possibly sexual, physical contact by a person with ID could be followed by removal and/or separation:

P: Well, if in the public we removed them right away. Immediately. Even if there's a fight. To be removed for the safety of the public. In a day hab type setting, a residential setting you do your best to separate. If you have more than one staff you get one out. You call them on it. You let them know that you are paying attention to what's going on.

I: So once the situation is handled or with those steps what else happens after that?

P: So after that basically it starts being reported to the team members. Of course paperwork gets filed. The necessary reports. Phone calls are made and it goes from there.

Document and communicate to others. As intoned in the preceding excerpt, once certain events have occurred, a series of communications may occur between the DSP and other involved parties. For one participant this was stated as part of a continuum of response:

So we, my thing is, I'm trying to talk to you, talk you down and you still don't understand it? The next thing is 'maybe we should leave and you still don't understand and you're fighting me? Then we have to help you out.' So that's – I'm calling people and telling them this is what's happening. I'm calling my office and calling the team and telling them this is what's happening.

Another participant reflected, "*So after* [direct interventions] *basically it starts being reported to the team members. Of course paperwork gets filed. The necessary reports. Phone calls are made and it goes from there.* In the words of a different participant, these series of actions "*depend on the severity of what happened. It might get put in significant events* [a type of written report that is available to a variety of parties including the Department of Health] *or regular progress notes, BSC tracking*". Another participant stated, "*the only way*

to get that information any further is documentation. It's the only way. When something like that happens I tell my supervisor". For another participant these efforts at communication widened to include general information about a person rather than just incident-specific events:

> *So a lot of it is just communicating with the teams. A lot of the time I'll be driving them to work and they will tell me and they haven't told their team. We'll pass by a place and they'll be like 'oh [name of business] – that's where guys hook up. I've hooked up with somebody there'. And I feel that you have to stay in complete communication with the whole entire team in order to help that person.*

This was furthered by another participant who described taking a cautious approach towards what to report and how to report it:

> *Now anything that is concerning, especially where it pertains to children, especially because we have so many people who have issues with children, I think you have to report to the BSC. Even if, and I'll tell them 'It wasn't, I don't feel like they were saying anything sexual or doing anything inappropriate but you know these are the facts of the situation and what happened'…I always conference with teams when there's concerning incidents or behavior that occurred. Incident reporting* [documents regarding specific incidents of possible abuse, neglect, or exploitation that are sent to external oversight portions of the Department of Health] *of course is required sometimes depending on what the specific situation is. Um, but in the grander scheme of things I always think it's really important, and I'm not going to say that all teams work this way*

The judicious aspects of external communication were also reflected by another participant who stated, "*We reported it to the state to cover us. That's just what you do*".

Offer education. Similar to preventive actions above, participants expressed education as a portion of response to pSCB. After speaking about confronting, redirection, and removal as options of response, one participant added, "*But there's also the education factor. The teaching. Always encouraging the appropriateness even when it's inappropriate*". Another participant expressed the opinion that educating individuals with ID and pSCB is essential despite the possible assumptions of others:

> *I think you always have to explain why. And I think that gets underestimated a lot in this field because people make the assumption that they won't understand and you just have to give a directive. And that's not true in a lot of cases. A lot of people make the assumption that 'Oh they just won't understand' if you explain why. Actually, in a lot of cases, people will. If you break it down and say 'When you do this, this is how the other person may feel, this is how they may react to you, this is what could happen."*

Similarly, another participant reflected,

> *If they make a bad decisions you should go back to educate some more…We educate. Because education is a thing for anybody to have. To get anywhere. We educate him on what's right and what's wrong. And pretty soon if we keep it up and keep it up – we are going to change his way of thinking.*

Another participant specified that this might take the form of a conversation wherein she might say,

> *'It's ok for you to talk to me, ask me how my day was, that kind of thing. It's not ok to ask me out to dinner or to say 'Can I take you on a date sometime?'' That kind of thing, 'That's not ok with me'.*

This same participant also suggested education as a response to pSCB directed at parties other than herself:

> *I think sometimes not normalizing the unacceptable or inappropriate types of things that they're doing and normalizing the 'hey, you know it's normal to have these impulses, its normal to want touch, it's normal to crave these things. There's nothing wrong with that' I don't even know if there is such a thing as 'normal' [finger quotes] but um, you know just saying 'hey, I understand the root of what you're trying to accomplish here and it's a really human need to want to be touched or to touch other people or that type of thing but there's appropriate ways of going about and there's not. He and I talked about it from there and we still talk about it to this day. You know about here's what's appropriate and if you want to get from point A to point B to point C here's the way you handle those types of interactions and getting to where you have an actual relationship that fulfills those needs for you.'*

Congruent actions were provided by another participant who described the following possible conversational exchange:

> *'Would you look at your mom like that?'; 'No'; 'Then don't look at me like that – it makes me feel uncomfortable'. Um, and then I ask them 'Has anybody looked at you or said anything to you that made you feel like 'whoa'? And if they say yes then I say 'Well, that's how this is making me feel'. I try and to get them, give them examples of how something has made them feel. Whether it may be a roommate trying to hit them*

or if a roommate has tried to come in their room. I try to put the shoe on the other

foot.

Punishment. Participants also spoke about times that punishment may be used as an

intervention for incidents of pSCB. For example, *"if they have this behavior, it could be in*

their plan where you have to take this away or that away or they can't go on this outing or

that outing and then it becomes punitive" One participant appeared to take this as a matter of

course for how interventions are enacted based upon the directives of others: "*If you do*

something like, you touch someone and I catch you touching someone, and I alert the team

and I tell everybody about it and you lose certain privileges like, you can't go into the

community for a week that's a consequence". This same participant expressed her personal

preference as

Unlike the above actions, punishment was sometimes portrayed by participants as

inconsistently applied, unreasonable, ineffective, or contrary to things they had learned. For

example, one participant stated,

> *I don't necessarily agree with, and I know some teams do this, some do some don't,*
>
> *with trying to implement artificial consequences such as 'when you do this then we're*
>
> *not going to go on this outing or that kind of thing' I don't know that that kind of*
>
> *connection really sticks with most people.*

Another participant provided a lengthy and passionate description of this dynamic as it

relates to both pSCB and general sexuality in people she has supported:

> *P: When I first got this job they told us that we cannot punish the clients. That the*
>
> *clients can't be punished. So, that's my understanding. That no one should be*
>
> *punished. You can't be punished but then I feel like this happened* [hands-on events

with children and other individuals with ID] *like 5, 6, 7 years ago and my client is*

still being punished because he goes in, he sits, he has to face the wall, he can't look

at anybody else or they take away points. It's like – if that's not punishment, I'd like

to know what is. And this is the same person that after 5 years, how long are we going

to punish him even though we say that we're not punishing him. So, I brought that up

and it was like 'You don't run the company.' And 'True. I don't. But you guys say as

plain as day that we are not supposed to punish people.' So, that bothers me about

the job…I don't think we should all be up in arms about things. That goes from the

top to the bottom.

I: Where is the 'top'?

P: From the head bosses to the staff. When something happens we shouldn't make a

big deal of it. It's just awful. Like one client – he was masturbating and the house

manager just walked right in his room. So they took away his points, they took away

his TV. He couldn't do a lot of things then. And it's like 'why? That was your fault!

You should not have just walked in his room. At least without knocking. Announcing

yourself.' But then they think that because we are staff that we have the right to do

that. We don't. I think we do not have the right to do that. I knock on people's doors

before I come in. I tell them I'm coming in. But, he still got a lot of stuff taken away

from him because he was masturbating. And it's like 'Just because you are

uncomfortable with what he is doing why does he have to be punished?' And I stated

that and it was like 'Oh, it's whoever. It's the house manager's choice' And I did not

agree with it at all. I did let him watch TV. I did.

Actions of, and Interactions with, Other Involved Parties

As examined above in the section 'Who Decides What to do in Situations Involving General Sexuality and/or pSCB?' participants spoke about navigating decisions made by a wide array of individuals including other DSPs and interdisciplinary teams that may include Behavior Support Consultants (BSC), case managers, occupational therapists, parents, non-related legal guardians, and others. In this section I present findings related to ways in which the participant DSPs described the active and interactive dynamics of these parties. In addition the word cloud generated from participant descriptions of the actions of other involved parties (Figure 4) may help to provide further perspective.

As presented above, once initial actions are taken by a DSP in response to pSCB a series of reports/communications may be made to the interdisciplinary team or members thereof. These individuals, in whole or part, then may decide on further actions of response. These decisions may not include the suggestions or input of the involved DSPs. As reflected by one participant,

 "I have very little power on the team. It's the BSC, the case manager, and the guardian. Sometimes it's just the BSC. They rule the team". Similarly, another participant intoned the concern of creating conflict if in disagreement with the actions of other parties: *If you even bring it up* [DSP ideas for support] *there's the potential of pissing off their guardian".* This same participant reflected further,

> *There's team member biases all over the place. The team member's feelings are involved. Their own personal view of how this person should be is in there and they don't put it aside and focus on the individual and how they want to live…People*

putting their own views on what other people want. You actually get to see it. It's

fucking weird. It's weird.

Another participant reiterated some of the above, stating,

In actuality you have a team who just kind of makes a decision just based on not

especially pertinent information or just 'Nope, this is the route that we're going to go

with.' and it really does not matter what is actually going on with this person from

day to day.

Another participant reflected on the sometimes-conflicting messages or directions provided by other involved parties:

I've had a therapist tell me one thing and then the guardian tell me another. I've had

a client be like 'That's not true'. They are not communicating. I am the person

working with this person. They see them twice a month. I'm the one who sees them 4

times a week. And yet they are telling me what to do…Sometimes I think that some of

the teams just jump to conclusions. I don't think they really talk to the individual. A

lot of the people on teams don't communicate with other team members.

This same participant also pointed out an exception to these observations:

I have one therapist, I work with the guy four days a week and his therapist comes

once a week. Just at his job. And it establishes a relationship between me and the

therapist. I feel I can trust him. He listens to me. And the client – he listens to him.

And it makes the client know that we are all on the same page. He comes to work. He

comes to his job and sees us communicating so he knows that we are in contact. I

think that has a big role because he's like 'if I do this then she is going to talk to him

about it and…'. A lot of them don't think that way but some of them do.

These contrary interactions were also reflected in the following statement of a different participant who stated, "*there have been incidents where staff has helped BSCs write plans and I think that's always a really good idea. Getting the staff input on how things are really going. What's effective and not effective.*

Further exploration of the consequences of the conditions and actions/interactions involving participant DSPs, people with ID and pSCB, and other involved parties follow below.

Consequences

As examined above, participants described their work as DSPs as individually focused, involving a wide range of positive and negative interactions, and encompassing an array of possible actions for prevention and response. Branching from these roots of conditions and actions/interactions the participant DSPs related a variety of thoughts related to their notions of etiology, what risk means in their daily work, frustrations with the current systems of supports and an overarching perspective of emotional investment and empathy for individuals with ID and a history of pSCB. While a case could be made that certain of these areas may represent 'conditions' I contend that each of the below may be better seen as a *consequence* stemming from years of experience with a multitude of individuals in a multitude of circumstances. I examine these consequences with representative excerpts below.

Participant Thoughts on the Etiology of pSCB in People with ID

As a result of the factors described above participants expressed a range of ideas regarding why some people they support engage in pSCB. The more prevalent themes of

response are presented below while other, less frequent, statements are listed at the end of this section.

       As a response to limits and restrictions. Many participants connected the actions of limitations and restrictions to the causation of some aspects of pSCB in people with ID. For example, one participant stated,

> *When you try to take all of that away from a person, there become other potential things that happen where this individual does inappropriate things with other people because he doesn't get to get it out because everything has been so removed…I don't think you can regulate too hard in peoples lives without creating some of the issues that are problems.*

For another participant, similar thoughts were connected to an underlying sense of empathy:

> *I tend to put myself in their place and where they're so controlled all day long and they're human and they have these needs and they have the intellectual disability on top of it. So I guess I give them a lot of room, which, right or wrong, I don't know. But again, they're human and I feel like they don't have an outlet and if they do have an outlet it's so controlled and monitored that it's so unnatural and I sometimes, I just feel sorry for them. I mean, you or me we can go and do what we need to do any time of the day and these guys, how frustrating that must be. And no doubt they act out and do these deviant, so called deviant behaviors.*

Another participant gave a lengthier perspective in this arena:

> *The thing is, if you're telling somebody that you cant do this, you can't do this, and you make a choice to pursue something that's actually a good thing to pursue – it's an adult relationship, it's reciprocal, it's not illegal, if you are telling them 'No' to all*

those angles to then they are going to revert to doing things behind your back or they are going to try to get away with doing it somehow. And usually if people feel that they have to sneak around to do something – they're not going to take the high road, you know? They're going to revert to something that could be disastrous to their life…I think we actually elevate peoples risk by taking those rights away…If you are constantly telling people 'no' and you're constantly restricting their ability to meet those needs then, that need is going to escalate and if they have the predisposition, I don't know if that's what you want to call it, to do something inappropriate anyway, to me it seems you're elevating the risk to tell them that they also can't do things that are actually not illegal and would be acceptable for an adult to do…You're basically 'backing up' a need. And when people have very basing human needs that are not being met – they're going to meet them somehow. And that's just the bottom line I feel like. If you're denying them a basic need at all, you know, I've even heard, and it's not like I feel that there is inappropriate protocol in place in some instances, if people are not even allowed to be hugged or anything – you know, that need is just going to get backed up, and if they have the predisposition and have a history of meeting that need previously in inappropriate ways the greater their need gets, the greater their risk goes up to meet that in an unhealthy way…When you oversupport, are over restrictive, you discourage them from doing things that are normal and appropriate and healthy then they have no opportunity to learn how to have a normal, healthy relationship.

This was further supported by another participant who stated,

People have to sneak around, have to be manipulative, have to be deviant, just to get away with something. Sometimes it's as simple as just a kiss. Some of these people have to hide, sneak, just to kiss and 'Oh my gosh, if someone finds out that you snuck around the house just to kiss some other dude then you are manipulative, you're a liar, and we've got to shut all this down because we can't trust you. Now you need extra staffing. Now you two have to be separated' What?! You know what I mean. Seriously, they didn't do anything wrong.

Another participant also voiced congruent, and equally passionate, thoughts in this domain:

It all goes back to like needing permission to give somebody hug. Permission to give somebody a kiss. We've never had to do that. Its natural for us. For me anyway. I could not imagine being around so many people everyday and not being able to receive something as simple as a hug. Just the physical attention – 'Hey, I told you, I told you – you've got to stay at arms length.' Can you imagine walking around the entire world staying arms length from everybody? How fucking rough would that be? And not only you, but other people doing that to you? You know what I mean? Walking into your own house and your own family you know? So any kind of that I, well, there's certain people that I've worked with that would have these kind of behaviors, physical, sexual, whatever because the restraint was some kind of physical attention.

Along with physical contact, another participant connected limitations on relationships (implied to be required by other parties) to increasing the probability of pSCB:

If the staff is doing their job, they're right there, and it's two staff, not even one – what do you think is going to happen here? It's just ridiculous. I'm more in the

thought process of how are they ever going to have a healthy relationship if they can only see each other once a week or once a month I mean. Then that whole "Oh my god! I can't wait to see you again" It makes it more intense and crazy. If they saw each other once a week they'd be like "God! I have to see them next week, I'm so annoyed!" You know, like in a normal relationship [laughs].

Current environments. Along with the above, participants expressed that the structure of environments and supports may, at times, lead to pSCB. The lack of privacy was primary for one participant in the following exchange:

I: The phrase you used was 'when you have people around all the time you lose your sense of boundaries around…

P: Sexual things? I mean yeah! You don't really, apparently you're not supposed to have sex or any sexual feelings or want to do anything around that but you also don't get a sense of privacy either so you lose that because there's always someone in your space. Someone always around. So, you're not really given time to be with yourself or with your own thoughts necessarily. Um, for some of our guys that's, it may not be a detriment per se but I don't think that we've gotten a lot of their social needs met or downtime either because they don't have 'alone time' [*finger quotes;* referring to individuals who are required in plans to always have a paid support present at some level] *if you want to call it that, or privacy either. I hate calling it alone time but…Some of them will touch themselves and do an inappropriate thing like that per se with other people being around. But there are always other people around them. All the time. So, where's your boundary? You're going to lose that pretty quickly. I*

imagine if I was one of them I'd end up masturbating around other people. Like

'What are you going to do about it? Leave me alone.' [laughs]

For other participants, the gender separation in certain programs was portrayed as a possible etiological factor. In one participant's words:

In my experiences with all the males, we keep the males together. We don't let them out of our sight or we don't let them go talk to females except where? Fucking [a community dance]? We house them together. They are in day hab together. They live together… You've got one horny guy with this horny guy and this guy's not getting any and he's not getting any so of course they are going to start helping each other out. I don't necessarily think they are all gay. I just think that's the opportunity that they have.

This was echoed by another participant who stated,

P: Unfortunately in the field a lot of the guys don't mingle with the opposite sex. Might come in straight meaning attracted to the opposite sex…

I: But then they are in a situation where they don't have any contact?

P: So yeah – they are forced to look at roommates now – it's institutionalized. Jail is the same way. After a while if you don't have conjugal visits, can't see your girl because she is not your wife – things happen.

For a final participant, this combination of limiting interventions and environments was also a potential source of etiology:

The whole point is to teach them 'ok what is appropriate, a normal healthy appropriate sexual relationship.' But, if you restrict them from ever doing that then or if you over react to any little nuance of any relationship that's consensual that they

do have then how are they supposed to do this? I guess it's really frustrating at times.

Um, because you know, no you do not want them molesting children but if you never

allow them to have an appropriate healthy relationship either, the bottom line is, and

I know people don't want to hear this and I'm not saying that people go out and

molest children normally, but people have very basic needs and if they are restricted

from meeting those needs at every angle then that's where I think you see worse

behavior a lot of the time. So, you know I understand wanting to keep people safe and

I understand, well, dignity of risk is a better one to use rather than rights. I feel like

dignity of risk is not allowed for individuals who have sexual behavior histories

Past abuse. Experiences of past abuse were also mentioned by participants as possible etiological paths toward pSCB. As stated by one participant, "*Where are they coming from? Some of them from institutions or they've had sexual abuse back grounds and they're just acting out what was done to them*". This was reiterated by another participant who stated, "*Sometimes they've come from environments where there's so much molestation and things that have gone on in their environment that they grew up, they don't really understand what normal healthy sexual behavior is*". Providing a specific example another participant related,

the one who does the bathroom smearing or [fecal masturbation]. *He's just so*

awesome sometimes and it's so sad because I think all of it comes from abuse – he

was so abused as a child. I can't even be mad that he's, I mean, I know it's not

appropriate but I can't even be, I just feel like 'God. What can we do to help

him?'…He was so abused, he just has no idea. I don't think he knows. He's not like

'Oh, I should touch children.' It's more like it's some kind of, he was just treated so

badly that he never grew up understanding what love is and appropriate. Just never.

The following participant expanded this again to cover a wider range of the topic:

P: I think a lot of it is their past. Like the way they were brought up. A lot of it – that's

all they've known their whole life. So, that's their normal.

I: What is it that they've known their whole life?

P: Having little kids given to them. Or having things done to them when they were

little. Or being told to do these things when they were little. I think that, and it's sad

to say, but I think that a lot of people with developmental disabilities get taken

advantage of when they are younger. So, I think that, that's their normal in a way.

Because if that's what I've been told to do or that's what's been done to me – then

why shouldn't I do it to somebody else?

One participant expressed a degree of conflict in her conceptualization of a certain

individual:

I have a client and I want to say it's his fault but it's not his fault. He was molested by

his mom who had all these personalities. First she was the mom and next she was the

friend. Then she was the girlfriend and then she was the sister. When she was the

girlfriend it was up to us to step in to try to stop it.

Finally, while experience of abuse was offered as a potential cause, another participant

described a degree of conflict in the following statement, "*I've come to understand this as*

maybe because of things that they've been through. Their life and thinking that that's ok

because that's all that they know. I could definitely see that but that doesn't make it right".

Biological conditions. Regarding particular cases participants referenced possible medical conditions that may speak to the etiology of changes in or development of pSCB. Recalling a particular individual, a participant recalled,

> P: *I had posed a question to a team member of another client who dry humps clothing in his room and stuff. And I asked his guardian, who happened to be his mom, I asked staff first – has he ever had a happy ending?*
>
> I: *Ejaculated?*
>
> P: *Yeah – and I asked the mom, the guardian, because I had never seen evidence of it. And I'm thinking that might be a lot of his problem right there you know [laughs]. But nothing ever came about it. I think that the desire was there obviously but I would think 'Ok – why hasn't there been a happy ending?' Because – he physically can't because of his medication? Physically he should be able to because that's a natural thing.*

Also speaking to possible biological pathways another participant described a individual who,

> *had an accident that caused a traumatic brain injury so he's relearning a lot of um, so he and I worked together really closely of course, you know, sitting down doing math problems and reading and writing and writing paragraphs and learning how to do all those kind of things and he just kind of randomly started saying 'I love you' and 'Let's go to dinner' and he was actually not super inappropriate in how he went about it.*

As one participant summed up, "*There could be some health issues going on. Thyroid and testosterone and estrogen and stuff. Making sure there's not a chemical imbalance going on*"

In a longer passage, a different participant related how many of the above factors (restrictions, environment, and medical condition) may interplay:

I've learned with TBIs – traumatic brain injuries – they might remember how they were before the injury. Say they were a super smooth mac daddy and now they have a limp in their walk and not everything is the same. They might feel like they can go back to that. Unfortunately some people don't see that in the community and are like, 'This guy is in a wheelchair – I'm not going to give him the time of day because' Maybe a stereotype. But the guys we provide for – they don't understand that – 'How come no one will talk to me now?' and it's got to be frustrating. Then to have so many restrictions on you and you can't even go on a date by yourself and you are not able to obtain a job so you are not able to get the clothes to dress up for the date and take the female on the date – pay for dinner and pay for a movie. So say you do meet a female and she wants to go on a date and she wants to go back home with you. You have 4 other roommates that have problems with females. Now you can't take her home. But you pay rent there. Super frustrating. And now you've got staff like 'No you can't do that – that's inappropriate. It's in your plan'. All they understand is 'I'm a dude. I want to get laid. What's up with this!?' and it's hard to talk them down from that need.

Attention and reaction. Perhaps related to the environmental factors above some participants discussed how certain types of pSCB may be given impetus by a desire for attention or to test reaction. As put by one participant regarding public exposure, *"They like seeing staff freak out you know? [laughs]. I've heard that one – 'I just like to see how the staff reacts. I like to see you freak out'"* Likewise, another participant stated, *"It happened to*

me at [a healthcare setting] *before. Pulled down the pants. But, that's more trying to get to the staff then anything. Trying to test the staff's limits. See what they will do. What they can get away with"*. Referring to an instance involving a person touching female DSPs' genital areas without permission a different participant summed up, "*he was kind of testing us out to see what he could get away with"*. Another participant similarly reflected, "*in the beginning I think they were testing me like 'Let me see how far I can get with her'"*. For a final participant the general idea of 'attention' was framed as a nearly inescapable aspect of etiology:

> *Usually, like 99.9% of the time, it's attention seeking behavior one way or the other. They want to be noticed. Even negative attention is attention. Even somebody getting upset with somebody. Even getting arrested or going to jail or seeing a judge. It doesn't matter how far you take it – it's still attention. A lot of it is attention seeking. Not always. There are some 'not good' people but it's all attention. When you're doing something in public – you want attention. When you're pulling your junk out, you want attention. When you're screaming your head off and pulling your pants down running down the aisle at Wal Mart, you want attention. When you are beating on your staff, you want attention, You want some kind of reaction. I think that is what a lot of people look for. It all goes back to like needing permission to give somebody hug.*

Mental Age. Several participants mentioned aspects of 'mental age' as a possible explanatory mechanism of pSCB. In the words of one participant,

> *The ones that are adults and they're going after teenage girls – yes, that is predatory but you have to keep in account where their mental age is. I mean if their mental age*

is 12 then that's ok to them. So I understand that. It doesn't make it right but I guess I

don't have a negative feeling toward them. Some people do like 'Oh my god that's

horrible' but I guess I try to understand where they're coming from and why that

would seem logical to them.

For another participant an age comparison was used to describe an "*extremely hormonal*

young guy and he was really young then and he does seem to be maturing now somewhat.

But at that point in time he was kind of like a 16 year old boy". Another participant

integrated a reference similar to metal age in describing her experience with a particular

person:

I really don't think that he's straight out like a pedophile. What I think is that he was

abused as a kid and his mentality level and what he knows as connection and 'ok'

what he learned as a baby I don't think that he understands that it is not appropriate.

Lack of attention to the concept of 'mental age' was also framed as a potential concern in

labeling of certain actions as sexual:

Like 5-6 years olds are curious about each other. That's not sexual. That's curiosity.

I think for certain clients they are still kind of stuck at a certain age. We wouldn't

normally think of an 8 year old as being sexual or a sexual deviant. But when it's a

24-year-old male with an intellect of an 8 year old we automatically think that's it's

sexual

In summary, these DSPs provided a litany of ideas regarding potential etiologies of

pSCB in people with ID. One participant, however, summed these thoughts up with a pointed

reference to the possible effect of individual history on this overall equation:

There's a lot of reasons people have these inappropriate sexual behaviors. It's not always about sex. Sometimes it's about scaring somebody. Sometimes it's about just trying to be offensive. Sometimes it's about, 'This is how so many people for so many years characterized you and it's how you're supposed to be'. And I think that they believe then – 'Well this is me. I'm this person because this is how they've treated me for so many years. This is how I'm treated. This is how my plan says I am.' And I think that they get comfortable being a certain way because that's how they've been told. They've been told, 'This is you'.

Changed Opinions

Despite, or perhaps because of, the often challenging circumstances of this work, participants expressed a great deal of emotional investment in the processes behind their daily work and the people whom they support. These thoughts were often integrated with statements about how their opinions regarding sexuality, pSCB, and people with ID have developed over their years of work. As put by one participant,

P: I'd say I'm a lot more open. I don't know if open, but maybe more, I have more empathy. Um, and understanding like the intellectual level and why they would seek out maybe somebody that's 12. Before I was like oh my god that's horrible, how could that happen. I was maybe more judgmental and now I sort of have more of an understanding of how that happens and why that happens. And plus – plus where are they coming from? Some of them from institutions or they've had sexual abuse back grounds and they're just acting out what was done to them and I get it you know. It doesn't make it right. But I have empathy.

I: And that's a difference maybe from years ago?

P: Oh yeah, yeah. I looked at them as like horrible. They're monsters. They should be locked up. And now thank god they're not locked up because horrible things would happen to them.

Another participant similarly reflected,

P: When I first started, I didn't really think about people with disabilities and having sex. It wasn't really something I thought about. And then I started thinking about it once there were all these barriers that were put in place from their teams and other things going on and it was like, "Oh, well, so you got in trouble so now you can't get this magazine" or these weird, stupid plans that happen to be in place. So, I never really thought about it actually until I started working at [study site agency] *with people that have sexual issues. I never really thought about it. So…*

I: So it's changed?

P: It's changed. It's changed and it's changed but it makes you see people in a different light especially when you're in team meetings and talking about it and you're going "Ok this is your opinion, and this is what you believe is happening but this is not what they want." They are sitting there screaming that they want to have sex and they're going "Well, why don't we prolong this until after they do the relationship 3 tier class" which is going to take them like a year and a half to do or they are just pushing it longer and longer and longer so they don't have to deal with it. So yeah, it's changed. My perception has changed.

The aspect of changed perspective and relationships was emphasized by another participant who stated,

I didn't know. At first it was a little terrifying and I'll be honest, I didn't really want to work with people with that kind of, not so much really just disabilities but the ones who focused on sexual stuff so I was really actually nervous and kind of uncomfortable and kind of I would say prejudiced against because I just had this one viewpoint of people who committed sexual crimes and I didn't really understand everything behind it. I just had this one viewpoint and I was like 'I really need the money but I don't really want to do this'. But then you build relationships with them so today, it's like second nature I don't even know how to tell you how I work with people with intellectual disability because I don't see them that way anymore… remember I told you at the beginning, I was really terrified and like "Oh my god! Totally against pedophiles and I thought they should all be shot dead". I did not really understand. But now, my perspective has changed.

Speaking more about a changed opinion of general sexuality and people with ID a further participant recalled,

Before I got in this field I was a young kid and my grandmother, my grandfather we would go to church and would always see the group homes at church and you know, as a kid you're wondering, what is that, what are they doing? Why are they acting so funny? As a kid you ask your grandparents those questions. As I got older I started to learn more and more about life and what the disabilities were and what was being done. I guess growing up I thought they didn't, well, I don't know what I thought honestly. But one thing I thought was that they shouldn't have relationships probably. Because it was an unknown. You know what I'm saying? I didn't know anything about it. But going into the field and being in this field all this time – they're human beings

just like us and if they can handle it, if they are mature enough to handle a

relationship then more power to them.

As to if the field as a whole has changed, this same participant stated,

I think they try to work on it and I think they are trying hard to change it by getting

people more dates, exploring healthy relationships. So, that's changed. In a way,

that's changed. I don't know about sexual relationships, how people feel about that in

the workforce in this field. I think it's still kind of taboo I guess. I don't think a lot of

people support it. I don't even talk about it much. We just talk about it when it comes

up. It might be different. This is just my impression of it. I myself, like I said, I don't

have a problem with it if they go through all the right stuff and do what they need to

do to have that healthy relationship, to be together, that's great, they found

somebody. They deserve it just like me and you. We all deserve to be happy and if

they find someone that makes them happy then more power to them.

Speaking of more visceral initial reactions and current perspective another participant stated,

When I first started it was all 'eww! That's gross. That's nasty – why are you doing

that?' Now, I've grown and I know that these things are human nature. It's just how

you go about it. So, I think that has changed in me. I don't think that 'Joe' touching

himself is a bad thing any more. I don't think, I think it's bad how he cums

[ejaculates] all over the floor and does not clean it up. I think that's bad. But as far

as anything else – I think I've changed in perspective. I'm telling you, if you'd have

seen me 22 years ago, I'd be like 'Oh my god!?'. We had one guy when I started who

would masturbate in his hand and when he came – he'd lick it. I almost fell on the

damn floor. I tell you I had never seen anything like that in my life [laughs]. In my

life! But, now it's like 'huh'. It does not bother me as much as I used to back then because, we don't all do that, but somehow some way we all have something sexual going on all the time. A hand touch, a hug, a kiss. So, its, changed a lot. I don't think things that I saw as nasty back then – I don't think they are nasty now. I think they are human nature.

For another participant, experience in this field resulted in a wider scope of changed opinion regarding sexuality in general:

I hate to say it but it's not even just disabilities. I used to have a big homophobia problem. Horrible. But within the first two years of working in the field I kind of let that go. I let it got to the point that [I'll say] *'I'm not that way. I'd appreciate it if you did not look at me in that way. I'll be your staff. I'll help you out. But I'd appreciate it if you did not look at me in that manner.' Just like if they come to me and I said 'I'd appreciate it if you did not talk to me that way.*

Referencing ideas for areas the system of supports could improve, another participant reflected on her changed perspective:

P: I think that they need to have sex more. The ones that can express their desire. I can't speak for someone that's not verbal. But for folks that can – I think that it is healthy. It's healthy. If you've never had sex – oh my god – I can't imagine never ever having sex. It's – we're humans. We are sexual creatures. Whether it's sexuality with others or self pleasure. That's a release. I think that would benefit a lot of people.

I: Was that the same view you had when you first started?

P: I never, when I first started in this field – no.

As succinctly put by a final participant, "*when I got hired – never in a million years did I think about this aspect of their world. Never. I see them at the store. I see them with their parents. I never thought about this side of it.*

Risk

The concept of 'risk' was explored with each participant as part of the semi structured interview. In the above discussion of 'Preventing pSCB' there were emphases on qualities of vigilance, being aware, and setting boundaries that seemed to pervade the actions and interactions of these DSPs. These could be seen as manners of reducing or attenuating risk in certain circumstances and may be considered in conjunction with the following. When 'risk' was specifically introduced as a topic, content shifted to larger concerns about the system of supports and possible effect on people with ID. Per one participant, due to the conditions and actions involved, "*you risk taking their identity or their sense of self or agency*". When probed further about risk, this same participant responded, "*We walk that boundary. It's a tightrope. Just do your best.*" Another participant was hesitant to directly frame her work as having elements of risk. She stated, "*I invest time in spending time with them and doing things that are going to help them. So I don't really see risk in it so I'm not quite sure…*" A different participant extended the conversation on risk to frame the sometimes restrictive actions of other parties such as members of interdisciplinary teams or family members: "*Maybe some of them are just so scared and they just don't want something to happen that they take extra precautions. They go above and beyond and they take away their rights in a way*".

From a slightly different angle, another participant recalled a specific circumstance of confused directives in relation to the concept of risk:

My risk is when I worked in a house with three guys and they all liked children. So, the risk was – one was a runner. The risk to me was – 'Am I supposed to chase this one and leave these two by themselves?' So I was always complaining about that. Always. Like, 'ok, you've got me in a house with people, three people in the house who love children' and I don't mean 'love' in the loving way – 'and one runs a way – what am I supposed to do?'' I figured let the one run away and call the cops. Maybe the cops will find him because if I leave these two then you've got two people to worry about instead of just that one. So, let's just take it with these two – and one was really dangerous – so let's focus on these two. If he runs, he runs. He never ran on me but I was always thinking – 'What am I going to do if he runs?, Who am I going to call? What's going to happen while he's out there by himself?' Because he was known to do this kind of stuff. And it was like, 'No, you have to go chase him.'; 'Ok, so while I'm chasing him, what's going on at home?; 'Oh, you can't leave them.'; 'What!? What do you mean I can't leave them? What am I supposed to do – take them on the chase with me? That's not going to happen.'

For a final participant the aspect of risk involved in the job was easier to identify as evidenced in the following exchange:

I: So what is your job related to risk?

P: Making sure they are safe. Safety is a big thing.

I: Is that constant?

P: Yeah it is.

I: How much do you think about it?

P: All the time. When we are in the community. On transport.

Rights and Sexuality

Likewise to the above, participants were asked to provide thoughts on 'rights and sexuality for people with ID' as part of the interview. Several participants were fairly direct in response to this line of inquiry. For example, one participant said, "*these are very basic human needs. Sexuality is a very basic component of being a human being.*" Expanding on this line of thought, another participant responded, "*they do have the right to be sexually active. It's a desire, an urge, we all have it. The trick is, teaching them what is appropriate, what isn't appropriate. That's the really hard part of it…They do have the right to have sex. They do not have the right to have sex other than with someone of legal age*". Explaining this in terms of some individuals' histories a different participant expressed,

> *They have every right that we have. Or they should, in general, have every right that we have. Unfortunately some of them are convicted child or sexual predators so some of those rights have been taken away. Yeah, they have every right just as we do. As far as I'm concerned their rights are our rights.*

As introduced here, and expanded in the section 'Arrival at a Grounded Theory' below, participant responses commonly contained elements of internal or external conflict. In reference to this one participant simply stated, "*It's kind of different though because a lot of these individuals, they have a team*". In the following excerpt, one participant, with an element of dry or frustrated sarcasm expressed a clear perspective in this domain:

> *I: So when you hear the word 'rights' in relation to people with intellectual disability and sexuality – what do you think about?*
>
> *P: [laughs] Oh man – you have the right to do what I tell you to do. You have the right to follow your plan. You have the right to…oh my god… rights, rights. Yeah, no*

I don't – It's not the same. We talk about 'You have the same rights as I do'. No they don't. That's bullshit. No you don't – "You need 15 people's permission for me in my car to take you to buy a Playboy. And we all know what you are going to do with that Playboy. How does that make you feel? Then you go in your room with the Playboy and I saw you shut the door and I saw you take the Kleenex box with you. We all know what you are doing". What is that? It's – no rights.

In response to the same question another participant was less vehement and replied,

P: The same as ours. I don't want to say that we are normal quote unquote. Everybody is normal in a sense. Everybody is a person. Some people weren't equipped or taught ways to deal with what they are going through or they've seen, or what was done to them. It's just an ugly circle that keeps going on and on. For the most part I actually think that they have the same rights – disability or not. But when it comes down to it in the end – they are a little more protected than we would be being as we don't have a disability.

For a different participant this line of inquiry led to consideration of some specific quandaries she has encountered:

I think they have a right to date. A right to date who ever they want as long as it is not a minor. I think that, I mean everybody has sexual desires. Everybody has hormones. It's their right to act on them. They need to be taught how to act in a certain way. But if they have a girlfriend – there's a lot of teams where they are like 'Ok, you can date her but you have to have a chaperone.' And I think slowly the chaperone will go away if they start acting right. But a lot of times, like these two clients who are engaged and their teams won't let them see each other because they are both sex offenders.

And it's just like 'If you guys get together and date – then bad things will happen'. And I don't know – well, in a way that's taking their rights away. Like, why can't they have a chaperone? Why can't they be with each other? They can't see each other at all. Why can't they have a paid support staff to hang out with them? All they want to do is see each other and this is kind of taking their rights away but the team agrees on it. His team doesn't agree. Her team agrees on it. And this has been going on for a year now. So, I think they have a right to see each other – it's just teaching them the appropriate way to do it.

A further participant took this topic to a wider pondering of rights and human sexuality:

They just need human contact. Everybody needs human contact. And when they touch one another or something – we are all up in arms? I think that's wrong. I don't think we should put a big stamp on it. I think we should just go 'oh' and go about our business because if two people engage in something – why do we have to be all 'Oh my god! What have you done! You shouldn't be touching like that!' I don't think we should be doing that. I think it's really childish. Because they are grown up and they know what their body needs. And if you have two grown ups consenting to do this – who are we to stop it? Why are we stopping it? So, that bothers the hell out of me. It's like – yeah, that bothers me really bad because everybody has a right to be themselves and do what they want to do…Why can we get to say what we want and we don't want but just because they live in a group home they don't get to say that? Why can't they have the same opportunity? Why can't they have the same things we have? If I want a one night stand – I'll go get one. How come they can't have that?...We make good decisions and bad decisions. Why can't they?

For another participant, the discussion of rights led to the following statement that was preceded by a heavy sigh:

[sighs] I think all their rights should be honored and they have the same rights we have. I just feel that sexuality sometimes is not…it's a difficult subject and it's not necessarily given to them. They are not even thought of sexually a lot of times. Or if they are it's more in a restrictive like 'Hey you're not supposed to do that' or whatever. That's about it.

Lastly, another participant spoke about limitation of rights in relation to legal standards and notions of safety:

P: To a point. To a point. They have choice. We all have choices. I can choose to break the law or I can choose not to. I have a right to vote. I have a right to go to work if I want to if I can find a job. I have – now, in regards to sexuality. You know what – it's 10 o'clock – I'm horny. I'm going to give so and so a call. Staff answers. 'So and so is not here' but they should be able to have the option. The availability. The means to have relationships. Access to meet new people. It's all chemistry.

I: So that's sounds – that's the philosophy?

P: The philosophy yes.

I: Where you're coming from. Is that what happens in practice?

P: Not for a lot of individuals.

I: How is it different?

P: Um, For some. For some, they are in a position where they could get hurt, exploited, abused…Some don't have the ability to, the option to based on their

demographic that they are attracted to. If they are attracted to kids – that's against

the law.

Frustrations

At many points in the interview participants expressed direct or implied frustrations with aspects of their work. In every case, these frustrations involved external aspects of their experience and never in reference to general frustrations with people with ID. As examined above the concept of 'Rights and Sexuality' contained a multitude of frictions for these participants and may be considered a key variable in the other frustrations presented below. Contained also in these responses were some ideas for how the system or particular responses might be changed.

Desexualizing people with ID. These participants voiced strong opinions regarding how others sometimes desexualize or attempt to prevent sexual actions by people with ID. For one participant the frustration involved another DSP:

Well the staff freaked out that was working with her. Made a big deal of it like "that's

dirty, that's wrong" But it's like – that's human nature. She's doing it in her own

bedroom. She's in private. She's not out there for the whole world to see. Give her

some space man! That's her room. Give her some time. She'll come out when she's

ready. We'll take care of her, give her a shower you know?

This was similar to another participant's statement that,

P: People usually view sexuality of any way, whether its appropriate or inappropriate

and people usually judge. Of course there is direct care that judge and put their

personal feelings into it. And no, not everyone is willing to teach. Not everyone is

even willing to touch that stuff or go there. I think it takes a very special direct

support person to even get involved in any of these behaviors with these individuals to begin with. I don't think everyone can do it.

I: Is that particular to sexuality in people with intellectual disability or do you think it's sexuality in general?

P: No – in my field it's people with disabilities – with intellectual disabilities. There's so many fucking hypocrites out there you know what I mean? People don't want to be judged about their own sexuality – 'Oh I'm free to do whatever the hell I want. No one can judge me'. But, no, these people that we serve, we put our thumb down on them and tell them 'No. This isn't right. You can't do this. You cant express yourself like that. No, you can't talk to this guy. No you can't call that girl.' No. It's much different.

For another participant, frustration regarding blockades to sexuality for people with ID were expressed as follows:

The one client, they said 'Oh, we're trying to find him a girlfriend'. Yeah – when he gets that girlfriend – then what? Then what? Because they're still going to be like 'you can't hug, you can't kiss, you can't hold hands'. There's a whole lot of 'can not dos'. I've noticed that a lot of companies, I haven't seen a company yet that's all for 'teach the clients how to have safe sex', 'let them have consent'. I have not heard of one company that will do that. You've got the clients who will get out of the company to be able to do what they want to do. But, while they are at the company – you can forget it. You're going to 'palm it' the whole time… I feel like we are always stopping them from doing what they want to do. We are stopping them from being the humans they want to be. We are stopping them from loving somebody. From wanting to be

with somebody. And I feel like that's what we are doing. We are on this side 'You

can't do this and this and that.' But, I'm on this side too where I want to say – 'Ok go

do this and this and that' because I feel that everybody should experience something

once in their lifetime before they die. It would be sad for my client to be 50 something

years old and die and never feel how a woman feels. Never know how it is actually to

hug somebody and say 'I love you' besides his family members.

For another participant the efforts to contain sexuality for people with ID stretched to a larger

macrocosm:

There's a lot of uptight people out there that don't even want to talk about it. They

don't even talk about it in general. I think that in order to – we need to train them all

on sex. Sexuality and morality – we don't. Religion – but we do not enforce our

opinions. We give them as much information as we can and let them decide.

As similarly expressed by another participant,

The DD Waiver in general, whether they have any risky sexual history or not, is

sometimes very restrictive in the area of human relationships and sexuality but

particularly when they have you know any type of sexual behavior concerns, it

becomes even worse. And, I just wish that there was a way to make people more

aware. Or even to change some of the ability that people have to make those

decisions for them. Not change it, alter it entirely, but modify it to where you now,

they need to meet this criteria before you could even come to this decision that they

need to do that. That would be awesome.

A final participant analogously (and humorously) extended these musings to include

historical aspects of American culture:

Looking through the DD Waiver standards because I've looked at them off and on since I've started working in the field just to see – is this right? But there's no clear answer. I feel like there should be. I feel like a lot of them, we're trying to take away any sort of sexuality and we're worried about legal ramifications or repercussions because of what could happen with them having sexual activity in one way or another or I don't know. I don't think there's a clear answer of where that comes from. I want to blame the Puritans just because it seems like it started there because our country started there but whatever [laughs]. Those sexless jerks! [laughs]

The effects of history. As examined in sections above (i.e., How can you tell if something is sexual?' and 'Response to pSCB') the sexual history of individuals with ID was often referenced as a compass for making interpretations and decisions. The sometimes far-reaching effect of these histories was described by participants as a source of frustration in their efforts to support people with ID and pSCB. As one participant summed up,

I think a lot of them are not given a chance again. It's just like 'You did this and this is who you are now.' I think a lot of them, they are capable of being taught the appropriate way. They are capable of being taught 'You know, you shouldn't be looking at a 13 year old little girl. You're 35.' I think if they were given the opportunity…

Another participant expressed similar thoughts stating,

I think sometimes I see a lot of, with our type of clientele in particular, sometimes there's almost just an assumption that they're doing something inappropriate when they're not. So, you know it's kind of a fine line and that's a huge challenge for people you know. Where do we make the distinction of, you know, this is actually a

normal, healthy, acceptable behavior so let's encourage this rather than discourage this?' but…when you're seeing that 'Ok this person is literally being like totally overenforced about things or you know, like I said, I know a lot of it is a grey area and it's hard to say and people jump to conclusions a lot and you really can't, there should definitely be more training about how do you deal with people who have historical information like this. You know where maybe they did something when they were like 15 and maybe today they are 25 and they haven't done anything since then. How do we eliminate some of the focusing on like 'Well, they did this when they were 15 so we need to watch this and this and this and this?' And it's like really? You know, how do we eliminate some of that because what happens is instinctively, especially with people who are newer to the field, they panic and then they think 'Well this person is a raging child molester.' So, they are watching everything they do and over reacting to everything they do. It would be nice if there was a specific training program for dealing with people with those types of histories.

Another participant related similar frustrations regarding a particular individual and decisions made by a legal guardian:

His [relative/guardian] *keeps it really tight – really tight with his money. And I think she holds things from the past that have happened with her daughter against him and treats him kind of poorly. You know I don't ever hear her say anything directly abusive or anything to report but just watching how he lives his life.*

A further participant expressed how these history effects might be connected to lack of personal contact by others involved in decisions:

Because that's something that they did six years ago, have you spent enough time with them to understand that what happened six years ago was no longer relevant even four years ago?

Likewise, a final participant stated,

Unfortunately sometimes in this field the paperwork is a little outdated. People have grown since then. I always notice that it's always the worst things in the book that they note so you can always be ready. But it's been like 6 years since they pulled down their pants and started masturbating in front of hundreds of people. But, it's possible.

Too many inputs. As one participant put it, *"we've got to get all these teams involved and if one team doesn't agree with the other team then the whole thing is stopped and they can't even see each other. And its like ugh come on, how would you like that?"* When comparing what she thinks should happen to what actually occurs in regards to some types of pSCB another participant stated,

What actually happens is that everyone is up in arms, every one is mad, all the BSCs are called, everybody's called, the teams called and it's like 'oh my god! So and so sucked someone's dick!' and it's like 'Really!? So we have to tell everyone what's happened?' No, we didn't. We could've just said – 'Ok why did you do this?' If that is what you want to know. 'What made you want to do this? Were both of you willing to do this?' Find out what happened before you get all up in arms about it. We have this – 'Oh you've got to tell this person and that person and call this person' and it's like why? Why? He said it was ok for him to do that so why do we have to bring in all these people to tell them? Who cares? I just think its stupid. If you've got two

consenting adults – no matter who they are. Because everyone has feelings. I think

that you should give them the opportunity to say 'this is what I want and this is what I

don't want'.

Likewise, a different participant related,

because when you're telling people 'Ok, you can only embrace when you get to your

date and you can hug when you leave.' Who would tolerate that? You know what I

mean? Who would tolerate 15 people sitting around a table telling you how you can

go on a date? You know that's so far above and beyond… I understand wanting to

have a certain measure of control and making sure an individual is safe but literally

when you're sitting at a table with 15 people deciding whether or not two people can

hug on a date that's a bit extreme for anybody…I cannot even imagine how awful it

would be to have a team of you know 5, 10, 15 people deciding everything for you

Musing on the possible reasons behind this dynamic a final participant stated, "*Because*

everybody wants to be on the same page I guess. Everybody wants to help. Everybody wants

to put their two cents in. I don't know. I almost think it's for everybody else's benefit instead

of the individual's".

Too little input from DSPs. In some conjunction to the above, many participants

voiced frustration with their own lack of input in these processes. As expressed by one

participant, *"I wish the system would listen to us more. I wish they would take what we say*

and believe that what we say is worth listening to". This was furthered by another

participant who stated,

You have a lot of really good support staff in this field who could contribute

something really valuable information wise to the person's life that could actually

effect the bottom line of you know 'what happens with this person today and what's

going to happen with this person tomorrow?' And in actuality, you have a team who

just kind of makes a decision just based on not especially pertinent information or just

'Nope, this is the route that we're going to go with' and it really does not matter what

is actually going on with this person from day to day.

Congruently, from another participant:

The team makes the decision. So, you report the incident and the case manager, the

guardian, every one like that, will have their say in it and usually staff don't have a

say, they just report it. They don't have a say in what should happen.

This dynamic was reiterated by another participant who stated,

They see them twice a month. I'm the one who sees them 4 times a week. And yet they

are telling me what to do? I honestly think that they need to give the direct support

staff more of a voice. The teams do. Like I said, we are in front of it all. Especially the

residential staff. They are the ones who are with them the most. They need to listen. I

don't know if its true, but this is what I've seen, and it's almost like they think of the

job coaches and the residential staff because we don't have degrees, it's like 'well,

you really don't know as much as I do so, we are not going to really listen to what

you have to say'. When we are the ones who are with them everyday. We're the ones

telling you what is going on and you are still telling me to do something different. It's

not right. So I think there needs to be communication on the teams and I think they

need to give the direct support staff more of a voice.

Frustrations with not having a reliable place for input was also extended to in-agency

dynamics:

The worst part of the job is not being heard by management. Not having your

opinions taken seriously based upon what you have experienced at the house. Trying

to relay the needs of the clients or the house to upper management. Saying 'this is

what we need or this is what happened' and them being like 'We got it, we got it' and

nothing being done. That's the worst part of the job.

As a final participant related, "*You feel like you're muted*".

All blame, no credit. Continuing from the above, these DSPs sometimes expressed

frustration with how they are recognized in the continuum of supports for people with ID and

pSCB. As one participant passionately expressed,

Direct support is the most thankless job that I have ever worked in my entire life. And

that's fine. I deal with that. I enjoy what I do but it really is the most thankless job.

You could be with somebody 40 hours a week, every single day, every single week, for

years and years and years. You could be the face that this person sees the most out of

anybody – parents, therapists – but the second something goes wrong – your fault.

"Ok well, I'm following your plan. I'm doing what you fucking told me to do". And

"no – your fault. You must have done something wrong." You know weeks go by,

nothing goes wrong and this guy is improving, you guys work well together, no

negative behaviors. Nothing. And all these guys take the credit for it. "Oh it's my

plan. Oh it's what I told you to do with that person. I'm the reason why this person is

doing so well. Not you, you just work with them." So it's a lot of bullshit…. Yeah,

we've got to follow plans. Yeah, we go sit in these meetings and don't fucking say

anything. Like I said, you're just there. Nobody wants to hear your opinion. Nobody

cares. If something goes wrong, it's all your fault. If things go great – they take the

credit. Not always, but a lot of the time.

For another participant, this type of frustration seemed to strike at a core belief about the

field:

This is what I truly believe…is that the direct care staff is the backbone of any

company. They are in the trenches day in day out. They are the ones who have to deal

with everything. From the good to bad to behavioral. They are the one's that deserve

all that credit. That's my honest opinion. I think they should be rewarded a lot more.

More raises then they do. Getting awards. Getting recognition. This goes for every

company across [this state]. I've worked for a few companies and I know first had

how some of these companies treat their direct care. Like they are nothing. I believe

that they are the backbone of every agency out there. That's it.

Failure to listen to people with ID. As with their own input, participants expressed

frustration that people with ID are not provided input into decisions regarding sexuality and

related response. One participant suggested that the system might be improved if all parties

Just take time and talk because sometimes what you think happened really didn't

happen. So I think that if you talk to someone and hear both sides of the story and not

just one side of the story I think that is a better thing to do. We do a lot of that too. It's

a one sided story the part that we hear. We don't often hear their side of the story. It's

always 'It's this way. This is what happened. You are lying' It's like, 'What makes

them a liar? They are trying to tell us something. They get frustrated because they are

trying to tell you sometimes that they are attracted to that person over there but

you're not paying attention. So, when it goes to another level why are you mad?

This was supported by the statement of another participant: "*Well they* [the team] *pretty much call*[s] *the shots. If the whole team isn't in agreement then you sit there until the whole team is in agreement even if the individual wants it. It's the teams' decision. The individual doesn't really get a say".* Another participant responded similarly to the following query:

> *I: And what would make a bad team?*
>
> *P: Does not listen to what the client wants or has to say. Dismisses what the client has to say. Does not want them at meetings. I've worked with that too. Pisses me off.*

A final participant located a possible underlying dynamic to this level of non-interaction:

> *Because my understanding of that whole process is that a BSC has 50 clients and I know I'm exaggerating, maybe. They have 50 clients and what they're doing is taking the previous report and they're adding on top of it, they're not, this is what it looks like to me. They're taking that previous report, they're sitting down with the person for 45 minutes and they're asking them these questions from previous interviews and that person is not going to respond how they normally respond. That person is only going to say what you are expecting them to say anyway. Take them out to lunch!*

What Makes a Good DSP?

Participants were also asked to describe aspects of what they thought 'makes a good DSP' for people with ID in general. While some excerpts are presented below one might consider the following list of themes derived from participant responses as another way of considering the experience and perspective of these DSPs. Collectively, participants related that a 'good DSP' in this field would need to be caring and willing to act while remaining non-judgmental, open minded, respectful, and patient with good ethics, honesty, and a ready-for-anything attitude that includes sexuality as a right, ability to teach, teamwork, and a long

term view tempered by humor and personal coping mechanisms, all while not seeing the work as 'just a job'. As participants tended to speak about these concepts in longer, narrative-like groupings I have presented them as such rather than with short snippets divided by commonality. Specific participant thoughts on what might be added to this list when supporting people with ID and pSCB are presented after this initial portion regarding DSP work in general.

Several participants put particular emphasis on the quality of 'patience' before moving on to other aspects. As one participant stated,

Patience. Patience and understanding. It's really short and simple but patience and understanding and you learn a lot of it being in this field…Because you are dealing with people who are going off, you're dealing with people who can't understand stuff, you're dealing with people who can't tell you what they want and you have to be very very patient to try and understand what is going on. Patience.

This was similar to another participant's statement who went on to talk about qualities of communication, understanding, and teaching:

Patience. That's the biggest one…If you don't have patience, you don't have any business being in this field. [and] *They* [good DSPs] *are communicative. They communicate with others. They talk about things. They're able to talk with the individual and not treat them like 'Hi. You are just there'. That's a good staff. I don't think you need to be active, like up in their grill, like 'Hey, hi I'm in your face all the time [laughs]. There's a fine balance…To understand the balance of their needs I guess. They should be understanding of the person they are working with. The challenges. And what they need advocacy with too. Like if they say they need to do*

something – help them figure it out. It's not that hard. Helping the guys pick up the phone at the appropriate time and saying 'hey, do you want to hang out?' Figuring out how to make plans. They all need help with that

A different participant reflected further regarding the concept of patience as it relates to his work:

P: Patience, open mindedness, willing to teach. God, patience is a big one. And the open mindedness is a big one. Um, being able to separate your own feelings and own beliefs. Being able to just put yourself out there for someone else and basically just serve them and teach them for the greater good of themselves and the community around them.

I: And so what is it about patience? What kind of patience?

P: Oh my god, well, you have to get used to the fact that you are not ever going to see immediate results about anything. Ever. Ever. You never will. It will take you years and years and years and years of going and going and going. Same behaviors. Same days. Yesterday can be just like the day before just like today, just like tomorrow. A lot of repeating yourself. You deal with the verbal abuse. You deal with the physical abuse. You deal with everything else in between. You deal with the team members. You deal with other direct care staff. You deal with the public. Just patience all around. Shit. That's what I believe is one of my best qualities in working with these individuals is just taking a step back. Or, if you have a really rough day – being able to just suck it all in and just start over. Not an easy thing to do. I've seen many staff come and go because they couldn't handle it. I've seen many staff burn out because they've stuck around thinking they could and I've seen instances where these direct

care should not have ever been with these individuals in the first place. Patience is

huge.

For another participant, the willingness to pay attention and take action were primary:

You have to be willing to work with the individual. You can't just be ignoring them

because that's actually where the problem stems from. Whether you're terrified or

not, that's what your job should be – not the TV, not your phone. What your job

should be is 'what is that person doing'. Like on shift, like I told you, I'm in the

middle and I'm always focusing on what they are doing because that's my job. Not

talking on my phone in the backyard or watching TV or reading a book. It's "I'm

here to spend time with you so what do you want to do today?" Maybe looking at it

from a different perspective that "I'm here to make cash" because if you're here to

get a paycheck, that's probably not a very good job for you. Not only is it emotionally

draining and stressful, um, your job is to be there for that person and if you only want

to be there for the paycheck you're probably not going to be there for that person and

it's just not the job for you.

Similarly, another participant stated,

I think that a really good support staff is somebody who really legitimately cares

about that person. And not just that person but about that person's well being.

Somebody who is not 'just there'. Somebody who cares about the type of, the line of

work that we do because not everybody can do it. And if you can't do it then you have

no business being there because you are hurting the person more than helping them. I

think a good direct support staff is somebody who pays attention to the client. Who is

focused on the client. Isn't just a warm body.

Likewise, another participant reflected,

> *I think it's someone who wants to be there. Who wants to be able to help somebody*
>
> *change their life. Somebody who wants to help someone get on the right track and see*
>
> *things happen for other people. That's what it is right there.*

Lastly, a further participant described some of the balancing that may be part of this work.

Or, as he stated,

> *They've got to be kind hearted. A good work background. Good ethics. A good heart.*
>
> *They have to know when to be firm and not go over the line. Not to abuse or anything.*
>
> *Because that line can very easily be crossed if you're not paying attention…Between*
>
> *being firm and being abusive. So you've got to put that into perspective. You've got to*
>
> *be firm but respectful. Big hearted, firm, respectful and a good, just good ethics.*

Specific considerations when supporting people with ID and pSCB. In certain

instances participants spoke about additional qualities they felt necessary to be a 'good DSP'

for a person with ID and pSCB specifically. Similar to parts of the above, one participant

replied, "*The desire to want to teach them, want to help them learn that there's another way*

of doing things. Something to get what you're looking for. The passion". A different

participant stated that in order to be a 'good DSPs' in these situations one should "*Put your*

own shit aside and work with this person and what this person is trying to do. You have to

put all your biases and all that stuff aside. And you have to focus on that person. Another

participant stated,

> *I think that it, it becomes a little heightened with the sexually challenging behavior in*
>
> *that you have to be the kind of person who is comfortable being firm and saying, well,*
>
> *you have to be a lot clearer in saying what boundaries are there in some cases. And*

you have to be the kind of person who is comfortable talking about things like that. I think you have to be the kind of person who's not easily embarrassed and really willing to defuse that type of situation. You really have to be comfortable telling people 'Ok, I understand that this is what you were doing' and you have to be comfortable addressing the fact that, that, these are very basic human needs…[and] I think it's really important to be able to be, to make a distinction between work and home because otherwise you might take a lot of it home with you.

A final participant found an important aspect to include,

Being comfortable with your own sexuality because a lot of things might be said or seen that you totally don't agree with and you might and well we know if you are upset and have to make a judgment call the things might not work out in a good way. You have to know yourself as a person and as staff. Once you are able to do that then you are able to give the positive reinforcement instead of things coming out worse.

Considering the intensity and variation of the conditions, actions/interactions, and consequences described above in conjunction with the myriad of skills and attitudes necessary for success according to these DSPs, it is logical to ponder the reasons these individuals have remained dedicated and engaged in their combined 127.6 years of service.

Why Stay in this Work?

Finally, all participants were asked to respond to queries "Why stay in this work?' or 'What keeps you in this work?' Connected to the 'Best Parts of the Job' in an earlier section, this topic was also aligned in participant statements with a sense of creating relationships and seeing/being part of growth in individual's lives.

To make a positive difference. Overwhelmingly, participants spoke about making a difference in peoples' lives, helping, and creating meaning with people with ID. For one participant, this sense of seeing and effecting change was connected to helping people with ID find jobs and gain a variety of skills:

> *I stay in it because it's meaningful to me. With employment in particular it's meaningful to me to see how happy, something so many people take for granted, but how happy people can be to even just get a fast food job when nobody would even consider hiring for them for it before. But it's also you know, just teaching people life sills is very meaningful to me. Very rarely do I solely just job coach or just take them on an outing, there's like millions of little opportunities every day to reinforce a good life skill that might get this person further down the road.*

For another participant, the quality was initially more elusive but developed as she considered and spoke on the topic:

> *I don't really know. I don't really know. I know that I've been doing it for ten years and you know there is a fear about going outside and doing something else and this is what I've known. Um, but I think it's, if you can at least make some small change in somebody's life - then your life is great. And for me, I'm affecting at least nine people because I have nine clients and trying to make their lives better. Trying to help them make their lives better.*

A further participant implied that the benefits of this close work might run both ways as she stated,

> *I like working with them. I like working with people with disabilities. I get something out of it that some people don't. Some people are like "this is my job…" but me, I*

enjoy spending time with these people. And it's not like I'm looking at it like "Oh, I like people with intellectual disabilities" it's more like I build a relationship with that individual and I am invested in seeing them succeed. So, I invest time in spending time with them and doing things that are going to help them.

Similarly, another participant reflected, "*I think at the end of the day I feel emotionally rewarded, socially rewarded in a sense. Like I've done something to help someone else.* Another participant described the gravitational pull of relationships with individuals as a key part of what keeps him in the position of providing direct support:

I've actually found and actually believe that I am good at what I do. And I like it. I think I stated before that I think there is a lot of abuse and neglect that happens. Just what I believe. Not anything that I actually know. But it makes me feel better knowing that I'm in the role and not somebody else. I've worked with the same individuals for 10 plus years. I've seen a lot of progress made in some individuals. I've seen a lot of attachments that I did not want to be that person that got close to somebody and then left them. Because I know a lot of these people have dealt with that. I went to school, I went to college, I graduated and even started a job in a hospital doing something completely different...And I still, even going to school, even graduating, even starting another full time job – I never left this field or this agency. I cut myself down to PRN and then I went back to part-time because there are certain individuals, probably 2 or 3 specific ones, I just did not want to leave. I just did not want to remove myself from their lives. And I didn't. Now all the sudden I don't even work in a hospital anymore. I don't even see those people. I'm full time back to this craziness that is this field.

The aspect of making a difference was further reflected by another participant who stated,

I feel like I am making a difference. I feel like – and I didn't realize I would be this

passionate about it – I feel like I make a difference every single day. I feel like if I'm

not going to work with them – would they still have a job? If I didn't tell them not to

do that – would they still be here? I have a client who – if he doesn't work, he gets

super depressed. That's his life is his job. He works 4 days a week, 4 hours a day and

he's been there 13 years, that's what he's know for. And if I wasn't there, what would

happen? I feel like they are being a contributing member of society partly because of

me. I'm there to help them.

Progress toward increased agency and autonomy was a key factor of the continued draw of

the work for a different participant who said,

The big picture of seeing them succeed at something. You always want to see them

succeed at doing something on their own. That's my big picture. To see them get out

of this company. Be on their own. Have a job. Be able to pay a bill. Be able to live

without someone over their back all the time. That's the big picture. That's what I

want to see. That's what keeps me going.

Being present and engaged in support of meaningful lives for people with ID was also

reported by another participant who stated,

I really enjoy it. I love seeing the happiness when they are having a good day and

they get to do things that they weren't able to do before because there hasn't been

staff, shortage of staff, or there were staff and they just didn't care so the clients just

sat there. So, that's the main reason I stay in this field – is just to see that…That's

what keeps my heart happy. Even on a bad day I still enjoy going to work. Even if it's

a challenging day it's like 'Ok – someone is going to do something today.' I still go

and I still enjoy it.

Creation and continuation of relationships was also noted by a participant who said,

It's pretty cool to get to know them and their personalities. To bond with them in that

way and to gain that trust because they know that you are there to help them. So I, I

think that's what brought me into the field and what's kept me in the field. It's really

a good feeling to know that you made a difference in someone's life.

For another participant, the caring aspect of the work as a DSP was seen as a good fit with

her general personality: "*Obviously there must be some reward to it or I wouldn't keep doing*

it. It's just comfortable. This work feels comfortable. I am a caretaker at heart, a giver, so

this kind of fits in that realm". This was reiterated by a final participant who reflected, "*I just*

like to help people. Like I said before we got started – I did the group home shuffle myself. I

can understand what it's like a lot more than some staff that might not have been put through

the same thing".

It's not the money. The aspect of pay was raised by several participants in response

to this line of inquiry. For some, it was used as a humorous introduction to their wider

response. For example, two participants initially and identically replied, "*It's not the money*

[laughs]. That's for sure". and, *"It's not the money. That's for sure". [laughs].* . According

to a different participant, *"It's definitely not a job for everybody. The turnover rate is really*

high. The pay's not great". From a different perspective, a further participant related,

You can't be there just for the check. Those make the worst staff. The ones just there

for the check, I tell them 'If you think you're going to get rich doing this kind of work

then you are in the wrong field because you are not going to get rich. If you're in it

just for the check – you need to go work at McDonalds – probably make a little bit

more'. It's not about the money. I mean you can pay bills and stuff granted but, it's

not about the money when you're working with people.

A final participant firmly stated,

You can't expect people to do some of the stuff that we do and put them in positions of

direct care when you pay them shit. It's, "I'm not doing that, nope, I'm not doing

that." And unfortunately with a lot our lower functioning individuals you see a lot

more, and I hate to use the word neglect because I know that's terrible, but it's 'Don't

go above and beyond or out of your way.' And, yeah, it's very frustrating. It leads to

higher turnover. There's much higher turnover in staff because you get paid more to

go and be a manager at McDonald's than for doing what we do. So, that's the reality.

And you get to clock out at the end of the day and you probably didn't get feces

thrown at you. You know?

Summary and Conclusion

In the above findings these particular DSPs gave voice to a panorama of conditions, actions/interactions, and consequences that compose their work in support of people with ID and pSCB. From the mundane to the extraordinary, the daily endeavors of the participant men and women appeared to encompass an exceedingly wide range of histories, emotions, events, decisions, and outcomes. Their described enterprises involved facets of personal perspectives integrated within the wider array of our current systems of supports for people with ID. At the crossroads of safety and empowerment, risk and rights, action and inaction, the voices of these participants present an opportunity to examine aspects of the dynamic

algebras involved when providing such specialized support. Such examinations are the focus of Chapter Six – Discussion.

CHAPTER 6 DISCUSSION

Introduction

In the previous chapter I presented the findings of the research interviews with the intent of allowing the voices of participants to be heard with minimal interpretation. In the present chapter I delve deeper into these data via exploration of an inductively driven grounded theory, comparisons to literature from other fields, and in juxtaposition with the research reviewed in Chapter Two. In addition, I examine this set of data through the lens of theory provided by Foucault and subsequent Foucaultian writers. Following these sections I provide a discussion of personal subjectivity as it related to the research process. Lastly, I present the strengths, limitations, and possible future research pathways related to this research.

Arrival at a Grounded Theory

While it may be initially difficult to surmise from this ocean of data, one may find common tides that pull across these findings as a whole. In this section I propose a possible connective undercurrent in the form of a grounded theory I refer to as 'Being Between'.

The statements of participant DSPs about their work with people with ID and pSCB referred to a series of conditions, actions/interactions, and consequences wherein these individuals maneuver amidst discordant extrinsic and intrinsic forces. It is this concept of working while being between that constitutes the grounded theory of this research. The overall theory of *Being Between* is summarized as follows: the experience of these DSPs, who support of people with ID and pSCB in community based settings, involves a nearly constant navigation of decisions, actions, and interactions related to risk and rights and bounded by sometimes competing and often directly divergent aspects of professional

requirements/duties and personal beliefs. From the physical to the philosophical, the daily to the years long, a pervasive sense of *Being Between* encompasses nearly all aspects of the work and experiences of these DSPs. In the following sections, I present examples and exploration of the different types of *Being Between* inductively derived from the statements and descriptions of participants.

Development of This Theory

As with any inductively derived set of thoughts involving such a wealth of data there were/are a myriad of possible analytical routes. Other eyes may see these data differently in whole or part. What I present here is my subjective analysis stemming from the methods used (Chapter Four) to examine the findings I presented in the previous chapter.

I developed the main code 'Between' early in the interview and coding process based upon a statement by a participant. As interviews continued and the process of constant comparison became more involved, I placed many excerpts in this general category and began to write analytic memos regarding the idea of what it might mean to 'be between'. During this reflective process and further passes of coding I began to subdivide the main code into a series of 'child codes' (the Dedoose terminology) in attempt to further delineate the processes and dimensions contained within. This resulted in 32 child codes for types of 'between' at the end of the coding process. Further, during later interviews, as theoretical coding was taking shape, I began to briefly explore the concept of 'between' with participants. In all cases, there was no perceived or stated resistance to this phrasing. In some cases these theory-driven prompts led to further extrapolation of concepts from participants. For example, in the following exchange that occurred in a later interview:

P: So we have these fine lines drawn for us about how we do things and how we create these relationships and how we gain trust to be able to help and to educate and then, yeah, you have somebody else who wants to be involved or tell you what you are doing is wrong or 'tell me what you learned so I can create more rules for you to implement on this individual. It's rough.

I: So it sounds like you're kind of caught in between when you're working in direct support?

P: You are caught in between. Direct support is the most thankless job that I have ever worked in my entire life. And that's fine. I deal with that. I enjoy what I do but it really is the most thankless job.

This was repeated in a similar exchange in a different interview:

P: …We are on this side 'you can't do this and this and that' but I'm on this side too where I want to say – 'Ok go do this and this and that' because I feel that everybody should experience something once in their lifetime before they die. It would be sad for my client to be 50 something years old and die and never feel how a woman feels. Never know how it is actually to hug somebody and say 'I love you' besides his family members. So, I just…

I: So it sounds almost like you are in between what you…

P: What I believe and what they believe. I believe this but I've got to do this because this is what they [management or teams] *believe. Therefore in order for me to have a job I have to do what they believe even though I believe it's wrong. I feel like we are one hundred percent wrong when it comes to that.*

Checks on this emergent theory also included discussion and draft review with a critical friend and efforts toward member checking. These processes are explicated further in Chapter Four. Throughout the above process I endeavored to remain open to all emergent/possible codes that, to me, appeared to have a theoretical quality. Some of these (e.g., Frustration; Constant Conflict) had similar attributes to the code of Between. These failed to develop, however, as during memo writing I reached points where I felt these concepts did not "explain variation as well as the main point made by the data" (Strauss & Corbin, 1998, p. 147). In other cases, I chose to subsume potential theoretical codes (e.g., Powerful and Powerless; Risk and Rights) under the concept of 'Between'. For a while the code Risk and Rights was positioned in my thoughts as the primary point of these data. I avoided wholesale commitment to this concept however, as it kept ringing with the bells of 'theory confirmation' due to the fact that risk and rights constituted main purposes of this research and played key roles in some assumptions I outlined prior to data collection. In the end, risk and rights continued to be present in the data and formulation of the overall theory but as part of a much larger continuum of events, actions and consequences that compose the overall theory as presented below. At various points in memo writing, in an attempt to be less general in nosology of concept, I named the final theoretical code 'Constantly Between' or 'Perpetually Between'. These terms were discarded, however, as there were some clear instances of spaces in these data that did not fit the absolute nature of 'constant' or 'perpetual'. I believe the final theoretical code 'Being Between' retains simplicity and coverage while imparting a sense of the experiential dynamics conveyed by participants throughout the interviews.

Late in the memo sorting process I divided the main concept of 'Being Between' into four subtypes: (a) Conditional Betweens; (b) Interpersonal Betweens; (c) Intrapersonal Betweens; and, (d) Decisional Betweens. I then assigned each of the child codes to one of these subtypes. Each subtype is presented below with the underlying 'betweens' explicated and exemplified via excerpts and discussion. The excerpts included below are not exhaustive but represent what I considered to be the best portrayal of these concepts from the available data. While no one participant expressed statements that fit into all topics discussed below, all participants voiced points of conflict and confusion about multiple aspects of their work. Again, per Strauss and Corbin (1998), "[i]n grounded theory representativeness of concepts, not of people, is crucial" (p. 9). Such representation was my aim in the following.

Conditional Betweens

These DSPs spoke about certain qualities of the general experience of the job in which there appeared to be a sense of competing feelings or perceptions. In reference to the organization of preceding sections (i.e., Conditions; Actions/Interactions; Consequences) the following may be considered the 'betweens of conditions' or 'betweens of consequences' depending on one's preference or perspective (e.g., consequences become the conditions of the ongoing work and said work results in consequences that become further conditions and so forth).

Between firm and respectful or abusive. At times, participants described attempts to find the balance between styles of support. There was a sense of a line dividing actions that were firm but effective and the potential for these actions to cross over into potential abuse. This quality was directly related by one participant who stated that a 'good DSP's' actions lie "*between being firm and being abusive. So you've got to put that into perspective.*

You've got to be firm but respectful. Big hearted, firm, respectful and a good, just good ethics". Similarly, another participant described, *"being very clear. Being very stern. I just think knowing… I don't know how to describe it. Just knowing how to act, how to be professional".* Lastly, a different participant stated that in order to be good at this job DSPs *"have to be very stern. There is no 'Ok, I'll let you do this but don't tell anybody'…I think you have to be stern. You have to be respectful towards them. And considerate".*

In essence, certain conditions or events seem to demand that DSPs find a way to address situations with an eye on being direct as tempered by an attitude of overall respect and ethics. Drawing and enacting these lines may involve an algorithm of balancing an individual's preferences for interaction within situations that can effect their or other's safety. As presented in parts of the previous chapter, DSPs may find themselves in positions wherein physical restraint may be used or a person's sexual preferences prevented due to legal or social boundaries. To put it bluntly, certain individuals with ID whom these DSPs work with have severe histories or current interest in actions that might, or have, resulted in significant harm to others or themselves. With these considerations in mind DSPs are asked to figure out, often without warning, how to handle individual moments within matrices of competing concerns. Having to 'draw a line' without 'crossing a line' constitutes the essence of this between.

Between stressful and rewarding. Participants framed overall descriptions of the daily experience as covering a spectrum of emotions. The daily events can be intense while the overall picture was one of growth and effecting positive change. In the words of one participant,

> *It's kind of stressful, to be honest. Um, well because you're like dealing with people so in general that's stressful. Um, and they're not machines, not something you can control. So, that's stressful. It also is rewarding, because you learn different things about yourself and other people.*

A different participant also captured this sense of between reward and stress as part of the daily mixture of variables when he stated,

> *Everyday is different you know? Some days are better than others just depending on the client's mood. You know if they are in a great mood, its probably going to be a great day. We're going to go out and do exciting things. There's days where they could be in a bad mood and they just take it out on you. You've kind of got to deal with it. Work with them to de-escalate their behaviors and to...get back into a better space so they can have a better day.*

Another participant also expressed a palpable sense of conflicted experience due to some external sources of stress:

> *A lot of people can't handle it. I'm cool with it. I enjoy what I do. I enjoy the relationships that I've made with the individuals I've worked with. I have lasting relationships. I can't walk by the day hab, I can't walk by another agency without 20 guys coming up and wanting to talk with me, hang out with me. It's just what I do and I feel good about that. Those are the things that make me feel good. I don't care what other people say or do. Yeah, we've got to follow plans. Yeah, we go sit in these meetings and don't fucking say anything. Like I said, you're just there. Nobody wants to hear your opinion. Nobody cares. If something goes wrong, it's all your fault. If things go great – they take the credit. Not always, but a lot of the time.*

The mixture of individual variables in the people with ID along with interactions involving other parties appear to create a kaleidoscope of emotional responses across both short and longer term phenomenologies for these participants. Times of intense gratification intermixed with episodes of taxing complexity are involved in the work of these DSPs. Riding this roller coaster of interactions and resultant emotions DSPs may find themselves in an state of ever-changing perspective that, as one participant described in different areas of the interview,

You never know how your day is going to go. This is why I love my job. Most people would hate this…[and] *It can be really, I don't even know how to explain it. Draining. It can be really draining and exhausting. Some people can be really emotionally demanding not so much like physically, so at the end of the day you can be really filled emotionally and drained.*

Between powerful and powerless. The participant DSPs described working in an overall environment wherein they are both intensely powerful and often powerless. Tasked with enacting countless aspects of individual support while working in a system of multiple hierarchies, these DSPs expressed an admixture of moments of potency punctuated with a pervasive sense of impotency. On the powerful end of the spectrum, one DSP described how he may utilize the position to enact direct interventions involving a person with ID and pSCB to "*try to get more on the safety you know? If someone is pushing themselves on somebody or what not, we get that person to safety and we start calling the team right away*". In this manner, DSPs may enact direct power over individuals with ID by placing limits on autonomy or choice including direct removal from interactions or environments and initiating a series of communications to other involved parties. Once these calls are made, a series of

recommendations or directives may be provided to the DSP. At times, these missives may be

authored by individuals with less frequent contact (e.g., agency management,

interdisciplinary team members, legal guardians) and contain instructions contrary to the

perspective of the individual working in direct support. As stated by one participant,

> *What concerns me most sometimes is, and it depends on the team, sometimes it's the*
>
> *BSC that is the issue. You know maybe they see, and this is a lot of the feedback that I*
>
> *get from direct support staff that I've worked with over the years is, 'How is*
>
> *somebody who spends once or twice a month with this individual going to tell you*
>
> *what is going to effectively support their behavior in all possible scenarios?' And you*
>
> *know, it's a good question. It's a good question…So in actuality what actually does*
>
> *happen is you have a lot of really good direct support staff in this field…who could*
>
> *contribute something really valuable information to the person's life that could*
>
> *actually effect the bottom line of you know 'What happens with this person today and*
>
> *what's going to happen with this person tomorrow?' And in actuality you have a team*
>
> *who just kind of makes a decision just based on not especially pertinent information*
>
> *or just 'Nope, this is the route that we're going to go with' and it really does not*
>
> *matter what is actually going on with this person from day to day.*

Similarly, this crossing of powers was framed by another participant in the following

manner:

> *It confuses the shit out of direct care. Because here we are on the front lines. Being*
>
> *with somebody 8, 10, 12 hours, 14 hours a day trying to gain trust, trying to make*
>
> *some kind of relationship…*[and] *you have somebody else who wants to be involved*

or tell you how what you are doing is wrong or 'Tell me what you learned so I can

create more rules for you to implement on this individual'. It's rough.

From the above excerpt it is also evident that these DSPs are also powerful in the

relationships and resultant trust they can build with people with ID – sometimes over the

course of years of daily interaction. Yet, this earned personal power appears to be mitigated

by directives that some participants felt could pose a threat to the relationship between DSPs

and people with ID. While the voice of the DSP may ring loud in the ears of people with ID,

these same voices may be silenced within the larger context of supports. As one participant

summed up regarding the power of DSPs in wider aspects of the system, "*You feel like*

you're muted". To rebalance these aspects of power another participant suggested,

I honestly think that they need to give the direct support staff more of a voice. The

teams do. Like I said, we are in front of it all. Especially the residential staff. They

are the ones who are with them the most. They need to listen. I don't know if its true

but this is what I've seen and it's almost like they think of the job coaches and the

residential staff because we don't have degrees, it's like 'Well, you really don't know

as much as I do so, we are not going to really listen to what you have to say'. When

we are the ones who are with them everyday. We're the ones telling you what is going

on and you are still telling me to do something different. It's not right.

Evidenced in the above, this participant theorized that the educational, title, or license status

of other involved parties may be seen as trump to the experiential expertise of DSPs. This

results in a 'top-down' dynamic wherein DSPs are asked to directly enact interventions,

support styles, or other actions contrary to the personal preferences or the preferences of

individuals with ID whom they feel they know best. For one participant, being between these forces creates a condition wherein,

> *You are the enemy on all fronts at all times. Sometimes. You're just the enemy. You've got to be the enemy to the team. You've got to be the bad guy to the individual. It's just one of those things you deal with. And you're the lowest paid on the rung. You're the lowest rung. You're the least paid. You don't make shit and you've got to deal with this.*

This was furthered supported in the statement of another participant who said,

> *It can be very distressing at times because you see a lot of people who've been in the system for a long time and you see a lot from other arenas of their life, their team members or other aspects of their life, you see a lot what could be perceived as rights infringement and that can be really distressing. Not being able to help in those particular scenarios.*

For a final participant this navigation of power seemed to result in a conundrum between what was desired and what could be enacted:

> *A lot of times I want to be the brave one – but I can't…I mean, a lot of the times I feel bad because I will, I will just say 'That's not my problem.' And I know that's wrong but what can you do about it? Because if you talk to the big people then you are worried about your job. You're worried that you won't have a job if you speak up…Now, if it's anything about my guys – I will stand up for them. I'll report that this and this and this is happening – 'Do not punish him, do not take away this point'. Things like that. I will do that. But besides that…'What do you want me to do? I'm staff.'*

From the above excerpts it is evident that these DSPs portray their experiences as working at the crossroads of influences often beyond their control. From the clear themes explored in the previous chapter regarding the importance of developing relationships and 'making a positive difference' it appears that these DSPs value the input and individuality of the individuals they support regardless of historical or current concerns. Their statements above, however, intone that their perspectives, in matters of decision and direction regarding human or individual rights may, at times, be akin to voices crying in the wilderness. Simultaneously powerful and powerless, these DSPs navigate moments of authority through a lens of subordination.

Between immediate and longer term. Crossing over with the above areas, participants described working in an environment of moment-to-moment decisions while keeping an eye on sometimes elusive longitudinal outcomes. The manners by which the actions of today influence a series of tomorrows were a frequent refrain in these data. According to one participant, the individuals with ID whom she supports "*are all about 'now' – they don't think of the long term. As direct support staff we have to think about the long term for them. We have to help them think about the long term*". From a different angle another participant related that sometimes intense interactions must be placed within the larger context of achieving effective change:

> *That can be a real stressor when that's all you're dealing with – getting hit and getting punched. Then you've got to learn strategies to work around that. How to figure it out. How it can be a better environment for everyone involved. Sometimes that takes time.*

For different participant, the mixture of long term history and short term responsibilities was considered in the context of how past events are conveyed:

> *Unfortunately sometimes in this field the paperwork is a little outdated. People have grown since then. I always notice that it's always the worst things in the book that they note so you can always be ready. But it's been like 6 years since they pulled down their pants and started masturbating in front of hundreds of people. But, it's possible.*

Likewise, a further participant said,

> *I file that historical information away so that I'm aware 'Ok this person has the ability to do this – x, y, and z' but it's kind of far removed. We're here in the moment, we're here in the present day and it's not something I keep actively at the forefront of my mind at all times when they're with me it's more just a general filing I keep back here* [motions to back of head] *where 'ok, if I were to see them exhibit unusual things' then my mind will float a little more to the forefront of 'we need to watch this or let somebody know'.*

Lastly, a different participant captured a gestalt of this mixture between past, present, and future saying, "*You have to get used to the fact that you are not ever going to see immediate results about anything. Ever. Ever. You never will. It will take you years and years and years and years of going and going and going*".

The concept of between immediate and longer term was captured by these participants as they spoke both about their cognitive experiences in dealing with the longitudinal stressors of the job as well as what some saw as necessary components of providing effective support in individual instances. Similar to being between stressful and

rewarding as examined above, it appears that these DSPs contend with moments of intensity that must be informed by a perspective of patience. This 'seeing the forest for the trees' requires constant refocusing between what has happened, what is happening, and what might happen tomorrow or ten years down the line.

Between seeing potential to help and not. Participants also reflected on times they may have felt that they are able to assist in comparison to other times they felt they were not. While intertwined, this differs slightly from preceding sections in that the focus in this 'between' resides in a quality of hope. As presented in the preceding chapter, these DSPs collectively expressed that seeing change for the better in a person's life was the best part of the work and what keeps them going. Conversely, feeling unable to help was framed as one of the worst aspects. Without the hope for positive change, a keystone of the experience for these DSPs may be lost. As one participant stated, this move between seeing and not seeing potentials for effect developed over time to encompass a wider (though not complete) array of individual histories:

> *Some of those stories I heard in the beginning – I hate to say it but I was judging the person. I could see how you would be like 'This person is never going to change. That's disgusting. How could they do that?' But then you get to know the person. You get to know that that is not really who they are. And yeah, for some of them – that is who they really are and that's why they can't be in the community and if that's the case then they shouldn't be in the community because they are a risk of harm to themselves and to others. But, for the most part, that does not define who they are. They have these desires. They've done these things and it's your job to put that aside and just like – when I'm at work with them I'm not thinking about that. When I'm at*

work with them I'm thinking about their task at hand. How to keep them out a

situation if something arose. Helping them feel like they are doing something, like

they are contributing to this community. And they are.

Another participant relayed that a significant conflict in this line of work was not aggressive events or other discrete behaviors requiring intervention but instead, "*[c]hallenging to me is constantly, constantly, constantly, trying to help somebody who is not willing to be helped or is not willing to accept the help or just does not show any sign at all of being helped. That's very challenging".* Further, in the excerpt below, another participant connected these feelings of knowing what might help but being unable to enact or complete to the powerful/powerless dynamics discussed above:

And I think that sometimes that's why what happens on the team becomes really

problematic. There's a lot of them who focus on things that really aren't super

relevant to helping that person be successful today. Um, and you know unfortunately

when you are in the direct support role your job is to help that person be successful

today. And tomorrow it'll be the same thing you know. And I think that's where a real

divide comes in sometimes between direct support staff and teams. Teams get kind of

wrapped up in things that, it's not that they're not important, but they are not super

relevant when you compare them to what's actually going on with that individual.

In this statement one can see aspects of many of the above types of between. This participant seems to know what might be helpful yet, perhaps due to issues of power, is unable to get this through to the team. This participant intoned this perspective through the lens of short and longer term considerations (i.e., 'today and tomorrow'). The 'divide' between DSPs and

teams can be considered a source of stress while the outcome of seeing the individual

succeed (as defined by this participant) would, presumably be rewarding.

In summary, the quality of being experientially between extends to conditions and

actions/interactions of the work as described by these DSPs. From individual relationships to

hierarchies of sometimes conflicting parties participants statements reflected a sense of being

caught in the middle. As examined below, these balances also extend to participants'

alignments within their own selves.

Intrapersonal Betweens

At times the participants described internal conflicts of thought or action. This

included ideas, concepts, or schemas about the nature of their relationships with people with

ID as well as personal alignment with certain assigned duties. Again, specific aspects

described below can be seen as involving aspects of the conditions, actions/interactions and

consequences encountered by these DSPs when working with people with ID and pSCB.

Between roles. Participants spoke about qualities of their work connected to the

nature of relationships developed with the people whom they support. At varying times

participants used metaphors of parenting, friendship, family, and other roles that were all

couched within an overarching need to establish or keep 'boundaries'. As these were often

framed as internal schemas regarding the dynamics of relationship I have included them here

rather than under 'Interpersonally Between' below.

Considering the swirl of potential roles played by DSPs one participant reflected,

I'm not there to be their best friend you know? It's like being a parent – you've got to

-Well, it's not like being a parent. It can be but I don't want to – you have to, to

establish boundaries in a way that they know you care about them and are there to

care for them.

A similar stumbling over how to frame the role was expressed by another participant who stated,

Like [individual's name] *is getting to the point where he's getting ready to potentially*

have sex with his girlfriend and to me it's like 'No! he can't, he can't have sex with

his girlfriend! No." Because, you know, he's like my kid [laughs]. But I have to put

that aside because like 'No. Why can't he? Because I don't want him to?' No. I can't

do that…You've got to put your own personal stuff aside and let your, not child, but

the client you've developed a relationship with, go have sex. And you're going 'I'm

going to try and not freak out at this moment'. Yeah.

Likewise, in the following exchange, a different participant appears somewhat between the role of parent and not:

P: It's like keeping an eye on your own kids. You need to show them right from

wrong.

I: How do you make those calls?

P: You know, they're grown adults and you talk to them like they're an adult and just

explain to them the consequences.

A further participant explained some of the difficulty with these navigations of perspective:

I know we try really hard to make the distinction to people 'No we're staff and this is

the nature of the relationship' and you do make that distinction but then at the same

time these are people who, in a lot of cases, you are the only person they see on a

regular basis. So, you know they do become a little more attached I think. And you

know it does go both ways. I've seen it go both ways with direct support staff. Where some direct support staff have become very attached to them as well. And that can become very problematic on a typical day when it's making sure that people really know where the boundary line is between. And I think that's really challenging for everybody on a day to day basis where the people that you know the best and the people you work with, it's something that you really have to monitor as far as making sure that you are keeping the boundary line clear but also making it where they can develop a good rapport with you and feel comfortable with you and maybe even take guidance from you…I know they don't like us to look at it in these terms but it's really like an extended family. You know? You have your up days and your down days and you develop that rapport of being able to work with people really well and also say 'You know, I'm sorry. I'm really having an off day today. I didn't mean to snap at you' It's kind of like, like family [laughs].*

Or, as explained by another participant,

They are people and they have personalities that you get attached to. Quirks, senses of humor and all that. They just have some issues that aren't always easy to deal with…It's how you approach your work. You can't care for somebody and not become personally attached in your head. And I think some days that's where, when you're tired and you've worked so many hours in a row it's hard not to get attached and then take things personally.

This same participant also expressed the confusion of other perceived roles with an individual he supports stating,

It's kind of a mystery why he's not in jail I mean I think if he had certain

competencies he would be in jail but just, I mean he's not in jail so someone decided

that that's not the issue. So then why is he still under so much structure that he may

as well be in jail? And that's not something where I feel like I'm helping somebody

per se. I feel like I'm the jailer or he's not where he's supposed to be.

Another participant added to this complexity of potential roles embedded within the work in

the following exchange:

P: You wear many hats…

I: What are all those hats you wear?

P: Counseling. Mentoring. Nurse. Big brother if you will – some will like to call you

mom, dad, or brother – which is totally inappropriate as far as me just being staff but

it is kind of hard not to get close to some of the guys.

A final excerpt captures the above in a brief but potent fashion: *"It's your job to play almost*

every single role. To keep people safe."

From the above it is evident that these DSPs expressed a wide swath of ways they

conceptualize the roles they may play in the lives of people with ID and pSCB. In many of

these statements the comparison was immediately contradicted or couched in qualifying

terms as the essence of the relationship often remained elusive to language or direct

metaphor. Perhaps this is related to the exceedingly wide array of concrete and abstract

duties that are involved in supporting the daily lives of people with sometimes complex

support needs. Perhaps it is related to the intimate environments and proximities involved in

this work. Perhaps it is related to the long term contact shared between these DSPs and the

people whom they support. Regardless of the impetus, the consequence is one of caring,

coupled with confusion. I am not implying that these DSPs are 'confused' in a pejorative sense. Instead, that *despite* confusion in how to refer to or describe the roles they play, the caring comes through loud and clear. In this aspect, there is no 'between' in the above. There can be no argument made for 'Between Caring and Not' in the voices of these men and women.

Between duties and self. At times, participants described incidents or parts of the job as being somewhat contrary to personal beliefs or opinions. In one example of this internal friction a participant stated,

> *P: Some of the hardest parts are learning the histories of some of the individuals I work with. That's really rough. Getting past things that not only have happened to them but trying to look past things that they have done and just trying to keep a regular relationship with some people just knowing what you know.*
>
> *I: What specifically is kind of an example of that?*
>
> *P: Specifically an example of that is maybe abuse that they have put somebody else through. Physical or emotional or sexually. Specifically stuff with children is hard. That's probably the hardest. And having to deal with that and know all this and learn all this and know what you are supposed to do with this individual and still come in and smile and carry on your day and go about like things aren't there. Kind of trying to ignore that stuff and help the individual move past whether they are working on their issues or have been working on their issues or if we're just basically preventing them from doing anything again.*

This quality of separating personal beliefs or emotional reactions from the duties of the job was reflected by another participant who recommended,

> *Put your own, put your own shit aside and work with this person and what this person is trying to do. You have to put all your biases and all that stuff aside. And you have to focus on that person.*

The difficulties in this approach were outlined by a different participant in the following exchange:

> *I: So you said that it sort of can be hard to keep your own logic out of it.*
>
> *P: Well, you're tempted because you have your own point of view because that's how we are as human beings. We try to be objective but no one is 100 percent objective. I know that for my own moral compass and what I've been taught, doesn't always work with what our guys need or have experience with in their lives. The way that some of our guys act, they can be seen as threats in the community in certain ways but they're not…they've been through a lot. They are not animals or monsters. They're people who have really bad coping mechanisms and we're helping them throughout the years I guess.*

The above excerpts suggest that when working with individuals who have particular histories (i.e., nonconsensual sexual contact with others including children) DSPs may encounter a level of ongoing intrapersonal distress. This, in turn, seems related to attempts to ignore or minimize the internal voices of dissent and concentrate on the tasks at hand – focus, work, support, help, repeat. As one participant put it,

> *You've kind of got to come out of your own self. Which, I think staff kind of grow exponentially if they allow themselves to. They are able to find better coping mechanisms for themselves in the long run. But you've really got to filter all the other stuff out you know? [laughs]*

Another source of potential conflict may stem from the definition of what is included under the umbrella of the term 'sexually challenging'. As related in the previous chapter, when asked about what types of pSCB they have encountered, many participants included discussion of people with ID engaging in dating, intimate relationships and/or intercourse. To reiterate these findings, it appeared that it was not the intimate or sexual acts *themselves* that participants found challenging. Rather, it was the fact that various conditions of the work (e.g., others' limits on these activities) *cause* dating, intimate relationships, and/or sexual intercourse to *become* challenging for DSPs to support. Specifically, when general sexuality (e.g., involving consensual or clearly legal actions) is included as a type of 'challenge' for an individual or a team, participants' ability to remain objective was further compromised:

> *I think it's the definitions of sexually challenging. I think that, to me, if they're masturbating in their room, they're doing it in an appropriate place? I don't want anything to do with it. Sorry. I will follow your plan if you have it written in there but I can get a little wiggle room if I read it, 'over-read' it, you know like 'Well, that doesn't technically cover that situation, so thanks, bye'. I don't think you can regulate too hard in peoples lives without creating some of the issues that are problems.*

As related by a further participant, some directives or assigned limits seemed to result in less emotional separation of self than others:

> *Ultimately, if you are in that moment, like if you are in that moment and when you are working with that person right? If something happens and the team decides the consequence but my job is to try to make sure that that thing doesn't happen. That's my job. So, the team is not involved in that. That is me following the plan, trying to do my best, to make sure that incident doesn't happen. Dating is a little different. That's*

a different scenario. Obviously if they can't even see each other, that incident isn't going to happen. When those two staff do let them see each other it's going to suck but you've got to do your best and be like "Ok, well, the team decided – you get one kiss." [laughs] *It's really sad but it is kind of funny because it's like "Oh my god, you guys are ridiculous".*

As evidenced in the above excerpt, topics of general dating and sexuality may highlight this divide between duties and self. Another participant expressed similar distaste:

P: They [the team] *said 'Oh, we're trying to find him a girlfriend'. Yeah – when he gets that girlfriend – then what? Then what? Because they're still going to be like 'you can't hug, you can't kiss, you can't hold hands'. There's a whole lot of 'can not dos'. I've noticed that a lot of companies, I haven't seen a company yet that's all for 'Teach the clients how to have safe sex', 'Let them have consent'. I have not heard of one company that will do that. You've got the clients who will get out of the company to be able to do what they want to do. But, while they are at the company – you can forget it. You're going to 'palm it' the whole time.*

I: So it sounds almost like you are in between what you

P: What I believe and what they believe. I believe this but I've got to do this because this is what they [the management; the team] *believe. Therefore, in order for me to have a job, I have to do what they believe even though I believe it's wrong. I feel like we are 100% wrong when it comes to that. As far as anything else – we might not be wrong about that. But when it comes to human contact I think we are wrong. I think we are wrong. I think we should give people a choice, a chance to do what we do every day. You know, go to the club, have fun, have a drink. I'm not saying get drunk*

but have a drink. See what liquor tastes like. Something. Not to be in the house all day

long. The same thing day in and out. They come home. They play games. They go to

their room and do whatever they do. They've got computers and stuff like that. One,

he had a computer and he downloaded some porn. So what. Why does he have to be

punished for his porn? He got punished. It's like 'What!?' I've got porn in my house.

I have books and movies and everything. No body is telling me I can't watch them.

Why do we get to tell him that he can't watch them. He's not a rapist. He's not going

to act out on anything. So, why does he have to be punished? Why do we have to take

his stuff off his computer because he wants to look at a piece of ass? Is that right? No,

it's not right. I answered my own question. [laughs] *No, it's not right.*

As a consequence of these dilemmas, a final participant stated,

I feel like we take way too much control over them doing things that adults should do.

You know, um, because the bottom line is, if two people are adults and they choose to

enter into a relationship with each other whether its romantic, whether it's sexual,

whatever it is, if nobody is being hurt in the process then that's a basic right they

should have to pursue. You know, and in a lot of cases I feel like it isn't. I think we

actually elevate peoples' risk by taking those rights away.

In the previous three excerpts DSPs described conditions of job duties (i.e., follow

plans that may place limits on sexuality or relationships) that result in required

actions/interactions with people with ID (i.e., enact behavioral limits or punish) with the

consequence of the individual's sexuality being minimized while compromising participants'

sense of right and wrong, ethical and unethical. No participants voiced full agreement with

the limits sometimes placed on consensual sexual relationships for people with ID. It was

further speculated by participants that these directed interventions may result in an individual acting in perhaps more intense or frequent challenging manners. Specifically, certain participants described how the attempts to prevent or respond to pSCB may actually result in pSCB. In other words, the consequence meant to eliminate a particular behavior, may beget the behavior. This potential for reciprocal actions and consequences was best represented in the statements: "*I don't think you can regulate too hard in peoples lives without creating some of the issues that are problems*" and *"I think we actually elevate peoples' risk by taking those rights away".* While plans for prevention and consequence may be decided around tables days, weeks, or months distant from particular incidents, DSPs are at the crux of these forces – required to repeatedly act (or enforce), in possibly counterproductive ways, that are contrary to personal opinion (and perhaps human rights). This too, is not a fleeting 'between' but one that may involve multiple situations, with multiple individuals, over the course of years.

Between work and home. Participants also described how the factors described above continue to resonate once the day's duties are complete. According to one participant, "*I think it's really important to be able to be, to make a distinction between work and home because otherwise you might take a lot of it home with you".* Another participant echoed these efforts to divide the personal and professional stating,

> *I try to leave the job at the job and go home and unwind. Usually when I leave, I try not to think about them until I go back. Then I go back and I'm right there at their side. When I get back to work I'm like 'How come this is happening to them and this is being done to them?' But, it is what it is. When it comes to the guys sometimes I'm just a big old crybaby because I think they get treated wrong sometimes.*

Reciprocally, participants also described how external or personal concerns may intrude into job duties. For one participant this was framed as cut and dry: "*You leave your problems at the door when you go in there because you've got a whole other set of problems to deal with. The group home's problems. Everything that goes on from day to day*". Another participant was equivocal in this area as she stated, "*You're not supposed to bring your outside stuff to work. But you do*".

As shifts end DSPs transition back into private worlds replete with the responsibilities and conflicts common to all. The burdens of the work day (or years) may encroach into personal time and spaces. Conversely, concerns of home must be left at home or risk trespass into the already conflicted duties of work.

Interpersonal Betweens

Participants frequently described interactions with people with ID and pSCB as well as interactions with others in the field or general community. These interactions too contain qualities of being in the middle. At times these 'betweens' were described as literal and physical. At other points, they were framed in emotional or relational terms and examples.

Physically between. As described by these DSPs, certain circumstances involving people with ID and pSCB require direct physical action(s) that place their bodies between. For example, one participant described how "*you've got to get into their line of vision and talk to them about something else*" when individuals with certain histories of pSCB are judged to be inappropriately staring at others in the community. Using a term (i.e., body block) defined in the previous chapter, another participant described instances wherein,

I'll use myself to body block. If we are in the mall and I feel like they are going

towards someone to try to touch them inappropriately – I'll put myself in between the

guy or the girl and who ever it is in the community that they are targeting.

According to another participant, these types of actions may be encouraged by outside

parties: *"some of the plans do include blocking where you stand in front of the person to*

block them or redirect inappropriate looking". In the words of a different participant, *"I've*

never been more of a door in my life than I have now in this field. [laughs] *Like, 'Hello, you*

can't look through me. I am a wall'".

Other aspects of the work with people with ID and pSCB may also include physical

intervention. For example, a participant recalled "*a gentleman…who was very sneaky about*

this... He would attempt to take advantage of people in transport vans. You know, try to take

his hand and stick it down the pants, lower functioning people than him usually". In response

to these events this participant described:

So, of course to separate the two individuals to secure the safety of the other

individual who was considerably lower functioning than him and probably had no

idea what he was really doing…Separate them. Take him aside, and he became really

angry and punched a radio if I remember right.

Extending this 'physical between' to larger domains of the work, a further participant

reported,

I've prevented a guy from shoving a piece of broken glass in his throat. Many, many

times they have tried to hurt themselves. I've worked in situations where two

individuals were trying to constantly trying to hurt each other. Constantly breaking

up fights.

As evidenced in these examples, the quality of between for these DSPs includes not just emotional or moral conundrums but direct corporeal actions to address or prevent situations of perceived risk or enacted harm. Placing one's body between, in situations of potential peril, appears to be a common aspect of this work.

Between teams and people with ID. As examined in the interpersonal betweens above, participants related experiences wherein they felt caught in the middle of team decisions regarding interactions with the individuals with ID whom they directly support. Interdisciplinary teams, as described in Chapter Four, may be composed of a multitude of various players (i.e., Guardian, Case Manager, Behavior Support Consultant, Occupational Therapist, Physical Therapist, Speech-Language Pathologist, and managers of other services such as Supported Employment or Customized Community Support) both internal and external to the agencies by which DSPs are employed. These team members may compile and direct plans of action across a range of goals intended to be person-centered for the individual with ID whom they are all ostensibly there to support. The job of the DSP is to enact these plans. As exemplified below, participants often expressed that they felt the goals/plans set by teams are, at times, in conflict with what the person with ID might actually want or with what they, as DSPs, understand as being most effective for that person. Again, as related in a preceding section, the dynamic of powerful/powerless is interwoven in within these conflicts.

According to one participant, "*There's team member biases all over the place. The team member's feelings are involved, their own personal view of how this person should be is in there and they don't put it aside and focus on the individual and how they want to live.*" Similarly, another participant stated, *"There are a lot of teams that are just really resistant to*

the idea that 'Hey, maybe these people [with ID] *could make healthy decisions themselves instead of us making it for them.'* After years of observing this type of pattern, a further participant remarked,

> *P: You see people in a different light especially when you're in team meetings and talking about it and you're going 'Ok this is your opinion, and this is what you believe is happening but this is not what they want.' They are sitting there screaming that they want to have sex and they* [the team] *are going "Well, why don't we prolong this until after they do the relationship 3 tier class" which is going to take them like a year and a half to do or they are just pushing it longer and longer and longer so they don't have to deal with it. So yeah, it's changed. My perception has changed. It's opened my eyes to see how fucked up other people are.*
>
> *I: People…*
>
> *P: In terms of people putting their own views on what other people want. You actually get to see it. It's fucking weird. It's weird.*

Capturing this interposition in brief, another participant stated that teams *"tell us what we can do but it's what we can't do"*.

Another participant described how this type of 'between' might translate into interactions with people with ID whom they support. Specifically, this participant spoke about instances wherein a person she supports complains about team decisions:

> *There's really nothing I can say. I can't say 'well hot damn this is wrong!' because then it's like 'you are giving your opinion. You can't give your opinion.' So, I don't know what to say to him. All I say is 'wow'. 'Wow' to every thing he tells me. 'Wow'. Then I'll think about it and be like 'I should not say what I was going to say'* [laughs]

and I'll just say 'Wow' [laughs]. *Sometimes I want to say 'Get mad! Tell them they*

are dragging their feet!'

A final participant related what the experience may be like for the people with ID in these

situations:

I know if it was me, I'd be going behind everyone's back. I'd be the worst client in the

world. I promise you that. Tearing shit up. And then it trains them not to trust. We ask

these guys to trust. "I will help you. Tell me your feelings. I will help you. Trust me

with this stuff." Yeah, trust me and then I'm going to go tell 15 other people what you

just told me about what turns you on. You know what I mean? Like, it's bullshit.

In these team dynamics DSPs are required to report information about actions and

interactions of individuals with ID. As a consequence of inequitable positions of power (for

both DSPs and people with ID) participants related that they are often unable or unwilling to

give feedback or confront conflicting directives. Nevertheless, as described by these

participants, DSPs must then return to their daily duties including execution of plans that

may cause intense feelings or reactions in the people with ID whom they support. While

teams may decide and direct, DSPs must enact and thus, may be seen as the agents of the

intervention/limitation by people receiving support. As these DSPs' ability to personally

advocate has been compromised (e.g., *"You feel like you're muted."*) there is a consequent

inability to advocate *with* people with ID.

Between other DSPs and people with ID. Men and women working as DSPs work

alongside each other in support of people with ID in various situations. Participants described

instances involving conflict or aspects of being between the actions/reactions of other DSPs

and the individuals receiving supports. According to one participant, *"it's sad to say but I've*

seen some really really bad direct support staff. They are there for the paycheck. They are a warm body and they really don't care what happens to a client". Another participant described differing scenarios involving other DSPs *"who come in and they want to baby the clients. It's like, 'That's not our job to baby them. We are supposed to get them ready to be able to do something on their own'".* A further participant expressed frustration with the presumed actions of other DSPs:

> *I've worked in the field forever and when I'm doing my job, I'm going to tell you, I don't think a lot of staff are doing that and that's my opinion because I'm hearing of these incidents and I'm like 'What were you doing?' And it's funny because they are like 'You don't know what you're talking about' and I'm like* [laughs] *'I do. I used to work in that house and it's funny because there was two of you* [staff] *at that time and it used to be just me and like three people* [receiving supports]'. *Like when they are making dinner – where are you? Because I'd be in there and I can't cook* [laughs] *and I'd be like 'Ok guys we are going to figure this out together, we're all going to burn this together'* [laughs]. *And they'd be eating dinner and I'd be helping them with their chores so I'm like 'What are you doing that these things are happening? I thought that's what our job is. You're at that house but are you at the house?'*

The above was furthered by another participant who stated that *"working with staff that aren't following the plans and are reacting in anger",* was a source of conflict in the daily work. Another participant related a specific scenario connected to above which involved walking in on a young woman who was masturbating:

> *Well the staff freaked out that was working with her. Made a big deal of it like 'That's dirty, that's wrong' But it's like – that's human nature. She's doing it in her own*

bedroom. She's in private. She's not out there for the whole world to see. 'Give her

some space man! That's her room. Give her some time. She'll come out when she's

ready. We'll take care of her, give her a shower' you know?'

Speaking in more general terms a final participant stated,

I believe there is probably a lot of stuff that goes down that we don't know about that

shouldn't. I'm sure there is abuse. I'm sure oftentimes there is neglect. I understand

how somebody might look away, turn away, walk away. Not know how to handle

themselves in a certain situation or maybe just not want to deal with it.

Adding to the situations of between in previous sections, the above excerpts introduce another dimension to this dynamic. As these DSPs negotiate internal conundrums and external conflicts of team processes they also find themselves at crossroads with other DSPs who may have differing levels of commitment or perspective.

Between individual and community. At a wider level than the above, participants elucidated situations in which they are between individuals with ID and the general community. As examined above in the section 'Physically Between' these DSPs related situations involving interpositioning themselves between individuals with ID and other members of the community to prevent or redirect potentially concerning interactions. At times, being between individuals with ID and others in the community was framed by participants as a more general or less overtly direct set of actions or perspectives. For example, touching on aspects of roles and relationship, a participant framed her experiences as,

You become like a family. You are the only thing between them and the

outsiders…Sometimes I feel like we have to be a barrier between people who don't

understand what is going on. Sometimes people want to help when there is no reason to help. That's another reason I say we are the buffer because they don't know what they are helping about.

As expressed by another participant these actions between an individual with and the general community can be wide ranging and occur,

Especially in public or in community inclusion programs like day hab too. When you're out with them you're walking that boundary too like how they interact with society doing things like going to get a soda from the gas station or buying shoes, or going to school like how do you get help going to class and finish your GED or what ever you do.

Likewise, a further participant described a series of events, across duties and roles, wherein she might have to navigate situations between the individual and community:

I remember when I first came in this field I worked at a house with three clients – two in wheelchairs and one ambulatory and they wanted to go to the casino. We'd be going and walking through and people wouldn't get out of they way of the wheelchair. We'd have to stop and go, stop and go and it's like 'Excuse me. Excuse me.' It's like, 'Get out of the fucking way – she's in a wheelchair'. We're a buffer. We are also a buffer. We have to – as much as I would like to scream 'Hey, I've got a client here!', we don't wear badges, we don't wear t shirts with the company name on it. Because we want them to feel, to be integrated in the community and not be spotlighted. But we also want to make sure that they are safe in the community. That they are not going to be in an environment that could trigger behaviors. Say for instance you have a client that does not like large groups. Well, you are not taking

him to the zoo on the free day. You're not taking him to the concerts when there are

15000 people. If they have issues with sexual attraction to minors you are not taking

them to the zoo or a pumpkin patch. You have to not put them in positions where

things can get triggered. It's not fool proof. It still happens so you have to say –

'Let's go down this aisle at the grocery store instead.

I: Always kind of...

P: Yeah – always. You are secret service. [places hand to ear] *'I've got a three year*

old in a diaper here – let's go to aisle 8'. You know?

Should a concerning event occur that involves members of the wider community a

participant stated, "*In the event that it does happen, I'm going to get between and apologize*

and I'm going to apologize for them. Apologize it happened. 'Please, just let me take care of

it' and just walk the person away". Such verbal interactions may also be initiated by a DSP

towards a person with ID to prevent having to get physically between. For example,

Like if a kid walks by – seeing the excitement in their face and you having to redirect

them and sometimes even being like 'Stop staring. That's inappropriate. Just stop it'.

Just, it's just difficult sometimes because you can almost see them wanting to act out

on it. And I have to give them respect because I've never had a client act out on it.

There's been times that you know if you weren't there to prompt them that they

wouldn't have thought twice about it.

These DSPs work in community-based settings with individuals with highly variable

histories and support needs. The job duties are exceedingly wide ranging and include

assisting individuals with ID with a multitude of interactions that are sometimes of a

concerning and possibly sexual nature. At each step in these processes DSPs may find

themselves standing between (physically or symbolically) the individuals they support and members of the general community who may not fully understand or appreciate the complexities of the situation. In these circumstances, DSPs are expected to simultaneously relate, integrate, navigate, and alleviate situations of life alongside people with ID and pSCB. These conditions of the work may result, for better or worse, in a sense of 'us' and 'them' or, as a participant stated in the first excerpt of this section, *"We are the only thing between them and the outsiders"*.

Decisional Betweens

Participants also spoke about many points of decision wherein they must choose if or how to direct various actions or interactions involving people with ID and pSCB. Regardless of plans or agreement with plans, the job comes to a head in a series of individual moments that may have no clear answer. These dilemmas involve wide concepts of diverse interpretation that exemplify the fluctuating internal and external moral intersections regularly navigated by these DSPs.

Between appropriate and inappropriate. Participants described parts of the job in support of people with ID and pSCB as making calls regarding the concepts of appropriate and inappropriate. In these points of decision participants choose whether or not to act with consideration of context, individual history, and established relationship with the person whom they are supporting. Intimating the variation of the concepts underlying these decisions a participant said, *"there's always that really fine line of what's quote unquote appropriate"*. Similarly, another participant stated that making these calls can be, *"a pretty significant challenge,…assessing you know, are they actually doing something inappropriate or are they doing something totally normal for their age, their gender, that type of thing"*. In

resonance with this, a different participant stated, *"The trick is, teaching them what is appropriate, what isn't appropriate. That's the really hard part of it"*.

When probed further about the operational definitions of the terms appropriate and inappropriate the participant who referenced the 'fine line' stated,

> *I guess inappropriate is a social construct term in the way that I would look at it. Like yelling in the library, in the middle of the library. And yelling, sometimes it's obscenity, like 'fuck' or saying something sexual in nature like 'Oh he's got a boner!' or whatever and just, that's happened oddly. But, just it's volume and sometimes it's just the word like calling people 'bitches'.*

This reference to aspects of societal expectations as related to appropriate/inappropriate was repeated by another participant in the following exchange:

> *I: So how do you know if something is appropriate or inappropriate?*
>
> *P: By, I feel that if you know that it's going to make somebody uncomfortable, or if you know that, and it sucks to say, but by society's standards, if that is not ok then you probably shouldn't be doing it or saying it. And it's, I'm sure everybody thinks weird things – but you shouldn't act on them.*

Another participant took a more personally derived tack to describe making the determinations between appropriate and inappropriate:

> *Anytime it makes me feel uncomfortable and it's sexually in the wrong direction. I'm a female so you know, anything sexual and offensive or inappropriate, any comments to do with a woman's body or even a man's body and something I know that person wouldn't agree to. When it makes me feel uncomfortable that's when I'm like "ok that's…" and I'm not very quick to be like "that's inappropriate. You don't discuss*

that. You don't talk to me about it either. It is not appropriate to talk to someone that

way".

A further participant provided specific examples of his definition of these terms:

Appropriate is, everyone has sexual feelings. Everyone has those feelings. Everyone

has the need to feel sex, to feel love. Appropriate would be – you go into your

bedroom with the door shut locked, windows closed, curtains drawn, very private

thing. Appropriate is talking about your feelings with somebody appropriately.

Asking the questions. Inappropriate would mean deviant, manipulative, you know

when they are doing something they are not supposed to be doing. Which a lot of

them do. You know, in public. Public stuff. Age inappropriate stuff.

Repeating a metaphor from above, a different participant reflected that making these calls

requires monitoring individual behavior, context, and potential consequences all in

consideration of the *"thin line between their individual human rights and what is appropriate*

and what's not.

A swirling set of terms, (e.g., normal, deviant, manipulative, wrong) each with their

own individually and societally determined connotations, were used by participants to

demark when actions may be taken to stop or encourage certain actions. Taken in context

with the conditions and interactions described above, these participants must temper

individual definitions and consequent actions with understanding of laws, current social

mores, and duties as defined by other parties. Each of these parties may have disparate

perceptions of what constitutes appropriate and inappropriate; what must be stopped and

what is 'allowable'. When differing understandings emerge, these DSPs may find themselves

at odds – powerful in interactions with individuals with ID but often powerless to affect the

provided directives. At each turn, resultant decisions of action or inaction may place DSPs between the people whom they support, members of interdisciplinary teams, or members of the larger community. Thus, for these DSPs, the multifactorial determination of appropriate or inappropriate is a key variable in the 'algebras of between'. When aspects of safety, empowerment, risk, or rights are introduced to these equations, the mathematics become even more complex.

Between safety and empowerment. In addition to making decisions between appropriate and inappropriate participants discussed the presence of concepts related to safety and empowerment for people with ID and pSCB. For one participant, "*the ultimate goal of what we do where I'm at is, you know, helping people transition from meeting their needs in unhealthy ways to meeting them in healthy ways"*. According to another participant, while engaged in the concrete job tasks related to teaching skills and encouraging independence in different milieus she is always aware of *"'This is what this person does and this is how I'm going to keep them safe, this is how I'm going to keep people in the community safe, and this is how I'm going to keep me safe'"*. In a refrain of the 'Between Roles' presented above another participant described DSP decisions at the intersection of safety and empowerment:

> *Giving them as much information as possible of what interests they have. To know that there is support. They have someone to fall back on if they need to. They are not just out there by themselves. It's a little safety net. Just like as a parent – letting your kids do more and more. Until they get to – yeah – that's a hard thing and it's a hard thing sometimes with clients. You don't want them hurt. That's a natural thing. So*

you have to 'Alright – ok,' loosen up the leash. We have to keep remembering that.

We are not jailers. We are not jailers.

Efforts to attain equity between these two goals may result in over correction to the side of safety. For example, a different participant stated,

You always want to be really hypervigilant sometimes. Especially like when you first start working. It just sets the territory - hypervigilance like 'They are not going to do anything' and that works for some people but for the boundary I see with most people, it's kind of a feeling, you feel like you're taking away their ability to be independent, make certain decisions.

This feeling of 'taking away' when navigating safety and empowerment was expressed by another participant who stated,

I feel like we are always stopping them from doing what they want to do. We are stopping them from being the humans they want to be. We are stopping them from loving somebody. From wanting to be with somebody. And I feel like that's what we are doing.

A final participant intoned that preference to the side of safety may relate back to the underlying power balance in team dynamics and who takes the blame when safety has been compromised:

P: ...You could be with somebody 40 hours a week, every single day, every single week, for years and years and years. You could be the face that this person sees the most out of anybody – parents, therapists – but the second something goes wrong – your fault. 'Ok well, I'm following your plan. I'm doing what you fucking told me to do'. And 'No. Your fault. You must have done something wrong.' You know weeks go

by, nothing goes wrong and this guy is improving, you guys work well together, no

negative behaviors. Nothing. And all these guys take the credit for it. 'Oh it's my

plan. Oh it's what I told you to do with that person. I'm the reason why this person is

doing so well. Not you, you just work with them." So it's a lot of bullshit.

Continuing this line of thought later in the interview the same participant also reflected how

these decisions regarding safety may also place them at odds with other DSPs

P: You know who gets blamed. The staff do. Because 'they're not paying attention'

[finger quotes]. *They did something wrong. 'You're not doing what you were*

supposed to be doing'.

I: Do you believe it's their fault or do you think that's who gets blamed.

P: Both. It could go either way. There's a lot of staff who don't pay attention to

anything other than their phones. I think we hire a lot of people who think they were

hired to babysit a TV. So there's a lot that goes into it. But even if it happens right in

front of you. You put two people in the back seat and they fight it's, 'Well, where were

you?'; 'I was driving'. 'Nope, all your fault. You could've done something different'.

Protection from harm in juxtaposition with a desire and/or mandate to increase skills

and autonomy constitutes another set of convoluted decisional intersections described by

these participants. Again, in context with the sections above, these decisions do not stand on

their own. They are pervaded by differentials of power and definition, multiple concepts of

primary role, and immediate versus longer term considerations and thus, can lead to internal

or external conflicts.

Between rights and risk. Closely related to the above, and the earlier section

'Between Duties and Self" participants delineated part of the job in support of people with ID

and pSCB as juggling the overarching presence of risk and rights. The addition of 'sexual rights' in the interview process elicited both strong statements regarding and conditional explications of these concepts. For one participant the retention of sexual rights was connected to a necessary absence of risk. In her words, *"having rights as long as they're being safe. To themselves and others. I think they should have the same as you and I. Why should it be different?"* Another participant also saw the discussion of rights as diluted by conversations and decisions stemming from others' concepts of risk:

> *I: So when you think about rights and sexuality and intellectual disability it sounds like*
>
> *P: They don't have any [laughs]. They do but they don't. They do but they don't. They don't have the right to like… They have to have a team meeting to see if they can have sex with their girlfriend that they've dated for like 5 years. It's kind of ridiculous. You know, or they just can't go out and have sex with, like I said, sex with somebody that's a stranger. They can't do that. I mean they can't yeah…*

A different participant implied that the entire concept of sexual rights for people with ID and pSCB may be stymied by avoidance of the topic and overarching limits on the actions of the person:

> *I wish it wasn't so stigmatized. Everybody has a right to these feelings. Everybody is going to feel these feelings. I think my least favorite thing is when we are trying to shut down those feelings...You have your individuals with the inappropriate behavior and have evidence of having inappropriate behaviors. Maybe they've broke the law. Maybe they have hurt somebody. But we shut them down completely. Like 'you can't*

have these feelings whatsoever because these feelings are just going to lead you to hurt somebody again'. I don't think you can stifle a person like that.

A further participant speculated as to the etiology of these limitations on rights while attempting to differentiate for herself why decisions are made in this manner:

Maybe some of them [teams] *are just so scared and they just don't want something to happen that they take extra precautions. They go above and beyond and they take away their rights in a way…That's not because you are taking away their rights – it's because you are keeping them safe.*

Another participant outlined the steps that may be taken when DSPs find themselves between decisions of sexual risk and rights and how often he has seen this come to fruition in nearly two decades of work:

P: Just letting the team know I guess. Like "This is what we want to do." Let the house manager know, let the service coordinator know, the BSC know, the guardians know. That way it wasn't a surprise. Let people know that hey they're trying to pursue something here. And let's help them reach what they want to pursue. Because it's their right. If they are going to do it the right way like us with our relationships. Everyone deserves a relationship. If they do it the right way without gaming or trouble and forcing someone to do it then more power to them. Let them have their relationship…So that everyone's in the loop that 'So and so wants a relationship with so and so and they want to start having intercourse and what not'. Just got to make sure they're safe, it's a safe environment for them. Make sure that they have their safety equipment like their rubbers, their condoms like that and make sure that they're safe.

I: How often have you seen that happen? Somebody who has been able to navigate all

of that?

P: Of the individuals we serve?

I: Yeah

P: Honestly, maybe twice if that. Twice

These concepts of risk and rights were reciprocally connected by other participants. As stated

by one, *"I think we actually elevate peoples' risk by taking those rights away".* Reflecting on

the same concept another participant said, *"I don't think you can regulate too hard in peoples*

lives without creating some of the issues that are problems".

Conceptualizations of safety, risk, rights, empowerment, appropriate, and

inappropriate dominate decisions regarding the sexual interests and actions of people with ID

in these data. While there in the moments, these DSPs contend with a multitude of personal

and professional considerations with deep variation from individual to individual and team to

team.

In What Conditions were DSPs not 'Between'?

There were areas of these data wherein participants seemed clear about the experience

and consequences thereof. Specifically, when speaking about the 'best part of the work' and

'why stay in the work' as presented in Chapter Five, participants were of common voice both

internally and across responses. Developing relationships and seeing positive change and

growth were clear and prevalent themes containing almost no hesitation, conflict, or

secondary reframing. Indeed, it may be due to these commonalities of experience that the

sense of being between was so palpable elsewhere in these data. The one negative case

example of this otherwise consistent pattern came from a participant who recalled an incident

with a person with ID who "*expressed how he would like to rape me so it was like, not ever am I going to be put in that situation where I would work with that person*". Later in the interview, however, this same participant went on to describe long term relationships with other individuals with alleged histories of violent, sexual acts against others and a marked sense of frustration related to violations of sexual rights for people with ID. Seeing change via long-term relationships penetrates the experience for these DSPs. It provides a place of focus through the otherwise turbulent and multiple forms of being between (See Figure 5 for a visual representation).
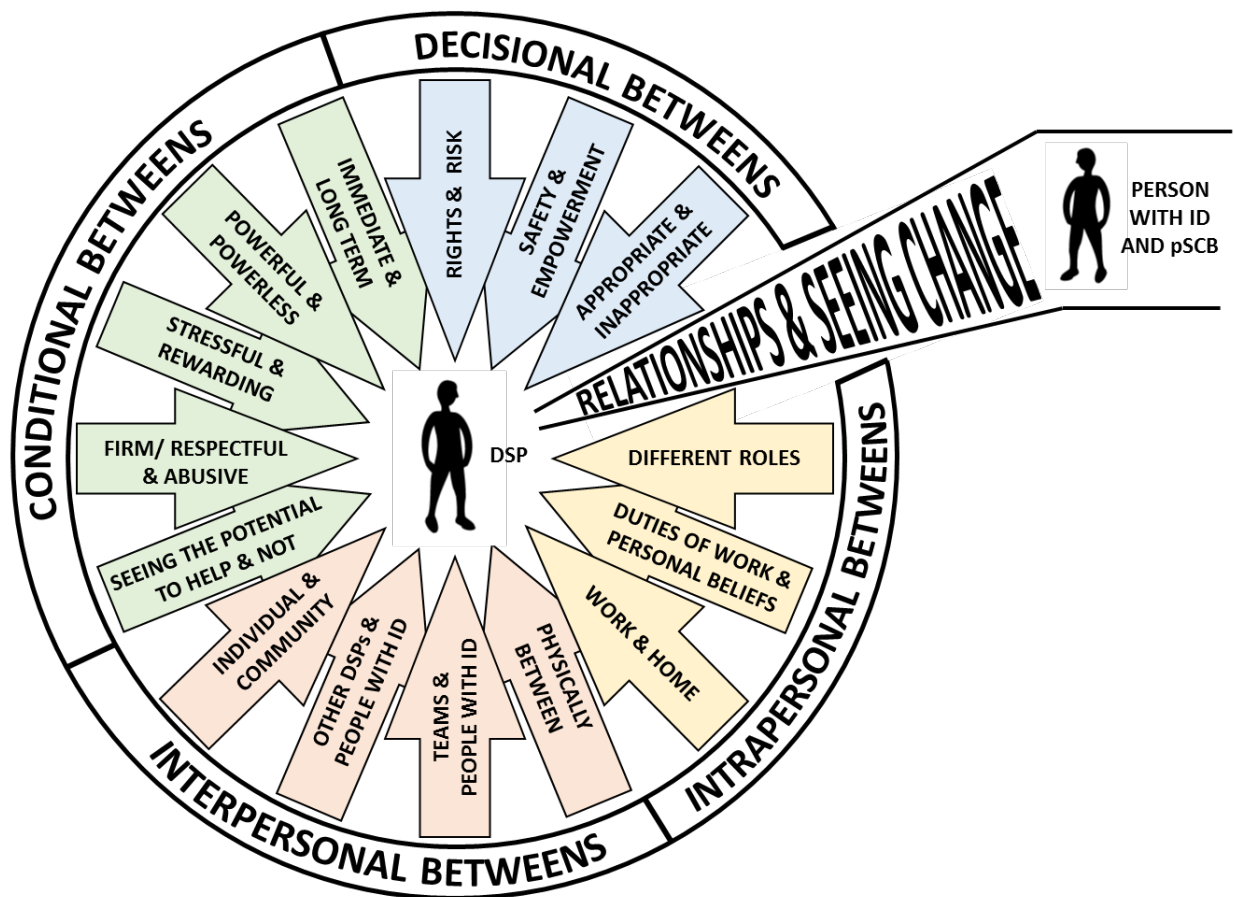
Figure 5: A visual representation of the grounded theory 'Being Between' stemming from the experiences of Direct Support Professionals (DSP) who support people with intellectual disability (ID) and possibly sexualized challenging behavior (pSCB). Creation of relationships and seeing change may provide a place of focus in the otherwise tumultuous navigation of competing internal and external forces.

In this graphic representation one may see the experience as related by participants in this study. Surrounded by competing external and internal discords, as long as focus remains on individual relationships and seeing change over time, there is a place of exit. One might also imagine, in this graphic, alternate scenarios wherein the competing influences and points of potential conflict become primary and interfere with the DSP's view of potentials for relationship and change. The circle of arrows rotates and one factor or another then obstructs the potentially sustaining perspective.

Aren't We all 'Between'?

It can certainly be argued that 'being between' is simply part of the human experience. I do not debate this. We all navigate various competing forces in our lives and struggle at times to figure out what we believe, what we are supposed to believe, and what options there may be to choose from. We are all certainly under the weight of various hierarchies of government, employment, and family. We may, at times, disagree with the dictates or demands that stem from these relationships. So, while 'being between' may indeed seem familiar, I contend that DSPs working with individuals with ID and pSCB occupy a particular place in these crossroads. The grounded theory as presented above may help to reveal parts of an experience markedly dissimilar from most. From a wide perspective, these DSPs are working in regulated systems of supports with oversight and mandate from federal, state, and local levels. They are employed as part of agencies with contractual obligations and financial requirements. The work is often greatly influenced by licensed professionals physically distant from immediate concerns. Parents and legal guardians of divergent perspectives are involved at varying levels of commitment. Intimately powerful and sometimes externally powerless, the DSP in these circumstances may stand

with, and often directly between, people with ID and the influences of all of the above. Add to this the variable of general human sexuality. Add to this the historical riptides regarding sexuality and people with ID (Chapter One). Add to this legal and social notions of deviant, predator, pedophile, and offender. Combine the above with concepts of community integration, autonomy, dignity of risk, duty of care, human rights, and social justice. Now shake, stir, and blend all of these ingredients. Now, make a decision about an individual's possibly sexual action in a given moment. Is it a 'risk'? To whom? According to whom? Do you act or not? In what way? Toward what ends? What did the plan say? Do you agree or disagree? What happens if you make the 'wrong' decision; take the 'wrong' action? Who defines 'wrong'? Too late. The moment has passed. Do this for close to minimum wage on a daily basis for years on end. In the words of one participant, *"We walk that boundary. It's a tightrope. Just do your best".* That, in essence, is the particular 'between' induced from the voices of these men and women.

Comparison to Reviewed Research

In Chapter Two I presented reviews of the research regarding: (a) the general roles, duties, experiences, and related effects of people working as DSPs in the lives of people with ID in community-based settings; (b) the views, attitudes, and practices of DSPs in regard to supporting the sexuality of people with ID who live in community settings; and (c) stakeholder views, opinions, or experiences regarding work with individuals with ID and pSCB in any type of support setting. In this section I will situate and compare the findings of my research within the overall contexts of the results of the aforementioned reviews as well as in reference to selected similar studies.

In some traditions of Grounded Theory it is recommended that a review of related research not occur until after the data has been collected and analyzed. This is intended to provide a control for the potential influence said research may have in resultant interpretations. Due to the constraints of this manuscript's development, I conducted the reviews of related research many months before the initiation of data collection and approximately a year prior to analyses. During that time I avoided reading studies again or editing the related chapter. In essence, with the amount of work that occurred between the initial and this, secondary consideration of these reviewed studies, the findings may have echoed distantly in my head but my focus was on capturing the experience as told by participants. Thus, the analyses below represent relatively fresh eyes towards these data.

To recapitulate, the overall findings of the reviews of the 37 articles from the above domains were:

(h) The role of DSPs encompasses an exceedingly wide array of concrete and subtle actions or purposive inactions that reach nearly every facet of daily life for people with ID (e.g., Clement & Bigby, 2010; Clement & Bigby, 2011; Bigby et al., 2012);

(i) When matters of sexuality are introduced into the equation, these duties may become intensely complex, sometimes emotionally charged, affected by geographic and cultural variables, and confusing for specialized practitioners and DSPs alike (e.g., Hamilton, 2009);

(j) In circumstances where risk of harm (perceived or actual) is associated with possibly sexual expression, further emotional or professional practice complications may arise for providers at all levels (e.g., Hamilton, 2009; Taylor et al., 2003; Wilson et al., 2011)

(k) These difficulties may be compounded by a lack of clear definition of terms which multiplies as factors (e.g., DSP, sexuality, pSCB) are added to the equation;

(l) Poor or absent training and policy resulting in inconsistent support is a common refrain across all reviewed areas (e.g., Abbott & Howarth, 2007; Bigby et al., 2012; Christian et al., 2001; Clement & Bigby, 2010; Lockhart et al., 2009; Wilson et al., 2011);

(m) Decisions of how to support or limit, contain or allow, restrict, or ignore are frequently guided by individual and personal variables of DSPs and other support providers (e.g., Abbott & Howarth, 2007; Clement & Bigby, 2010; Christian et al., 2001; Hamilton, 2009; Parkes, 2006; Wilson et al., 2011); and

(n) Very little research (three of the 37) in any of the reviewed areas has been conducted in the United States.

In short, the findings of my research are in alignment with much of the above and add facets or fill in missing pieces for others. I discuss specific comparisons and contrasts to the reviewed research below.

Comparison to Research Regarding General Roles, Duties, and Related Effects of DSPs

As evidenced in the first review of research there appears to have been an increase in methodologies which sought to capture and present the expressed or observed experience of DSPs who work in community based settings with people with ID. However, in this body of research conducted from 2009-2014 (n=10) the data from DSPs was often aggregated with responses from participants from other service domains (e.g., nursing, upper management) and thus, the individual or collective voices of DSPs were difficult to surmise. Windley and

Chapman (2010), Hatton et al. (2009), and Wilson et al. (2011) were the exceptions to this and thus provide the best conduit for comparison to the current findings.

In brief recapitulation, Windley and Chapman (2010) utilized interviews and focus groups with eight UK based "support workers" (p. 310) who had a history of working with people identified as having "profound and multiple learning disability or people with challenging behavior" (p. 313). These authors found that participants expressed competing views regarding their work. Specifically, concepts of health, safety, and protection were juxtaposed with focus on autonomy and quality of life. While Windley and Chapman did not expressly address matters of general sexuality or pSCB, certain parallels to participant responses in the current study are clear. In summarizing parts of their data Windley and Chapman stated "although most respondents favored a combined 'facilitative' and 'care provider' role, it could be argued that this reveals an underlying tension in staff roles between dependency and enablement, at times promoting independence yet at other times monitoring and controlling behavior" (p. 316). This is highly similar to the positions expressed by DSPs in the current study regarding the multivariate roles they may fulfill in the lives of people with ID and pSCB. The related tensions between safety and empowerment, rights and risk, as examined above are also similar to the findings of Windley and Chapman. The situation of pSCB that may pose a risk of harm to others in the community or DSPs themselves, as suggested in the findings of the current research, may serve to further complicate these dichotomies. Extending on Windley and Chapman, this study also revealed how certain DSPs may use a variety of comparative metaphor in attempts to describe the overall aspects of the job. In addition to the preceding, Windley and Chapman surmised that "poor communication and assertiveness skills were factors" (p. 316) for the support workers they interviewed.

Again, these are similar to the statements of DSPs in the current research wherein poor communication within interdisciplinary teams was a common frustrated refrain. Regarding the issue of assertiveness, however, the DSPs in the current study had a different take. Rather than the problem residing in their abilities to be assertive within team contexts, the DSPs in the present study expressed clear frustration with how their attempts to be assertive (i.e., advocate for sexual rights for people with ID) have been ignored repeatedly. This, at times, has led these DSPs to choose silent withdrawal over speaking up. It was clear from the excerpts in the current findings that participants had consistently clear voice and were capable of speaking in direct, incisive manners about these complex topics with an eye on individual specific supports. While it could be argued that 'they need to get better at speaking/being assertive', it is possibly a more logical course to focus upon improving the listening skills of others involved in these processes.

As presented in Chapter Two, Hatton et al. (2009) utilized panel discussion and interviews to create measures of and analyze the job roles and duties of "direct support staff" (p. 54) who worked with people with ID in the UK. Participants included 122 direct support staff as well as people with ID, family members of people with ID, and service managers. Per Hatton et al. participants identified essential core competencies of direct support staff with "greater emphasis on the personal qualities of individual workers and less explicit emphasis on the specific skills required of the support worker post" (p. 61) than previous research in this domain. In relation to the current study, the findings of Hatton et al. relate a connected picture. Rather than a focus on the concrete, or task-based aspects of the job, participants in Hatton et al. perceived relational aspects as the most important factors for success. Similarly, DSPs in the current study described creation of connected relationships with people with ID

as the best part of the work and as a factor in what helps them stay in the position despite significant sources of stress. In short, relatedness and personal connection appear to be common themes between these data sets. The direct support workers in Hatton et al. also emphasized the ability to deal with stress as a core competency. When considered in conjunction with the findings of Windley and Chapman above, multiple role identification with a necessity of close connection may serve to create an atmosphere of stress secondary to confusion. This is markedly similar to the notions of 'between roles' and 'between stressful and rewarding' stemming from the current data set as presented above.

From a more general perspective, the findings of other research reviewed in this domain consistently suggested a mountainous level of responsibility involved in the daily jobs of individuals who provide direct support to people with ID. As outlined by Bigby et al. (2012) these kaleidoscopic job roles are further refracted when one considers that DSPs are often tasked with provision of direct support to multiple individuals with ID who inherently have markedly different support needs. This was common to the findings of the current research as well in that participants related specific stories of individualized support within the global concept of *"it's your job to play almost every single role"*. When issues of sexuality are combined with the above, the reviewed research and present findings also find points of alignment and discord.

Comparison to Research on Views, Attitudes, and Practices of DSPs in Regard to Sexuality

In the set of research reviewed regarding the attitudes, views, and practices of DSPs related to sexuality for people with ID, overall findings indicated a move towards a human rights-based conceptualization. The statements of DSPs in the current study consistently

reflected a similar refrain. To readdress a point made in Chapter Two, however, individuals'

statements concerning what they would or should do may not align with what actually occurs

in a given situation (Ajzen & Fishbien, 1977). In the current research, statements of distaste

with what they saw as limitations on human rights, were consistent across participants. Both

general statements and case-specific examples, with sometimes intense tones and language,

were voiced by participants regarding this topic. In addition, participants described a general

exasperation with previous attempts to confront what they saw as disparities between rights

and practice. So, while these DSPs opinions are in line with the trends of similar research

regarding sexual rights for people with ID, the impediments to fully realizing these rights

were framed as almost entirely outside of their control either by action or input. One's

attitude does not much matter if one actually has no choice of related action.

What is unclear in these data is how stated beliefs align or diverge within the

occasional moments in practice where DSPs *are* making in-vivo decisions about allowing or

disallowing certain actions by people with ID. Certainly there are incidents wherein

restrictions or limits placed by others do not speak to the details of particular situations.

Closest to this in these data were participant descriptions of deciding between what is

classified as appropriate or inappropriate. Akin to the findings of Abbot and Howarth (2007),

Christian et al. (2001), Hamilton (2009), and Parkes (2006) it is clear that participants must,

at times, engage individually-based and subjectively derived notions of social propriety in

order to support or limit the sexual expression of people with ID. While various reviewed

studies (Evans et al., 2009; Grieve et al., 2009; Hamilton, 2009; Lockhart et al., 2009; Wilson

et al., 2011) suggested training as a way to address these concerns, it is difficult to imagine

trainings comprehensive enough to address the multitudinous variations of possibly sexual

events encountered by DSPs. This is especially germane when DSPs are tasked with providing inclusive supports for people with ID who have alleged or adjudicated histories of violent sexual actions involving harm to others. Further, any trainings in this domain would themselves be at least partially influenced by local or regional differences in standards of behavior or legal statutes. This is not to say that we should let 'perfect' be the enemy of 'good' and decline any training on sexuality due to its possibly subjective constituents. Indeed, 10 of the 12 participants in this study reported having received training on human rights and ID as part of professional development. Eight of the 12 participants reported having received training in sexuality and ID. Perhaps these factors influenced participant responses. There were, however, few and only very brief references to trainings in the data gathered from interviews. Instead, participants tended to use personal comparison to outline their thinking on sexual rights for people with ID. In short, in our current systems of supports, DSPs are not (and perhaps cannot be) provided a comprehensive handbook for making these calls. So, while the statements were clear, how these moments of decision are enacted in real time is not accessible by interview alone. These issues and others are further explored in more detailed reference to certain selected reviewed research below. Specifically, due to aims of research and methodological similarities the works of Hamilton (2009), Wilson et al. (2011) and Lockhart et al., (2009) provide the best points of entry for more thorough comparison to the findings of the current research.

Hamilton (2009), conducted observations of and interviews with thirteen "direct support workers" (p. 306) in New Zealand to assess beliefs and practices related to sexuality and the people they supported in community based residences. In his analysis of the collected data, Hamilton described support workers as operating from binary positions that included

concepts of normal-abnormal, natural-not natural and appropriate-inappropriate. In summary, Hamilton suggested that these support workers envisioned their work as being "protectors…or empowerers" (p. 309). Hamilton's conclusions, based upon data from a similar sample size and milieu of work as the DSPs in the current study, closely resemble my findings and interpretations. The grounded theory of 'Being Between' as presented earlier is rich with binomial splits in the statements of DSPs and appears to both support, and be supported by, Hamilton's work. Hamilton's use of observation to triangulate participant statements added an additional dimension to his work. Specifically, Hamilton found that while participants expressed notions of equality of sexual rights and access, their actions in practice were more directly limiting and restricted to what he termed "doing normal" (p. 309). As discussed above, verbalized opinions may not necessarily align with applied actions. A comparison on these parts of his data is unavailable due to the strictly interview-based nature of the current study. Where the findings of the present study diverge from Hamilton however, is participant integration of larger systems issues that may lay behind many of the possibly restrictive practices. Specifically, Hamilton did not explore how directives of other involved parties may sometimes dictate the actions of direct support workers within their particular systems of supports. Essential to the concept of 'Being Between' are the wider conditions of interpersonal interactions. These appeared to be connected to some instances of intrapersonal conflict and related struggles of participants to remain connected to the people whom they support. In addition, the participants in Hamilton's study were not working with individuals with histories of or current preferences for sexual actions that had a possibly illegal or aggressive content. In contrast, the DSPs in the current study described numerous situations involving high intensity interactions with the

potential of harm to themselves or others. In summary, the findings of both Hamilton and the

present study suggest that individuals working in positions of direct support may experience

competing concepts in matters of the sexual behavior of people with ID. While the current

study would have benefitted from a method of observation similar to Hamilton's, his findings

would have benefitted from an exploration of participant perspectives regarding larger

systems issues and related locations of perceived power.

Wilson et al. (2011), as more thoroughly examined in Chapter Two, utilized a

combined approach of interview, observation, and analysis of permanent products (i.e.,

policies, progress notes) to examine the practices of "paid disability support workers" (p.

278) employed at three Australian community-based residences for people with ID. Wilson

et al. specifically focused on support worker roles in regard to the sexuality and sexual

expression of people with ID. Per Wilson et al., findings suggested that participants played

the role of "interactional gatekeepers" (p. 272) in regard to the allowed or disallowed sexual

actions of the people with ID with whom they worked. Per the authors, support workers

utilized factors such as personal values and perceived risk to others to make these calls on

"ethically and morally challenging issues" (p. 286). Parallels to the current research are clear.

DSPs in the current study expressed a similar frequent navigation of in-the-moment decisions

on course of action based upon concepts of appropriate/inappropriate and risk/rights in

regards to possibly sexual actions of people with ID. In contrast, the support workers in

Wilson et al. were working with young men with ID but no stated history of potentially illicit

sexual behavior or actions against others. The DSPs in the current study worked with people

with ID in regards to both general sexuality (e.g., masturbation) and pSCB with a history of

or current significant risk to others. Further, as stated by Wilson et al., the sexuality of people

with ID may be "problem-led within a service-centric risk-hierarchy that renders to a secondary consideration the 'right' to develop a healthy...sexuality" (p. 286). This correlates to the findings of the current study in that low-risk-of-harm sexual actions by people with ID (e.g., masturbation in private, consensual sexual relationships) were referenced in participant discussion of what may be included under the term pSCB. To reiterate, the DSPs in the current study were not stating that these actions were themselves 'problematic' but that they became challenging due to the restrictions and limitations sometimes imposed by others in the 'risk-hierarchy'. While the participants in Wilson et al. were surmised to be operating in a "policy vacuum" (p. 286), the DSPs in the current study appear to be confronting similar issues within a plan and input hurricane in whose winds their voices are lost.

As introduced in Chapter One, Lockhart et al., (2009) provided the definition of sexually challenging behavior (SCB) utilized throughout the body of the present study. In deference to the potential that some actions, which are labeled 'sexual' in nature, may actually have no concrete sexual component, I added the modifier of *possibly* to their term and thus arrived at the acronym pSCB. To review, Lockhart et al. provided the following definition of SCB as inductively derived from a series of interviews with participants from a provider agency in Ireland:

> '[s]exualized challenging behaviors' [SCB] are those that are deemed inappropriate as a result of the nature of the behavior (including touch or contact, exposure or display, masturbation, language, communication or images, invasion of personal space or boundaries, fetishism, or aggressiveness linked to sexual arousal) or the setting in which they occur (i.e., a public or observed place). These behaviors may be self-directed or directed at others, including targeting or fixating on individuals. Where

others are involved, the contact may be unwanted or nonconsensual. These behaviors

occur on a continuum from minor behaviors up to and including sexual assault. In

addition, the behavior may interfere with normal activity or be harmful or distressing

to self or others. [The label of SCB should not be used to] further disempower or

stigmatize…[or] conceptualized as a deficit intrinsic to the individual [but instead] to

emphasize that this behavior challenges the services and their staff to find more

effective ways of understanding the origins and functions of an individual's behavior"

(p. 294)

Further, per Lockhart et al. the above definition "does not include any reference to behavior

that would be considered normal and acceptable in a person without disability of the same

age…and echoes the importance [the authors] place on behavior impinging on the

individual's community presence, autonomy, and dignity" (p. 299). As stated in the findings

of the present study, at no time did I provide participants with the above definition. Instead, I

simply asked participants to "tell me about some of the sexual behavior concerns you have

experienced in your work as a DSP" and, later in the interview, "how do you know if a

certain behavior is sexual or not?" (see Appendix A, Questions 4 and 8). Overall, the

situations and incidents described by participants in these data were consistent with Lockhart

et al.'s concept of SCB. Notions of physical contact with self or others, situational and

environmental context, and a resistance to using the terms to disempower or stigmatize

individuals were all outlined in participant responses. In consideration of the findings of the

present research and on further review of the above definition of SCB, Lockhart et al.'s

reliance on the use of the phrases, 'deemed inappropriate', 'distressing to others' and

'considered normal and acceptable', is notable. The responses by DSPs in the current study

clearly reflect all of these qualities. Inappropriate and appropriate (similar in nature to normal and acceptable) were consistently invoked by participants in order to describe sets of actions that respectively required or did not require intervention. Certain events of pSCB described by participants were classified as challenging not due to the nature of the behavior itself, but due to others' distressed reactions. In relation to the discussion of other related research above, who decides what constitutes 'appropriate' sexuality is a matter of complex variables in which DSPs may frequently play a role governed by internal or external factors. Further, in regard to Lockhart et al.'s emphasis on the label of SCB being used to "find more effective ways of understanding the origins and functions of an individual's behavior" (p. 294), the DSPs in the present study were sensitive to both factors. Specifically, participant explorations of possible etiological explanations for pSCB were highly sensitive to the possible roles of history and reaction to what they saw as unnecessary restrictions sometimes invoked by others with more distant connection to the individuals with ID whom they support.

Comparison to Research Regarding Other Stakeholder Views, Opinions, Or Experiences Regarding Work With Individuals with ID and pSCB

As outlined in the findings of the review of this research in Chapter Two, none of the eight studies examined provided the separated perspectives of individuals clearly working in positions of community-based direct support with individuals with ID and pSCB. Indeed, only two studies were located that addressed this group of providers at all. In the case of Lockhart et al. (2009; discussed above), direct support worker responses were aggregated with those of participants from other parts of the service sector (e.g., nurses) and thus may represent a set of experiences different from those of individuals working in positions of direct support. McKenzie et al. (2001) examined survey data from nurses and "social care

staff" (p. 51; undefined in text) in regards to support of people with "learning disability who display sexual offending or sexual offending type behavior" (p. 58). While the contributions of both studies are important, especially considering the dearth of research in this topic as a whole, the combining of data from individuals with presumably marked differences in training and duties (Lockhart et al.) and the lack of description of setting, job duties, or developmental conditions of individuals receiving support (McKenzie et al.) prevents a thorough comparison. Thus, it appears that the present research occupies a currently singular space in this literature base. Therefore, a limited comparison to certain other studies on this particular topic follows.

As noted above and more thoroughly described in Chapter Two, McKenzie et al. (2001) conducted a survey of nursing and social care staff at two "medium security" (p. 59) residential providers for people with "learning disability" (p. 59; undefined in text) in England. Similar to the participants in the present study, respondents in McKenzie et al. worked with individuals who had a history of alleged or adjudicated sexual assault towards adults or children, sexual attraction toward minors, exposure, verbal threat of a sexual nature and "inappropriate masturbation" (p. 61). Respondents from both groups reported a perception of high difficulty involved in the work perhaps due to lack of specific training. In connection with the present study, respondents in McKenzie et al. who were identified as nursing staff reported "negative attitude[s] toward the [people]" (p. 60) who had the concerning sexual history while those in positions of social care retained a positive view of the person but a negative view of the particular concerning sexual behaviors. While McKenzie et al. did not provide a description of the duties involved in the position of 'social care staff', it is presumed that these individuals filled a role more similar to DSPs in the

present study than to nursing staff. If this was the case then the findings of McKenzie et al. somewhat align with the findings of the current research. Specifically, the individuals who presumably have a closer, more direct or daily involvement in the lives of people with developmental conditions and pSCB are more likely to divide the behavior from the person and thus create relationships despite difficult histories. Again, absent more robust description of participants, further comparison with the findings of McKenzie et al. would be purely speculative.

Robertson and Clegg (2002) interviewed "qualified social workers and community nurses who had some experience of sex offending in men with learning disabilities" (p. 172). These authors were specifically investigating "factors affecting participants' risk appraisals and their confidence in their risk judgment skills" (p. 172). While the participants in Robertson and Clegg occupied decidedly different positions of support than the DSPs in the current study, there are parallels in response. Specifically, similar to the set of conflicting inputs related by DSPs in the current study, participants in Robertson and Clegg expressed attempts to balance conflicts stemming from internal and external sources of information regarding the perceived risk of the men with learning disabilities with whom they worked. This commonality may intone that certain experiences of being caught between dichotomous or multivariate perspectives on risk and related responses extend beyond the particular relationship between DSPs and the people with ID and pSCB with whom they work.

Again in the UK, Taylor et al. (2003) conducted pre- and post- tests with "qualified and unqualified staff [social workers and nurses] working in inpatient and community settings" (p. 204) with men with ID and histories of sexual aggression or sex offense. In between testing conditions participants attended a training "intended to raise awareness,

provide information, and introduce participants to a range of issues in this clinically complex

and challenging area" (p. 204). Per Taylor et al., the pre-test results indicated that the vast

majority of respondents indicated a lack of confidence in supporting people with ID and

concerning sexual histories perhaps due to a lack of training in this subject. This is similar to

the findings of the present study wherein 10 of the 12 participants reported having received

training in sexuality and ID on the demographic information form but, in certain cases,

voiced a lack of general training in methods of support for people with histories of pSCB that

involved aggressive or harmful behavior. When training is lacking there may be difficulty

finding a common language or points of reference leaving everyone to speak about risk from

dissimilar perspectives. This again, may demonstrate some of the reasons behind certain

conflicts in practice and beliefs, which trickle down to the immediate actions of DSPs and

affect the lives of people with ID.

From a different perspective, Hubert et al. (2007) interviewed five mothers of

adolescent boys with "learning disability" (p. 363) who had histories of sexual offense

including allegations of rape of younger children. The participants in Hubert et al. expressed

experiences of deep personal connection with their sons simultaneous with significant

antipathy towards their reported actions. In addition, these participants expressed that they

felt unsupported by involved professionals who may only become involved when something

further goes wrong in their boys' lives. This sense of conflict and lack of professional

involvement outside of troubling situations mirrors many of the experiences described by

DSPs in the current study. Once again, it appears that these experiences of being amidst

competing internal and external forces continue to extend into many of the professional and

family relations when a person with a developmental condition engages in concerning sexual actions.

Hutchinson et al. (2012) interviewed community practitioners in the UK who provide risk assessments for people with "learning disability and a history of sexually abusive or offensive behavior" (p. 53). Participants in Hutchinson et al. worked from varying disciplines including social work, psychology, psychiatry, nursing, and case management. The authors' analyses of these data suggested that the participants "appeared to occupy the gap between objective and subjective elements of risk, yet were simultaneously in the frame for a decision relating to what can be done" (p. 57). This was elaborated by Hutchinson et al. to result in professionals having to "mediate between these opposites" (p. 58) of risk to the community and care for the individual. Here again, are parallels to the experiences of the DSPs in the current study. Managing risk while attending to rights or care appears to involve a complicated set of calculations for all involved regardless of title or scope of service.

In summary of the above, it appears that across disciplines and settings, individuals who work with people with ID (or other developmental conditions) and pSCB may experience conflicts similar to the participants in the present study. What differs in many cases however, is the particular set of responsibilities and relationship between providers and the people whom they support. While nurses, social workers, and physicians may experience similar conflicts as DSPs, their duties and related contact may be much more limited in scope. Further, if one's job is to assess or direct certain courses of care then one may be more prone to presenting a course of action with confidence rather than let others know of the underlying internal and external conflicts. If this is the case, then DSPs in these situations may be provided directives from sources who are just as torn but not willing to share this

experience publically. The closest relationship between previous research and the present study appears to stem from the mothers in Hubert et al. (2007). The close personal contact over the course of years is similar between these sets of participants. While DSPs are not biologically related to the people they support, the metaphors to parenting and friendship shared by DSPs are a close corollary. Their positions both involve provision of life-wide supports, in situations they cannot fully integrate, with inputs from others that add further conflict to already complex situations. In each of the comparisons above, the frustrations or conflicts expressed by participants or respondents implied or stated a sense of emotional turmoil secondary to being unsure of what course of action to take. This quality is further explored in the potential supporting theory of moral distress as examined below.

Moral Distress – A Potential Supporting Theory

While the above comparisons to closely related literature evidence a strong connection to the findings of this research, the picture remains somewhat incomplete. As a feature of grounded theory it is recommended that researchers endeavor to access and compare research from other fields that may also speak to some of the emergent ideas or theories. Late in the stage of theoretical formulation and write-up I began to search databases for areas of crossover with other avenues of research and general literature that were not connected to sexuality and people with ID or DSPs. From these efforts, nursing research regarding the concept of 'moral distress' stood out as a potentially supporting theory. Specifically, moral distress appears to speak to some of the dynamics revealed in the grounded theory 'Being Between' thoroughly presented above. In the following section I present some of the major points in moral distress research and discuss how they may compare to the findings of the present research.

A Brief Review of Moral Distress Theory and Research

Attributing the overall concept of moral distress in nurses to Jameton (1984), Choe, Kang, and Park (2015) defined the term "as the unpleasant feelings when a nurse cannot take an action he or she perceives as ethically correct because of institutional constraints" (p. 1685). Kälvemark et al. (2004) expanded this definition to include "traditional negative stress symptoms that occur due to situations that involve ethical dimensions and where the healthcare provider feels she/he is not able to preserve all interests and values at stake" (p. 1082–1083). Various authors have investigated this phenomenon as it relates to different ends of the nursing field. Selected examples are summarized below and then compared to the findings and theory of the present research.

Choe, Kang, and Park (2015) conducted interviews with 14 nurses in Korea with an aim "to explore and understand moral distress from the perspective of and as experienced by critical care nurses" (p. 1686). Following transcription and coding, Choe et al. concluded: (a) "Participants felt uncomfortable when work processes and tasks prevented them from advocating patients' autonomy or respecting human dignity" (p. 1687); (b) "Participants experienced ethical anguish when either they or a fellow nurse did not adhere to the principles of standard nursing care, even in situations where they were not expected to lie or give excuses for the behavior" (p. 1688); (c) "Participants sometimes experienced moral distress when they were provided with limited autonomy in decision-making during situations where they disagreed with patients' familial caregivers and/or physicians over a course of treatment" (p. 1688-1689); (d) "Ethically misguided behaviour of physicians (e.g., discontinuing treatment when the patient or family is unable to pay or not being truthful with patients) often caused participants moral distress" (p. 1689); and (e) "Administrative policy

that was deemed ethically misguided often caused participants moral distress" (p. 1689).

Parallel with the findings of my research with DSPs who support people with ID and pSCB, the participants in Choe et al. (2015) were torn in situations that they felt threatened patients autonomy and dignity. In addition, the influence of powerful others (e.g., parents, physicians, policy) also contributed to these nurses' experiences of moral distress. As presented in the grounded theory explication above, DSPs also expressed feelings of distress when their personal opinions conflicted with others who were perceived as handing down directives by which they must abide. Also similar, the nurses in Choe et al. exhibited aspects of moral distress when they felt their own autonomy was abridged. Certainly, the experiences of DSPs as presented here have significant crossover with this as well.

Musto and Schreiber (2012) utilized grounded theory to "to develop a substantive theory of the processes mental health nurses use when they experience moral distress" (p. 138). In order to address this aim, these authors interviewed 12 nurses who worked in mental health settings with adolescents. Per Musto and Schreiber "most participants identified that the experience of moral distress began after an event that involved safety [and] viewed keeping the adolescent safe as one of the primary responsibilities of their nursing" (p. 139). In order to address feelings of moral distress, the participants in Musto and Schreiber had ongoing conversations with a variety of others including "supervisors, peers/co-workers, professional bodies, and friends and family" (p. 141). When these conversations were seen as productive, participants reportedly experienced changes in their views of concerning events. Overall, Musto and Schreiber developed a grounded theory of "doing the best I can do" (p. 139) to encapsulate their gathered data regarding how nurses in these situations cope with experiences of moral distress.

Congruent with the described experiences of DSPs in the present study, the nurse participants in Musto and Schreiber (2012) evidenced a refrain of safety as a primary component of their jobs. Also similarly, DSPs spoke at times about 'doing your best' to cope with the twists and turns of being between. Dissimilarly, while the nurses in Musto and Schreiber used pointed dialogue to cope, few DSPs spoke about how they might talk through their conflicts with others. Granted, there were no questions directed at this topic in my work with participant DSPs and thus, it remains unclear what variation of coping mechanisms they may utilize.

A Comparative Summary of Being Between and Studies of Moral Distress

As discussed above, it appears that there are significant parallels shared within the theories of, and research regarding, moral distress and the concept of being between. There are however, some key differences. From what could be surmised in these data, nurses and other healthcare providers, in the situations explored in the studies above, have relatively brief contact with the individuals in their professional care. Even if an individual were in an extended care setting, the relationship length may be short compared to the contact between certain DSPs and individuals with ID in community-based programs, which can extend over many years of hours long, daily contact. In other words, the situation of moral distress may pass for the above nurses as a person is discharged from care. DSPs however may be contending with the results of being between for many consecutive years with the same individuals. Secondly, the boundaries and depths of relationship may differ between nurses and DSPs. Nurses, it may be assumed, have a more clearly demarcated set of duties and roles with the people who temporarily become their patients. DSPs, on the other hand, may have such a huge variety of roles in the lives of people with ID that it feels like a little bit of

everything. The title 'nurse' is likely more constrained than the various titles for people who work as DSPs in community based settings. In relation to this, DSPs may support individuals with ID and pSCB in a wide variety of settings (i.e., residential, general community, employment locations, group day programs) that each involve a myriad of conditions and interactions wherein they are between. Nurses, in contrast, often operate in contained, institutional settings with presumably highly regulated sets of actions. In addition, nurses are licensed, and depending on the area, may have professional oversight boards to address complicated situations. In other words, nurses, while distressed in the above situations, may have greater options for seeking resolution and the professional potency to do so. Lastly, in the sample of DSPs there were instances of being between involving both the actions of individuals in their care as well as with other involved parties. The conflicts of participant DSPs involved legal as well as hard to define social factors connected to sexuality and possible sexual expression. Other than the participant experiences examined in Musto and Schreiber (2012), few such events were present in the reviewed moral distress research.

In summary, while the concepts of moral distress and being between share significant overlap in the emotional consequences of conflicts of opinion and power, there are areas wherein the two diverge due to highly differing conditions and actions/interactions. Nonetheless, moral distress presents a related and supporting theory to being between. From a different perspective, it may be argued that 'Being Between' plays a causal role in the experience of moral distress. When between, one is torn amidst competing forces of powerless self and powerful other(s), concepts of right and wrong, ethical and unethical. If, as in the experiences of the DSP participants in this research, such rifts are influenced by undercurrents of deep care for and long term connection with the individual who is ultimately

subjected to the divergent forces, then the result may be a situation of extended moral

distress. One is then left adrift in a sea of options that may be seen but not accessed while

others control the rudder and potentially place blame for errors in navigation. A theoretical

perspective, which may speak to the interplays of these forces, is engaged to further analyze

these data below.

These Data as Seen Through the Lens of Foucault

As related in the beginning of this chapter, in the tradition of grounded theory, I

endeavored to remain open to these data in order to allow the participants' words to emerge

into findings. Such endeavors must, however, always fall short as nearly every researcher

enters a project with preconceived notions and ways of organizing or explaining the

dynamics of the topic at hand. I will address many of these confounding factors in a section

that follows this (Subjectivity in this Research). In the present section however, I examine

these data through a theoretical lens stemming from the works of Michel Foucault, and

extensions thereof by subsequent authors of the Foucaultian tradition. As stated by

Drinkwater (2008) "what we can do, with the help of Foucaultian tools, is to acknowledge

and begin to describe tactics of power and strategies of freedom, and in doing so open up a

critical space" (p. 241). Specifically to these ends, I analyze portions of these data in

reference to Foucaultian concepts of sexuality, power, the subject, and the Panopticon.

Sexuality

In Chapter One I provided a summation of how matters of sexuality have, in many

ways, influenced the creation and course of systems of supports for people with ID in the

United States for much of the past 150 years. In brief review, via denial, eugenical

sterilization, isolation, formal measurement, and enacted concepts of risk versus rights,

American systems of supports for people with ID have historically struggled to address sexuality. In the present study, DSPs described perspectives, techniques, and frustrations related to these same concepts in current practice. Per Foucault (1976/1990), "we must conceptualize the deployment of sexuality on the basis of the techniques of power that are contemporary with it" (p. 150). These conceptualizations were essential to Foucault

> not to determine whether one says yes or no to sex, whether one formulates prohibitions or permissions, whether one asserts its importance or denies its effects, or whether one refines the words one uses to designate it; but to account for the fact that it is spoken about, to discover who does the speaking, the positions and viewpoints from which they speak, [and] the institutions which prompt people to speak about it… (1976/1990, p. 11)

When considering the statements of participants, interactions regarding sexuality of people with ID were often framed as avoided or non-existent within certain structures of the supports systems wherein they work. For example, when asked about the possibility of intimate, perhaps sexual, relationships for people with ID a participant responded,

> *I don't think it is encouraged as much as everyone says that it is. I don't. And like I said – I think it's stigmatized. I don't think people want to talk about it as far as direct support. It's something that people don't want to face head on. It's something that people just want to look away from and ignore. And I think its something that people view as negative. All the time. Across the board.*

In the above excerpt, this participant appears to imply that the issue of sexuality for people with ID may be spoken *around* in systems of support (i.e., *"everyone says that it is"*) but rarely spoken *about* or enacted except, perhaps, via denial or avoidance. As to the results of

these actions/inactions, this same participant later stated, *"It's all bullshit."* This was

similarly reflected in a more metered tone by another participant:

> *I think they try to work on it and I think they are trying hard to change it by getting*
>
> *people more dates, exploring healthy relationships. So, that's changed. In a way,*
>
> *that's changed. I don't know about sexual relationships, how people feel about that in*
>
> *the workforce in this field. I think it's still kind of taboo I guess. I don't think a lot of*
>
> *people support it. I don't even talk about it much. We just talk about it when it comes*
>
> *up.*

Again, per these participants, a restricted nature of dialogue regarding sexuality for people

with ID appears to be present in parts of this contemporary system. Avoided until *"it comes*

up" implies a passive or purposeful ignorance that echoes with much of the history presented

in Chapter One. Beginning in the 1800s when, as Foucault (1976/1990) summarized,

> sex gradually became an object of great suspicion: the general and disquieting
>
> meaning that pervades our conduct and our existence, in spite of ourselves; the point
>
> of weakness where evil portents reach through to us; the fragment of darkness that we
>
> each carry within us: a general signification, a universal secret, an omnipresent cause,
>
> a fear that never ends, (p. 69)

and continuing to the eugenicists' eliminative efforts, and institutional isolation, sexuality for

people with ID has been, and continues to be, at least partially informed by elements of

denial and direct or passive repression.

Sexuality for people with ID, from a Foucaultian perspective, is not so much about

whether or not the physical actions of intimacy and intercourse occur, but that this topic

continues to be avoided or not directly spoken about even within groups who, at times, may

speak about and direct nearly every other aspect of peoples' lives. From one participant's perspective, such avoidance of support was in direct opposition to her observation that "*I think a lot of clients just want to have sex. They don't know how to do it right. They just want to do it*". Expressing how this might be changed to a more open dialogue, another participant reflected, "*They* [people with ID] *have to want to talk about it. I think you should try your hardest to get them to talk but they have to want to. If they can*". When, however, matters of sexuality do 'come up' in these structures, when individuals with ID want to and are capable of expressing themselves regarding sexuality, the outcome may also revert to one of redirection or delay. This was reflected by a participant who described,

> *when you're in team meetings and talking about it* [sexual relationships] *and you're going "Ok this is your opinion, and this is what you believe is happening but this is not what they want." They* [people with ID] *are sitting there screaming that they want to have sex and they* [the team members] *are going "Well, why don't we prolong this until after they do the relationship three-tier class", which is going to take them like a year and a half to do or they are just pushing it longer and longer and longer so they don't have to deal with it.*

Another participant used a personal comparison to highlight the overall result of these dynamics:

> *I mean because we have rights to make the mistakes that we do but I mean we have the choice of when to have sex as adults, and we've kind of robbed them of the choice. Because they're intellectually disabled they don't have a choice.*

It is important to note with the above that this participant was speaking in a sardonic or irritated tone. Indeed, as presented earlier, several participants expressed frustration with the

lack of conversation or 'desexualizing' of people with ID. This, in conjunction with their hope for greater emphasis on education and talking openly about these matters, places these DSPs between "who does the speaking, [and] the positions and viewpoints from which they speak" (Foucault, 1976/1990, p. 11). From the perspective of these DSPs, sexuality should be spoken about but is not. When people with ID 'do the speaking', it may be met with resistance and redirection from others who, it is implied, make decisions regarding "the administration of bodies and the calculated management of life" (Foucault, 1976/1990, p. 138). It is then the duty of the DSP to manage others' calculations in a system where *"you feel like you're muted".*

Flowing beneath the above are matters of power. Who speaks about sexuality for people with ID, and when or to what ends, may include DSPs and people with ID but only insofar as DSPs "function within a hierarchy, an organization to which the service user relates, but of which that individual is not a part" (Drinkwater, 2008, p. 235). Tasked with providing encompassing supports for people with ID, their voices, and the voices of people with ID, seem to be overwhelmed when applied to matters of general sexuality.

Power and the Subject

As introduced above, the findings of this research suggest that sexuality for people with ID may be enmeshed within complex systems of interaction wherein some invested parties may directly or indirectly further silence voices already resistant to speak. These complexities are further heightened when possibly sexual actions by people with ID are labeled in certain ways. In order to assemble a framework for this analysis I will first provide a brief summary of the Foucaultian terms and perspectives regarding power and the role of 'the subject'.

In the Foucaultian lens, the notion of power laid not just in the towering institutional edifices of official rulers and systematized hierarchies - though these certainly caught his attention (Foucault 1975/1995). Power, in Foucault's (1982) concept, was also a historically embedded, entrenched presence throughout all human interactions

> which categorize the individual, marks him by his own individuality, attaches him to his own identity, imposes a law of truth on him which he must recognize and which others have to recognize in him. It is a form of power which makes individuals subjects. There are two meanings of the word 'subject': subject to someone else by control and dependence; and tied to his own identity by a conscience or self-knowledge. Both meanings suggest a form of power which subjugates and makes subject to. (p. 781)

Further, for Foucault (1982), power was "a mode of action which does not act directly or immediately on others. [Instead,] it acts upon their actions: an action upon an action, on existing actions or on those that may arise in the present or future" (p. 789). Thus, due to interplays of power, certain individuals are labeled as subjects and then subjected to the governing limits decided by others.

In the above section it was evident that the 'subject' status of people with ID (i.e., the fact that they are labeled with ID) sometimes results in their being subjugated to relationships wherein powerful others decide courses of action regarding their sexuality. As Brown (1995) argued, the application of a label intended to provide greater degrees of equity may also result in some loss of equity and social power for the individual so labeled. In her words, "legal recognition becomes an instrument of regulation… political recognition becomes an instrument of subjugation" (Brown, 1995, p. 99). Brown's dissection can be juxtaposed with

Petersen (1997) who noted, "[a]ny type of difference can potentially be objectified, and made a basis for assigning a special destiny to certain categories defined in this way as a matter of political will" (p. 194). These arguments dovetail with what Foucault (1982) defined as a "*system of differentiations* which permits one to act upon the actions of others" (p. 792, emphasis in original). Evident at many points in these data, however, participants appeared to be resisting the simplicity by which certain labels applied to people with ID and pSCB (e.g., deviant, pedophile) can become that person's reality and thus create a 'subject' from the individual. Or, as Foucault (1982) stated, "Every power relationship implies, at least *in potentia*, a strategy of struggle, in which the two forces are not superimposed, do not lose their specific nature, or do not finally become confused" (p. 794, emphasis in original). For example, in the following excerpt a participant related the development of her current understandings:

> *Some of those stories I heard in the beginning – I hate to say it but I was judging the*
> *person. I could see how you would be like 'This person is never going to change.*
> *That's disgusting. How could they do that?' But then you get to know the person. You*
> *get to know that that is not really who they are…So, my opinion has greatly changed.*
> *That's something they have done. But, it's something that they are working on and*
> *it's not that person. It's just part of who they are.*

Similarly, another participant recalled,

> *When I first started we were more a program geared to working with these types of*
> *individuals who had inappropriate sexual behaviors so I was kind of whacked over*
> *the head with it right away. So right away it was like, 'Whoa, whoa – you can't do*
> *that. You can't think that way. You can't do that." And then of course, getting*

through it, getting to know people more, seeing things around me – it's not exactly

like that. Not everyone is a deviant. Not everyone is out to sneak around and hurt

each other. It's natural. It's, these people that have to sneak around, that have to be

manipulative, that have to be deviant just to get away with something. Sometimes it's

as simple as just a kiss. Some of these people have to hide, sneak, just to kiss and 'Oh

my gosh, if someone finds out that you snuck around the house just to kiss some other

dude then you are manipulative, you're a liar and we've got to shut all this down

because we can't trust you. Now you need extra staffing. Now you two have to be

separated' What?! You know what I mean? Seriously, they didn't do anything wrong.

In the above, this participant lays light on the manners by which certain sexual histories can

create a set of interventions that themselves play a causal role in further actions. These

actions, that are framed as a reasonable response to label-based limitations, are then

recursively re-labeled as a part of the nature of this individual (i.e., *"they have to be deviant*

just to get away with something") and potentially used to further justify restrictions wherein

the individual becomes "subject to someone else by control and dependence" (Foucault,

1982, p. 781). This cycle of the subject and related powers was also reflected by other

participants in the following excerpts. As one participant stated,

To me, what's really really challenging with individuals with sexual behavior issues

or concerns I guess we should say, is um, I think that there's a tendency to over do it

where anything and everything they do can be misconstrued as doing something

inappropriate when it's not always.

Similarly, another participant explained,

I think that they are under a microscope. If they mess up once then it's on their record

forever. And it's like, 'This is the way you are going to be forever and you're never

going to learn how to be, how to have a normal relationship'…It's just like, 'You did

this and this is who you are now'.

Further, in a close reflection of Foucault's alternate meaning of subject, which referred to

how a person becomes "tied to his own identity by a conscience or self-knowledge" (1982, p.

781), another participant summarized,

Sometimes, it's about 'This is how so many people for so many years characterized

you and it's how you're supposed to be'. And I think that they believe then – 'Well

this is me, I'm this person because this is how they've treated me for so many years.

This is how I'm treated. This is how my plan says I am.' And I think that they get

comfortable being a certain way because that's how they've been told. They've been

told, 'This is you'.

Last, one participant voiced discomfort with the gestalt of these powers that create subjects

stating, "*Why do we have to label it? We label things and why do we have to? A person is a*

person. Whether he has problems or not – he's still a person…They see clients – I see

people".

Such conflicts were described by Foucault as,

struggles which question the status of the individual: on the one hand they assert the

right to be different, and they underline everything which makes individuals truly

individual. On the other hand, they attack everything which separated the individual,

breaks his links with others, splits up community life, forces the individual back on

himself, and ties him to his identity in a constraining way. (Foucault, 1982, p. 781)

In essence, participants provided a sense of struggling to accommodate multiple perspectives and assumptions. It might be relatively simple should these struggles be contained within the dyads of DSPs and the individuals with whom they work. Each of these actions/interactions are, however, embedded within dissonant matrices of power wherein the perspectives of DSPs, though based upon close relationship, may not be given equal, if any, weight. Regardless of these discords, DSPs are in positions that sometimes require enacting restrictive or avoidant measures in the lives of people with ID. In certain cases this requires a set of monitoring strategies and actions of direct confrontation that involve continuous and minute observation.

The Panopticon

Per Foucault (1975/1995), the Panopticon was proposed as a model for prisons by Bentham in the later half of the 19th Century. Specifically, Foucault described Bentham's Panopticon as a prison with a large central tower concentrically surrounded by another tower of isolated cells. From within the shadowed central tower, guards could observe the actions of all without themselves being observed. For Foucault, the physical structure of the Panopticon was secondary to the underlying intent – the application of technologies of constant surveillance aimed towards the government of others' behavior. As stated by Foucault (1975/1995),

> "The Panopticon…must be understood as a generalizable model of functioning; a way of defining power relations in the everyday life of men…It is polyvalent in its applications; it serves to reform prisoners but also to treat patients, to instruct schoolchildren, confine the insane, to supervise workers…It is a type of location of bodies in space, of distribution of individuals in relation to one another, of

hierarchical organization, of disposition of centres and channels of power, of

definition of the instruments and modes of intervention of power, which can be

implemented in hospitals, workshops, schools, prisons. Whenever one is dealing with

a multiplicity of individuals on whom a task or particular form of behavior must be

imposed, the panoptic schema may be used" (p. 205).

There are several examples of these concepts within the data set of this research. For

example, one participant stated that when working with people with ID and pSCB,

You need to be aware of your surroundings at all times. A lot of people say this is an

easy job. And it is an easy job but you've got to be on top of everything. You need to

be aware of your surroundings. You need to know what they are doing. It is easy but

you've just got to be focused is all. You've definitely got to be focused and be aware

of what is going on at all times.

This sense of constant observation was reiterated by another participant who described,

You're not paying attention to anything else but what he's doing or what he's looking

at and trying to figure out what he's thinking. And if his eye, his head tilts slightly this

way and he starts staring at a child. Yeah.

A further participant described the job as being "*literally on guard like the whole entire*

shift…it's your job to almost play every single role. To keep everybody safe." For another,

participant the comparison to correctional systems was, in some situations, more direct as he

stated, "[it's] *like a penal system where you're kind of like 'No, you can't do this'…I feel like*

I'm the jailer". In addition to these efforts of vigilance and micro observation, the 'on guard'

participant above related how any relevant sexual data may be passed along to others

involved:

If something happens at home they have to let us know so if they are acting weird that day – that's why. So a lot of it is just communicating with the teams. A lot of the time I'll be driving them to work and they will tell me and they haven't told their team. We'll pass by a place and they'll be like 'Oh [name of business] *– that's where guys hook up. I've hooked up with somebody there'. And I feel that you have to stay in complete communication with the whole entire team in order to help that person.*

As stated by another participant, when issues of sexuality or pSCB occur, the job of the DSP includes efforts to "*let the house manager know, let the service coordinator know, the [behavior therapist] know, the guardians know*". In a more emphatic statement a further participant summed it up as follows:

'Oh you want to be with this person? Well we need to talk to this person, this person and this person. And then we'll need to talk to this person, and this person, and this person. And then these people need to meet and talk about it. And then, when we finally do – you all can go and have a coke somewhere but we're going to have two people at the table over there watching it'.

For this same participant, certain efforts of monitoring and communication were anathema to his concept of sexual rights:

We talk about 'You have the same rights as I do.' No they don't. That's bullshit. 'No you don't. You need 15 people's permission for me in my car to take you to buy a Playboy. And we all know what you are going to do with that Playboy. How does that make you feel? Then you go in your room with the Playboy and I saw you shut the door and I saw you take the Kleenex box with you. We all know what you are doing.' What is that? It's – no rights.

Such continued conflict may be a result of these constant observations and reports as "this form of power cannot be exercised without knowing the inside of people's minds, without exploring their souls, without making them reveal their innermost secrets. It implies a knowledge of the conscience and an ability to direct it" (Foucault, 1982, p. 783). In this panopticon of sexuality for people with ID, the smallest gestures are noticed, all actions are analyzed, deeply personal preferences and perceived transgressions are shared with the chorus, leading to further levels of focus on the minutiae of a person's daily life.

The ultimate goal of panoptic efforts was to induce individuals to become their own guards; to internalize the process and act as if the powerful observer was there even when absent (Foucault, 1977/1995). In these data however, it is suggested that engagement of all seeing observers and managers of sexuality may serve to increase the very behaviors they were designed to eliminate. In the words of one participant,

> *Some of them will touch themselves and do an inappropriate thing like that per se with other people being around but there are always other people around them. All the time. So, where's your boundary? You're going to lose that pretty quickly. I imagine if I was one of them I'd end up masturbating around other people. Like, 'What are you going to do about it? Leave me alone.' [laughs] ... You don't really, apparently you're not supposed to have sex or any sexual feelings or want to do anything around that but you also don't get a sense of privacy either so you lose that because there's always someone in your space. Someone always around. So, you're not really given time to be with yourself or with your own thoughts necessarily.*

In combination, the observation and communicative aspects of this panoptic schema was seen as a significant source of conflict for one participant. In his words,

What it does is it leads to disappointment. It leads to frustration. It leads to anger. And then it turns into probably some form of manipulation. I know if it was me, I'd be going behind everyone's back. I'd be the worst client in the world. I promise you that. Tearing shit up. And then it trains them not to trust. We ask these guys to trust. "I will help you. Tell me your feelings. I will help you. Trust me with this stuff." Yeah, trust me and then I'm going to go tell 15 other people what you just told me about what turns you on. You know what I mean? Like, it's bullshit.

Again, in these examples, the effect of the panopticon is reversed from its intent. The targeted behavior becomes more frequent or less inhibited despite, or perhaps due to, the incessant presence of others, their watchful gaze, their constant communication, the "'apparatuses of security' that are necessarily installed inside of a power…that reigns over people by regulating and positioning them" (Waldschmidt, 2008, p. 192).

It is important to note that these actions and interactions of surveillance do not occur in a vacuum. Indeed, the watchers may be themselves watched; their fidelity to plans monitored by increasing hierarchies, which hold further powers to ensure compliance:

I: Why do you think that is? Why are there all those steps?...

P: Just everyone covering their bases so they don't get in trouble.

I: Who gets in trouble?

P: The whole team.

I: From who?

P: The state…Yeah. By the state, by the maybe behavior therapist, maybe the director of the company. I mean if you consent to all this stuff without going through the

proper steps someone will get in trouble for it. So you've got to go through the proper

guidelines. Which, you know, it's not fair to them.

Thus, in summary of the above, the effects of the panopticon may be as intended for DSPs and perhaps for others professionally involved. They monitor and regulate their own surveillance and reporting behavior despite the absence of direct observers. So, while the effects may be as intended for DSP compliance, the overall effects of these multiple layers of observation on people with ID may actually serve to at least partially perpetuate their continued 'necessity'.

In addition to the above, the holistic mechanisms (e.g., education, social coaching, employment support) utilized in support of individuals with ID and pSCB as described by participants remain reminiscent of Foucault's general concept of the prison. Again, speaking of more philosophical notions rather than objective brick and mortar correctional facilities, Foucault (1975/1995) described the prison as "omni-disciplinary…[in that] prison must be an exhaustive disciplinary apparatus: it must assume responsibility for all aspects of the individual, his physical training, his aptitude for work, his everyday conduct, his moral attitude, his state of mind" (p. 235-236). Extending from this same passage, Carlson (2008) stated, "the institutions for the 'feebleminded' were 'omni-disciplinary', insofar as they monitored, studied, documented, taught, punished, and trained their inmates in the hopes of making them useful human beings" (p. 143). It is tempting to take Foucault's and Carlson's respective historical trails from prison to institutional correlates and simply extend them linearly into explanations of contemporary systems of supports for people with ID. Drinkwater (2008), however, contended that this "tendency to seek institutional remnants…precludes the analysis of new forms of power at work, new types of relation,

different kinds of actions upon actions, different techniques for inciting desired behaviors"

(p. 232). So, while these intricacies of 'omni-disciplinary' efforts across the range of human

behaviors and responses are present in the overall relationships between DSPs, they are, in

many ways panoptically enhanced when matters of sexual concern are present. Specific to

the aims of this study, certain of Drinkwater's 'new forms, and types' may be seen in the

power, relations, actions, and techniques described by participants in relation to prevention

and response to potential or actual instances of pSCB by the people with ID whom they

support.

From an alternate perspective, some of these panoptic measures (i.e., monitoring and

responding to eye gaze via confrontation or redirection) could be considered beneficial uses

of power due to their potential to protect individuals' continued freedoms in the community.

Per Tremain's (2008) summary of Foucaultian 'positive power', "although modern power

appears to regulate life in purely negative (repressive) terms by prohibiting and controlling

subjects, it actually governs them by guiding, influencing, and limiting their conduct in ways

that accord with the exercise of their freedom" (p. 10). In other words, without the "systems

of surveillance" (Foucault, 1982, p. 792) enacted by DSPs in the community, the larger

freedom of certain individuals with ID could be jeopardized due to possibly sexual actions

directed at others. By limiting certain immediate freedoms of action, these concrete and

abstract structures may help to ensure longer-term liberties. This is akin to Stainton's (1994)

postulate that the only reasonable restrictions to another person's autonomy occur when one

is attempting to ensure or protect that person's relatively larger freedoms and related

autonomies. In specific, certain actions described by participants as preventative or

responsive technologies directed at certain instances of pSCB (e.g., confrontation of certain

types of staring, avoidance of, or removal from certain locations/activities) may be seen

under the mantle of Foucaultian (1982) 'positive power'. From this perspective is it unfair to

characterize the work of DSPs in these conditions as akin to a prison or Panopticon of ill

intent. Each of these men and women were clearly dedicated to increasing the skills, abilities,

and integration of the people whom they support regardless of involved histories. Indeed,

their actions at times were clearly aimed and framed as efforts to help keep individuals from

engaging in actions that might or would likely lead to criminal justice involvement. It is,

again, tempting to connect these practices to the threads of institutional practice based on

containment and conclude that we have created community-based institutions. This is too

easy; too dismissive of the intricacies involved and the actions or intents of these

participants. In the alternate, we may consider these efforts from Drinkwater's (2008)

concept of new forms and types of power relations. Participants described working in support

of individuals with histories of alleged or adjudicated sexual actions against others. Hearing

of these histories frequently leads to intense emotional reactions from others. In many cases,

as demonstrated above, initial reactions of disgust and directed power by DSPs in this study

were replaced over time with a sense of empathy, connection, and focus on the future. Their

eventual engagement of power, observation, and the life-wide supports Foucault framed as

part of 'the prison' are in some cases perhaps more liberating than any truly institutional

alternative.

In summary of the above analyses, the experiential descriptions provided by

participants in this research touch on many aspects central to Foucaultian notions of control,

power, and the subject as related to sexuality for people with ID. In each area the interplays

of these forces are bidirectional. Participants described enacting aspects of governmentality

over people with ID while themselves being governed from multiple sources. Their words reflect a resistance to powerful forces of labels of the subject on the people whom they support. This occurs while they are themselves often placed into positions of the silenced subject due to external powers. In effect these DSPs often appear to be managing a panopticon of vigilance and constant awareness related to others' sexuality while themselves being observed from secondary and tertiary panopticons. Tendrils of the history of sexuality and ID may certainly influence some of these practices. What one may see in the current context, however, represents a novel juxtaposition of rights and risk with a constant gaze upon the "fear that never ends" (Foucault, 1976/1990, p. 69).

Power in the Interview Process

Just as matters of power intertwined within the data, power may also have played a role in its collection. Specifically, the difference in roles and professional positions between interviewer and participant could have influenced participant responses. According to Våhåsantanen and Saarinen (2012) the role of power between researcher and participants, may be directly addressed during an interview process. In order to assess for the possibility of interviewer/power differential I undertook a direct approach as described below.

As a part of the interview guide all participants were asked if they felt there was anything about the process, or me as the interviewer in particular, that might have changed the ways they responded to questions. As a preamble to this, each participant was made aware of my role as a doctoral student and the aims of the research during informed consent procedures. In addition, my other professional roles (i.e., licensed counselor, employee of the Department of Health) were addressed verbally and in writing. Specifically, I explained that my other professional roles were separate from the interview and research process. The one

exception, as explained to all participants verbally and in the written informed consent document, was if they spoke of instances of abuse, neglect, or exploitation of a person with ID who was identifiable, I would be required under my counseling license to report these events to state oversight agencies. No such instances occurred at any point.

In response to the question of interviewer effects, all participants responded along the same vein. While some simply stated 'No' and spoke no further about the topic despite prompts, others were more direct. One participant stated, "*I don't think so. I'm pretty straightforward with how I feel about this line of work*". Similarly, another participant responded, *"Not at all. I mean we are out and about, I'm off the clock, you are doing a paper for your thing, just two men talking about stuff that is important to both of us. So, no holds barred. I'm with you right now"*. Likewise from a further participant: "*I think there was a lot to think about so I'm not sure if I touched on everything but honestly I was completely comfortable*". For another participant, the relatively anonymous aspect to the interview was framed as a reason for her openness:

> *No. I don't think. Because I don't know you and you don't know me. So, we are talking as two individuals so therefore I am not higher than you. You are not higher than me. So therefore, we are just two individuals talking. I don't think it has any impact whatsoever. Whatsoever. You ask a question and I answer it and that's the end of that.*

In other cases, participants expressed that the opportunity to talk about these topics was welcome and, perhaps, increased the depth of information shared. For example, as one participant expressed, "*The fact that you wanted this pleased the hell out of me. The fact that*

somebody wanted to get our perspective on it pleases the hell out of me". Similarly, another participant stated,

> *No. I'm like an open book kind of person. I'll talk to anybody about any thing if they want to talk about it. So it's unfortunate, I don't even get the opportunity to talk about these kind of things a whole lot so I'm probably being more open than usual because generally speaking I don't have a very popular opinion in IDT meetings and I've stopped trying to express it in some cases. Um, but, its actually a good opportunity to get to talk about it more.*

In another case, my particular former role as a BSC in this waiver system were mentioned but stated to not have had an effect:

> *No. I answered how I feel. I know you were what you were before so your point of view is probably different than mine but that's how I feel about it. I'm not, you may agree with some of what I said or maybe not. But, that's not the point. The point is for me to tell you what I feel about it so…*

For another participant my other professional role as a state employee was referenced as a potential positive factor:

> *No, No. It's probably because you do work with the state that I would answer the questions the way that I did and being more truthful. Because if you were just somebody like asking these things from the outside who doesn't have to sign confidentiality agreements and all that stuff I probably wouldn't give you that much information.*

This was also reflected in the words of another participant who stated, "*I have a good comfort level with you. I've been honest with you. I haven't felt intimidated. I've heard your*

name a lot over the years". Lastly, for one participant, the research endeavor itself was framed as having a positive impact on the interview process. In his words, "*I think I feel more open with you discussing because I know you are pursuing an academic reasoning behind it. You're looking for qualitative data. You're looking for more of that versus if someone was just a BSC or whatever".*

Overall, it appears that the inherent power differentials in interview-based research were not a significant factor in the depth or nature of the information provided by participants. The certain participants, however, who declined to speak on the topic beyond basic denial may have done so due to the power differential itself. Perhaps the inherent inequities prevented them from responding in more forthright manners. Regardless of participant statements as outlined above, it is possible (if not likely or assured) that my presence and the nature of the interview relationship itself impacted the ways participants responded to questions and/or the depth of information provided. This is an inescapable factor in all interview based research and is addressed below in the section outlining limitations of this study.

Subjectivity in this Project

Along with my biases toward the naturalistic paradigm and the works of Foucault I am a person with a particular history and set of assumptions that likely influenced aspects of this research. This includes but is not limited to choice of topic and questions, methods of investigation, and reaction to or partitioning of participant responses both in vivo and during analysis. Below, I discuss the particular factors of my reaction to the data, how these may relate to pre-formed assumptions, and my position and both insider and outsider within this

project. Many aspects of my history as related to general and specific aspects of this project are presented in Chapter Three and are briefly referenced or recalled below.

Strongly Held Beliefs

To review, in Chapter One, I outlined certain of my strongly held beliefs as written before any data collection began. These were:

- Dignity of risk and human rights are a constant refrain in many aspects of support for people with ID in our current system of support;

- Issues of sexuality are regularly framed in these terms but few professionals seem to understand how to consistently enact support from these frameworks;

- When confronting issues of sexuality and ID, DSPs are at the crux of the risk and rights process;

- There are DSPs who do an exemplary job of balancing the issues of risk and rights regarding sexuality on an individualized and daily basis;

- There are also DSPs who struggle with how to support rather than control or manage the sexual expression of people with ID;

- This may often be due to the competing voices around the table – the demand that nothing go wrong coupled with the mandate to not violate rights;

- We are still trying to integrate and sometimes eliminate attitudes and practices that can be traced to all portions of the historical conversation regarding sexuality and ID;

- The default position in our current system of support is to restrict, limit, contain, and monitor.

Upon review of the above, I can see clearly that there is significant crossover between these beliefs, the findings, and my subsequent analyses. It is possible that I 'found what I was

looking for' (i.e., confirmation bias). It is also possible however, that my invested and often 'insider' work in this topic allowed me a perspective close to the truths as spoken by participants. Further exploration of my positions, their potential effects, and my reactions may be found below.

Throughout all portions of this project I have felt a deep connection to the topic, the participants, the process of coding, the thinking through (and around, and over, and underneath), the write up, edits, and ideas for the future. Because of these connections I endeavored to be true to the data; to return to recordings and transcripts as a matter of habit; to sometimes incessantly write notes on conflicting or cautionary thoughts; to avoid reading from my previous writings or related literature; to follow the guidelines of method. So, while I am not surprised by the findings I hope that others may see them with fresh eyes, ask different questions, and seek to find 'new or forms or types' within these pages.

Personal Process

It is fitting that as I write these words I am in the same restaurant, sitting in the same seat as I did when conducting two of the interviews. This was unintentional and realized only after an hour of editing other sections of this manuscript. I can still clearly hear the words of these participants, as well as all of the others, ringing in my head. From proposal to final draft, my process of research has been swirling in thoughts and actions of multiple levels. Despite the number of pages and hours devoted to this research I could spend just as much time, fill just as many lines with other thoughts, courses of consideration, conflicts, and personal reflections. This to me is the nature of qualitative or naturalistic research. If there are multiple truths then one may continue to find them long after one has stopped looking.

From choices of topic and study site, to formulation of research questions and interview guide, to coding decisions, theoretical musings and analyses, I am constantly reflected in these pages. Until my conversations with a critical friend I had struggled to figure a way to discuss my experience in this house of mirrors that is qualitative research. With her assistance, I came to better understand that if I was reflected in the theory then I could use the theory to reflect upon myself.

My Personal Experience with 'Being Between'

As I pondered on and developed the grounded theory of 'Being Between' as presented above I thought about many other individuals I have known who work within this and other systems of supports for people with ID. I reflected on how they too might feel 'between' at times when dealing with complicated matters of another person's sexuality. I began to notice these navigations in other interactions of my daily work. Secondary to my work with a critical friend I began to consider the interplays of my own 'betweens'. Following our conversations, I was overwhelmed with reflections about how I too may often sit in the middle in both concrete and abstract manners. Currently, I am between positions of student, teacher, and state employee. In each position I have responsibilities that are all related to systems of support for people with ID, which often involve matters of sexuality and risk. My framing of risk and rights may fluctuate depending on 'who' I am at a given moment, in a particular meeting or classroom or conversation. Thus, I am consistently between feeling like I understand and feeling like I have so much more to learn. Over the past year I have facilitated several trainings across the state on the often difficult conjunctions of dignity of risk and duty of care. In each session, and particularly since my conversations with my critical friend, I am struck with how I am often doing this training for

myself and my own attempts to understand rather than just for the attendees. In each session I adjust this slide or that example after fretting about how it does not fit or truly access the tensions I see as a nearly daily event in my work.

Corollary to the above, I am between outsider and insider to this topic, these data, and the participants who provided it. As an insider, (i.e., from an emic position) I am deeply invested in the topics of sexuality and related rights for people with ID. Through the course of proposing this research I read as much on the topic as I could find. In these ways I am an academic insider to this topic. In addition, I am also a personal and professional insider. I knew some of the participants through years of work in this system. I have worked with them in some of the situations that were described. In these situations I cautioned myself via memos to simply focus on the words spoken rather than what I thought the participant might have meant. During interviews I endeavored to ask clarification of terms or situations even though I might have had direct knowledge thereof. From a wider professional emic perspective, I oversee the statewide project to assist teams with situations of possible sexual risk for people with ID. Again, many of the particular situations described by DSPs in this project were known to me either from direct work with individuals and teams or via word of mouth communications from people I oversee in my professional position. Due to these factors, throughout the research process and up to the writing of these words, I focused on regularly reflecting on how I may be reading into the statements, hearing what I wanted to hear and organizing it as I would rather than as the participants were. Through these efforts and reflections I decided to utilize the organizing structure (i.e., conditions, actions/ interactions, and consequences) provided by Corbin and Strauss (1990) rather than some of the personal organizing schemes I had developed during initial analyses. To further address

these concerns I also endeavored to provide as much voice to participants as possible in both the previous and current chapters. While not a perfect replication of the words as spoken (i.e., inflection, body language) or the complete transcripts, I believe these methods allow for readers to access a depth of the data and potentially find different truths.

As an outsider to these experiences, there were several participants whom I had never met before and who had little to no knowledge of my work in this field. To them, I was a stranger asking questions and I had no presumptions about how they might respond. There were also many situations or sets of actions described by participants of which I had no previous knowledge. I also have no correlates in my history to the intensity of supports provided by these men and women. From this perspective I was distant from the data and those who shared it.

For many years I worked as a BSC in this system of supports. I wrote plans. I trained staff. I spent much of my time with the people with ID whose most intimate lives were shared with me. I am sure that I wrote plans that were disagreeable to all, including myself. I presented myself as assured perhaps because I feared what would happen if I did not. While I endeavored to avoid it, there were many times I failed to ask the people working as DSPs what they thought or directly sought the input of people with ID who 'received my support'. As related previously, I am currently in a position of power at a statewide level in regards to risk and sexuality for people with ID. I have taken and conducted a multitude of trainings on these topics, read as much as I can, talked with anyone who would listen, and argued with myself incessantly at times. Despite my training and experience I cannot honestly say that I have ever felt completely 'solid' on a decision regarding another person's sexuality. I find it odd that I even have such a position, that anyone has such a position, that such a position

even exists. The times I have felt completely confident were and continue to be consistently followed by tossing in bed, fretting over alternatives, and wondering why I had not seen them before. There are always exceptions, always 'what ifs', always places between where I am and where I hope to be. My experience in collecting and dissecting the data in this project also reflects this process. There are other thoughts in here; other places to find other truths. I know it. I will continue to consider them for a long time to come. From a larger perspective this process has also caused me to ask more questions of myself and the systems of supports we have created. What assumptions are we/I operating from? Is this the best we can do? Are we simply repeating some mistakes of the past in an endless cycle of slightly different details? What do the people we 'support' think of what we are doing? Are they 'between' as well? Do they know it is 'being done' or is the ocean of power so vast that one hardly notices the water anymore? What is next?

Regardless of the crossover in experience of 'being between' as a general concept, I cannot, under any stretch of metaphor, honestly equate my experience with that of the men and women who participated in this research. While I have had some limited experiences with providing direct support to people with ID and pSCB (Chapter Three), my stints in these positions were relatively brief and I never experienced the intensity of situations described by these participants. As I stated above, the stories and experiences shared by participants 'ring true' to my relatively distant perspective of their daily work. These stories will continue to reverberate with me as I endeavor to play a part in the creation and continuation of systems of supports in which all voices are integrated.

Strengths of this Research

This interview-based research with DSPs who support people with ID and pSCB was strengthened due to aspects of design, presentation, and place in the research base. I discuss these supporting factors below.

Participants and Geography

This project would be literally nothing without the time, effort, and words of the men and women who chose to participate. This particular set of DSPs, with over 120 years of combined experience working with people with ID composes a significant strength of this research. In addition to their general work, each of these participants had significant experience working with individuals with ID and pSCB, including some individuals with intense histories of actions involving children or other vulnerable individuals. This represents the first time to my knowledge that DSPs working in an American community based program to support people with ID and pSCB have participated in research to share their voices, stories, and perspectives on this particular topic. Indeed, aside from the work of Ioannou et al. (2014) in Canada and published in the newsletter for the *Association for the Treatment of Sexual Offenders*, this research currently occupies a singular space in the literature on ID and pSCB overall.

Deep Exploration and Trustworthiness

The interview utilized in this research covered a wide range of topics related to the experiences of DSPs who work with people with ID and pSCB. From the best parts, worst parts, particular events, exploration of larger concepts of risk and rights, to what these participants thought should change, a large swath of the experience as told by participants was portrayed. More than just a brief survey on a particular topic, this wide angle approach to the research provided participants with a largely open space to discuss their work from

multiple angles. While the nearly 800 pages of transcripts contain more information than could be shared in this manuscript, the included excerpts furnish a portrait of their work rich in both scope and depth.

Throughout this manuscript, in order to honor the commitment participants have towards their work and the time spent interviewing with me, I have endeavored to provide 'voice' for, and fidelity to the words of participants as shared in the interview process. Rather than parse out individual words or phrases I chose to include sometimes lengthy excerpts in order to give as much context as possible for how participants framed and developed their thoughts in various topics. In addition, in each section I attempted to include as many examples, each from a different participant, with as little repetition of excerpts as feasible. In these manners, this research and its presentation provided as thorough an exploration as feasible given some of the limitations addressed below. In addition, I undertook robust efforts (i.e., transcript review, detailed member checking of findings) to ensure that participants were given opportunity to provide feedback at various points in the process. While several participants chose not to participate in these opportunities, those that did were unanimous in their endorsement.

Limitations

Of course, no research project is without limitations. Some of the areas discussed below stem from givens of the type of research design and data collection strategies utilized while others are related to choices I made in recruitment and presentation of data.

Small Sample Size and Atypical Aspects of Participants

As these data were garnered from the voices of 12 participants, this represents just a small fraction of the individuals working in positions of direct support. It is possible that the

individuals who chose to participate represent a particular subset of DSPs at the study site. Specifically, participants may have volunteered for the research due to particularly strong opinions and a desire to share perspectives.

Likewise, the participants in this study may have been somewhat atypical. The mean length of employment in positions of direct support was over 10 years. Thus, the perspectives shared by participants may represent aspects of the experience steeped within longer-term relationships than may be typical in the overall population of DSPs. Further, nine of the 12 participants reported either working on undergraduate degrees (n=4), having an undergraduate degree (n=4), or having a graduate degree (n=1). The level of education in this sample may also exceed certain averages in the DSP population as a whole.

The Particularities of The Study Site

In addition to the above, all participants were recruited from a single service agency. As presented in Chapter Four, the study site for this research may be unique in the service system in this geographic area. From their focus on supporting people with ID and pSCB to the employment statistics (e.g., very low turnover rate), this agency occupies a unique space and defies some of the general patterns in community based services. These factors, combined with the nature of small-sample qualitative research, limit the ability to generalize from these data to the larger populations. I hope, however, that the depth of information provided allows for a transferability of findings to agencies or individuals similar to those that participated in this study.

Reliance on Interviews Alone

The data presented in this research were gathered solely from the spoken words of participants. I did not conduct any observation or other checks to assess how the statements

of participants matched their collective or individual actions. In essence, participants

provided their individual phenomenological perspectives and recollections regarding their

experiences. In some cases these recollections may not holistically reflect objective facts or

differing perspectives of certain events or interactions. Regardless of statements related to

interviewer effects (above), it is possible that participants edited or chose to reflect

perspectives in line with what they thought they should say. Similarly, it is possible that

individuals' statements about actions or perspectives do not actually reflect what occurs in

the course of their work with people with ID and pSCB. Extensions of this research should

include different methods of data collection including observation in order to assess how

statements may be translated into actions.

Location of Interviews

Participants were asked to choose the time and location of the interviews. With a few

exceptions that took place in private residences, most of the interviews were conducted in

public settings such as coffee shops or restaurants. In each of these cases I asked the

participant if she or he were comfortable talking about sometimes sensitive matters in these

locations and efforts were made to find the quietest, least populated areas of these locations.

While no participant appeared uncomfortable, asked to suspend the interview, or move

locations it is possible that the environments in which interviews were conducted impacted

the content or depth of information provided. Future research of this nature should include

the option or requirement of fully private locations for all interviews.

Aggregation of Data

While demographic information of participants was collected and presented in

Chapter Four, these data, aside from brief reference to gender of participant excerpts, were

not analyzed in relation to patterns of response. Likewise, I chose to not continually connect

excerpts to particular participants via pseudonyms. While the aggregation of the interview

excerpts served to provide a further layer of protection and confidentiality to these

participants, it concurrently limited analyses or exploration of how personal history,

education, age, and gender may have influenced perspectives. Future research in this topic

should include efforts to connect and analyze demographic and historical data to patterns of

response.

Future Directions

The Perspectives of People with ID

It cannot be stressed enough that the views and perspectives of people with ID who

are supported in this system have not been represented in this research. All the philosophy,

planning, discussing and so on, ad infinitum, ultimately and finally boil down to the daily

lives of individuals who, via various pathways, have ended up receiving supports within the

structures of these systems. As examined, the participants in this research revealed a world

filled with care and relationship that, nonetheless, includes multiple levels of scrutiny and

diverse concepts of safety and risk. In order to gain a more complete understanding of these

dynamics and their effect in individual lives, it is essential that the voices of individuals with

ID and pSCB be accessed and introduced into the literature. It is a necessary next step in this

field to access these individuals' understandings of sexuality, risk, and rights and experiences

of the limitations enacted or supports provided.

The Perspectives of Other Involved Parties

As repeatedly intimated by participants, there are often a litany of individuals from

many disciplines and relationships who are also involved in planning supports for people

with ID and pSCB. From agency management to therapists, parents, guardians, and employees of state oversight systems there are multiple points of entry to explore these topics of sexuality, rights and risk in the lives of people with ID. These individuals reflections on the same or similar topics as addressed in this research must be explored in order to build a more vigorous conceptualization of how all of these parts fit together in the creation of systems of supports.

Agencies with Different Philosophies or Histories of Practice

As related above in Limitations, the particular site accessed for this study is just one of many provider agencies in this state and one of thousands nationwide. If we hope to gain a larger picture of the conditions at play for individuals with ID and pSCB, the DSPs who provide daily support, and the other involved parties, we must also look to other agencies and DSPs who provide supports to people with ID. Simply put, perspectives and practices related to sexuality, rights, and risk may differ greatly from agency to agency. While regulations may attempt to speak to and guide all involved, the methods by which policies, standards, and guidelines are interpreted and enacted (or ignored) are likely to vary. As presented in Chapter Four, my choice of study site was purposeful and based upon the agency's reputation in providing consistently exemplary support for people with ID and pSCB. There are other agencies in this region that have less than exemplary reputations in this domain and many others with unclear practices or histories. Extensions of this research to other agencies would serve to increase our understanding of these phenomena.

Aspects of the Larger Influences

In culmination of the above, this research did not examine larger aspects of agency policy, state standards, federal regulations and the various constituents of potentially

involved legal systems. At each level, these documents and dictates may influence or mandate the actions of any or all at each layer in the systems of supports for people with ID. Analyses of these documents in reference to how they address or fail to address the issue of sexuality for people with ID would be necessary in order to arrive at a truly holistic conceptualization.

Conclusion

Through the use of semi-structured interviews and subsequent analyses of transcripts I aimed to examine the experiences of DSPs who work with people with ID and pSCB. Twelve individuals with at least one year of experience in the above volunteered to participate in these interviews. Findings of this research suggested a depth of caring and connection coupled with sometimes intensive, continuous efforts of monitoring and teaching, across nearly all domains of daily life. Support of sexual rights within situations of actual or perceived risk were a source of intrinsic and extrinsic conflict for these participants. Using the inductive techniques of grounded theory, a concept of 'being between' was developed and examined in an attempt to portray and explain these multiple sources of conflicting conditions, actions, interactions, and consequences which may cause DSPs to remove their voices from these important conversations. The theory of moral distress from the general nursing literature appears to support some of this conceptualization. These data were also compared to reviewed research and found to be supportive of and supported by the findings of previous authors on these topics. A Foucaultian analysis of these data revealed interplays of power and panoptic observation of the sexuality of people with ID that have positive as well as unintended or counterintuitive effects. Lastly, my personal perspectives and potential influences on interpretations were presented.

As Craft and Brown (1993) stated,

Whether staff members like it or not, whether they acknowledge it or not, they are

enormously powerful in the lives of people with [intellectual disability]. Powerful in

terms of the physical environments that are provided in day and residential service;

powerful in terms of the social environments they create; powerful in the spoken and

unspoken feedback they give about client aspirations and behaviour; and powerful in

offering models of adult men and women with adult lifestyles making adult choices.

(p. 3)

Suggested by the findings of this research however, due to a failure to listen or acknowledge

their voices, the significant power of DSPs may be relentlessly attenuated and result in their

pulling back or removing themselves from essential conversations regarding risk and rights

for the people they know best. To act as if we understand and they do not recapitulates

mistakes of our past and risks placing the sexuality of people with ID in a feedback loop with

little opportunity for escape.

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APPENDIX A: INTERVIEW QUESTIONS

Note: Research questions are:

1. How do DSPs describe their experiences in working with individuals with ID and a history of pSCB?

2. How do DSPs in the study sample define or describe behavior that may be of a sexualized, challenging nature?; and

3. How do DSPs conceptualize risk and rights when supporting individuals with ID and a history of pSCB?

GRAND TOUR QUESTION/PROMPT:

"Tell me about your work and experiences as a Direct Support Professional with people with intellectual disability."

FOLLOW UP TOPICS/PROMPTS FOR ALL PARTICIPANTS:

(use "Tell me more about that." or "I'd like to hear more about that, can you expand?" as encouraging prompts for more detail if necessary)

1. **What is the best part of your job as a DSP?**

2. **What is the worst part of your job as a DSP?**

3. **What types of challenging behavior have you encountered from the people with ID that you have supported?**

4. **Tell me about some of the sexual behavior concerns you have experienced in your work as a DSP?**

5. **Tell me about the first time you encountered a behavior of possible sexual concern while working as a DSP.**

6. **What steps did you take when this occurred?**

7. **How often do you experience situations like this?**

8. **How do you know if a certain behavior is sexual or not?**

9. **What do you think should be done when a person with ID acts in a possibly sexual and challenging manner?**

10. **Is this different from what actually happens?**

11. **What would you change about how people with ID and a history of pSCB are treated/supported?**

12. **Tell me about a time when you thought about risk during your work with a person with ID.**

13. **When you hear the word 'rights' in relation to people with ID and sexuality – what do you think about?**

14. What quandaries have you found in your work with people with ID and pSCB?

15. What keeps you in this work? OR *Why* do you do this work?

16. You and I are in different roles. Do you think this difference affected the way you answered the questions in this interview or the information you provided? If yes, how?

17. Is there anything I didn't ask that I should have?

18. Is there anything else you'd like to tell me?

19. Do you have any questions for me about this research project?

POSSIBLE FOLLOW-UP QUESTIONS/PROMPTS FOR CERTAIN PARTICIPANTS: (To be used if responses to above need further exploration or clarification)

1. **What is your view or perspective regarding people with ID and sexuality in general?**

2. **What training or support needs do you have regarding sexuality and intellectual disability?**

3. **Has your opinion changed about sexuality and people with ID during the time you've worked as a DSP?**

APPENDIX B: INFORMED CONSENT DOCUMENT

The University of New Mexico Main Campus IRB
Consent to Participate in Research
[Version Date 082914]

The Experiences of Direct Support Professionals in Supporting People with Intellectual Disability and a History of Sexualized Challenging Behavior

Introduction

You are being asked to participate in a research study that is being done by Jason Buckles (Investigator) and Professor Ruth Luckasson (Dissertation Committee Chairperson) from the Department of Educational Specialties/College of Education. Professors Julia Scherba de Valenzuela, Susan Copeland, and Jan Armstrong are the other members of the Dissertation Committee.

This research is studying the experiences of Direct Support Professionals (DSP) who have worked with individuals with intellectual disability (ID) and a history of possibly sexualized challenging behavior.

You are being asked to participate in this study because you are over 18 and have at least one year of experience working as a DSP in residential or community agencies with individuals with intellectual disability and a history of possibly sexualized challenging behavior. We estimate that eight (8) to fifteen (15) people will take part in this study at the University of New Mexico.

This form will explain the research study, and will also explain the possible risks as well as the possible benefits to you. We encourage you to talk with your family and friends before you take part in this research study. If you have any questions, at any time, please ask one of the study investigators.

What will happen if I decide to participate?

If you agree to participate, the following things will happen:
- You will be asked to complete a form providing basic demographic information about yourself, your work and training history; and
- You will participate for about one and a half (1.5) to two (2) hours in an individual interview about your work and the focus of the study. Your interview will be recorded and will be conducted at a time and location that is convenient for you and which will offer privacy.
- Interview recordings will be transcribed.
- At the end of the interview and transcription process the interviewer will contact you individually by email or telephone depending on your preference. During this contact the interviewer will share certain findings of the research based upon information

gathered from you and other participants in order to determine if these findings accurately reflect your contribution.

- After this, information will be analyzed and reported and the study concluded.
- No names or identifying data about participants will be included or reported.
- There are no plans for long-term follow up.

How long will I be in this study?

Basic participation in this study will take a total of 1.5-2 hours over a period of one day. Optional follow-up portions of the study (e.g., review and comment regarding a brief summary of findings) may take an additional hour and would occur several weeks after the interview. There is no requirement to participate in the offer to review and comment.

What are the risks of being in this study?

- There are risks of stress, emotional distress, inconvenience, and possible loss of privacy and confidentiality associated with participating in a research study.
- There is the risk that if certain information regarding abuse, neglect, or exploitation of an identifiable individual with intellectual disability is shared during the interview process – this information will be reported to the State of New Mexico agencies (i.e., Department of Health Improvement; Adult Protective Services) that investigate these types of events.
- There is the risk that if you share information concerning imminent harm to yourself or others – this information will be shared with authorities.

For more information about risks, ask one of the study investigators.

What are the benefits to being in this study?

Benefits may include:

- Opportunity to talk about your work experiences and share information about aspects of your job supporting individuals with ID;
- Your knowledge and experience will contribute to a better understanding of the day-to-day job of DSPs who work in sometimes exceptional circumstances;
- You will be provided a $20.00 gift card to a local store (e.g., Target, Wal-Mart) once you complete the interview portion of the study. You may choose to withdraw from the study even after completing the interview. You may keep the gift card in any circumstance.

What other choices do I have if I do not want to be in this study?

You have the option not to take part in this study. There will be no penalties involved if you choose not to take part in this study. However, participation in the recorded interview is the only way in which you may be included.

How will my information be kept confidential?

We will take measures to protect you privacy and the security of all your personal information, but we cannot guarantee confidentiality of all study data. Specific measures to ensure confidentiality include:

- Gathered information on written documents or recorded digital files will be kept in the sole physical possession of the Investigator until transferred to secured locations as soon as possible following your completion of the documents.
- Information (without your name) will be entered into encrypted electronic files and secured via a password to both open the operating system of the computer as well as a different password to open any specific documents.
- Written records and physical copies of digital recordings will be kept behind a locked door in a locked file cabinet in the Investigator's office.
- Only the Investigator and members of the Dissertation Committee will have access to the encrypted documents and locked areas.
- All data will be stored for 5 years from the date of study completion and then will be destroyed via secure shredding or complete and secure electronic deletion.

Information contained in your study records is used by the investigator, the Dissertation Committee Chairperson and the rest of the Dissertation Committee. The University of New Mexico Institutional Review Board (IRB) that oversees human subjects research will be permitted to access your records. There may be times when we are required by law to share your information. Your name, however, will not be used in any published reports about this study. In the written report when using quotes gathered from interview data I will use the generic "a participant said…". I will not connect quotes to any information that may be used to identify you.

Finally, you should understand that the investigator is not prevented from taking steps, including reporting to authorities, to prevent serious harm to yourself or others, and/or report suspected abuse, neglect, and/or exploitation of individual(s) with intellectual disability.

What are the costs of taking part in this study?

There is no cost to participants taking part in this study other than costs incurred through driving to a community location for the interview and loss of time during non-work hours.

Will I be paid for taking part in this study?

There is no direct monetary compensation. You will be given a $20.00 gift card to a local store (i.e., Target, Wal-Mart) following completion of the interview. You may still choose to withdraw your consent for participation after the interview. Your information will be securely destroyed if you choose to do this. You may keep the gift card in any case.

How will I know if you learn something new that may change my mind about participating?

You will be informed of any significant new findings that become available during the course of the study such as changes in the risks or benefits resulting from participating in the

research or new alternatives to participation that might change your mind about participating. You will be contacted through your stated preferred method of contact – phone or email.

Can I stop being in the study once I begin?

Your participation in this study is completely voluntary. You have the right to choose not to participate or to withdraw your participation at any point in this study without affecting your future health care or other services to which you are entitled.

You may request that your data no longer be included by contacting the Investigator in writing at jasonkbuckles@gmail.com or PO Box 6493, Albuquerque, NM 87197. You may also choose to submit a verbal request by calling the Investigator at 505-615-2223. If you choose to verbally withdraw you may be asked to provide certain demographic information to confirm your identity.

The Investigator may choose to withdraw a participant in the following circumstances:
- If the participation in the research process appears to be causing extended intense emotional distress.
  - This would *not* include instances of fleeting anger, irritation, or frustration that pass after a few minutes.
  - This would include any instance where the emotion of the participant becomes so overwhelming that the interview process cannot reasonably continue or be re-initiated.

Whom can I call with questions or complaints about this study?

If you have any questions, concerns, or complaints at any time about the research study, contact the Investigator – Jason Buckles – at (505) 615-2223 or jasonkbuckles@gmail.com

If you would like to speak with someone other than the research team, you may call the UNM office of the IRB at (505) 277-2644.

Whom can I call with questions about my rights as a research participant?

If you have questions regarding your rights as a research participant, you may call the UNM Office of the IRB (OIRB) at (505) 277-2644. The IRB is a group of people from UNM and the community who provide independent oversight of safety and ethical issues related to research involving human participants. For more information, you may also access the OIRB website at http://irb.unm.edu.

CONSENT

You are making a decision whether to participate in this study. Your signature below indicates that you read the information provided (or the information was read to you). By signing this consent form, you are not waiving any of your legal rights as a research participant.

I have had an opportunity to ask questions and all questions have been answered to my satisfaction. By signing this consent form, I agree to participate in this study. A copy of this consent form will be provided to you.

_____
Name of Adult Subject (print)

_____ _____

Signature of Adult Subject   Date

INVESTIGATOR SIGNATURE

I have explained the research to the participant and answered all of his/her questions. I believe that he/she understands the information described in this consent form and freely consents to participate.

_____
Name of Investigator/ Study Team Member (print)

_____ _____

Signature of Investigator/ Study Team Member   Date

APPENDIX C: DEMOGRAPHIC INFORMATION FORM

1. DATE: _____

2. AGE AT TIME OF INTERVIEW: _____ **Years**

3. GENDER (Circle One)   MALE   FEMALE   OTHER (specify)
_____

4. RACE (Check as appropriate)

       a. _____ I CHOOSE NOT TO SPECIFY

       b. _____ BLACK or AFRICAN AMERICAN

       c. _____ AMERICAN INDIAN OR ALASKA NATIVE (print name of enrolled
or

       principal tribe: _____

       d. _____ WHITE

       e. _____ ASIAN INDIAN

       f. _____ CHINESE

       g. _____ FILIPINO

       h. _____ OTHER ASIAN – Print race, for example – Hmong, Laotian, Thai,

       Pakistani, Cambodian etc.: _____

       i. _____ JAPANESE

       j. _____ KOREAN

       k. _____ VIETNAMESE

       l. _____ NATIVE HAWIIAN

       m. _____ GUAMANIAN or CHAMORRO

n. _____ SAMOAN

o. _____ OTHER PACIFIC ISLANDER. Print race, for example, Fijian, Tongan

and so forth: _____

p. _____ OTHER SPECIFICATION – Please describe:

_____

5. ETHNICITY (Check One)

a. _____ Hispanic

b. _____ Non-Hispanic

c. _____ I choose not to specify

6. DO YOU HAVE ANY NEED FOR SPECIAL ADJUSTMENTS/ACCOMODATIONS

IN ORDER TO PARTICIPATE IN THE INTERVIEW? (Circle One)   YES   NO

IF 'YES' - PLEASE DESCRIBE:

_____

__

_____

__

7. EDUCATIONAL HISTORY

A. High School Degree? (Circle One):   YES   NO   GED

B. Undergraduate Degree? (Circle One):   YES   NO   IN PROCESS

If YES or IN PROGRESS what is/was your Major?

_____

C. Graduate Degree? (Circle One):   YES   NO   IN PROGRESS

If YES or IN PROGRESS what will be/was your degree and major?

_____

_

8. EMPLOYMENT AND EXPERIENCE

    A. Time employed as a Direct Support Professional: Years _____ Months _____

    B. Describe your job duties as a Direct Support Professional:

_____

____

_____

____

    C. Why did you choose this job?

_____

____

_____

____

    D. Other than work as a Direct Support Professional, what is your experience with people with intellectual disability?

        a. Family Member(s):

_____

        b. Friend(s):

_____

        c. Other:

_____

9. SPECIFIC TRAINING IN SEXUALITY AND INTELLECTUAL DISABILITY

    A. Have you had any specific training in intellectual disability?

YES   NO

a. If 'YES', please describe:

_____

–

_____

–

B. Have you had any specific training in *sexuality* and intellectual disability?

YES   NO

a. If 'YES', please describe:

_____

—

_____

—

E. Have you had any specific training in *human rights* and intellectual disability?

YES   NO

a. If 'YES', please describe:

_____

—

_____

—