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A QUALITIATIVE ANALYSIS EXPLORING THE DEVELOPMENT OF

PROBLEMATIC SEXUAL BEHAVIORS IN ADOLESCENT

MALES WITH DEVELOPMENTAL DISABILITIES

by

Maria J. Watters

A dissertation submitted in partial fulfillment
of the requirements for the degree

of

DOCTOR OF PHILOSOPHY

in

Disability Disciplines

Approved:

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UTAH STATE UNIVERSITY
Logan, Utah

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ABSTRACT

A Qualitative Analysis Exploring the Development Of Problematic Sexual

Behaviors in Adolescent Males With Developmental Disabilities

by

Maria J. Watters, Ph.D.

Utah State University, 2018

Major Professor: Dr. Jared Schultz
Department: Special Education and Rehabilitation

Adolescents with developmental disabilities (DD) experience regular physical and

sexual development. Some adolescents with developmental disabilities engage in

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population in terms of prevention of PSB, and provision of effective treatment after PSB

has begun, their experience must be understood and contributing factors identified. It is

with this in mind that this study was designed, with the purpose being the exploration of

the experiences of adolescents with DD who have engaged in sexually problematic

behaviors, including compulsive or addictive patterns of behavior, and to identify the

contributing factors for engaging in these behaviors. A grounded theory approach with a

directed analysis component was used. Eleven participants were interviewed including

five persons with developmental disabilities (PWDD) and six parents regarding the

experiences of seven different individuals with DD who have engaged in PSB. Results of

this study indicate that the presence of a DD increases the complexity of this experience. A model was created to explain the overall process of engaging in PSB as requiring exposure, motivation, opportunity, and deficits in sexual education. In addition, nine different factors were identified that may be contributing factors that increase the risk of an individual with DD engaging in PSB. These results may be of value for parents of children with DD, service providers, and educators.

(183 pages)

PUBLIC ABSTRACT

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Adolescents with developmental disabilities (DD) experience regular physical and sexual development. Some adolescents with developmental disabilities engage in problematic sexual behaviors (PSB). In order to be able to address the needs of this population in terms of prevention of PSB, and provision of effective treatment after PSB has begun, their experience must be understood and factors contributing to risk identified. With this in mind, this study was designed to being the exploration of the experiences of adolescents with DD who have engaged in sexually problematic behaviors, including compulsive or addictive patterns of behavior, and to identify contributing factors for engaging in these behaviors. A grounded theory approach with a directed analysis component was used. Eleven participants were interviewed including five persons with developmental disabilities (PWDD) and six parents regarding the experiences of seven individuals with DD who engaged in PSB. Results indicated that the presence of a DD increased the complexity of this experience. A model was created to explain the overall process of engaging in PSB as requiring exposure, motivation, opportunity, and deficits in sexual education. In addition, nine factors were identified that may be contributing factors that increase the risk of an individual with DD engaging in PSB. These results may be of value for parents of children with DD, service providers, and educators.

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CHAPTER I

INTRODUCTION

Importance of the Problem

Sexual maturation and growth are fundamental to being human. Growing from childhood to adulthood and experiencing puberty to become sexual beings is normal, natural, and inevitable (Attwood, 2008). For humans, sex can serve a variety of functions including reproduction, recreation, and/or expressing love and affection. Sex can be a powerful force for joy, love, and good. However, it can also become a powerful force for pain, hurt, shame, and regret when it is misunderstood or misused. Sexuality permeates society and can be seen throughout the media in the news, TV shows, movies, magazines, and countless other platforms (Dillman, Carpentier, Northrup, & Parrott, 2014). Access to sexually explicit and pornographic materials is on the rise. A survey of 15,426 adults in the U.S. found that approximately 75% of men and 41% of women have intentionally viewed pornographic materials online (Albright, 2008). Sexual topics instigate debate on nearly every level of society from education and criminal justice systems, to medical science, human rights, and individual family rights and values. Individuals with disabilities are no exception. In some cases adolescents develop problematic sexual behaviors (PSB) as they progress through this developmental stage (Ray, Marks, & Bray-Garretson, 2004). Individuals with developmental disabilities (DD) go through regular sexual physiological development including changes in hormones, appearance, and sexual drives (Sullivan, & Caterino, 2008) just as their non-disabled peers and as such are

also at risk of developing PSB.

Moving through adolescent development with all of the physiological changes may be particularly challenging for adolescnents with DD. Individuals with DD face obstacles that may prevent them from exploring and understanding their own sexuality and development. These blocks include factors such as societal attitudes towards individuals with disabilities as subhuman, asexual (Doyle, 2008; Smart, 2008), or too innocent to discuss sexual topics (R. Young, Gore, & McCarthy, 2012). Adolescents with DD may experience challenges in the form of deficits in communication and social skills, and often have increased difficulty in managing the emotional, physical, and sociosexual challenges that come with growth and development (Sullivan & Caterino, 2008). The results of these challenges include limited access to appropriate sexual education materials (Barnett & Maticka-Tyndale, 2015; Sullivan & Caterino, 2008; Tarnai, 2006), and increased risk of being sexual abuse victims (Mahoney & Poling, 2011; Martinello, 2014), with reported rates of up to 4 times higher than their nondisabled peers and as being more chronic in nature (Martinello, 2014). In addition, because it is developmentally normal for adolescents to have sexual curiosity (Owens, Behun, Manning, & Reid, 2012), it is possible they are viewing sexualized material in an attempt to learn and to satisfy that curiosity.

While the majority of individuals with disabilities lead productive and healthy lives, engaging in PSB can lead to a lower quality of life due to the consequences of these behaviors (Tissot, 2009). These consequences may range in severity and impact but can include loss of freedoms within the home, loss of opportunities for engagement in job

placements or community activities, and loss of personal freedoms. Person freedoms may be lost due to incurring charges within the criminal justice system and it has been indicated that individuals with DD may be overrepresented within the criminal justice system (Coffey, 1989; Lindsay, et al., 2002; Petersilia, 2000). In the last 20 years several researchers have reported increased incidence of sexual offending in populations with DD. Specifically, individuals who have DD have been estimated to be responsible for up to 40-50% of abuse against their peers with DD (Martinello, 2015). Lindsay et al. (2002) reported in their review of the literature the following statistics: 3.7% of offenders with intellectual disabilities (ID) had been convicted of sexual crimes compared to the 4% of non-ID offenders similarly convicted; 21-50% of offenders with ID have committed sexual crimes; and recidivism rates range from 30.8%-68%. While there are methodological concerns in many studies, these numbers warrant additional attention as the majority of individuals who engage in PSB may never reach the criminal system (Brandes & Cheung, 2009). This indicates that the sexual development, education, and experiences of individuals with DD cannot be ignored. Little is known about the experience of individuals with DD or what factors may contribute to the development of PSB, especially those that are illegal.

Accurate information regarding rates and type of PSB among individuals with DD is difficult to obtain. However, there is growing consensus that there are concerns about engagement in PSB. In a review of the literature (Dewinter, Vermeiren, Vanwesenbeeck, & Nieuwenhuizen, 2013) exploring autism spectrum disorder (ASD) and sexual development, they identified a high comorbidity rate of various PSB among individuals

with ASD. Behaviors most commonly seen in individuals with ASD included public masturbation, fetishism, arousal to children, inappropriately addressing sexual topics and behaviors with others, voyeurism, frottage, and exhibitionism (Ward & Bosek, 2002). Case studies reported behaviors ranging from public masturbation to rape. Other studies have indicated that up to 90% of individuals with ASD may display PSB towards others (including strangers, caregivers, or service providers) in varying degrees of seriousness, which may in turn jeopardize community integration and placements (Sullivan & Caterino, 2008) as well as the ability to engage in healthy and appropriate relationships (Tissot, 2009).

The purpose of this study is to explore the experiences of adolescents with DD who have engaged in sexually problematic behaviors, including compulsive or addictive patterns of behavior, and to explore the contributing factors for engaging in these behaviors.

Context and Significance of the Study

Developmental disabilities refers to a general category of disabilities that include impairment in physical, language, or behavioral areas (CDC, 2013). Individuals with developmental disabilities make up a highly heterogeneous group of people. What this group of individuals has in common is that they have experienced a delay, or failed to reach developmental milestones as well as a delay or failure in acquiring living, educational, and social skills as expected for their age (CDC, 2013).

There are many challenges faced by individuals with DD on a daily basis. Many

of these challenges are associated with the ability to engage and connect in learning and social environments. Some of these challenges include: deficits in social skills including interpersonal problem-solving, misinterpreting the meaning and intentions of others potentially leading to aggressive responses (Timms & Goreczny, 2002), difficulty communicating in both receptive and expressive language (Tullis & Zangrillo, 2013), difficulty conceptualizing problems, application of acquired knowledge (Timms & Goreczny, 2002), social prejudices, difficulty projecting consequences (Ward & Bosek, 2002), inflexibility, difficulties in paying attention, and being highly reactive to change and sensory stimuli (CDC, 2015a). This can create a challenge in the development of a sexual identity as sexual knowledge and the development of appropriate sexual behavior is highly dependent on socialization and learning from social interactions (Tissot, 2009) . Appropriate sexual behavior is often learned through informal interactions in peer groups, in which many individuals with disabilities are not included (Sullivan & Caterino, 2008).

Additionally, individuals with DD may have limited access to sexual information and training (Murphy & Elias, 2006; Søndenaa, Rasmussen, Palmstierna, & Nottestad, 2008; Ward & Bosek, 2002), and the education they do receive may be provided in response to inappropriate behavior rather than as part of a regular, preventative curriculum (Tullis & Zangrillo, 2013). When education is provided it may be presented in a manner that is not easily accessible or understood (Murphy & Elias, 2006). Access to appropriate sexual education is critical for developing healthy and appropriate sexual behavior (Sullivan & Caterino, 2008). Social deficits and lack of education inadvertently may set the stage for developing inappropriate and/or addictive sexualized patterns of

behaviors. Early exposure to pornography, even when sought out of curiosity or to gain information, may also be a significant contributing factor for engaging in sexually inappropriate, compulsive, or abusive behaviors (Alexy, Burgess, & Prentky, 2009; Mancini, Reckdenwald, Beauregard, & Levenson, 2014). This combination of factors, coupled with a limitless source of online sexual materials, may place individuals with DD at an increased risk of acting out the sexual behaviors modeled for them through pornographic materials as they experience sexual urges and feelings.

These contributing factors are of particular salience during adolescence. Adolescence is a challenging transition for many individuals, with and without DD. During adolescence individuals with DD generally go through regular sexual development and inappropriate sexual behaviors often become an area of concern during this time (Sullivan & Caterino, 2008). Social deficits and lower functioning skills may have a pronounced effect on developing sexuality and knowledge of what to do with sexual impulses and urges (Tullis & Zangrillo, 2013). This is particularly the case as these individuals may miss out on important social learning and may lack basic coping skills (Barnett & Maticka-Tyndale, 2015). Adolescence is also a time during which interventions and treatment have increased chances of creating positive change and productive outcomes. The adolescent brain has regions that are high in plasticity, making it susceptible to both positive and negative influences (Arain et al., 2013). When viewed in this light it becomes evident that PSB, among adolescents with DD, is an area of concern that needs to be addressed by families, service providers, and professionals in a holistic manner.

Understanding sexual behaviors in adolescent populations with DD is a challenging and complex task (Griffin-Shelley, 2010). Service professionals in the field of disability, specifically rehabilitation counseling, are trained as disability professionals, which makes them different from other counselors (Patterson, 2009). Disability professionals work in a wide array of job positions and due to the increasing amount of diversity within the field there are constant changes in job functions, tasks, and areas of competency (Leahy, Muenzen, Saunders & Strauser, 2009). The Commission on Rehabilitation Counselor Certification (CRCC, 2010) code of ethics states that rehabilitation counselors are to assist individuals with physical, mental, developmental, cognitive, and emotional disabilities. Additionally, they are to do so in the most integrated setting possible to meet the personal, career, and independence goals of their clients. Understanding the experience of adolescents with DD who have engaged in PSB is critical for knowing how to address their treatment needs. Professionals who work with individuals with disabilities in any capacity, or in sex-specific treatment will likely be called upon to work with individuals with disabilities who have sexually-related issues and concerns. There has been a call to action for all professionals involved in the assessment, treatment, and care of individuals with DD who have sex-specific concerns (Dewinter et al., 2013). Rehabilitation counslors then, should also be prepared to work with this population and be educated regarding their experience and treatment needs.

Prior to exploring exactly what interventions should look like for this population, it is important to first understand and delineate what the experience of individuals with DD who struggle with PSB looks like; what issues do they face? What impact does this

have on family and social interactions? What emotional consequences do they face? Does it follow the same pattern of addiction presented by models geared towards adults or general adolescent populations? These questions remain unanswered and unaddressed in the current research and literature.

Purpose Statement and Research Questions

The purpose of this study is to explore the experiences of adolescents with DD who have engaged in sexually problematic behaviors, including compulsive or addictive patterns of behavior, and to explore the contributing factors for engaging in these behaviors.

Due to the lack of published literature and research related to the experience of PSB among adolescents with DD a grounded theory methodology with a directed approach will be utilized. Grounded theory is a qualitative social research process, which involves learning and creating a theoretical direction as data are collected, a development of a hypothesis occurs as information is gathered (Glaser & Strauss, 1967). Utilizing a directed approach will enable the existing literature and theories to inform the questions and verify if any existing theories are valid for this population while still allowing for the integration of new codes and ideas informed directly from the data. A combination of these approaches is particularly appropriate in this instance due to the inherent assumptions that go into the existing literature related to individuals with DD who engage in PSB. There are assumptions regarding the ways in which individuals with DD interpret and interact with the world around them, these assumptions make it difficult to create a

non-biased measurement tool for data collection, such as a survey. In contrast, grounded

theory requires an inductive, active learning process that guides the researcher to

conclusions along the way (Freeman-Longo, 2000), thus allowing for the data to inform

the results without pre-conceived notions or ideas influencing the data collection. The

research questions to be explored utilizing this method were as follows.

> RQ1: What is the experience of individuals with DD who have engaged in problematic sexual behaviors?

> RQ2: What are some of the potential risk factors that may contribute to individuals with DD developing problematic sexual behaviors?

Definition of Key Terms

Adolescent: Transition period between childhood and adulthood during which a

body goes through puberty and the brain continues to develop, includes ages 10-24

(Arain et al., 2013).

Developmental disability: A general category of disabilities that include

impairment in physical, language, or behavioral areas that occurs during the

developmental period (CDC, 2013). Characterized by an experienced delay, or failure to

reach developmental milestones as well as a delay or failure in acquiring living,

educational, and social skills that would be expected for their age (CDC, 2013).

Developmental disabilities can occur from birth or can become evident anytime during

development up to 22 years of age (Boyle et al., 2011). Specific conditions that fall under

the umbrella of developmental disability include attention-deficit/hyperactivity disorder

(ADHD), autism spectrum disorder (ASD), cerebral palsy, fetal alcohol spectrum

disorders, fragile X syndrome, intellectual disability, muscular dystrophy, Tourette syndrome, and visual or hearing impairments (CDC, 2015b).

Family: The most commonly accepted definitions of family are those that include a parental unit that can be homosexual or heterosexual, married or unmarried, and at least one child or a single-parent household with children (Powell, 2014). For this study this definition will be further expanded to include any unit in which there are children and a primary caregiver (biological parent, adoptive parent, extended family caregiver, or guardian) and will also include siblings within the family unit.

Pornography: There are diverse definitions of this term. For the purposes of this study, pornography definitions as outlined in a review of the literature (Owens et al., 2012) have been combined to include any material that depicts sexualized images of the male or female body, specifically focusing on the genitalia, material that depicts sexual activities and behaviors in an unconcealed way including photographic images, audio files, or video content. The primary purpose of this material is to elicit sexual arousal.

Problematic sexual behaviors (PSB): Any sexualized behavior that is considered outside of socially appropriate norms or expectations such as public masturbation, exhibitionism, voyeurism (Ward & Bosek, 2002). This may also include sexually compulsive or addictive behaviors that persist in spite of negative consequences. These behaviors are recurrent and interfere with normal functioning and incur negative consequences to the individual and/or others (e.g., spouse, family members, employer, etc.) that is characterized by feeling unable to decrease or stop behaviors (Egan, & Parmar, 2013; Levine, 2010; Štulhofer, Jelovica, & Ružić, 2008). PSB also includes

illegal sexually abusive behaviors such as forced sexual contact of any kind (including rape, groping, frottage, etc), contact with persons unable to give consent due to age or intellect, or the use of bribery or coercion to engage in sexual contact (Balogh et al., 2001). Sexual behaviors may be considered problematic due to crossing legal boundaries, such as assault, stalking, or indecent exposure, or they may be considered problematic due to personal distress and significant variance from cultural norms.

Sexual education: The majority if middle school and high schools in the U.S. seek to provide students with some form of sexual education; however, the content varies greatly (Scull, Malik, & Kupersmidt, 2014). Sexual education for this article is defined as any attempt by families or schools to provide a child or adolescent with education or training regarding sexual topics. This may include topics such as abstinence, contraceptives, sexual health (including sexually transmitted infections), and media influence on sexual health and decision (Scull et al., 2014).

Social learning: First explored by Albert Bandura, social learning is defined as the learning that takes place by observing behaviors in others and then taking those observations and modeling them (Boeree, 2006). In other words, learning by observing the actions and behaviors of others. Bandura identified four steps to modeling which are (1) attention—individual must attend to what is occurring, (2) retention—individual must remember what was observed, (3) reproduction—individual must start attempting to re-create what was observed and have the ability to do so, and (4) motivation—individual must feel he/she has a reason to recreate what was observed (Boeree, 2006)

Summary

This chapter provided an overview of the problem that this study will address, provided context for the problem, identified the purpose and research questions, and provided definitions of key terms. Chapter II provides a review of relevant literature, including an overview of the scope and extend of problematic sexual behaviors among adolescents, what is known of risk factors for developing these behaviors, and how this information applies to individuals with developmental disabilities. Chapter III describes the methodology used in this study, providing an overview of the grounded theory approach with emphasis on the directive approach utilized. Chapter IV presents findings from the interviews. Last, Chapter V provides a discussion of the findings, implications, and future research recommendations.

CHAPTER II

REVIEW OF THE LITERATURE

In order to understand the significance of PSB among individuals with DD, it is important to start with what is known. The many terms and definitions used for problematic or addictive sexual behaviors need to be defined and understood within a model or framework in order to have clinical utility. Within this chapter the literature exploring and defining PSB in a broad context will first be discussed. Second, this focus will then be narrowed to help gain understanding of what is understood of PSB in relation to adolescents. Lastly, the focus will be further narrowed to explore the challenges that are present when attempting to understand sexually addictive behaviors among adolescents with DD. Specifically this final section will emphasize the relative dearth of information available for individuals with DD who engage in PSB.

Problematic Sexual Behaviors

There is a wide range of behaviors that can be considered "problematic" and the definition of this can be easily influenced by factors such as culture, age, gender, personal experiences, and education. Thus, it is important for the purposes of this manuscript to have a consistent definition of this term. The definition to be used throughout this dissertation for PSB, as provided in Chapter I, is any sexualized behavior that is considered outside of socially appropriate norms or expectations such as public masturbation, exhibitionism, or voyeurism (Ward & Bosek, 2002). This includes sexually compulsive or addictive behaviors that persist in spite of negative consequences. These

behaviors must be recurrent and interfere with normal functioning and incur negative consequences to the individual and/or others (spouse, family members, employer, etc.) that is characterized by feeling unable to decrease or stop behaviors (Egan & Parmar, 2013; Levine, 2010; Štulhofer et al., 2008). Problematic sexual behaviors also includes illegal sexually abusive behaviors such as forced sexual contact of any kind (including rape, groping, frottage, etc), sexual contact with persons unable to give consent due to age or intellect, or the use of bribery or coercion to engage in sexual contact (Balogh et al., 2001).

Society has both accepted and stigmatized terms such as sexual addiction, potentially limiting their utility. In the literature there are many labels used to describe sexual behaviors that are considered problematic, some of these terms include; sexual compulsivity, erotomania, hypersexuality, promiscuity, sexual dependence, sexual impulsivity, sexual obsession, nymphomania, paraphilia-related disorder, sexual sensation seeking, out-of-control sexual behavior, pornography addiction, and internet sex addiction, etc. (Griffiths, 2012; Hilton, 2013; Levine, 2010; Spenhoff, Kruger, Hartmann, & Kobs, 2013; Voon et al., 2014). The terms that appear most frequently in the literature are hypersexuality, sexual compulsivity, and sexual addiction. It is likely that much of the debate regarding terms that describe behaviors comes down to the way that terms are defined (Hilton, 2013). For the purposes of this disseration sexually problematic behaviors will be the umbrella term used in the place of these other terms, which may produce more immediate bias or reaction. However, it is still critical to review some of the background and history of the term sexual addiction as much of the literature

speaks specifically to this type of PSB.

In the current version of the Diagnostic and Statistical Manual (DSM-V), there is no designation for sexual addiction as a psychiatric disorder. The DSM-V states that there is insufficient peer-reviewed evidence to establish clear diagnostic criteria and descriptions (American Psychiatric Association [APA], 2013a). PSB may be difficult to define due to an inability to clearly identify sexual normalcy. Additionally, there is difficulty in identifying clear diagnostic criteria for what behaviors could/should be manifested to fit diagnostic criteria (Hall, 2011; Levine, 2010). For example, an individual who compulsively views pornography before being able to sleep is different from an individual whose sexual fantasies, thoughts, and urges consume his/her life and interfere with functioning. In both cases the behaviors are problematic, but their variance make them difficult to quantify (Hall, 2011). Despite the challenges of definition and quantifying addictive behaviors there is an increasingly large body of evidence suggesting that problematic and compulsive sexual behaviors, particularly in relation to pornography consumption, fit within the framework of addictive models (Hilton & Watts, 2011; Spenhoff et al., 2013; Voon et al., 2014; K. S. Young, 2008).

The idea of sexual behaviors being addictive is not a new one (Griffiths, 2012). However, the research to support this claim is only now emerging. Sexual material is more accessible today than ever before due the advent of the Internet and improved technologies for accessing online materials (Egan & Parmar, 2013; Griffiths, 2012; Hall, 2013; K. S. Young, 2008). Multiple authors have cited what is called the "Triple-A-Engine" that was originally presented by Cooper in 1998. The Triple-A-Engine stands for

access, affordability, and anonymity, each of which has been identified as key ingredients in the recipe for Internet addiction. Undeniably, sexual material on the internet also fits these criteria, being accessible, affordable, and easily accessed anonymously (Egan & Parmar, 2013; Griffiths, 2011; K. S. Young, 2008). Thus, a significant amount of the literature on sexual addiction focuses on pornography addiction, and specifically Internet pornography. The model of sexual addiction, however, is inclusive of a variety of sexual behaviors that cause distress, lead individuals to feel out of control, and have other addiction elements. These behaviors may include excessive sexual urges, masturbation patterns, cybersex, and strip club visitation (Spenhoff et al., 2013). Any of these may be present when discussing sexual addictions, or when discussing the much broader issue of PSB.

Models of Sexual Addiction as a PSB

Hall (2011) proposed a biopsychosocial view of sexual addiction, which takes into account the biological features and functions of addictive behaviors, as well as the psychological aspects, all within the context of society. This provides a holistic framework from which to view the various components of sexual behaviors and how they become problematic. It also provides direction and guidance for clinicians and treatment providers. It is for these reasons that this framework will be used in the current study to understand PSB.

Physiological aspects. When considering the process of addiction it is critical to understand the physiological processes that are occurring within the body. Having an understanding of the processes that are taking place adds clarity to the use of the word

addiction in relation to sexual issues. Additionally, having an understanding of physiological functions can serve to legitimize the experience of clients by minimizing feelings of shame and confusion of what is happening or why they cannot simply "stop it" (Hall, 2011). Clinicians, family members, and other associates might also benefit from education regarding the physiological processes occurring in sexual addiction in order to decrease stigma and judgments of moral character and personal worth of the addicted person. The physiological impact on sexual addiction can specifically be identified in the reward pathway system and in brain development (Hall, 2011).

The mesolimbic dopamine system is the most important reward pathway in the brain. It is responsible for responses to natural rewards such as food and sex, activities that ensure survival of a species. This pathway communicates with our brain and memory to tell our bodies that what we just did was good and that it should be repeated (Nestler Laboratory, n.d.). This reward pathway has been most studied in relation to drug addictions. Though less understood, this is the same pathway that is being studied more rigorously in natural addictions, specifically sexual addiction (Hilton & Watts, 2011; Nestler, 2005).

Dopamine is the primary neurochemical that is responsible for producing the pleasure and feel-good response, the brain then remembers what activities produced that response and seeks them again (National Institute on Drug Abuse, 2014). With repeated release of elevated dopamine levels, memories become more established and, with the help of proteins, a pathway in the brain is marked and then built up with each repeated dopamine "high." In consequence, the reward pathway for that particular activity

becomes entrenched. For example, cocaine and heroine can flood the brain with up to 10 times more dopamine than its usual level. The brain then begins to perceive these elevated levels as normal and requires elevated levels of dopamine to achieve a baseline level of experience. As a result tolerance is developed. In order to receive the same level of pleasure, greater and greater amounts of dopamine are required. Initially, elevated levels are required in order to achieve the feeling of a "high," however, with repeated use these higher levels are necessary for an individual to feel normal, at this point they have reached a state of dependence (Hall, 2011). While evidence of this reward pathway is most clearly established for drugs, there is increasing body of evidence that the same process is operant in sexual addictions (Hilton, 2013; Hilton, & Watts, 2011).

In addition to the reward system, other physiological impacts of drug addictions are cue-reactivity and cravings. Voon and her colleagues (2014) studied the neural correlates of sexual cue reactivity in relation to compulsive sexual behaviors. They found that compulsive pornography users craved pornography but did not have higher sexual desire than those who were not compulsive viewers. Essentially, they were dependent on pornography and craved it, but did not like it. This fits within the addiction model where individuals reach a point where they crave and seek drugs due to feelings of need rather than enjoyment. Compulsive pornography users also showed evidence of becoming sensitized, meaning they are more likely to notice environmental cues and be triggered to feel strong urges to view pornography. Voon stated that drug cue-reactivity and craving studies of nicotine, cocaine, and alcohol implicate certain networks in the brain. These same networks were also activated during viewing of sexually explicit materials,

particularly in individuals with compulsive (or addictive) sexual behaviors. This suggests neurobiological similarities across addictive disorders. In other words, in the brain, drug and alcohol addiction is mirrored by sexual addiction.

Other studies have indicated that in addition to chemical changes in the brain, actual change in brain structure may occur. Hilton and Watts (2011) explain that studies on cocaine addiction have shown measurable volume loss in several areas of the brain, including the frontal lobes. The behavioral manifestations of such atrophy include impulsivity, compulsivity, emotional lability and impaired judgment. This finding, Hilton and Watts explain, suggests that similar atrophy may be taking place with sexual addiction. A preliminary study from Germany looking specifically at pedophilia showed abnormalities in the frontal region of the brain as a direct result of sexual compulsivity. This indicates actual physical changes in the brain that are seen in the brain of those with addictions (Schiffer et al., 2007).

While much of the research on the physiological changes that occur in sexual addiction are in their infancy, there is increasing consensus among professionals that the processes found in sexual behaviors physiologically mirror the processes seen in drug addictions. Individuals with addictions who report feelings of diminished control in their own lives, inability to stop regardless of adverse consequences, and being easily triggered through normal life events (Spenhoff et al., 2013) can find some relief from shame and guilt in understanding the biological root of these feelings (Hall, 2011).

Psychological aspects. Just as it is important to understand the physiological aspect of developing PSB, it is also important to recognize the role of emotional and

cognitive influences. This allows for treatment to move beyond management of

physiological symptoms to address the deeper psychological issues that drive the

addiction (Hall, 2011). Hall (2012) suggests the Opportunity, Attachment, and Trauma

(OAT) model as a way of explaining the various psychological experiences that may

move individuals towards PSB. This model breaks down the four primary ways that

sexually addictive behavior was initially set up. Figure 1 shows a visual representation of

this model, it should be noted that in each case opportunity is a critical component of
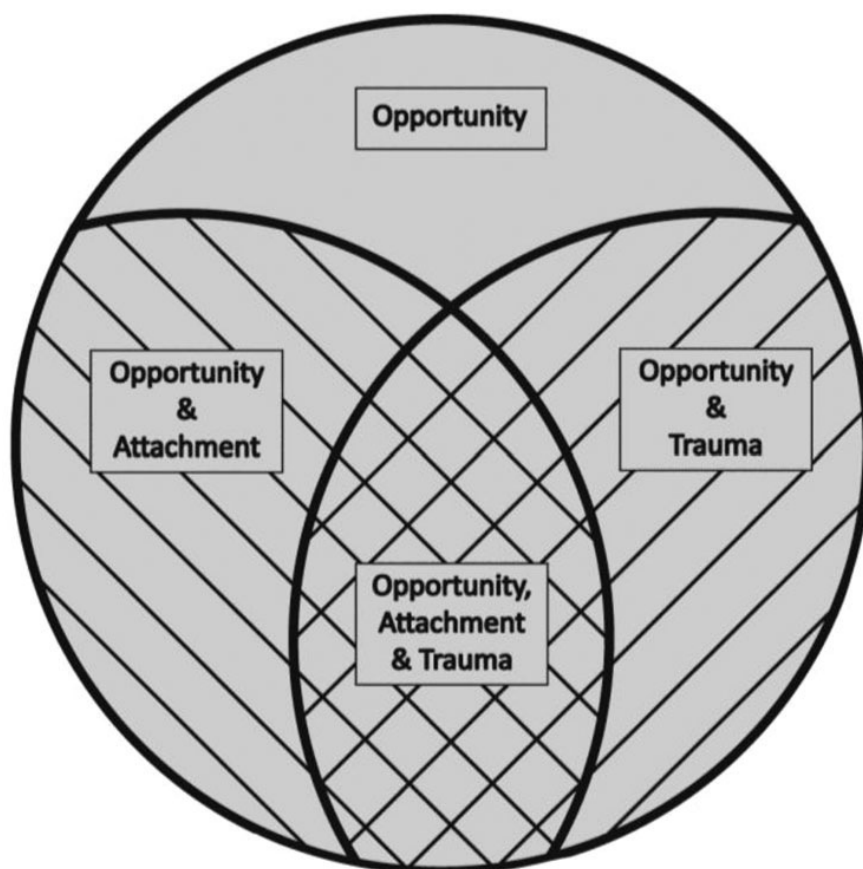
Figure 1. The OAT model for engagement in problematic sexual behaviors. This model breaks problematic sexual behaviors into four primary ways the behavior was initially set up: opportunity induced, attachment induced, trauma induced, or attachment/trauma induced. Opportunity is essential across each category as it is essential for a behavior to occur. Undersatnding the original source can play a role in effective treatment (Hall, 2012).

developing an addiction. Each of these regions will be briefly discussed.

Opportunity-induced addiction (Hall, 2013) emphasizes the reality that in order for any addiction to take place there must be an opportunity to engage in the initial behavior. In this case, having an opportunity to engage in sexual behaviors or activities is an essential precursor for developing an addiction. With the availability and accessibility of the Internet, opportunities for engaging in sexual behaviors are available to the majority of individuals and may be taken by anyone at any time. For some individuals, because opportunity for relationships or physical contact may not be available, opportunity to view sexually explicit materials online may alone be linked to sexually problematic behaviors developing. However, for problematic behaviors involving human interaction, opportunity is essential but often found in conjunction with other motivating factors.

Attachment-induced addiction emphasizes the role of early childhood attachments on subsequent adult behaviors. Secure childhood attachments are associated with adults with more positive self-esteem who can manage emotions and mild trauma, but if attachment is disordered or disengaged that individual is more likely to turn to addiction for comfort (Hall, 2013). A child who does not have his/her emotional needs met may have structural differences in his/her brain and may possibly be unable to internally produce natural opiates and thus, turn to external sources to stimulate the dopamine pathways to compensate (Hall, 2011). Individuals with insecure attachment patterns often experience anxiety, anger, and contradictory emotions when it comes to connecting with others. Being sexual may become a route used to indicate connection, as well as a way of

providing temporary relief from anxiety, insecurity, and depression (McPherson, Clayton, Wood, Hiskey, & Andrews, 2013).

Hall's (2013) model goes on to consider trauma-induced addictions. Addiction may be triggered by a single traumatic event, or by a series of traumatic events. Trauma can also have a direct impact on the structure of the brain, with the traumatic memory being stored in the limbic system and the brainstem, responsible for fight or flight, making an individual hypersensitive and unable to use his/her "thinking brain" long after the trauma has passed (Hall, 2011). Addictive behaviors can become a way of soothing a hyperactive amygdala and limbic system (Hall, 2013).

Last is the attachment/trauma-induced addiction. When trauma occurs within a family system there are likely to be both trauma and attachment concerns. Early trauma can make it difficult to form healthy bonds. Poor attachment may then make later traumas more difficult to get through in a healthy manner. Physical or emotional abuse in a child can lead to emotional regulation difficulties as an adult, and may be linked to sexually problematic behaviors (McPherson et al., 2013). Additionally, trauma and/or attachment concerns may create a desire for feeling in control. Sexual behaviors can give an illusion of control and can defend against feelings of vulnerability and ambivalence (McPherson et al., 2013).

These four categories are able to capture a wide range of psychological events that may lead to PSB. Other aspects of the psychological process of addiction may include sexual behaviors being used as a coping mechanism to regulate or escape/avoid mood and emotion when a person is uncomfortable, regardless of the cause of the

emotional distress (Laier & Brand, 2014; McPherson et al., 2013; K. S. Young, 2008).

When in the midst of PSB, shame can become a common denominator across experiences

and keep individuals trapped in their behaviors (Hall, 2011).

      Societal/systemic aspects. Families and society play a significant role in

determining the extent, scope, and severity of sexual behaviors. When it is conveyed that

sex is shameful, embarrassing, or negative, this can often lead to difficulty in embracing

healthy sexual needs and feelings. Systemic exploration of familial and community roles

and values can lend greater understanding to the development of the addiction (Hall,

2011). If society or the family have highly conservative or shame-based views of sexual

behaviors, there is an increased likelihood that individuals will seek out sexual content on

the Internet where they can feel safe from judgments and disapproval from others.

Unfortunately, the benefit of isolation that comes from using the Internet for sexual

purposes also becomes a detriment; users often feel more alone, feel out of control with

their sexual behaviors, and feel increasingly more helpless in their ability to stop the

behavior alone (K. S. Young, 2008).

      Internet pornography use can have significant impact on social relationships. In

one study of 349 males with sexually problematic behaviors, participants consuming and

masturbating to pornography reported higher rates of distress than participants reporting

other sexualized behaviors (such as phone sex, seeking out prostitutes, strip club/bar

attendance, etc). These participants reported seeking pornography in order to find sexual

intimacy but also reported feeling as though their needs were not being met. Despite their

needs not being met they compulsively continued to seek out pornographic materials

(Spenhoff et al., 2013). The desire for social acceptance and connection drives much of

human behavior and when it is not present loneliness is often the result. Feelings of

loneliness and isolation have been linked to sexually addictive behaviors, with long-term,

frequent viewing of pornography being a strong predictor of loneliness (Yoder, Virden, &

Amin, 2005). Seeking to meet the basic human need of connection via Internet

pornography or other superficial sexual encounters is an ineffective process with

potentially harmful consequences. While it is clear that viewing pornography does not

lead to negative consequences for all individuals, it can for some (Twohig, Crosby, &

Cox, 2009) and consequences may include: increased acceptance of aggressive behaviors,

particularly towards women and among those who are already prone to engage in

aggressive behaviors (Allen, D'Alessio, & Brezgel, 1995; Vega & Malamuth, 2007),

decreased desire to have sex with a partner, increased feelings of judgment from a partner

(Albright, 2008), religious and spiritual concerns, problems at work or school, and

damage in relationships (Twohig et al., 2009), and increased risk of depression, anxiety,

and stress (Levin, Lillis, & Hayes, 2012). It is unknown if these potential risks and

consequences are consistent across ages and/or populations such as those with

developmental disabilities.

Problematic Sexual Behaviors Among Adolescents

While most research to date has been directed towards adults with problematic

sexual behaviors, there is increasing attention to the experience of adolescents. In a

survey of clinicians, probation officers, caseworkers, and other professionals working

with adolescents who have engaged in PSB, all reported the need to improve their

understanding regarding the experience and treatment needs of this population (Brandes

& Cheung, 2009). Working with adolescents can be challenging as it is during this time

that individuals experience significant changes both physically and emotionally as they

go through puberty (Arain et al., 2013), including numerous changes in academic, social

and other environmental influences (Blakemore, Burnett, & Dahl, 2010). Physically the

brain continues to develop throughout adolescence and into early adulthood, and is

capable of making rapid changes and adaptations as new information is taken in and

processed (Arain et al., 2013). Some of the most commonly cited concerns that occur

during adolescence are often related to executive control and include not yet fully

developed impulse control, increased reactivity in the brain regions responsible for

reward motivation, immaturity of brain systems involved in basic emotional regulation,

and differences in ability to understand people, think through intentions and emotions,

and being self-aware (Pope, Luna, & Thomas, 2012).

Many models of adolescent development indicate that the negative or risky

behaviors associated with adolescence occur as a result of slow maturation of the frontal

cortical brain, as this region of the brain is associated with evaluating situations and

making complex judgments (Crone & Dahl, 2012). However, some research groups are

now suggesting that immaturity of the frontal cortical is likely only one piece of the

puzzle, with interactions across cognitive affective and social processing playing a role in

how neural systems develop and how adolescents make decisions (Crone & Dahl, 2012).

Regardless of the source there is no debate that adolescence is a period associated with

increased engagement in risky behavior and poor decision making.

Hormonal changes also play a role in behavioral changes among adolescents. Dopamine, as described previously, is the hormone responsible for the "feel-good" response and influences emotional reactions and our desire to repeat engagement in certain behaviors that initiated the reward pathway. In their review of the literature Crone and Dahl (2013) reported indicators that during early adolescence dopamine levels are at their highest but that during pre-adoescence is when there is an increase dompamine receptor density, followed by a reduction in these receptors. This pattern is reported to be more pronounced in males than females and may be linked to increased novelty seeking, exploratory behavioral and reward-seeking behavior at puberty. This decrease in dopamine receptors may also play a role in mood swings and difficulties regulating emotions (Arain et al., 2013). Serotonin is also potentially decreased through adolescence, and it also plays a role in mood changes, anxiety, impulse control, and arousal. This decrease is associated with decreased impulse control (Arain et al., 2013) as well as increased sensory-seeking behaviors, which are beginning to be identified as a result of puberty and hormonal changes rather than a function of age (Blakemore et al., 2010).

Other behaviors that are linked to hormonal influence include the influence of testosterone. In their review of the literature Crone and Dahl (2012) explain the imapct of various hormones on behaviors in adolescents. Testosterone influences neural systems that regulate reward and social motivation, indicating that testosterone promptes seeking of high social status with altered perception and appraisal of threats and rewards. Risk-

taking behaviors have been shown to be particularly apparent when an individual is surrounded by peers, likely in an effort to prove or maintain a social status. This may be of particular concern when considered in conjunction with the understanding that adolescents are also often more prone than adults to inaccurately reading others emotions (Blakemore et al., 2010). They often use the emotional regions of their brains when reading others' emotions, leading to more impulsive decision-making rather than logical decision-making (Arain et al., 2013). This misinterpretion of others may also be prounounced as adoslcents go through a transition phase between ages 12-16 where tey are just beginning to engage in more "other" oriented thoughts rather than "self" oriented thoughts. Individuals under the age of 12 tend to have less understanding of people's intentions when making judgement decisions (Crone & Dahl, 2012).

All of these factors can create challenges in determining where in society an individual fits, which is problematic because adolescence is also the time during which individuals are making decisions about their identity and defining their sense of self (McLeod, 2013). In their literature review Crone and Dahl (2012) identified what many researchers are calling a "social brain network," which is a network of brain regions that is important for making connections and thinking about impact on others that undergoes structural and functional changes during development. During this time frame adolescents are also enaging in social learning through observation and experiences with those around them (Crone & Dahl, 2012). Behavior in adolescents are shaped by a confluence of brain structure changes, adjustments in hormones, as well as social influences (Blakemore et al., 2010; Crone & Dahl, 2012). It is important to note here that

these studies are all conducted on adoelscents who do not experience any cognitive or developmental delays. So the developmental changes listed may not occur at the same time as among adolscents with DD. This could have implications specifically in realtions to the duration, source, and type of risk-taking or impulsive decision making seen among adolescents with DD. Impulsive beahviors in particular may persist in individuals with DD for longer than among those without DD.

Contributing Factors for Adolescents
Engaging in PSB

As understanding of the adolescent brain increases it becomes more apparent that adolescents may be particularly susceptible to influences such as the media, peers, and other societal messages again, good reference here from that other article about the social influences. They are prone to engaging in behaviors that they believe will increase their peers acceptance proximating examples of being normal appearing more adult-like, and/or decreasing tension or pressure. At the same time, adolescents are wired to seek out rewarding sensory experiences and to take opportunities to obtain something desirable when possible (Arain et al., 2013; Blakemore et al., 2010).). This makes adolescents particularly vulnerable to developing addictions. In fact, most drug addictions can be traced back to an initiation that occurred during adolescence (Arain et al., 2013). These tendencies, in combination with the increase in estrogen and testosterone associated with puberty, and increased sex drive during this time, places them at risk for engaging in risky and impulsive sexual behaviors in an effort to seek pleasure (Arain et al., 2013)

While most adolescents are able to navigate their increasing sexual behaviors

without incurring any significant problems, this is not true for all. Having curiosity about sexuality is developmentally normal and expected, but can also become problematic when inaccurate or unhealthy sources of information or experience are utilized to satisfy this curiosity (Braun-Courville & Rojas, 2009), or when peer groups and social norms indicate that inappropriate sexual behaviors are acceptable or even encouraged. Unfortunately, crime statistics for adolescents demonstrate that not all are navigating their sexual urges and desires appropriately. National data from victimization and arrest records (Dwyer & Letourneau, 2011) reported that adolescents accounted for 15% of forcible rapes and 18% of sex offenses other than rape and prostitution. Other estimates attribute up to 23% of all sexual offenses and 40% of offenses committed against children under 6 years old to adolescents (Eastman, 2005). With these kinds of reports for criminal acts alone it becomes apparent that when including the entire range of potential PSB there is a need to explore the contributing factors for developing these kinds of behaviors in adolescence. Remember that adolescence is a time of physical, cognitive, and emotional change where previous trauma, confusion, and negative experiences may come to the surface and lead to negative behaviors both sexually and nonsexually. In fact, many individuals who commit sexual crimes in adulthood began these behaviors while in their youth (Eastman, 2005). Thus, all of the contributing risk factors that exist for adults to develop PSB also exist for youth and, for many, this is when the behaviors begin to manifest. However, there are some contributing factors that appear to play a more prominent role in adolescents.

History of trauma or abuse. One of the most commonly identified and accepted

causes of sexually abusive behaviors is having a history of abuse. This abuse can include

pervasive exposure to violence in the home, neglect (Bentovim, 2002), emotional abuse,

particularly when in combination with sexual abuse events (Bagley, Wood, & Young,

1994), and being a victim of sexual abuse (Bagley et al., 1994; Bentovim, 2002;

Maniglio, 2009). Being a victim of sexual abuse specifically has been linked to various

concerns among adolescents. For example, victims of sexual abuse tend to be more

highly sexualized in their behaviors (Putnam, 2003) that are often high risk sexual

behaviors (Maniglio, 2009) and are at higher risk of becoming sexually abusive

(Bentovim, 2002; McPherson et al., 2013). In addition, higher rates of substance abuse,

depression, anxiety, suicidal and self-injurious behavior and decreased self-esteem have

been associated with childhood victimization (Maniglio, 2009; Putnam, 2003).

Adolescents who have been abused may also experience poor peer relations, which are

also linked to depression or anxiety. Depression and anxiety are often considered to be

risk factors for seeking sexually explicit materials online (Yoder et al., 2005) that, in turn,

tends to increase the risk of developing other PSB, creating a negative cycle (Owens et

al., 2012).

     Although not all who are abused end up becoming abusers, many who have

abused others were also victims themselves at one point. Some speculate that PSB may

develop as adolescents seek to combat feelings of vulnerability and sexual behaviors

provide a sense of control, thus reversing the feelings of powerlessness they felt in their

own abuse (Bentovim, 2002; McPherson et al., 2013). It has also been suggested that

youth who have not experienced sexual abuse themselves, but who grow up in a context

where they were exposed to violence or who had mothers who had experienced sexual abuse, may experience a similar impact from those events as those who were abused directly (Bentovim, 2002). Undersatnding the potential link between a history of abuse and PSB can help frame an understanding of the expriences of those who engage in PSB who have DD, as we will further explore in a later section this population appears to be at higher risk of having a history of abuse. This may indicate that a history of abuse is a particularly salient contributing factor of risk for individuals with DD.

Attachment. Poor attachments, particularly with parents or other trusted adults are another factor for development of PSB (Hall, 2011). Poor early attachment to positive role models or neglect from parental figures has been cited as being linked to poor outcomes for adolescents in school, social circles, and sexual health. Adolescents without this positive connection to adults may be more likely to form unhealthy or deviant peer relations that encourage negative, high-risk behaviors or provide support for developing offending behaviors (Bentovim, 2002). Thus we see that early childhood experiences, relationships, trauma, and mental health can have an impact on which youth go on to develop addictions, negative behaviors, or PSB (Trickett, Null, & Putman, 2011). There is still much that remains unexplored regarding the specifics of what leads some youth to abuse and not others.

Sexually explicit materials and pornography. Another contributing risk factor present that is believed to play a more significant role in adolescents than adults is that of viewing sexually explicit materials and/or pornography. While there are challenges to data collection and tracking, many reports state that youth are being exposed to

pornography or sexually explicit materials by an average age of 11 and that those ages

12-17 are the largest consumers of this material over any other age group (Yoder et al.,

2005). One report surveying Dutch youth reported that one-tenth of youth ages 12-13

years old stated fears that they are addicted to pornography (Hald, Kuyper, Adam, & Wit,

2013). This indicates that in some cases pornography use and addiction may be, on its

own, a PSB, however, it is also a contributing factor for developing additional

problematic behaviors.

Adolescents are being faced with many media messages encouraging sexual

gratification, pleasure, and objectification of others (Dillman et al., 2014*)* including on

regular TV where women's bodies are used to promote consumer products from cars to

hamburgers (Bensimon, 2007). With incredible ease of access to increasingly more

explicit material, youth are often learning sexual behaviors from these sources (Baxter,

2014; Braun-Courville, & Rojas, 2009; Zillman, 2000), especially from those that are

regularly portrayed in the media (Zillmann, 2000). While adolescents are often engaged

in sensation seeking activities, those with higher sensation seeking tendencies are more

likely to seek out pornography (Bryant, 2009). In addition, youth who report feeling

dissatisfied or depressed are also more likely to have early exposure (Bryant, 2009) and

may more readily develop addictive patterns (Baxter, 2014; Bryant, 2009). Some of the

other reported harmful effects of pornography on adolescents include creating distorted

ideas of sexuality and healthy sexual interactions (Braun-Courville & Rojas, 2009);

increased likelihood of unsafe sexual practices (Owens et al., 2012); generation of shame,

guilt, anxiety, confusion, and poor social bonds (Bryant, 2009); altered capacity for

successful and sustained human relationships including lower social integration (Owens et al., 2012); promotion and acceptance of aggression towards women (Baxter, 2014); objectification of women (Mancini et al., 2014); and increased likelihood of engaging in sexually abusive behaviors at a younger age (Alexy et al., 2009; Mancini et al., 2014). In addition, adolescents learn from social interactions and from observing others in their environment and the activities and behaviors observed in pornography can easily be integrated into their sexual identity (Owens et al., 2012). Social learning theory would also support this claim with emphasis on adolescents that are viewing sexual acts in mainstream media as normal and acceptable they are more likely to mirror them (Mancini et al., 2014).

In reviewing the literature, Owens et al. (2012) found that it is likely that the adolescent brain processes the stimuli provided in pornography differently than adults. With greater levels of cortical processing and encoding there is increased recognition and retention of perceptual information, and that this material leaves a deeper and more lasting impression on youth. Another study (Voon et al., 2014) indicated that by increasing the reward circuitry (dopamine paths) at this age there is a delayed development of the executive control systems of the brain responsible for impulse control and thoughtful decision-making, which also leads to more vulnerability to addiction and sexual conditioning. This indicates that there are physical changes in the development of the brain of adolescents who are exposed to sexually explicit materials, particularly when they continue to seek out these materials. This may become particularly problematic if other, more accurate sources of information are not present.

Appropriate sexual education is an important aspect of development for all adolescents (McDaniels & Fleming, 2016). While sexual education in public schools is required, there is no consistency in the content, methods, or delivery of sexual education materials in public schools (Swango-Wilson, 2009). Some schools choose to use an abstinence-only-until-marriage education program while others may use a comprehensive sex education program (Lerner, & Hawkins, 2016). While some may be concerned that teaching adolescents about sexual topics will encourage them to engage in sexual activity, there is evidence suggesting appropriate education will delay the onset of sexual activity and increase the likelihood of safe-sex habits (Doyle, 2008). Many parents have entrusted schools to teach their children about sex and have thus abdicated this task to their public education providers (Barnard-Brak, Schmidt, Chesnut, Wei, & Richman, 2014). Families may avoid talking to their children about sexuality for reasons such as shame, taboo, or considering it unnecessary. In other cases parents report not knowing what or how to talk about sexual issues (Gürol, Polat, & Oran, 2014). This would indicate that for many children sexual education outside of schools may not be happening, potentially leaving significant gaps in their knowledge and understanding of sexuality and appropriate sexual behaviors.

Models for Addressing PSB in Adolescents

Models for understanding and addressing PSB among adolescents are limited. Historically, adult criminal models have been projected onto adolescents including the language, assumed motivations, and treatment (Worling, 2013). Texts on the treatment of adolescent sexual offenders have moved away from adult criminal language, but still

struggle to capture the scope and range of problems presented and will often actively

avoid the use of addiction language or issues (Lundrigan, 2004). This creates a

dissonance between the earlier models of PSB in adults and what is understood to be the

experience of PSB development in adolescence. Lundrigan (2004) identified two primary

views related to the addictive nature of sexually problematic behaviors in adolescents and

then proposed a third, more integrated view.

The first view indicated that the development of PSB is a learned, or conditioned,

sexual response. Lundrigan (2004) labels this the "sexually compulsive view." According

to this view, individuals become conditioned to deviant sexual stimuli, which impacts

their arousal patterns, and has implications for the sexual behaviors they seek. Sexually

abusive behaviors develop as a result of continuing reinforcement of deviant fantasy

through masturbation patterns. Appropriate means of sexual expression may diminish as

arousal and reward increase for the deviant fantasy and arousal. This, in turn, may lead to

social isolation and desire to engage in sexual experiences that may be illegal,

inappropriate, or harmful. Cognitive dissonance plays a role in these individuals, as they

are able to recognize their fantasies are abnormal and thus use thinking errors to validate

their behavior as appropriate and desired by others in order to decrease the dissonance

they experience. The cycle becomes one of reinforcing deviant sexual fantasies. Those

fantasies become increasingly arousing and eventually develop into a desire to experience

them. At this point the actions do not appear to be inappropriate due to the thinking errors

that have been engaged in to justify the thoughts and fantasies. This allows the individual

to develop sexual compulsions in an inappropriate or abusive manner. Cognitive-

behavioral therapy approaches that address deviant arousal patterns and help adolescents identify and challenge thinking errors are widely used when this view is taken. Other approaches associated with this view are those that focus on arousal reconditioning via behavioral means or medication intervention in an attempt to alter the deviant arousal patterns (Lundrigan, 2004).

The second view presented by Lundrigan (2004) is focused on the addictive nature of sexually compulsive behaviors. This view explains sexual offending as relapse behaviors similar to those in an alcoholic or drug addict. Sexual urges are viewed as cravings to engage in the illegal, inappropriate, or harmful behaviors. Cognitive dissonance is present within this model as occurring when individuals are able to recognize that urges and cravings may be wrong, but feel pressured to follow through. Cognitive distortions enable them to move closer to their risk situations and eventually engage in the behaviors for the anticipated release or rush that they expect to be provided. The individual may then experience guilt and a sense of loss, and end up in a cycle of repeating the behavior in an effort to use sexual gratification to cope with those painful feelings. Treatment in this view is more likely to rely on peer support, such as that found in 12-step programs, and the focus is on relieving the excessive guilt and shame while increasing skills to find appropriate means of sexual expression. Barriers to future offending are then created by establishing boundaries to high-risk situations that may lead to relapse, as well as understanding the need for vigilance throughout their lifetime to avoid relapsing.

Lundrigan (2004) then presents a third view in which he identifies the ways that

these two approaches interact, and discusses how this approach may be more effective for adolescents' experiences. This approach emphasizes that not all sexually offenders are addicts, and that not all addicts are sexual offenders. However, recognizing where an adolescent more appropriately fits can make all the difference in treatment. Every sexually abusive act has a combination of operating motivations (such as recognition, acceptance, control, power, etc.) and that any given sexual offenders' behavior can be explained by understanding the unique combination of motivations for that individual. Motivations among adolescents can be sexual or non-sexual, usually considered along a continuum presented with "sex is minor" to "sex is a weapon or tool" to "sex is the main goal." Those on the "sex is minor" end of the spectrum may be dealing with a larger pattern of delinquent behavior, while those who use "sex as a weapon or tool" may be seeking to use sex as a means to an end of gaining power or control over another person. The "sex is the main goal" end of the spectrum may be indicative of compulsive thoughts and behaviors the individual fails to contain, and victimizing others is a means by which to obtain gratification. Lundrigan also points out that biochemical processes must be taken into consideration, particularly in the adolescent brain as was previously discussed.

Treatment within this merged perspective focuses on the need for professional involvement throughout treatment. Treatment should include addressing thinking errors, as well as recognizing thinking distortions, the creation of relapse prevention plans, and other work that may be more tailored to the needs of the individual. *Pathways* by Kahn (2011) is a treatment manual designed for adolescents that illustrates how these two views can be merged as it walks through the process of identifying thinking errors, but

also addresses behavioral cycles. It also helps youth identify their high risk factors while engaging in self-driven arousal reconditioning.

Professionals also tend to have consensus that treatment goals should assist adolescents to understand and interrupt their thoughts, understand feelings and motivations for PSB, improve social skills, develop healthy attitudes towards sex and relationships, and improve family relationships (Brandes & Cheung, 2009; Worling & Curwen, 2000). Emphasis on empathy for victims (Brandes & Cheung, 2009; Worling & Curwen, 2000), addressing previous trauma and victimization, discussing and repairing attachment issues, managing emotional deregulation, and developing a positive sense of self (Bentovim, 2002) have also been identified as important when working with adolescents. The role of shame, depression, and trauma should not be ignored, as they can create a cycle of negative behaviors in an attempt to avoid or escape negative feelings (Hall, 2011; Worling & Curwen, 2000). Creating open and safe communication with parents regarding media, pornography, and other sexual topics is one of the most effective ways to reduce the negative effects of media influences on children, and decrease risk of continual abuse of pornography (Rasmussen, Ortiz, & White, 2015).

Adolescence is an important period for education, training, and interventions as the brain is high in plasticity. While that makes the brain more susceptible to negative influences, it also allows it to be more receptive to positive influences and information (Arain et al., 2013). This means that just as the adolescent brain can change negatively, it also has the ability to repair itself and to create new pathways, connections, and patterns, even when it comes to sexual desires and arousal. It is largely supported that treatment in

adolescence decreases the likelihood of recidivism of PSB in the future (Calley, 2012; Worling & Curwen, 2000). Although little is known about the exact numbers of successful outcomes it is critical that professionals be prepared to work with adolescents who struggle with PSB. While all of this is informative, it is also critical to note here that these studies or discussions failed to address the needs or experiences of adolescenets with developmental disabilities. Their focus was on adoelscents on a more broad scale without consideration to the differences in the social, developmental, or educational needs of adolescents with developmental disabilities, which will now be explored.

Problematic Sexual Behaviors and Developmental Disabilities

While it is clear that researchers are investigating the impact of sexual materials and sexual addictions on adolescents, there is little investigation of this impact on adolescents with disabilities (Ray et al., 2004). Individuals with disabilities are often overlooked when it comes to sexual topics; however, they go through sexual development and are also susceptible to sexual influences. The issue of problematic sexual behaviors becomes more complex when disability is added to the equation (Griffin-Shelley, 2010).

Research indicates that individuals with cognitive, intellectual and developmental disabilities have an overrepresentation of offenses within the criminal justice system (Coffey, 1989; Lindsay et al., 2002; Petersilia, 2000). In their review of prevalence studies in prison sample, Søndenaa et al. (2008) found rates of 7.1% of inmates in prisons having intellectual disabilities (ID), and rates as high as 70% of prison samples having a

learning disability. The occurrence of aggressive behaviors and PSB is a concern for many individuals with DD. Some of these behaviors include public masturbation, voyeurism, frottage, exhibitionism, making inappropriate sexual conversation or jokes, and inappropriately engaging in fetish behavior (Dewinter et al., 2013; Martinello, 2015; Ward & Bosek, 2002; Wiggins, Hepburn, & Rossiter, 2013). Thus, it can be seen that individuals with DD are also at risk of engaging in PSB just as their non-disabled peers are, making it important to explore the uniqueness of their experience and learn more about the contributing factors of risk as well as specific educational and treatment needs.

Developmental Disabilities

The classification of evelopmental disabilities (DD) is a general category of disabilities that include impairment in physical, language, or behavioral areas that occurs during the developmental period (CDC, 2013). This can include impairments in a range of areas including physical, language, or behavioral development and all have some form of delay or failure to reach developmental milestones as well as a delay in acquiring living, educational and social skills as expected for their age. Because there are so many areas of development that can be impacted, individuals with DD experience a wide range of symptoms, functional limitations, and needs (CDC, 2013).

Developmental disabilities can be congenital, occur at birth, or can manifest anytime during development up to 22 years of age. They typically last throughout an individual's lifetime, the source and etiology of many developmental disabilities is still unknown (Boyle et al., 2011). Specific conditions that fall under the umbrella of developmental disability include ADHD, ASD, cerebral palsy, fetal alcohol spectrum

disorders, fragile X syndrome, intellectual disability, muscular dystrophy, Tourette syndrome, and visual or hearing impairments (CDC, 2015b). In a large-scale study, researchers from the CDC collaborated with researchers from the Health Resource and Service Administration investigating the trends and prevalence of DD in U.S. Children (Boyle, 2011). Using data on children ages 3-17 from the 1997-2008 National Health Interview Surveys, it was identified that one in every six children in the U.S had a DD in 2006-2008. This is an increase of 17.1% from 1997-2008, meaning roughly 1.8 million more children had a DD in 2006-2008 than 10 years prior. There are three diagnoses within developmental disabilities that have been receiving specific attention due to an increase in frequency of diagnosis in recent years. They are: (a) ID, (b) ADHD. and (c) ASD. Because of the increased attention there is more literature available on these DD than many others. A brief overview of these will be provided.

Intellectual disability. Intellectual disabilities are also known as intellectual developmental disabilities (IDD) and, historically, mental retardation. Maulik, Mascarenhas, Mathers, Dua, and Saxena (2011) pulled definitions from the World Health Organization (WHO), the International Classification of Functioning, Disability and Health (ICF), and the American Association on Intellectual Developmental Disabilities (AAIDD). These definitions combined describe ID as a cluster of syndromes and disorders that include arrested or incomplete development. Rates of ID are difficult to obtain due to a variety of factors such as variation in the causes of ID, multiple diagnoses within the cluster of ID, and testing for ID often being done in educational settings where results may or may not be fully made known to parents (Boyle et al., 2011). Additionally,

educational programs may use the more general classification of "developmental delay" up to 9 years of age for children, making the tracking and identifying of ID difficult (Boyle et al., 2011). However, it is estimated that 2-3% of the population has an ID (Daily, Ardinger, & Holmes, 2000). A cumulative meta-analysis (Maulik et al., 2011) indicates that worldwide estimates of ID have stabilized at 11/1000, or roughly 1% of individuals across the world having ID.

There are many causes of intellectual disabilities, some are known, and some remain unknown. Some causes include disabilities such as fetal alcohol syndrome, Down syndrome, fragile x syndrome, and other genetic disorders. Injuries, illnesses, infections, head injuries, or disease may also be potential causes of ID (CDC, 2013). ID's are characterized by impairment of skills, both in intellectual functioning and adaptive behavior, manifested during the developmental period. Adaptive behavior includes conceptual skills (language, money, and time concepts), social skills (interpersonal and social problem solving), and practical skills (daily living activities, employment). Historically, IQ was used as a primary factor for diagnosing ID. The IQ test is still used as a major indicator of intellectual functioning, which is the mental capacity that one has for problem solving, learning, and reasoning, etc. Today other tests related to conceptual skills, social skills, and practical skills are now used in conjunction with IQ to determine the presence of an ID (American Association on Intellectual Developmental Disabilities, 2013).

Attention-deficit/hyperactivity disorder. ADHD is a neurodevelopmental disorder that is typically diagnosed in childhood (CDC, 2014). Traditionally considered a

childhood disorder, more recent studies have suggested that the impairments associated

with ADHD are likely to extend into adulthood and have permanent effects on cognitive

and social functioning (Shaw et al., 2012; Sroubek, Kelly, & Li, 2013). ADHD has seen a

tremendous increase in prevalence in recent years with a 33% increase from 1997-1999

to 2006-2008 (Boyle et al., 2011). Rates have consistently increased at rates averaging

5% per year from 2003-2011, with approximately 11% of children ages 4-17 having been

diagnosed with ADHD as of 2011 (CDC, 2014).

ADHD is primarily characterized by inappropriate levels of inattention,

hyperactivity, impulsiveness, or a combination of these problems for a particular age

group (Shaw et al., 2012). Individuals can be diagnosed as predominantly inattentive

presentation, predominantly hyperactive-impulsive presentation, or as having combined

presentation (APA, 2013a). Symptoms of ADHD may manifest as difficulty organizing

or finishing tasks, excessive daydreaming, difficulty following instructions, frequent

squirming and fidgeting, difficulty getting along with others, speaking excessively or at

inappropriate times (CDC, 2014), poor decision making, stimuli searching (often

manifest as risky behavior), and overall challenges with executive functioning (Sroubek,

et al., 2013). The specific severity and manifestation of symptoms may vary

tremendously across individuals.

Autism spectrum disorder. ASD is defined in the DSM-V as a range, or

spectrum, of conditions that were previously classified separately but now all fall under

the general umbrella of ASD. ASD now includes pervasive developmental disability not

otherwise specified (PDD-NOS), Asperger syndrome, and childhood disintegrative

disorder (APA, 2013b). From 1997-2008 the prevalence of ASD has increased by

289.5% (Boyle et al., 2011). According to estimates from the CDC's Autism and

Developmental Disabilities Monitoring Network (2014), about 1 in every 68 children has

been diagnosed with ASD. This is a rate that has been increasing over the past decade.

Rates have likely increased due to improved medical care, specifically in prenatal and

neonatal care. Infants and children that have had historically high mortality rates, such as

those who are premature, have low birth weights, who are born with birth defects or

genetic conditions, are now more likely to survive (Boyle et al., 2011; Smart, 2008).

However, it is also possible that the increase in diagnoses could be attributed, at least in

part, to the broadened definition of ASD being used and better efforts being made to

provide families and children with a diagnoses. It is likely a combination of these factors

that have attributed to the increase seen in ASD diagnoses (CDC, 2015a).

While many rumors and theories exist, the exact cause(s) of ASD are currently

unknown. According to the CDC (2015a) there are likely many causes for differing types

(or severity) of ASD as well as different factors that make a child more likely to have

ASD. These factors include genetic, environmental, and biologic factors such as genetic

disorders and preconditions, and age of parents. Key characteristics of individuals with

ASD include communication deficits such as inappropriate responses in conversations,

inability to accurately read social cues and nonverbal interactions, and difficulty in

building appropriate friendships with peer-aged individuals (APA, 2013b). Additionally,

individuals with ASD can be characterized by a rigidness of thinking that often leads to

difficulty in conceptualizing problems and difficulty in applying acquired knowledge

(Timms & Gorenczny, 2002). Other concerns among individuals with ASD include a limited ability to connect consequences to actions (Ward & Bosek, 2002), being overly dependent on routines, high sensitive to changes in the environment, or being intensely focused on inappropriate items (APA, 2013b). Autism is considered a spectrum disorder because these features can occur at varying intensities depending upon the individual and circumstances.

Individuals with ASD frequently experience dual diagnoses. The most common dual diagnoses are specific phobias, obsessive-compulsive disorder, ADHD, and major depression (Leyfer et al., 2006). It is important to recognize and keep in mind the possibility of dual diagnoses, particularly the overlap of the three DD's discussed here, when considering symptomology, behaviors, and potential treatment interventions.

It is also important to consider the key features of DD and the way they interact with the environment to create a high-risk situation for engaging in inappropriate sexual behaviors, particularly without appropriate sexual education. These relationships and interactions will now be explored.

**Contributing Factors for Individuals with
DD Engaging in PSB**

Individuals with developmental disabilities face many obstacles that may prevent them from learning about sexuality or developing a healthy sexual identity (Barnett & Maticka-Tyndale, 2015; Tissot, 2009). While many of the contributing factors for developing PSB are similar to adolescents without disabilities, there are several reason these issues are particularly salient for individuals with DD.

History of trauma or abuse. It is a widely noted that individuals with DD are at higher risk of being victims of abuse than individuals without disabilities (Chang et al., 2003; Putnam, 2003). In addition, an individual with DD may experience abuse from a greater number of perpetrators and for a longer duration (Cramer, Gilson, & DePoy, 2003), with studies indicating that parents and extended family members are likely to be the perpetrators of abuse against children with disabilities (Balogh et al., 2001; Hershkowitz, Lamb, & Horowitz, 2007). Concerns have been noted that individuals with DD are more likely to be victims of violence and abuse (Jones et al., 2012) and are more suggestible, and vulnerable to abuse than their peers without disabilities (Grieve, McLaren, & Lindsay, 2007). As was previously explained, abuse of any kind can have a potential impact on the development of PBS. It has been indicated that a noteworthy proportion of individuals who engage in PSB were first victims of sexual abuse (Wiggins et al., 2013).

One theory for explaining this connection is that individuals with DD have more difficulty understanding what is happening to them or that what is happening may be wrong (Swango-Wilson, 2009). The abuse may also be internalized, resulting in aggressive or sexually abusive behaviors being replicated in their own interactions (Swango-Wilson, 2009). Beyond what is known for adolescents, little is known about the ways that trauma and abuse may impact individuals with DD or how much this is a contributing factor for developing PSB.

Attachment. Several authors have sought to draw a connection between a desire/need for attachment as a motivating factor for individuals with disabilities to

engage in PSB. Ludlow (1991 as cited in Tarnai, 2006) specifically stated that inappropriate sexual expression is often a sign of interpersonal needs not being met. Because individuals with DD are often socially isolated, have social anxiety and may have poor self-esteem, it is possible sex may be seen as a way to connect to others (Wiggins et al., 2013). However, it is interesting to note that while some hypothesize that a desire for attachment to others to be a cause of PSB, others have discounted the possibility or desire for reciprocal relationships in individuals with DD (Barnett & Maticka-Tyndale, 2015). Individuals with DD may have a desire for appropriate relationships, but with limited knowledge and social skills may not know how to realize them. Thus, their inability to engage in appropriate peer relationships may also impact the likelihood of individuals with DD to engage in PSB (Martinello, 2015).

Most studies examining relationships and the sexuality of individuals with DD rely on information from parents or other caregivers. Individuals with DD are rarely directly involved in the data collection process. In one study utilizing data from adults with ASD, participants reported concerns about their ability to find a life partner and fears of being misunderstood or of not knowing how to behave in sexual situations. In this study, individuals with ASD bluntly rejected that the neurotypical way of experiencing connection and sexual relationships should be the standard to which all are compared (Barnett & Maticka-Tyndale, 2015). In contrast to this statement, many descriptions for individuals with DD include some aspect of social withdrawal. For example individuals with ASD are often identified as having no interest in other people and desiring to be alone (CDC, 2014). With all of this in mind it quickly becomes clear

that there is very little understanding of the way that individuals with DD experience attachment or how this interacts with PSB.

Sexually explicit materials and pornography. Data related to the impacts of pornography on adults and adolescents are increasing rapidly. However, there are no studies examining the exposure, impact, or role pornography plays in influencing individuals with DD. Some authors are exploring the exploitation of individuals with DD that is occurring in various forms of pornographic material, but there is no information available on the impact of this or other types of pornography. It would seem logical that the same influences that occur in adolescents are also relevant for individuals with disabilities.

Individuals with DD display typical sexual interests, arousal, and curiosity, just as their peers (Barnett & Maticka-Tyndale, 2015; Owens et al., 2012). They are exposed to the sexual materials in the media and on regular television just as any other child. Sexually explicit and pornographic materials are easily accessible through a variety of means that children of all ages and abilities are likely to find and view, either intentionally or by accident (Owens et al., 2012; Yoder et al., 2005). Some individuals may find it as a result of seeking information regarding sexuality and being curious about how sex works (Braun-Courville & Rojas, 2009). If individuals with DD are viewing this material then it is likely that they are learning from them (Mancini et al., 2014). As was noted in the adolescent section, social learning theory implies that they are learning from what they are observing in the media and on sexually explicit website (Braun-Courville & Rojas, 2009; Zillmann, 2000). This is problematic for any youth, and is likely to be

particularly problematic for adolescents with DD who may have minimal alternative sexual education provided.

  Attitudes towards disability and access to sexual education. Attitudes towards individuals with DD have an impact on the type of sexual education they receive both at home and as part of their academic curriculum. Individuals with DD have often been perceived by society as asexual or unlikely to engage in any form of sexual relationship (Doyle, 2008; Smart, 2009; Sullivan, & Caterino, 2008). They also have been viewed at times as being too innocent to discuss sexual topics (R. Young et al., 2012) and in need of protection from such topics (Tarnai, 2006). Fears regarding what will happen if they are provided with sexual information have also been reported, such as fear that a child may not be able to control sexual impulses that may accompany sexual discussions (Brown & Pirtle, 2008), or that such information may increase the risk of being abused or of engaging in PSB with other children, or negatively impact social order (Tissot, 2009).

  Parents are often uncomfortable discussing sexual topics with their children, particularly those with DD (Brown & Pirtle, 2008; Nichols & Blakeley-Smith, 2009). This discomfort may be due in part to parents desire to remain in denial of the sexuality of their child with a disability (Swango-Wilson, 2009; Tarnai, 2006). Parents may feel inadequate, or feel that they lack direction and knowledge regarding how to engage in these discussions (Ballan, 2012; Nichols, & Blakely-Smith, 2009). Teachers also may feel uncomfortable or underprepared to teach sexual education to students with DD (Barnard-Brack et al.,2014). Often services and educational training is instigated only in crisis or after a PSB has emerged (McDaniels, & Fleming, 2016; Nichols & Blakeley-

Smith, 2009; Tullis & Zangrillo, 2013). Teachers and other professionals may also feel that individuals with DD are unprepared to receive or understand sexual materials and subsequently withhold this content (Barnard-Brack et al., 2014). These attitudes can significantly hinder the ability of individuals with DD to engage in and benefit from appropriate sexual education, which may have ramifications far into the future (Swango-Wilson, 2009). Having limited access to appropriate information and training has been identified as a likely contributing factor for developing PSB (Tarnai, 2006; Wiggins et al., 2013).

However, in spite of these attitudes and beliefs there appears to be increasing agreement that individuals with DD should have access to appropriate sexual education (Barnett & Maticka-Tyndale, 2015; Doyle, 2008; Nichols & Blakely-Smith, 2009; Sullivan & Caterino, 2008). The specific delivery and content of sexual education materials continues to be explored and debated. Schools receive guidelines at both a federal and state level and if they accept funding from thse sources are required to provide information regarding the biology of sex (Doyle, 2008), the details of what is required varies by state but there is a general push to be more inclusive of other content, especially in terms of education for students with DD. Content areas that have been recommended for inclusion in sexual education include: reproductive information (Barnett & Maticka-Tyndale, 2015); discussions about morality of sexual activity (Brown & Pirtle, 2008); information regarding sexual health (Doyle, 2008); information on non-heterosexuality, negotiation of sexual needs and sensory experiences, courtship skills, signs of a good relationship, signs of abusive relationships (Barnett & Maticka-Tyndale,

2015); and informed use of technology (Tullis & Zangrillo, 2013). In a qualitative study exploring sexual experiences among adults with ASD, Barnett and Maticka-Tyndale (2015) reported that none of the 24 participants felt they had received adequate sexual education. In the United States sexual education programs that are designed specifically for this population have not yet been clearly established (Swango-Wilson, 2009).

In addition to the challenges of establishing the content of sexual education materials, there are many challenges to presenting sexual education materials in an accessible manner. Material may often be presented in a manner that is too complex, reliant on discussions that are complicated, delivered at a pace that is difficult for students with DD to keep up with (McDaniels & Fleming, 2016), or is so broad that students are overwhelmed (Swango-Wilson, 2009). Information may also be presented in a manner that is not easily translated into real-life situations (McDaniels & Fleming, 2016). Ideally, training should be individualized to meet the needs of the students (McDaniels & Fleming, 2016). Barnard-Brack et al. (2014) summarized this well in their statement "…the goal is that sex education not be viewed as a question of 'are they ready to learn this information?' but instead be approached as another skill that needs to be taught through IEP" (p. 93). Sex education programs specifically designed for this population do not appear to exist in the U.S. at this time (Swango-Wilson, 2009).

Functional limitations/developmental influences. In a review of the literature, Tarnai (2006) identified not being informed or having inadequate socio-sexual skills as the most frequently hypothesized contributing factor for the development of PSB. Individuals with DD are frequently identified as struggling with social skills, specifically

those related to interpersonal communication (Timms & Goreczny, 2002). Because adolescents gain sexual knowledge and information from social interactions, these social deficits may hinder the ability of those with DD to develop healthy sexual experiences or knowledge (Barnett & Maticka-Tyndale, 2015; Wolfe, 1997). Also in his review of the literature, Tarnai (2006) identified limited cognitive abilities and ability to gain insight or understanding of social rules, difficulty with critical decision-making, low body and self-awareness (pleasure seeking without understanding or insight), and lack of emotional and cognitive maturity as developmental risk factors for individuals with DD. In addition he identified the lack of social opportunities to express sexuality, social immaturity, anxiety or stress, preoccupation on sex or sexual topics, and being under stimulated and seeking stimulation found in sexual behaviors as potential contributing factors.

A literature review conducted by Sevlever, Roth, and Gillis (2013) on individuals with ASD and their sexual experiences identified several more potential contributing factors. These included factors such as having difficulty emotionally connecting to others, and limited experiences of feeling empathy for others. Limited intimate relationships may also lead to sexual frustration or to feeling dissatisfied with one's sex life, as there may be more interest in sexual activities than are being realized. Poor impulse control, a proneness toward obsessing, or compulsive targeting of specific behaviors that become focused on sexual acts also place individuals with DD at risk of engaging in PSB. Last, Sevlever et al. reported preliminary findings suggesting that individuals with ASD may be more prone to experiencing deviant sexual arousal than their non-disabled peers.

All of these potential risk factors should be interpreted with caution as there is limited research available to support many of the claims made (Sevlever et al., 2013). However, they do highlight that there may be developmental or functional limitations that play a role in the development of PSB. While there are many hypotheses regarding what these developmental processes are exactly there is little empirically supported data or knowledge regarding the experience of individuals with DD. As a result, families, health care providers, and other professionals are often left guessing as to the source of behaviors or how to intervene with them.

In summary the primary factors identified throughout the literature for engaging in PSB that have been identified for individuals with DD engaging in PSB are history of trauma or abuse, attachment issues, exposure to sexually explicit materials and/or pornography, and attitudes towards disability and access to sexual education materials. While most of these risk factors are relevant across populations and ages, including those without disabilities, it is important to note the way that functional limitations may interact with these risk factors in individuals with DD. Table 1 illustrates how the functional limitations most commonly present in ASD, ADHD, and ID may interact with identified risk factors.

Models for Addressing PSB Among
Individuals with DD

As illustrated in this literature review, there is little information available regarding how to prevent or intervene in PSB among individuals with DD. However, there is an organization within the United Kingdom called Sex Offender Treatment

Table 1

Problematic Sexual Behavior Risk Factors and Developmental Disability Functional Limitations Interactions

Risk factor	ASD functional limitations	ADHD functional limitations	ID functional limitations
History of trauma or abuse	• Increased risk of being abused, have multiple caregivers and service providers. • May struggle to understand abuse or may see as pattern for behavior and model or accept it.	• Increased risk of being abused • Often high energy and with difficulty following instructions potentially increasing chances will be bullied or abused.	• Higher risk of being abused, have multiple caregivers and service providers. • May struggle to understand abuse or may see as pattern for behavior and model or accept it.
Attachment issues	• Less likely to form traditional attachments as child but may seek sexual acts as replacement or to find connection. • Lack of knowledge of social cues may play a role. ASD may be characterized by lack of desire for social connection, complicating implications for attachment as risk factor.	• May struggle with attachments due to erratic, and impulsive behaviors often causing difficulty in getting along with others. • Struggle to find connection with others but able to recognize sexual topics and may seek to find connection with others through sexual means.	• May have limited social skills or struggle understanding application of skills observed and seek sexual acts as way to connect to others. • Lack of ability/skills to engage in appropriate peer relationships may lead to having inappropriate peer relationships.
Exposure to sexually explicit material or pornography	• Existence of stereotypic or repetitive, obsessive behaviors already exist. With potential to hyperfocus on environmental stimulus sexual behaviors may easily become part of a fixated or repetitive behavior once it is seen modeled in some way. • Rigid thinking may increase risk of this being modeled if seen as acceptable. • Rigid thinking also makes it difficult to distinguish between what places are and are not appropriate for sexual behaviors. • Engage in sensation seeking behaviors, particularly for those with sensory issues, may be seeking to meet sensory need through PSB.	• Often engage in stimuli searching, characterized by risky behaviors. Exposure to such materials in combination with poor social skills and this high sensation seeking may increase risk of PSB, which deliver high level of sensory input. • Prone to daydreaming; sexual fantasy may be based on what is seen as common and acceptable, regardless of appropriateness of source.	• Limited problem solving and reasoning skills increase chance may interpret actions depicted as appropriate or normal. Difficulty conceptualizing what seeing and making sense of it. • May lack understanding of social cues or where/what different sexual behaviors are appropriate.

(table continues)

Risk factor	ASD functional limitations	ADHD functional limitations	ID functional limitations
Attitudes towards disability/access to sexual education	• Often perceived as too innocent to teach sexual topics, uninterested in sexual activity or relationships, unlikely to have relationships requiring education. • Concerns that if provided sexual education will increase curiosity, "give ideas," and individuals will lack ability to apply information appropriately. • Difficulties in communication may make it difficult to discuss sexual topics or identify gaps in understanding. • Parents and providers discomfort, lack of confidence in addressing sexual topics may prevent discussions. • Teachers unsure how to present materials, poor understanding of risk factors. • Use of euphemisms to explain sexual content may not be understood. • Sexual education presented via methods and at a pace that is not accessible or easily understood. • Lack of individuation of sexual education, may not be in IEP.	• May be seen as too immature to manage or have access to sexual materials. • May struggle to understand how to apply information learned in appropriate ways, such as appropriate application of consent. • Access to information will give ideas and increase risk of seeking sexual opportunities. • Parents and providers discomfort, lack of confidence in addressing sexual topics may prevent discussions. • Teachers unsure how to present materials, poor understanding of risk factors. • Poor accessibility of classroom content related to sexual topics may limit understanding. • Lack of individuation of sexual education, may not be in IEP.	• Limited intellectual gains overall and this may be pronounced with sexual education. • Seen as less likely understand or need sexual material. • Difficulties in communication may make it difficult to discuss sexual topics or identify gaps in understanding. • Access may cause increased curiosity and desire to experience. • Parents and providers discomfort, lack of confidence in addressing sexual topics may prevent discussions. • Teachers unsure how to present materials, poor understanding of risk factors. • Use of euphemisms to explain sexual content may not be understood. • Sexual education presented via methods and at a pace that is not accessible or easily understood. • Lack of individuation of sexual education, may not be in IEP.

Note. Data synthesized from Ballan (2012), Barnard-Brak et al. (2014), Barnett & Maticka-Tyndale (2015), Braun-Courville & Rojas (2009), Brown & Pirtle (2008), CDC (2014), Doyle (2008), Grieve et al. (2007), Mancini et al. (2014), Martinello (2014), McDaniels & Fleming (2016), Nichols & Blakely-Smith (2009), Owens et al. (2012), Putnam (2003), Sevlever et al. (2013), Smart (2008), Swango-Wilson (2009), Tarnai (2006), Timms & Goreczny (2002), Tullis & Zangrillo (2013), Wiggins et al. (2013), R Young et al. (2012), and Zillmann (2000).

Services Collaborative-Intellectual Disability (SOTSEC-ID) that has made an effort to address the issue of PSB among adults with ID who have engaged in sexually abusive behaviors. Their goal was to develop and present a model to guide intervention (SOTSEC, 2015). The model presented utilizes a group context and, similar to those models recommended for adolescents, focuses on both the cognitive approaches as well as addictive aspects of treatment. Group sessions are organized to focus on the following aspects of recovery: human relations and sex education, cognitive processes such as thinking distortions that allowed them to act out, teaching of the sexual offense model, victim empathy, relapse prevention planning, and follow up. The sexual offense model recommended for application to this population will now be further explored.

The sexual offense model presented by SOSTEC-ID was originally developed to aid in the understanding of child sexual abuse, and was not specifically designed for application to those who offend against adults, or for those with disabilities (Goodman, Leggit, Weston, Phillips, & Steward, 2008). The model does, however, provide a valuable framework that enables participants and facilitators to understand the individuals' PSB and the steps that led to it. This model can be broken down into four phases that describe the PSB process (SOSTEC, 2015). First, in order to sexually offend an individual has to think about their sexually abusive behaviors (fantasies). Second, the individual must make excuses about why these thoughts are acceptable in order to overcome any internal barriers that would prevent them from following through. Third, they must plan how to gain access to potential victim, though this may not be an entirely conscious process. And fourth, they need to overcome any victim resistance and engage

in the behavior. This may include grooming, force, manipulation, bribes, or other methods of gaining control.

These focus areas and themes can be found in mainstream group treatment for men without DD, and the primary difference here is adaptations in language and recommendations for presentation of material that make it more accessible to individuals with ID (Goodman et al., 2008). Activities to improve the functionality and accessibility of the materials in group have included utilization of visual materials and video clips, engaging in role plays to model healthy relationship dynamics, active learning, and quizzes (Wiggins et al., 2013). This model provides a framework for a psychosocial intervention with a population for whom treatment options are extremely limited. Other interventions for individuals with DD with PSB have included hormone therapy similar to those used to treat hypersexuality in other populations (Jones & Okere, 2008), utilization of aversive stimuli to engage in arousal reconditioning (particularly among those with more severe disabilities), and cognitive-behavioral approaches for those with more mild to moderate disabilities (Tarnai, 2006). Treatment recommendations have also emphasized social skills training to assist in interpreting when sexual behaviors are appropriate or inappropriate and when consent is present or not (Wolfe, 1997). Beyond these basic recommendations, there is little guidance for professionals on how to intervene with this population beyond what is recommended for neurotypical adolescents. While this model presents a feasible method of intervention delivery, it does not help explain the process or experience that led these individuals to engage in PSB.

Current State of the Research

Randomized control trials (RCT) are considered by many to be the most rigorous, "gold standard" of evidence (Strauser & Wong, 2010). However, in many areas of study it is not possible to complete a randomized control trial. Such is the case when it comes to PSB among individuals with DD. In this instance, research may be limited to pre/post data or other forms of quasi-experimtal and qualitative design. It is important to note that having a certain type of experimental design does not imply or guarantee strong evidence, nor does being qualitative in nature indicate weak design or evidence At this point in time the research in this area is dominantly qualitative in nature and is largely based on surveys and or interviews.

Of the 21 articles reviewed specifically related to PSB among DD, 10 were based on survey, focus group, or interview data. Four of the articles were reviews of various aspects of the available literature, four were discussion articles, with one article utilizing a national sample for a data analysis. The remaining articles were case studies. It is important to note that of these articles only three of them utilized data collected directly from the individual with DD themselves. This lack of research and data collected directly from individuals with DD leaves many potential gaps in understanding their experience. In addition, the lack of RCT literature may be limiting, but while there are many challenges to conducting RCT, it is still possible for the quality and depth of research in this area to be advanced through improving and expanding the research designs being utilized, specifically through the inclusion of individual with DD in the research process (Beail & Williams, 2014). In addition, improving the understanding of the experience of

individuals with DD from their own perspective. It is difficult to move into prevention, training, or discussions of interventions for individuals with DD who engage in PSB without first understanding what their experience is or what risk factors may be present. This study is intended to expand the literature in this field to address the gaps in overall understanding of the experience and potential factors contributing to risk from the perspective of the individuals with DD who have engaged in PSB.

Summary

Issues surrounding the development and treatment of PSB are influenced by a variety of social and moral concerns. Research efforts are expanding knowledge and understanding of adults' experiences of PSB, specifically when those behaviors are addictive in nature. Increased attention is being given to the experience of adolescents who have been identified as being at increased risk due to developmental stage (Arain et al., 2013), attachment, media exposure (Braun-Courville & Rojas, 2009), and other factors. Additionally, adolescents with DD are being exposed to the same media influences and factors as those without disabilities, but without many of the social and educational supports to which their peers without disabilities have access (Barnett & Maticka-Tyndale, 2015; Owens et al., 2012; Yoder et al., 2005).

It would be impractical to assume, based on this foundation, that individuals with DD are not experiencing averse consequences as a result of these exposures. While data have indicated that individuals with DD are engaging in a variety of PSB of varying severities (Dewinter et al., 2013; Sullivan & Caterino, 2008; Ward & Bosek, 2002), there

is still much to be learned regarding what their experience is, and which contributing

factors truly do lead to these types of behaviors. Thus, the purpose of this study was to

explore the experiences of adolescents with DD who have engaged in sexually

problematic behaviors, including compulsive or addictive patterns of behavior, and

explore the contributing factors for engaging in these behaviors.

CHAPTER III

METHODOLOGY

Grounded Theory

The current study will use a qualitative, grounded theory approach utilizing a directed process of analysis. Glaser and Strauss developed grounded theory with the purpose of enabling researchers to generate novel theory from emerging data (Glaser & Strauss, 1967). Grounded theory may also be used to a gain fresh perspective of known phenomena (Skeat & Perry, 2008; Stern, 1980). It has been found to be useful when the objective is to understand complex experiences and interactions, and is considered to be particularly appropriate as a design choice when a phenomenon has not been adequately described, or when there are few theories that explain it (Skeat & Perry, 2008). Using this approach provided the opportunity to explore the challenging area of social action and interaction related to PSB, resulting in in-depth knowledge about the experiences being observed, maintained, and/or limited (Skeat & Perry, 2008).

Grounded theory is often described as a process of inductive reasoning, also known as "ground up" reasoning in which the researcher does not begin with a hypothesis about the phenomenon to be studied, but rather remains open to the theories that may emerge from the data (Glaser & Strauss, 1967; Licqurish & Seibold, 2011). When using a directed approach this process of reasoning is adjusted to allow for existing evidence to be utilized and integrated into the research process, bringing in a deductive reasoning aspect as well (Hsieh & Shannon, 2005). This will be discussed in greater

depth in the following section. The integration of this approach is possible due to grounded theory being considered a flexible approach that enables researchers to have a clear methodological approach with core techniques while still having freedom in determining how those are implemented (Ralph, Birks, & Chapman, 2015; Skeat & Perry, 2008). When various methods of applying grounded theory were reviewed, core techniques were identified that are consistent across all variations of grounded theory approaches. The core techniques include theoretical sampling, simultaneous data collection and analysis, continual comparison in analysis, memo writing to aid in analysis, and integration of a theoretical framework around core strategies (Skeat & Perry, 2008).

Theoretical sampling is the process where data collection is controlled by the emerging theory (Glasser & Strauss, 1967). It is a technique that allows for the researcher to choose participants based on the need to learn specific information rather than on the basis of seeking representativeness or generalizability. Sampling then moves forward as guided by the data analyses and participants are chosen in order to advance understanding of emerging concepts (Skeat & Perry, 2008). The goal is to find where there are gaps in understanding and seek participants or data sources to address them. The ultimate goal is to develop and saturate categories of data as they emerge. The sample is considered to be adequate when no new codes are identified as individuals are added to the sample (Glaser & Strauss, 1967; Hoare, Mills, & Francis, 2012). One study investigating when saturation is likely to occur suggested that most codes are established early on in a sample and that saturation is likely to occur within 12 interviews. They found that out of 60 interviews,

94% of the codes identified within the first six and 97% of codes were identified within 12 interviews (Guest, Bunce, & Johnson, 2006). While the generalizability of these results has not been established, this would suggest that with an appropriate theoretical sample saturation may occur early on, within 6-12 interviews.

As data are collected researchers should be engaging in an ongoing process of analysis. This ongoing analysis informs the direction of the data collection and is explicitly aimed at identifying gaps in knowledge to be filled as data collection continues (Calman, n.d.). Seeking comparisons of what is emerging in the data and asking questions is fundamental to the analysis process (Glaser & Strauss, 1967). As data analysis continues, the intent is to identify categories, or concepts, which emerge that are more broadly applicable than the details of the stories being told. Identification of concepts allow for a theory to develop that is applicable beyond the context of the immediate study (Skeat & Perry, 2008). Data should be continually compared through the coding and analyses process. Memo writing is a key factor throughout this process. Memos are informal notes or diagrams that enable a researcher to interpret the data by asking questions about it while engaging with it. Memos also serve as an audit trail and provide a record to track the researcher's developing ideas (Hoare et al., 2012). In addition, memos can serve as an additional code and category generating method (Saldaña, 2012).

Directed Approach

When utilizing a directed approach, the flexibility of grounded theory is utilized

to enable the use of existing research and theory to inform the questions asked during the interview process, as well as to inform the initial codes used while still allowing for additional codes to be generated as needed (Hsieh & Shannon, 2005). Using this in conjunction with grounded theory provides the opportunity to use existing information and models in questioning and coding while inductively verifying them using the grounded theory principles. The primary risk of using a directed approach is the possibility of the researcher approaching the data with a bias based on existing literature. This could lead to focusing exclusively on confirmatory evidence rather than being open to generating new constructs (Hsieh & Shannon, 2005). Grounded theory's focus on the context, experience, and individuality of participant's experiences can help reduce this risk.

Leung (2015) stated "the essence of qualitative research is to make sense of and recognize patterns among words in order to build up a meaningful picture without compromising its richness and dimensionality" (p. 324). The result of a grounded theory methodology in partnership with directed approach is a theoretical model that can be used to explain the area studied, a theory that explains how the different parts of the process are linked, and potentially provide a viable explanation of the phenomena being studied (Skeat & Perry, 2008).

All of these factors make grounded theory with a directed approach an excellent fit for exploring the experiences of adolescents with DD who have engaged in PSB. There are currently no existing theories that appear to fully describe the experience of these individuals, or of their families. The models that do exist require re-examination as

the impact of functional limitations due to disability that individuals with DD experience are not taken into consideration. As a result, they may have limited utility in describing the individuals experience, and facilitating intervention. This leaves families, service providers, and individuals without adequate information or guidance for understanding, preventing, or managing PSB. By understanding which aspects of existing theories may be applicable to this population, as well as allowing for identification of any new potential constructs that may better explain their experiences, could improve our ability to address their needs. The benefits of a theoretical framework would include describing this experience, and helping practitioners and other professionals to have a greater understanding of how to appropriately intervene.

Participants

Participants consisted of a convenience sample selected from past residents of a residential treatment center specializing in treatment of PSB in youth, with a branch of the program specifically designated for serving youth ages 12-18 with DD. This is a private program that does not accept adjudicated youth, however, some youth may have had criminal charges pending at time of treatment or may have criminal behaviors since exiting the program. This program only serves males, limiting the sample to male adolescents. Any individual previously enrolled in treatment with a diagnosed DD was eligible for participation. It is important to note that most adolescents experience dual or multiple diagnoses, often including ASD, ADHD, and ID. Individuals were eligible for participation in this study if they had a diagnosed DD, and had been admitted and

subsequently discharged from the treatment program with confirmed PSB.

Parents of individuals with DD who had been previously admitted into the program were also invited to participate in a separate semistructured interview. This interview included the same questions as those asked to the person with DD (PWDD), with minor changes to account for the changed perspective. Semistructured interviews questions for both parents and indivividuals with DD can be found in Appendix B. Additional clarifying questions were asked of parents as needed. The purpose of this interview was to verify and deepen the understanding of the experiences of the PWDD engaging in PSB. This interview was also important due to the functional limitations that some individuals with DD had related to communication, memory, and/or an understanding of events that have occurred.

The participating PWDD had been in treatment due to confirmed PSB. Each underwent an initial assessment period as a part of their regular treatment during which they completed a full sexual history disclosure, and any required reporting took place between the therapist and client. This means that participants had confirmed PSB(s), as well as details of what those behaviors entailed, already established and shared with their therapist as well as with their parent or guardian.

Data Satiation

While grounded theory does not have a required number of participants it has been hypothesized that approximately six to twelve participants may be sufficient sample size to reach up to 97% saturation of coding (Guest et al., 2006). For doctoral work four to ten interviews have been recommended (Beail & Williams, 2014). It was anticipated

that five to six persons with developmental disabilities (PWDD) and five to six parents/ caregivers would be interviewed. Of the 11 families initially contacted, 8 agreed to participate. Seven of the families had individuals who were interviewed. Of the seven families interviewed, four included both PWDD and parents, two included parents without the PWDD, and one was the PWDD without his parent. After interviewing the five PWDD and six parents of PWDD for a total of 11 interviews, no new themes were emerging, indicating data satiation, thus no additional interviews were sought.

Participant Demographics and Characteristics

Table 2 provides an overview of demographic information of the participants whose experience was being discussed. In the case of four of the interviews with PWDDs, their parents were also interviewed. This included three PWDDs who had one parent interviewed and in one case both parents participated in the parent interview. In two cases a parent was interviewed without her child with DD also being interviewed. In these two cases parents elected to be interviewed without their child with DD due to their concern that such an interview would be a disruption to their child's current status, or due to the unavailability of the child due to continued treatment placement. In one case, a PWDD interviewed without a parent also being interviewed. The parent interviews included five interviews where it was the mother only who participanted, and one interview with both the mother and father of the PWDD. Parents marital status was noted, but no additional demographic information was collected for parents. They instead reported information regarding their child with DD.

This means that while there were 11 total interviews, there were five interviews

Table 2

Participant Demographics of Persons with Disabilities

Characteristics	n [a]
Gender: Male	7
Race	
Caucasian	4
Not reported	3
Religious affiliation	
Catholic	1
Christian	3
Jewish	1
Not reported	2
U.S. Region	
West Coast	1
South Central	1
Pacific Northwest	1
East Coast	1
Mountain West	1
Not reported	2
Adopted	1
Parent status	
Married, living together	5
Single-parent home	2
Type of disability	
Intellectual disability	2
Autism	7
ADD/ADHD	5
OCD	1
Anxiety/depression	1
Sensory integration	1
Specific learning disability	1
Tourette's	1
Other mental health diagnoses	2
Age at time of interview	
18	2
19	3
20	1
21	1

[a] While there were 11 interviews conducted with 12 interviewees, they were about the experience of 7 individuals, thus the sample size (n) is reported as 7 for all demographic information. Additionally, all participants had multiple diagnoses; therefore, numbers in the disability categories are greater than 7.

with PWDD and six interviews with parents, these 11 interviews were focusing on the

experiences of seven different individuals. Thus, for the purposes of demographic

reporting, the sample size is considered to be seven ($n = 7$). All of the participants in the

sample were male, and four of them reported being Caucasian. The other three did not

provide information regarding race. Three participants reported being Christian, one

Catholic, and one Jewish. Participants came from all over the U.S. including one from the

West Coast, one from the East Coast, one from the Pacific Northwest, one from the

Mountain West, and one from the South-Central region of the U.S., two did not report

region. Five of the participants came from households where their parents were married

and living together, one of the participants in a dual-parent household was adopted at a

young age. Two participants were from single-parent households.

There was a range of disability diagnoses that were identified. Every participant

had a diagnoses of autism and all of them had at least one other co-occurring diagnoses.

The most commonly co-occurring disabilities were ADD or ADHD ($n = 5$), and mental

health diagnoses, including anxiety or depression ($n = 3$). Other co-occurring disabilities

included obsessive-compulsive disorder, Tourette's syndrome, learning disabilities,

intellectual disabilities, and sensory integration. At the time that they were interviewed

participants ages were 18 ($n = 2$), 19 ($n = 3$), 20 ($n = 1$), and 21 ($n = 1$).

In addition to demographic information, participants also provided information

regarding their experiences and interactions with sexual materials. Table 3 provides an

overview of this information. The age of exposure to sexual materials or behaviors varied

across participants, one participants was younger than age 6, three were exposed between

Table 3

Participant Problematic Sexual Behavior Information

PSB basic information	n^a
Reported age of exposure to sexual materials or behaviors	
Age six or younger	1
Age 7-9	3
Age 9-11	1
12 or older	1
Unsure	1
Age PSB discovered by parents	
10-11	2
14-15	5
Age of initial sexual education in school	
5th grade (approximate age 10-11)	2
6th grade (approximate age 11-12)	1
7th grade (approximate age 12-13)	1
Unsure	1
No sexual education in school	2
Victim of abuse	
Yes	4
Sexual Only 2	
Verbal Only 1	
Sexual and Verbal 1	
No	3
Experienced trauma	
Yes	2
No	2
Possible	2
NR	1
Age entered sex-specific residential treatment	
13	1
15	1
16	4
17	1
Time in sex-specific residential treatment	
less than 1 year	1
1-2 years	3
greater than 2 years	3

[a] While there were 11 interviews conducted with 12 interviewees, they were about the experience of 7 individuals, thus the sample size (*n*) is reported as 7 for all problematic sexual behavior information.

the ages 7-9, one was between the ages of 9-11, one was 12 or older, and one was unsure.

In contrast to the age of exposure, parents discovered or were made aware of the PSB much later, with five parents reporting that they found out when the PSB was occurring when the PWDD was between the ages of 14-15 and the remaining parent reporting that she found out when the PWDD was between the ages of 10-11. There were differences between participants related to the reception of formal sexual education. Two participants indicated they never received any formal sexual education while in school, one was unsure if he had, and the remaining participants reported receiving a sexual education class focused primarily on maturation in fifth grade ($n = 2$), sixth grade ($n = 1$), or seventh grade ($n = 1$). More details related to educational experiences will be provided in the following chapters.

Of the seven participants, four reported being victims of some kind of abuse. Of these four, two were victims of sexual abuse only, one was a victim of verbal abuse only, and one was a victim of both sexual and verbal abuse. Reports of verbal abuse were considered separate from reports of bullying, however, the experience of being bullyied was reported by multiple individuals in the semistructured interviews and will be discussed in later chapters as it was reported primarily as part of traumatic events rather than as an experience of abuse. Trauma, which was defined as any event or experience that was self-defined as being one that made a lasting negative impression, was experienced by two of the participants. Two reported that they possibly experience a trauma but were unsure. Following the discovery of their PSB by others, each participant eventually was enrolled in a residential treatment center that would admit students with

disabilities and would specifically address their PSB. Most participants entered treatment at age 16 ($n = 4$), this is approximately 1 year after most participants PSB were discovered by family ($n = 5$), and several years after reported initial exposure to sexual materials or behaviors. The remaining three individuals were admitted at 13, 15, and 17. Once in treatment only one participant was there for less than one year, while the others were in for 1-2 years ($n = 3$), or greater than 2 years ($n = 3$). So, while participants backgrounds and specific PSB were varied, each were admitted into the same treatment center where they were in treatment for extended periods of time.

While specific questions were not asked regarding what specific PSB participants engaged in, many behaviors were naturally reported throughout the interviews and may provide a useful context for the data collected and interpretation. The breakdown of the range of PSB that were reported throughout the interviews are included in Table 4. It is important to note that this table only includes those PSB that were voluntarily reported throughout the interviews, and that there may be others that were not reported. Additionally, due to this information not being specifically requested there are no frequencies included, as it is unknown how many participants shared similar PSB. It should also be noted that pornography as a problematic behavior was common across all participants, and each reported that they felt they did not have control over their pornography use. Regardless of the frequency, it is clear that there is a wide range of PSB included among this group of participants, ranging in severity.

Participant Profiles

Due to the sensitive nature of the topics discussed in their interviews extra care

Table 4

Range of Problematic Sexual Behaviors Disclosed

Behavior
Voyeurism
Fetish behavior (leading to law breaking)
Sexual addiction
Sexually abusive behavior (including abuse of family members, other persons with disabilities, younger children, and/or peers).
Soliciting or attempted solicitation
Frottage
Pornography (problematic per self-report)

Note. This table may not include all PSB engaged in by participants and does not include any frequencies as this data was not specifically collected

was taken to ensure the protection of participant identities. Thus, identifiable details as well as details of the PSB engaged in are not included in the participant profiles. All names are pseudonyms to protect the identities of those interviewed.

Alex. Alex was a 19-year-old male who reported being diagnosed with autism. Alex remembers being initially exposed to sexual materials indirectly through video games with friends at approximately age 8. He has been in various treatments and therapies for much of his life, and entered a sex-specific residential treatment center at age 13. He was in treatment centers off and on for seven years, at least four of which were in sex-specific treatment. Alex self-identifies as having a sexual addiction and currently lives with his aunt.

Amy. Amy was the mother of Alex. She has been a single-parent for much of

Alex's upbringing. Amy reports Alex's diagnoses as including autism, bipolar, intellectual disabilities, and sexual addiction with one episode of a psychotic break. She began to notice Alex's problematic sexual behaviors when he was approximately 11 years old. Alex had been in various therapies for much of his life and as his behaviors escalated, residential treatment was pursued. Amy reports that his sexual behaviors have significantly limited his ability to engage in basic life activities, such as employment, or to be safely integrated into the community.

Brett. Brett was a 19-year-old male who has been diagnosed with autism, ADHD, and an intellectual disability. Brett was sexually abused by a trusted peer starting at 8 years old. He entered treatment for his own problematic sexual behaviors at age 16, and remained in treatment for over two years before returning home. He now lives with his parents and is attending a community college.

Brady and Beth. Brady and Beth were the parents of Brett. Brady and Beth added sensory integration issues as a diagnoses in addition to what Brett self-reported. They first became aware of Brett's abuse and problematic sexual behaviors when he was 15. Brady and Beth report that Brett benefited from specialized treatment for his sexual behaviors, and now is working towards improving his independent living skills.

Caleb. Caleb was a 20-year-old male whose diagnoses include autism, ADHD, and obsessive compulsive disorder. Caleb remembers beginning to have sexual urges as young as age 5 as a result of exposure to inappropriate play with peers and he began viewing pornography regularly at approximately age 10. Caleb entered residential treatment for his problematic sexual behaviors at age 16. He returned home after turning

18 and currently lives at home with his parents.

Candice. Candice was Caleb's mother. She and Caleb's father live together in their family home. Candice first became concerned with Caleb's sexual behaviors when he was 6-7 years old, and he had tantrums when boundaries were set around sexual behaviors. However, it wasn't until Caleb had been expelled and his behaviors were continuing to escalate that they determined outpatient therapy was no longer sufficient. Candice reports that she feels that the combination of her son's obsessive tendencies combined with the addictive components of his sexual behaviors has made it very difficult to find effective therapy. Caleb has been unable to maintain educational or employment opportunities due to his inability to manage his urges.

Doug. Doug was a 19-year-old male who stated that he feels the majority of his struggles are connected to his ADD, depression and anxiety, but he also has been diagnosed as being on the autism spectrum. Doug reported experiencing verbal abuse as well as extensive bullying. He remembers being exposed to sexual content at age 11 or 12. He entered residential treatment for his sexual behaviors at age 16. He remained there for just under 2 years after which he returned to his family home.

Debbie. Debbie was Doug's mother and has been a single-parent for much of Doug's life. She reported being in an abusive relationship at one time that Doug witnessed. She began noticing potentially inappropriate sexual behaviors in Doug when he was 13 years old. She pursued therapy for Doug and their family at that time but as it was ineffective she ultimately determined residential treatment was necessary.

Gary. Gary was a 21-year-old male who is diagnosed with autism and learning

disabilities. Gary was initially exposed to sexual materials in the third grade at age 8-9 and reports that he was immediately hooked. He entered residential treatment programs starting at age 14 and entered a sex-specific residential treatment program at age 17. He was in this program less than one year and left at age 18. He then returned to his home. He has since been able to maintain consistent employment.

Erika. Erika was the mother of an 18-year-old male who is diagnosed with autism, ADHD, mood disorder, and who at one point was also diagnosed with bipolar disorder. Erika's child did not participate but Erika was still interested in participation. Erika is married and lives with her husband. Erika reported that her son was sexually abused by an older male child when he was young, he went through therapy at that time and showed no memory or concerns related to that abuse after completing therapy. However, her son entered residential treatment at age 13 due to other behaviors that could not be managed in the home. It was at their first overnight visit from residential treatment that Erika noticed problematic sexual behaviors in her child. He was exposed to sexual materials and behaviors primarily while in treatment for other behaviors at age 13. His behaviors escalated as he went through various placements where the treatment providers did not know how to address his sexual behaviors and were often inadequate and, according to her, were at times potentially damaging. He entered residential treatment specifically for his sexual behaviors at age 16, he remained in this treatment center for 1.5 years. After leaving treatment he returned to live at home.

Fiona. Fiona was the mother of an 18-year-old male who was diagnosed with autism and ADHD. Fiona's child was unable to participate but Fiona still desired to

participate in an interview. Fiona is married and lives with her husband. Fiona reported

that her son was sexually abused by an older female while in a private day school at age

14. It was only after he entered sex-specific treatment at age 15 that she learned the

extent and scope of his own sexual behaviors following the abuse and that he had been

exposed to and was viewing sexual materials prior to his abuse. After leaving his sex-

specific treatment program her son went on to another program to help learn independent

living skills and to transition out of the residential treatment environment.

Instrumentation

Participants were interviewed utilizing a semistructured interview format. The

items on the semistructured interview were developed for the purpose of this study based

on the comprehensive literature review. Questions were designed to provide the

participants opportunities to indicate if any of the previously identified potential factors

played a role in their personal experiences. These questions were included as part of the

directed approach. However, questions were also asked that allowed participants to

identify any other factors they felt influenced their development of PSB, allowing for the

open coding and ground-up approach that is a key component of grounded theory. The

interview protocol and question development was informed by feedback from the

dissertation committee, primary advisor, and the clinical director of the treatment

program from which participants were previously enrolled. The interview was designed

to include open-ended questions, which allowed for participants to provide personal

insight, experience, and opportunity to elaborate on the questions (see Appendix A). The

interview was semistructured to offer flexibility to the interviewer to ask clarifying and expansion questions when necessary. The interview for the parents or caregivers included the same questions as those asked of the PWDD, to verify and enhance the researcher's understanding of the experience of the PWDD.

Guidelines have been recommended by the National Federation Research (D'Eath et al., 2005) for interviewing individuals with DD, and include establishing rapport with the interviewee and being clear regarding his rights to confidentiality, as well as his right to not answer any questions. Other guidelines include using clear communication with familiar language, having clear topics, avoiding providing a list of options, avoiding implying there is a desired response, being cautious of rephrasing questions multiple times, and being aware of the potential limitations in experiences that may hinder the participant's ability to assess satisfaction with services provided. It was also recommended that a familiar person be the one to conduct the interviews and that the interviewer be willing to use alternate ways of communicating both verbally and nonverbally to enhance communication and understanding. Plenty of time should be allotted for the interview so that the questions can be fully addressed and explored without being overwhelming for the individual, as often it appears that interviewers fail to fully explore the experiences of individuals with DD (Beail & Williams, 2014). Interviews with both students and parents/caregivers were planned for approximately 1 hour. Given my history of working with these individuals within treatment and having contact with them previously, I conducted the interviews bearing in mind all recommendations for effective interviewing with persons with DD.

Procedures

Informed Consent

The invitation to participate was provided to potential participants via personal phone calls. Potential participants were verbally informed regarding informed consent including the purpose of the study, confidentiality, risks and benefits and the procedures that would be undertaken. It was specifically emphasized that interviews would be conducted separately with the PWDD and with parents. Once interest and willingness to participate was confirmed then a follow-up email was sent with greater details as well as a Qualtrics link to the informed consent documentation. A follow up phone call was provided upon request to verbally go over the informed consent document. In the event that the PWDD was not his own guardian he was still provided with full informed assent and opportunity to choose to withdraw at any time. Electronic signatures were provided using the Qualtrics survey system. At the start of every interview these documents were once again reviewed and verbally confirmed prior to beginning the interview.

Data Collection

Once participants expressed an interest in participating and had reviewed and signed informed consent documentation an interview was scheduled. Interviews were audio-recorded and then transcribed. Due to the critical importance of confidentiality in this type of study, additional measures were taken to ensure the de-identification and protection of data. During the time of transcription all information within the transcription was de-identified to protect the confidentiality of the participants and their

families. Audio recordings were destroyed following full transcription and analysis of the data. Transcriptions were identified via a coded name that only the primary researcher had access to the key. The identification key was destroyed after the full analysis of the data.

Data Analysis

To most effectively pull from the richness of this data the coding for the PWDDs and parent/guardian interviews were concurrently identified when possible. This helped to form a more complete picture of the experiences of each individual and added depth and clarity. This also allowed for any follow-up questions or clarifications to be identified and then conducted, particularly when there were discrepancies in the reports. These data were then assessed to determine how well they fit within the existing theories, and to identify potential gaps in the existing theories that did not include or explore the full experience and factors contributing to risk identified by the participants.

Initial coding. Data from the transcribed interviews was first analyzed using initial coding procedures, otherwise known as open coding. In this process data were regularly examined and were broken down into discrete parts and examined for similarities and differences (Saldaña, 2012). Line-by-line coding was used to complete this process with continual memos being utilized to assist in identifying processes, trends, and patterns (Saldaña, 2012). My memos included any thoughts, ideas, questions, self-reflections, or potential explanations that occurred to me throughout the coding process. These allow for my thoughts and interpretations to be traceable and at times were able to become a part of the data assessment.

Axial coding. The initial codes used were guided by what was observed within the content without relying on or utilizing the existing list of potential codes. Following the initial coding, axial coding was used. In axial coding dominant themes are identified, data is reorganized to group codes, synonyms or redundant codes are removed and the best representative codes are maintained and ultimately selected. This included utilizing the existing codes identified from the research to determine if they were representative of this population in this context. Grouping similarly coded data reduces the number of initial codes and allows them to be sorted and interpreted more accurately (Saldaña, 2012). The axial codes that were included based on the literature review, as enabled by the use of the directed approach, included the following potential factors contributing to risk.

- history of trauma or abuse,
- attachment issues,
- exposure to sexually explicit material or pornography
- and attitudes towards disability/access to sexual education

The possibility of including new axial codes was considered throughout the process, likewise the possibility of needing to remove existing codes was also taken in consideration. To determine the final axial codes, the content of the data being analyzed within the interviews and the appropriateness of fit was considered. The axial coding process was done in multiple iterations, in each iteration the codes were synthesized, combined, condensed, and then reviewed until the final, broad, axial codes were established. This is all part of the process known as selective coding (Cohen & Crabtree, 2006). This process allowed the researcher to go from over 500 potential codes to 17 primary axial codes which encompassed a complex array of experiences.

Themes. The process of developing the primary themes that addressed each of the research questions included reviewing audio recordings and transcripts multiple times while documenting relevant quotes, ideas, and including memos of thoughts and connections along the way. Throughout each iteration of focusing the axial codes the primary researcher was noting relevant themes and ideas as well. Due to the complexity and richness of the data, subcategories of the final themes identified were also considered. The final themes that emerged as key components for the engagement in and progression of PSB were:

- Exposure to sexual content or behaviors
- Motivation
- Opportunity
- Deficits in sexual education

Research question two specifically addressed factors that contribute to risk for engaging in PSB and the following overarching contributors of risk were identified.

- Abuse
- Trauma
- Viewing pornography
- Attitudes towards disability
- Access to sexual education
- Barriers to appropriate help/treatment
- Social isolation
- Level of parent preparation and ability to engage in education of child with disability
- Complexity of disability-related activity

Table 5 illustrates how the data expanded on and added to the codes that existed, and resulted in the final themes which emerged in this study. Abuse, trauma, and attitude towards disability were themes directly supported by the data and emerged as final themes in the study. Attachment issues were coded in with trauma in the final axial

Table 5

Axial Codes and Themes

Existing initial axial codes	Final axial codes	Final themes: Constributers to risk	Final themes: Overall experience/process
Abuse	Abuse	Abuse	Exposure to sexual content or behaviors, Motivation, Deficits in sexual education
Trauma	Trauma	Trauma	
Attachment issues			
Exposure to pornography	Pornography	Viewing pornography	
Attitude towards disability	Attitude towards disability	Attitudes towards disability	
	Power of language and labels		
	Access to sexual education	Access to sexual education	
	Barriers to treatment	Barriers to appropriate help/treatment	
	Lack of appropriate treatment options		
	Lack of resources	Complexity of disability-related activity	
	Lack of supports		
	Parent knowledge/education of sexuality and disability	Level of parent preparation and ability to engage in education of child with disability	
	Shame	Social isolation	
	Social isolation/acceptance		
	Exposure source		
	Opportunity and parental controls		Opportunity
	Disability-specific factors; impulsivity, fixations, etc. [a]		

[a] Disability-specific factors were found to be relevant across all areas as they are an inherent part of including a population with disabilities. Therefore, they are discussed separately and not included as either an overarching model or a contributing factor to risk.

codes. Exposure to pornography was modified to a final code of pornography to and then the final themes of viewing pornography and exposure to sexual content. All other final axial codes and their subsequent themes emerged as a direct result of the data. The final axial code of disability-specific factors such as impulsivity, fixations, etc., did not convert directly into any theme. Instead, this is discussed independently as being worthy of consideration across all themes and factors due to the way that disability-specific considerations factor into every aspect of the development of PSB. It is impossible to confidently explore any aspect of the development of PSB among PWDD without taking disability-specific concerns into consideration. Each of the final themes wil be defined and discussed in detail in Chapter IV.

Investigator Bias

When engaging in grounded theory it is important to note the potential sources of risk, particularly those that may come from the researcher and his/her experiences (Glaser, & Strauss, 1967). In this instance I needed to be aware of my own experiences and how they may have been influencing my opinions and interpretations of what the data was saying. In qualitative research it is not inherently good or bad for the researcher to bring his/her own experiences into the study (Beail & Williams, 2014). However, they should be clearly explored and presented.

My experiences of working within this treatment center over several years' period has created in me a desire to understand what led these young boys to require such intense interventions. My experiences have fueled my desire to understand their experiences so that I can better serve them and their families. In my work I have

developed opinions regarding the existence of a connection between pornography (frequency, content, and age of exposure) to engagement in PSB. I also have observed that people in the life of the PWDD may have inadvertently excused or ignored warning signs because of the presence of the disability. While these observations and experiences have driven my desire to engage in this research, they may inadvertently shape the way that I frame and interpret questions. It was important throughout this study that I remain engaged in self-reflection and memo writing and that I utilized my validity checks to ensure that my experiences were not turning into a negative source of bias that inappropriately directed or influenced the results.

Validity in Qualitative Research

Terms such as validity and reliability often have a tenuous relationship with qualitative research, but some quality assurance methods have been developed for their use in qualitative research (Beail & Williams, 2014). Qualitative investigators would be best served by considering validity issues throughout their project, specifically during the planning and assessment phase so they can present materials in a clear, forthright method that can be easily followed and understood (Whittemore, Chase, & Mandle 2001). Whittemore et al. outlined primary and secondary criteria as well as techniques for explaining validity in qualitative research. They proposed that credibility, authenticity, criticality, and integrity are primary criteria that are necessary for all qualitative inquiry. Secondary criteria include explicitness, vividness, creativity, thoroughness, congruence, and sensitivity. These speak to the ability of the reader to follow the interpretive effort and process of the researcher including their choices related to methodology,

interpretations, their investigator biases, and insight into the research judgement used. The techniques outlined are intended to be flexible in utilization and adaptation with the ability to be combined based on the needs and goals of the specific project (Saldaña, 2012).

This study was conducted in a manner that utilized the flexibility offered from qualitative research design. Validity techniques that were utilized included participant checking, memoing, providing a clear audit trail of decision making, retaining records of each iteration of coding, and the use of a third party checker.

For participant validity checks, also known as member checking, identified codes and concepts were brought back to the participant for clarification and validation. This was done to ensure that what was being interpreted was accurate and in line with what was intended, rather than being the product of the interviewer's interpretation of what was said (Beail & Williams, 2014). Engaging in participant checks is of particular importance when utilizing the directed theory approach, since existing codes based on the literature were taken into consideration. Directed theory enables the use of these codes, but warns against seeking to force the data to fit the codes. Researcher biases may not be inaccurate and may help to inform questioning, but they should not be projected onto the participants. Member checks minimize the risk of this happening.

Participants were emailed both their participant profile as well as their final coded data. For those PWDD who had not provided an email addresses they were contacted via text message to either obtain a personal email address or confirm permission to send their summary in the same email as the parent summary ($n = 2$). For both of these participants

their summaries were sent to the parent along with the parent summary. This meant that a total of nine emails were sent to participants. Six participants responded, one via text message; two made minor corrections to their participant summaries and two participants specifically confirmed the accuracy of their coded responses.

Third-party checks of the data throughout the coding process were completed by a colleague with experience and background in sexual health, disability services, and qualitative research. She had access to data only after it was fully de-identified and she reviewed the coding at each iteration, providing feedback and pointing out any discrepancies she felt may be present. When this occurred these areas were discussed until agreement could be established regarding an appropriate code. This third-party check allowed for open discussion of the codes and their interpretation and allowed for an additional guard against researcher biases negatively influencing the data interpretation (Saldaña, 2012).

Additionally, the transparency of the coding process with the inclusion of memos also acts as a tool for assessing validity. Transparent, clear, consistent, and reporting of the process from start to finish is a key component of validity in qualitative research (Whittemore et al., 2001). Within this study this has been accomplished through memo writing and retention of each iteration of data analysis.

Summary

This chapter provided an overview of the qualitative methods utilized in this study to explore the experience of individuals with DD who engage in PSB, and the

contributing factors of risk that might contribute to these behaviors. The purpose and value of combining a grounded theory approach with directed analysis techniques was explained. In addition, detail of the participants, instrumentation, data collection and analysis, and validity checks were also covered in this chapter. The following chapter will go into greater detail regarding the findings of this study and how they address the research questions.

CHAPTER IV

RESULTS

This study's primary purpose was to explore the experiences of adolescents with DD who have engaged in problematic sexual behaviors and to explore the contributing factors for risk of engaging in these behaviors. The specific research questions were, first, what is the experience of individuals with DD who have engaged in problematic sexual behaviors? And second, what are some of the potential factors that may contribute to the risk of individuals with DD developing problematic sexual behaviors? To address these questions, 11 interviews were conducted to explore the experiences of seven different individuals with DD who had confirmed engagement in PSB and to gather additional information from parents. Five of these interviews were directly with PWDD, and six were with parents. These interviews provided a rich data source for identifying key themes and factors that may contribute to risk of engaging in PSB. In this chapter, themes and ideas will be discussed and conceptualized. Themes that emerged will be defined within the context of a proposed model that addresses each of the research questions.

Development of Problematic Sexual Behaviors

The first purpose and question being addressed in this study is about gaining a greater understanding of the overall process that is experienced in the development of PSB among adolescents with DD. The range of behaviors varied greatly between participants, and individual experiences were unique. However, as the data was reviewed over several iterations a basic, overarching process emerged with key components that

were consistent across all participants and experiences, providing a broad context for understanding the development of PSB. These components were: exposure to sexual materials and behaviors, motivation to engage in sexual behaviors, deficits in sexual education and understanding, and opportunity.

Figure 2 illustrates how each of these components are related. Exposure, motivation, and deficits in sexual education each emerged as primary components in the process of engagement in PSB. However, before any of these components can lead to PSB there must be opportunity. The intial three components are not linear, nor is there a particular order in which these components seem to come together. Thus, it is important to recognize that this model is not a clear-cut formula of what will lead to PSB. The lines within this model indicate that there is a general progression of events where exposure, motivation, and deficits in sexual education, when followed by opportunity, would then lead to PSB. Without opportunity, there is no potential of engaging in PSB. Likewise, without the exposure or knowledge of sexual materials, motivation, and deficits in sexual education including what is and is not appropriate, PSB is unlikely to occur when
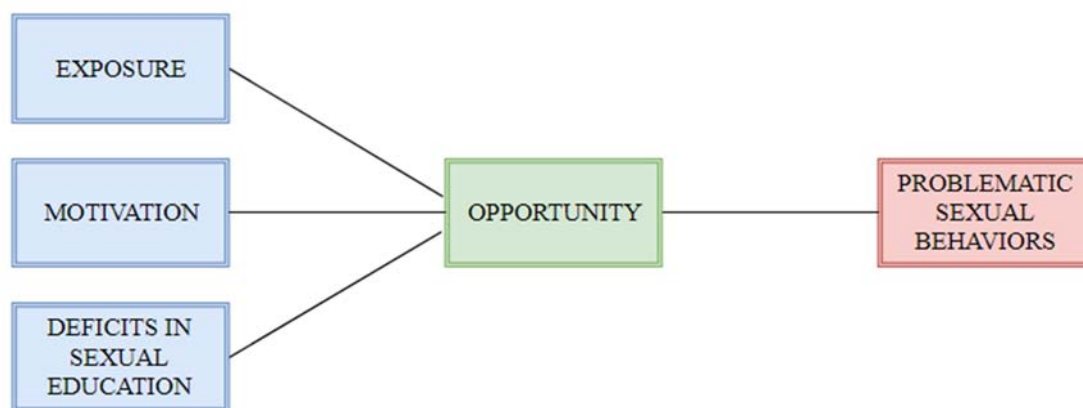
Figure 2. Model for engagement in problematic sexual behaviors.

opportunity is presented. This model indicates that these components are the common elements present in order to reach a place of engaging in PSB. The factors contributing to risk explored in research question two seem to primarily play a role in the exposure, motivation, and defecits in sexual education portion of this model where they can impact the likelihood of engaging in PSB once opportunity is introduced. In addition, the data indicate that it is highly unlikely to expect that a child will never be exposed to sexual content, or have opportunities to seek sexual materials, making some of these common experiences among youth and adolescents, most of whom are unlikely to engage in PSB. The difference between someone engaging in PSB or not is likely related to the presence of the contributors of risk. Therefore, it is critical to seek to understand how these components relate to the contributing factors of risk, and then to seek ways to minimize the overall contributors to risk of engaging in PSB.

Details of how each of the component in this model are experienced may vary, but ultimately each component appears to be present before behaviors become problematic. It is important to remember that this process is specifically referencing behaviors that are clearly problematic in nature, not normative levels of curiosity and sexual behaviors. So, regardless of the severity of the PSB, whether it be pornography as an addiction, is the PSB itself, or having hands-on victims of sexual abuse, the same process would still apply. Details of each component varied across participants and will now be examined in greater depth.

Exposure to Sexual Content or Behaviors

Exposure to sexual content or behaviors can come from many sources.

Participants referenced sources of exposure as including peers, family members and the media. Exposure at some point was reported by several individuals as being largely inevitable. However, the context and circumstances around initial exposure seemed to play a key role in the way that a PWDD viewed sexuality, sometimes creating a lasting impression or fixation on a particular type of behavior. Alex stated "Once you get something on your mind it is hard to get out. Even if you try for years and years it's probably going to be there just as bad as it was on day one." All of the participants mentioned feeling initially very confused and lacking understanding after initial exposure to sexual content. Alex said "There was a video game a friend of mine played that was very sexual in nature and he was making jokes about it. I didn't understand any of it...[it] got my mind running, I had no idea what that was." In another example sexual topics were introduced through sexualized play with a trusted relative where it was reported that seeing his relatives exposed body on multiple occasions led him to become fixated on seeing female bodies. "that's kind of where the voyeur kind of dug claws into me...it was half play but half something else I think."

No participants recalled receiving any form of specific or formal education either in the home or at school prior to their initial exposure to sexual content. The source and type of exposure, particularly when it occurs without any other sources of knowledge available, can influence a PWDDs perception of sexual activity as positive, negative; allowed or not allowed; or even normal vs. abnormal. Doug reported that he was first exposed to sexual topics by overhearing peer aged individuals on the bus. Based on what he heard and the way his peers talked about it, he knew that sexual stuff was "obscene,"

he went on to explain, "… simply because of how secretive they were about it... they would always whisper about it as if they did something wrong." He also mentioned remembering in movies that magazines were outdated but that "there were characters who would get in trouble for having magazines like that." Doug went on to explain that he was extra curious about what they were talking about because of the way they spoke about this topic and it also led him to know he needed to try to hide his curiosity and his efforts to learn more about sexuality.

When upon initial exposure inappropriate behaviors are presented as normal, that may be assumed to be truth. Referencing when he first remembers being shown pornography Brett stated "I was 8 years old with my friend and he was showing me pornography and telling me how this is what sexual activity was." He went on to state that he believed this statement and thought sexual interactions were "free and easy" and could be done with anyone. Brett's father further expanded on this by stating "I think that because he was introduced to pornography by a peer who he considered a trusted friend…that he thought that this was the norm."

Five of the seven individuals whose behaviors were being discussed reported being exposed to sexual materials before the age of 12. This is noteworthy because in every case initial exposure was reported as occurring prior to when participants were receiving any other education, either in home or at school. This left their knowledge of sexual materials limited to what the exposure source explained, and blocked opportunity to ask questions as the topic had not yet been broached in other environments and contexts. This is important to keep in mind as contributing factors are further explored,

specifically the access and appropriateness of education.

Exposure can be accidental or intention; subtle or explicit; and can occur at any age. However, the way that an individual is exposed and the content of the exposure can make a difference in what motivates them to pursue additional PSB. Nearly everyone will be exposed to sexual topics at some point in his/her life, so it is the combination of this with other factors that lead towards the development of PSB.

Motivation

There are many potential reasons that someone will desire to engage in or continue to engage in PSB after initial exposure. Regardless of diagnoses, functional limitations, or other factors, the choice to engage in PSB is fueled by some desire or goal. Some of the motivational factors that emerged from the data were seeking education and learning, seeking social acceptance and inclusion, including a desire to engage in 'normal' behavior, seeking a form of escape from realities and control in personal life, and the experience of physical gratification.

Each of the seven individuals whose experiences were being explored reported viewing pornography as being motivated by education or learning. Caleb stated "I went on pornography to figure out the positioning of sexual intercourse—how it actually looked." Brett added "I kept telling myself that it was education and I was trying to learn how all this works in a day-to-day life." Participants expressed being confused and curious about sexuality and pursuing PSB, including pornography use, as a means to gain understanding. Brett stated "I was confused; I was still trying to look for was a better understanding of sexual activity. I felt something was still there I was looking for." Brady

and Beth added from their parental perspective that hormones also likely play a role in motivating their child to seek out additional sources of understanding "I think the normal cycle of things is he's going through hormones raging too. He's trying to deal with probably his frustration over having a change in his body…he didn't understand why he had these feelings and didn't know what to do with them."

In addition to seeking education and learning, several participants mentioned seeking social connection and inclusion as well as normal social experiences as a motivating factor. In recounting his thoughts following his initial exposure to sexual materials Doug describes deciding that knowing more about sex might help him be socially accepted "…I didn't really have any friends so I did whatever I could to look cool. I knew that [sex] was something they constantly talked about…At one point I got tired of it and I was like, well, they're doing it so maybe that's the difference." Caleb addressed another aspect of this when he talked about being in a group therapy where a peer-aged individual mentioned engaging in sexual activity, he said, "I got really fixated on that…because if he can do it, then why am I not able to do it?." Caleb also mentioned feeling like if he talked about sexual stuff or engaged in sexual behaviors that people would pay attention to him "I knew it was wrong very early on in my life and despite the fact that I knew that I kept doing it. I think it's a combination of getting attention, drawing attention to myself, as well as the sexual aspect."

For many individuals with DD there may be several areas of their life in which they lack power and control over decision making. Several participants mentioned being bullied, or experiencing other losses or trauma. In response to this there was mention of

seeking escape from situations as well as power and control in their own life. "It was kind of like an escape for me, an escape from the reality that I was in." stated Alex. Alex also describes not wanting to stop because engaging in PSB made him feel like he was his "own person" who could "make my own decisions." Doug echoed this sentiment when he stated that he looked up pornography because the ones who bullied him talked about it like a great thing so he "thought it would be an escape." This becomes particular important when looking at the contributing factors of trauma and abuse and how they might motivate engagement in PSB.

Physical gratification was also cited as a primary motivator for engagement in PSB. Alex described it as a "rush" similar to what racers get, "It's tough to put into words... the rush it gave me. Same thing that racers get when they're racing, almost that tunnel vision, you just see nothing else but that." He further explained how this tunnel visions became obsessive and he fixated on sexual behaviors, struggling to make a decision to stop at any point. Caleb stated "I think it was a combination that I wanted to have over and over and over again, the [physical] rewards and sensual reward also." Several others described how this experience kept them returning and, in four of these experiences, a subsequent fixation and loss of control over their desires followed.

It is in the motivation phase that many of the contributing factors for engagement in PSB play a particularly strong role. These contributing factors will be discussed more completely in the following sections, but in every case there is some reason or combination of reasons that motivate individuals with DD to continue to engage in PSB. Disability-specific factors of impulsivity, fixations, obsessions, and difficulty in thinking

through consequences were all referenced in every interview as complicating factors that further influenced continued engagement in PSB. This will be discussed further in the section addressing functional limitations and developmental influences.

Deficits in Sexual Education

A key theme that emerged was the belief that education/knowledge would have mitigated some of the motivating for engaging in PSB and would have decreased the influence of other risk contributors. Sexual education in this context refers not only to formal sexual education based on maturation and sexual health, but also understanding the potential pros and cons of sexual behaviors on a personal, social, and legal level. Caleb stated that if he had known the pros and cons of pornography early on when he was getting into it, it could have "changed a lot of things." He also stated the belief that if he had had more education regarding sexuality in men and women then maybe he would not have engaged in a particular PSB that he later had to report in what is called a disclosure, he stated, " [if I had known] maybe I wouldn't have had a certain thing that was put in my disclosure." Two of the participants never received any form of sexual education and the remaining five reported it as being unhelpful or inadequate.

Doug articulated what was expressed by many participants when he explained how frustrating it was that sexual education didn't ever really help him understand what was going on or provide him with an outlet for understanding. He compared it to other educational systems where sex is portrayed as something normal with measures included of when and how it would be safe. "[here] the schooling system makes it feel like, oh, if you do it you're going to explode!" in contrast, he felt it would be more beneficial to be

approached in terms of consequences "…you can do it whenever you want but there's going to be way less consequences if you do it here."

In addition to feeling like the sexual education was inadequate or incomplete, every participant's reported experience included some element of feeling like they were unable to understand the materials being presented. This was enhanced by the learning difficulties associated with their diagnoses. Alex explains "with the autism it's kind of hard to grasp certain things, even just at first you just don't perceive it the same way." He expanded on this by indicating that even with one-on-one attention it can still be a challenge, " Even if someone sits there and explains it to you, bit by bit, it's still a little hard to learn about it." He then explained how nobody really did sit down with him to explain. "So I guess part of it was my lack of understanding and part of it was my blockage of knowledge or whatever you want to call it." Brett added that with his diagnoses it is sometimes harder to understand things, he stated "it takes me more time to actually get the concept, so I find a lot of struggle to get help to understand things more."

While it is impossible to know from this data the specific ways in which appropriate education on sexuality would have changed the experiences of the individuals interviewed, it is clear that the role of education cannot be dismissed as a factor for engagement in PSB. Additional details regarding the limitations and concerns around sexual education as a factor contributing to risk will be discussed in the following sections.

Opportunity

The opportunity, attachment, and trauma, or OAT model (Hall, 2012) was

described in detail in the literature review. Aspects of this model, including desiring

escape and emotional connection as motivators for engaging in PSB were supported. This

model also emphasizes the critical factor for engaging in PSB as opportunity. In order for

any individual to engage in PSB there must be an opportunity to do so. Opportunities

come in many forms and many participants made specific mention of how they felt it is

an impossible expectation to always be able to block opportunities. Gary stated "the

internet is everywhere so it would take a lot of hard work on parent's behalf to actually

keep their child sheltered from that sort of thing." All of the parents interviewed reported

implementing parental blocks on electronics and media devices but feeling that there was

always some work-around that their child found. Debbie stated "I, as a parent, put every

safeguard I knew of on electronics and they still found a way around them." Another

parent described how surprised they were to learn that environments that didn't appear to

them to provide opportunity were locations where abuse occurred. "we didn't have a

basement where the kids were unattended…we could hear and easily see where the kids

were, we thought they were in a safe environment but he saw it as an opportunity

environment."

In spite of the difficulties associated with blocking opportunities entirely,

whenever opportunities were limited, PSB either decreased or changed in nature. Doug

reported that in eighth grade the computer at home was broken so he wasn't able to

access pornography. Erika describes how her child only engages in certain behaviors

when opportunities arise. In those situations, he immediately takes advantage of those

opportunities to engage in his PSB. She reports that his constant seeking for opportunities

and lack of ability to regulate when opportunities arise has even led to law-breaking behaviors and an inability to maintain employment. It has become easier for individuals to seek opportunities to fuel their PSB. Specifically, the internet provides opportunities on an unprecedented scale. Caleb described his experience by stating "I wanted to voyeur a girl but I didn't have the opportunity to. So, what I did have was the internet, so I figured why go out and walk a mile or two just to find a girl and voyeur her when I can find something like that on the internet?."

Perpetually preventing opportunity appears to be a nearly impossible task. However, parents still reported that they felt that limiting opportunities for early exposure to sexual content and limiting access was an important task. Fiona explained that she believed that if opportunities are limited for PSB, specifically pornography, then there may be more opportunities for positive education and learning.

Factors Contributing to Risk of Engaging in Problematic Sexual Behavior Among Persons with Developmental Disabilities

This overarching model provides a broad understanding of the different components that must be present in order to have the potential to lead to PSB. At each step of this process there are factors that may increase the risk that an individual will engage in PSB. It is important to note that not every individual with a DD who is exposed to sexual materials will go on to develop PSB. Individuals may experience several factors that may contribute to their risk and never engage in PSB. While each factor may have the potential of further contributing to the risk of engaging in PSB, it does not mean that

if an individual experiences one, or even several, of these factors that he or she *will*

engage in PSB. However, with each contributing factors present, the likelihood of sexual

behaviors becoming problematic appears to be increased. It is beyond the scope of this

data to determine which contributors might carry more weight in leading to risk. These

factors vary greatly in terms of their source and method of influence, as there are a mix of

societal and individual influences present. In some cases it may be an experience that is

either had or not had, such as abuse, while in others it may be a range of exposure and

influences such as with pornography or sexual education. With that in mind, each of the

nine final themes, or factors, that were identified and supported by the data in this study

will be further expanded on and explained in terms of being contributors of risk.

The factors that were identified as contributing to increased risk of engaging in PSB

were:

- Abuse
- Trauma
- Viewing pornography
- Attitudes towards disability
- Access to sexual education
- Barriers to appropriate help/treatment
- Social isolation
- Level of parent preparation and ability to engage in education of child with disability
- Complexity of disability-related activity

Factors that were previously identified in the literature as potentially contributing

to PSB included a history of trauma or abuse, attachment issues, exposure to sexually

explicit material or pornography, and attitudes towards disability/access to sexual

education. The results of this study supported a history of trauma and abuse as separate

contributing factors. Exposure to sexual materials through viewing pornography, attitudes

towards disability, and access to sexual education became separate contributing factors.

Attachment issues did not emerge as a separate contributing factor. Barriers to

appropriate help and treatment, social isolation, level of parent preparation and ability to

engage in education of a child with a disability, and complexity of disability-related

activity were new factors that emerged as a result of this study.

Each of these contributing factors will now be clearly defined and explored.

While these will be described independent of one another, there is a great deal of overlap

between contributing factors and the way that they foster motivation and opportunity to

engage in PSB. Figure 3 illustrates each of these factors with some of their key elements

and how they maybe be potential contributing factors that feed into risk. While there is

likely a great deal of overlap between most factors, the ones with arrows indicate

directional relationships that were clearly identified in the data. Arrows all appear at the

same weight in an effort to remain neutral regarding the strength of the various factors.

This is important as it is not clear from this data which contributing factors may more

strongly create or relate to risk than others, thus they are not weighted.

Abuse

In the literature review various forms of abuse were identified that potentially

linked to engagement in PSB. These included pervasive exposure to violence in the

home, neglect (Bentovim, 2002), emotional abuse, particularly when in combination with

sexual abuse events (Bagley et al., 1994), and being a victim of sexual abuse (Bagley et

al., 1994; Bentovim, 2002; Maniglio, 2009). The existing literature also indicated that

PWDD were at higher risk of being abused than their peers without disabilities and that
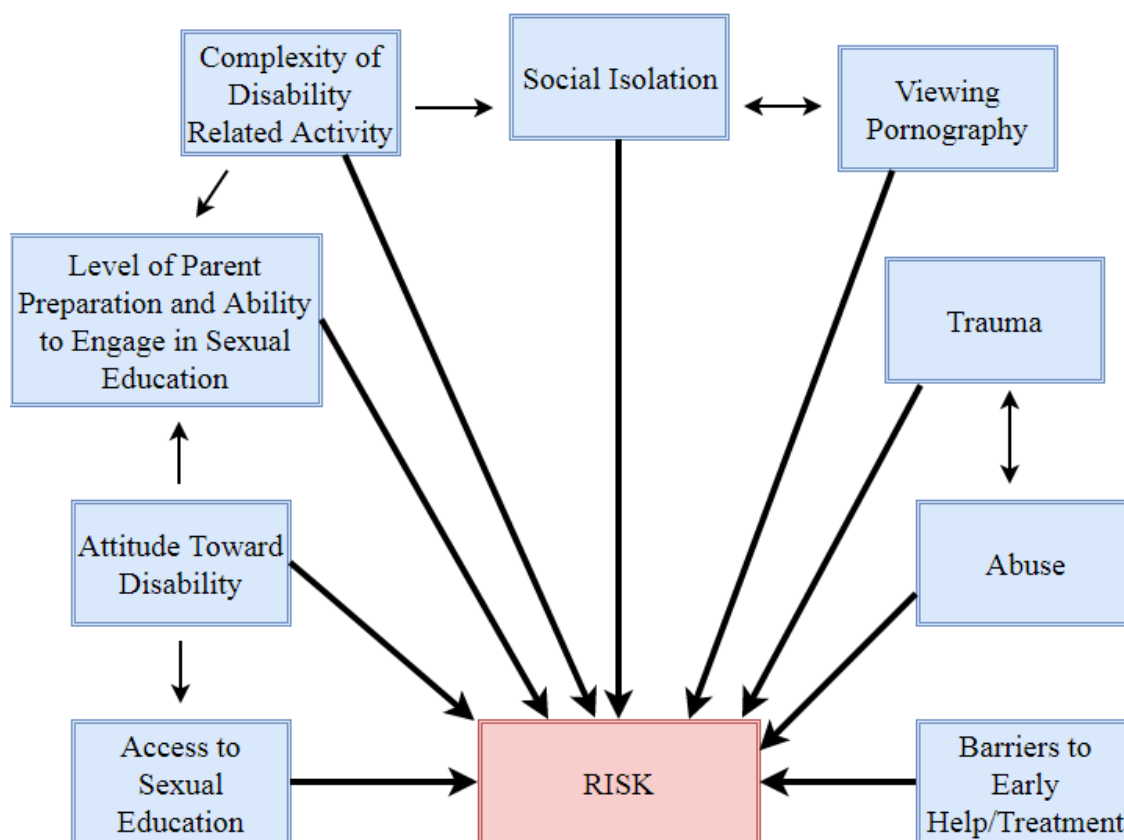
Note. Arrows between factors indicate the direction of reported relationships between factors. Arrows pointing towards risk indicate that these factors contribute to risk, there is no weight given to different contributing factors as that is beyond the scope of this data.

Figure 3. Factors contributing to risk of engaging in problematic sexual behavior among persons with developmental disabilities.

this abuse is likely to be perpetrated by family members, relatives, or caregivers (Balogh, et al., 2001; Hershkowitz et al., 2007). In this study four of the seven individuals whose experiences were being explored had experienced abuse of some kind with three of them specifically experiencing sexual abuse. In each case where sexual abuse was present it was clearly indicated by participants that they felt this was a critical factor leading to

their own engagement in PSB. However, in contrast to the literature, in this study when abuse was reported it was initially perpetrated by trusted peers rather than by family or care givers. As this experience was discussed by participants it was reported that being abused by peers normalized and modeled inappropriate behaviors, and led to an increased desire to feel in control in one's own life and to continue to find ways to be sexual gratified. Risks associated with being a victim of sexual abuse seemed to be particularly strong when the victim of abuse didn't feel confident or capable of reporting the abuse and seeking help.

Fiona stated that she felt that her son's abuse left him confused and that his lack of understanding of what had happened to him was the greatest influence for him to engage in his own PSB. She also added that him seeing someone do that and not have consequences perhaps gave him a sense of permission to model the behavior "someone did this to me and got away with it, so I can do the same. I think part of it he liked and he was like 'okay, I'm curious, this is something I need to learn more about'." She went on to state that this appears to be the critical event that led him down the path of PSB, she said "[prior to this occurring] I would have definitely pegged him for impulsivity or language or behavioral challenges, but never sexual." Fiona went on to state that within a short period of time following his own abuse her son modeled nearly identical abusive behaviors on a younger roommate in his school. Other parents had similar experiences. "There was an incident that happened when he was 4 with a 6-year-old boy who touched his penis. Then he acted out by touching his brother's." Following this event, Erika was able to seek treatment for her son and stated that no additional concerns arose around

sexual behaviors until her son entered a treatment center where he was re-exposed to PSB by peers.

Adding the element of a developmental disability was something that the literature indicated increases the risk of being a victim of sexual abuse (Chang et al., 2003; Putnam, 2003). Parents in this study supported that claim. Brett's father stated the following in reference to his son, "with his diagnoses he's also vulnerable or impressionable to others who may be more sophisticated and, unfortunately, I think that may have led to some of these issues that he's had with sexual abuse and other things." In addition, Brett reported that he felt like he wasn't able to report his abuse because he felt that nobody would believe him and he was afraid he would be in trouble. He stated that he was "scared of people that looked like they could have control over me. They could do what they wanted.." This aligns with the literature indicating that in many cases individuals with DD may be more suggestible, and vulnerable to abuse than their peers without disabilities (Grieve et al., 2007). In each of the instances where sexual abuse occurred in this study, abuse was perpetrated by an older peer who did not have a known disability diagnoses. Additionally, when these behaviors were modeled they were modeled on a younger individual, often one who also had a developmental disability diagnoses. Last, Brett adds that he felt that if he had been able to report his abuse early on and get help, that none of his other PSB would have occurred.

Many parents made the assumption that as long as their child was not a victim of abuse he would not be at risk for abusing others or engaging in PSB. While three of the participants were victims of sexual abuse prior to engaging in PSB, the other four had not

ever been victims of abuse. Debbie summarized this sentiment when she said "I always thought children didn't hurt other children unless they had been hurt first. I thought that's how it worked, so as long as I kept my children safe they would never hurt anybody." This desire to have one clear source to blame for the development of PSB was echoed by other parents. However, it is more likely that there is usually a combination of multiple factors contributing to PSB, and ascertaining the etiology is not so straightforward.

The experience of abuse was reported as being closely connected to experiences of trauma and at times was the traumatic experience referring to by participants. Abuse and trauma may be independent of one another, but also may occur in a back and forth relationship, as indicated by the dual-directional arrows in Figure 2.

Trauma

Within the literature review, trauma was closely connected to abuse and attachment concerns, especially when trauma is reported within a family system. Trauma could be a one-time event or prolonged exposure to aversive situations (Hall, 2011). Trauma was described in the literature review as contributing to PSB by causing difficulty with emotional regulation as well as leading to feelings and desires to be in control and to fight feelings of vulnerability and ambivalence (McPherson et al., 2013). These ideas were supported by the findings within this study.

Traumatic events reported in this study included being bullied, abandonment from a parental figure, prolonged stress and anxiety in the family unit, frequent moving and disruption of routine, and negative experiences in treatment focused on power and control. These experiences led to disruptions in life, and further isolated the individuals.

Doug reported, **"**my father wasn't around simply because...something happened to him and he used alcohol as an escape. That's basically what happened to me." He expanded on this by stating that the reason his PSB escalated was because he was "tired of dealing with the bullying." He stated that they had moved around often so he didn't have friends and "bullies were all he had." "I don't like new places so what I did have was this constant anxiety heaped on that maybe people wouldn't like me." Alex also experienced the loss of a parent and social frustrations and similarly stated "it [PSB] was kind of like an escape for me, an escape from the reality that I was in." Alex went on to explain that when he engaged in PSB he felt in control of his own life, "it kind of felt like I was my own person and I can make my own decisions."

Each of these experiences supports the idea that experiencing trauma can increase the risk of engagement in PSB. In these instances, the primary motivation appears to be seeking control and power in one's own life. As described in the OAT model (Hall, 2012) the two factors of abuse and trauma in combination are likely to further enhance the risk and desire to take control and model problematic sexual behaviors.

Viewing Pornography

Results from this study regarding the role and impact of pornography supported what was outlined in the literature review. Motivations for viewing pornography were outlined in the literature review as including a desire for social acceptance and connection which, ironically, tended to result in increased feelings of isolation and loneliness (Yoder et al., 2005). Figure two reflects this connection between social isolation and viewing pornography where these two contributors tend to feed off of one

another. Feelings of social isolation can increase the vieweing or pornography, and as more pornography is viewed, socially isolating behaviors may supported and encouraged. Other concerns that were specifically supported from this data included distorted ideas of sexuality and healthy sexual interactions (Braun-Courville & Rojas, 2009); increased likelihood of unsafe sexual practices (Owens et al., 2012); generation of shame, guilt, anxiety, and confusion (Bryant, 2009); acceptance of aggression towards women (Baxter, 2014); and increased likelihood of engaging in sexually abusive behaviors at a younger age (Alexy et al., 2009; Mancini et al., 2014). The literature also speculated that adolescents, especially those with disabilities, learned from what they were seeing in pornography, normalizing those behaviors as normal and acceptable (Mancini et al., 2014).

All participants reported that pornography use in and of itself became a problematic behavior with three reporting it as an addiction. Gary described this experience by saying, "I always was frustrated about it, I hated it. I did not like it but I clearly needed it... I understood it was an addiction." He went on to explain the physical pull he felt to go back to its use, "I can hate it for, whether it is 2 hours or 2 or 3 days, but then the next thing it's like, well, I need it. I need something. Clearly it always gave something to me." Five of the seven experiences explored referenced consumption of pornography as a behavior that directly led to engagement in other PSB. Brett stated "Ever since I was exposed to pornography…I thought to myself I would try to see how it actually worked and actually feels." Doug added that he felt that dangerous sexual behaviors were more likely "simply because that was what I--what was being portrayed

as normal." Gary stated "I remember a lot of it having to do with curiosity and then later actually trying stuff."

For those interviewed who reported feeling like they were addicted to pornography they all mentioned their disability fueling this problem by leading to a quick fixation process. Gary explains, "It was just a snap, it wasn't hey I looked at it once and then didn't see it for another 6 months and then 3 months and then 2 months. It was a snap." He stated that the physiological responses combined with his curiosity to make him want to keep going back and actually act out what he was seeing. Alex had a similar experience, "I kind of took a nosedive right into it all. It wasn't like I gradually got into it, it was just I jumped and leaped…" Amy further expands on this by stating "he now had an obsession with it and that is, as I understand it, very common with ASD. He just, it was compulsive, he couldn't stop and he still can't." This sentiment was repeated by both Candice and Erika.

All of the participants mentioned viewing pornography as an attempt to learn about sexual behaviors. Since they were relying on pornography as a teacher they stated that it normalized the behaviors they saw and made them expect that that was what was normal. Caleb described how he sought pornography to try and "figure out the positioning of sexual intercourse, how it actually looked." Brett stated that "I thought that's how it all worked."

Pornography being sought as a means to fulfill social desires was also identified by several participants. Gary talked about how he used pornography to try and meet his need for a girlfriend and social interactions that he was blocked from due to his

difficulties engaging in social interactions. Caleb also reported that he used pornography as a replacement for other behaviors, such as voyeuring, when he could. Erika described how using pornography in this way led to normalizing risky and inappropriate behaviors as well as negatively impacting the view her son had of women.

The extent and scope to which pornography negatively impacts individuals will vary greatly. But, this data supported that due to inclinations towards impulsivity, fixations, and obsessive tendencies individuals with DD may be at higher risk of learning from, normalizing, and internalizing what they see in pornography.

Attitudes Towards Disability

Attitudes towards disability as a barrier towards accessing information or sexual education was outlined in the literature review. Individuals with DD have often been perceived by society as asexual or unlikely to engage in any form of sexual relationship (Doyle, 2008; Smart, 2009; Sullivan & Caterino, 2008). They also have been viewed at times as being too innocent to discuss sexual topics (R. Young et al., 2012), and in need of protection from such topics (Tarnai, 2006). These views were somewhat supported in this data. However, rather than these views being presented by parents as a justification for not providing sexual education, they were provided as explanations of why the disclosure of PSB was a surprise.

Fiona explains that it was not that she felt sexual education was inappropriate for her child, but rather she hadn't observed the need. She stated, "…it's always appropriate to try and teach but he didn't talk about girls a whole lot, or boys for that matter, just any sort of desire to have that sort of connection." Other parents reported that they felt their

child was naïve to sexual content and materials. Erika stated that she felt her son was "very naïve in some ways" and that this likely led to him being more susceptible to negative influences. This connection between attitudes towards disability influencing parent preparation, as well as access to sexual education, can be seen in Figure 2. Often it seemed that education and preparation were simply not viewed as relevant or needed, due to the perception of the needs of the PWDD.

Once it was discovered, all parents expressed surprise and dismay that their child had engaged in PSB. Brady said "Who would have thought you'd have to drill sex? You look at them as innocent and you're kind of blinded by it, when there's disability." Debbie stated that she was particularly dismayed when she learned that her son had engaged in emotional manipulation in order to engage in his PSB "He manipulated her by saying, 'I don't have friends, no one wants to talk to me, no one likes me, I'm just gonna kill myself' until she gave in." She reported that she had never expected that her son was capable of this kind of behavior, or that she would have to worry about him hurting anyone, especially if he had been kept safe from abuse himself.

From the perspective of the PWDD it was mentioned that people seemed to avoid discussing sexual topics with them but it was unclear if it was due to disability factors or not. However, one PWDD reported that he felt that perhaps he was blocked from information because people were afraid he wouldn't understand or that they would hurt his feelings, "they're scared of hurting me, hurting my feelings, maybe destroying the relationships I had with them." Historically there have often been assumptions regarding PWDD lack of sexual desire, or their ability to engage in relationships. Participants with

DD in this study all reported a desire to engage in healthy relationships in the future. Parents' attitudes and perceptions of this as a possibility were generally positive, with all parents making statements such as "I hope it is possible" and "maybe one day." All parents, however, did specifically make mention that they felt that their child was not ready for relationships at this time and that they anticipated future relationships to be a very difficult goal to obtain.

Access to Sexual Education

Access to sexual education materials emerged as a primary contributing factor for engagement in PSB. In this study there were two participants who never had any sexual education provided to them, the other five had some access but felt it was inadequate or confusing. One parent describes the limitations of initial access, "you have all these different services for social skills and occupational therapy and physical therapy but the sex therapy or sex education is completely overlooked." She then went on to talk about how so many children with DD are placed in either private or charter schools to better meet their needs, or in self-contained classrooms. Once in these environments sexual education may be overlooked and not even be provided on a basic level.

Even when students with disabilities do have access to sexual education, there are many barriers to it being accessible and effective. The literature review on this topic indicated concerns that there were no set curriculums and that materials may not be presented in an accessible manner. Sexual education being presented in a manner that is too complex, delivered at a pace that is difficult for students with DD to keep up with (McDaniels & Fleming, 2016), or are so broad that students are overwhelmed (Swango-

Wilson, 2009) were concerns that were supported in this study. Additionally, information

may be presented in a manner that is not easily translated into real-life situations

(McDaniels & Fleming, 2016). These ideas of education needing to be provided in an

accessible manner with appropriate information, repetition, and context, was supported

across every participant who had experience with sexual education. Interestingly, rather

than feeling like they needed less detail, participants felt that more detail and information

would have been helpful, but provided in a more concrete, clear, and concise manner.

Gary explained it as "you've got a billion questions, right? So, someone needs to fill that

void that you were going to try and find anyway." Alex added "One thing I think would

have been most beneficial to me would be to be blunt and honest." For all five of the

PWDD interviewed, confusion was listed as a primary result of the attempts at sexual

education they had, regardless of if it was provided in the home or at school.

Without information being presented in an accessible manner there appears to be

little benefit in having sexual education, and potentially harm. Beth explained "he's very

literal so he doesn't understand abstract thinking well, he's very concrete. You have to

communicate straight forward with him." Repetition of content was also mentioned by

nearly all participants as being something that would be beneficial. One parent stated, "I

know with the boys that have special needs or are on the autism spectrum, I really they

really need that repetition ...you just keep going on until its memorized and I think once

it's memorized he was able to apply it."

An additional concern with education provision both in schools and in the home

was that it is most commonly provided as a reactive response instead of a proactive

prevention. This was discussed by both parents and PWDD as a concern. This was stated as being important for general sexual education as well as for educating the PWDD on how to recognize if they are being abused and what to do about it. Fiona stated, "…they even need to get educated on what it looks like if they're being mistreated sexually so they can communicate to someone." Brett talked about how in his home educational moments were usually done in response to some event or problem. His dad confirmed this by stating that he liked to take advantage of opportunities, but didn't ever have a direct talk. Fiona further adds that there needs to be something out there that is proactive, she stated, "I don't see anything out there that's proactive to teach, specifically kids with autism…"

There were several needed areas of education that were also identified by participants. These specifically included focusing on what a healthy relationship looks like, recognizing and knowing what to do if you are being abused, explaining consent and laws around sexual behaviors, giving context around sexual content, and recognizing empathy and impact on others. Consent in particular was identified by all participants as being something that was overlooked but of particular value. Doug summarized it when he said, "instead of learning just what it is and how to do it 'safely' which is just a condom or birth control, just telling us the different sexual laws, what was consent, that would have helped a ton."

Barriers to Appropriate Help/Treatment

A new contributing factor that emerged as a result of the data was barriers to appropriate help and treatment. In every case described, individuals with DD were either

actively engaged in, or had previously been involved in therapy of some kind prior to the discovery of PSB. However, after the discovery of PSB, or even following the early warning signs that there might be problems, there were immediate barriers that hindered or prevented access to the needed help. The primary block was lack of training and expertise among treatment providers to be able to provide services for individuals who both had a DD as well as the sexual component of their behaviors. Amy explained that finding resources was nearly impossible when all of her child's needs were combined. "There are a lot of places that don't take the sexual piece.." She further described her challenges to find anything that will provide a holistic treatment approach "there's always something missing," she said. Each parent had a story of searching for resources and treatment options and finding limited to no resources. Brady said, "There's just not the availability of sexual therapy." Candice reflected on the possibility that "had someone been more educated and knowledgeable and known about some of these programs he probably could have had more help earlier and maybe some of this could have been prevented.." She stated that there were no resources and she felt lost trying to navigate what to do. Debbie stated "no one knew autism…it took me a lot of searching to finally find a counselor who understood autism for him." She expressed her inability to even find a peer-mentor type program that would work with children with autism. Fiona and Erika both specifically talked about how there was a lack of agreement among professionals regarding what to do to treat the PSB once it came out. Erika added that she felt if there had not been so much guesswork among professionals about what to do they might have been able to get meaningful help earlier. She also stated that her son's

treatment providers did not know what to do and "they were a bit overwhelmed by it."

When treatment sources were identified there were many reports of potential

harm being done as a result of inadequate training on sexual topics. One individual

reported that her Board Certified Behavior Analyst working with her son minimized the

sexual behaviors and continued to encourage addressing other things. She stated that the

focus of ABA on behavior without consideration of teaching empathy and other key

factors for sexual behaviors was insufficient to help her child. Other providers

encouraged "quick fix" placements without full consideration of the potential

implications or problems. Amy talked about psychiatrists and psychologists prescribing

medications without taking the time to think through the potential consequences, she

reported that her son was on a medication that she later learned is typically kept away

from individuals with compulsive or addictive behaviors because it tends to enhance

them as well as sex drive. "The psychiatric piece was huge for him; it is crazy they would

keep him on [those] medications!" she said.

In other cases, well-intentioned treatment providers were reported as attempting

to use shame or power-based treatments to try to curb the sexual impulses and behaviors

and failed to address the compulsive nature of their experiences. Gary explained,

"shaming was really big for me…like how much my parents are spending on me, how

much people trying to help me…when you're talking about addiction that's one thing you

can't do." Candice explains how complicated treatment can become when you are

considered DD and PSB. Some people want to treat it as they would other problematic

behaviors with autism using ABA principles, while others might want to treat it more like

an addiction. Fiona also discussed the importance that treatment for PSB include processing of any previous abuse or trauma to get at the root of the problem. It is challenging to look at the big picture and consider how both of those factors might be influencing the PSB and need to be addressed. Additionally, nearly every participant mentioned that the only treatment option they could find for their combination of behaviors was residential treatment. While each participant also made some statement that while they felt they benefited from this placement, treatment options at a less-intensive level were not really available.

In spite of these short-falls every participant with DD mentioned relying on therapy and treatment to ultimately learn about what were and were not appropriate sexual behaviors. Doug said, "It was in therapy that I discovered the difference between normal and taboo." With such a heavy emphasis placed on therapy and treatment to address PSB, it is a clear contributing factor to lack access to competent service providers.

Social Isolation

Social isolation emerged as a clear and undisputed theme throughout each interview in spite of it not being directly asked about as part of the semistructured interview. Every participant mentioned a desire to be able to connect with others socially, or at minimum to be able to engage in the same behaviors in which they saw their peers engaging. There were two primary ways social isolation was reported as interacting with PSB. First, being socially isolated meant that PWDD were missing out on the social learning that often occurs, making them more heavily dependent on exposure sources for

information. Second, being socially isolated left PWDD seeking other ways to find

connection with others, which largely resulted in utilizing pornography. However, while

social connection was sought it was further complicated by difficulty reading social cues

and engaging in socially appropriate behaviors. Alex stated "that social piece with

autism, it's really hard to understand how you are affecting people." This difficulty was

referenced by nearly everyone interviewed. Wanting to connect without understanding

how your behaviors may negatively impact the other person further complicates the

sexual and relational aspect of engagement, potentially further increasing the risk for

PSB.

Because PWDD were missing out on social learning they relied more heavily on

the sources of information they did have. Brett stated, "I didn't have many people to look

up to…I found it really hard to talk to people a lot of times and I ended up being

isolated." Gary described one incident when the one person he considered a friend, and

the only person he ever had playdates with, showed him pornography. He felt like that

meant it must be ok "once someone gave me the okay I think that was the big thing, like,

hey just do it.." Candice and Erika both explained how since their son's didn't make

friends easily, once they felt accepted by a person or group of people they were quick to

join in on whatever behaviors they indicated were normal or desirable. "I think that's

how he got fixated," Candice said, "well, that's what she likes to do so that must be how I

get friends or meet girls."

Social skills trainings classes and programs are common among individuals with

DD, but several participants mentioned how those classes completely overlook training

on developing romantic relationships or developing empathy for others. This further limits the ways that PWDD know how to connect, leaving them to rely on other sources once again to instruct them on what is and isn't appropriate in relationships and sex. Caleb mentioned "I know what flirting is, I don't really know how to do it though so say I like a girl and I want to kind of intrigue her or attract her to me I wouldn't be able to do that very well." Specifically referencing the empathy side many participants acknowledged that they struggle with knowing how their actions are influencing other people. Alex stated "It's hard to get the concept of how you are hurting people." Parents reported that learning about empathy and how you are impacting other people should be basic part of what is taught.

The second primary way social isolation increased risk of PSB development was because it left PWDD with no appropriate social outlets. Gary explains "My ability to feel needed wasn't being met and that's a self-defined thing…I had no way to express or interact." Caleb adds his thought by stating, "When I'm not social with certain people that could be a contributor to me misbehaving and acting in ways I shouldn't." Debbie reported that she felt her son always had a desire to be "one of the guys" and how he would do almost anything to try and fit in. This included telling inappropriate jokes and making up inappropriate sexual stories. And then she explained that because he did not have a social outlet at school he brought negative sexual behaviors into the home. Erika explained that her son is isolated in his life and so he constantly seeks out connections online via sexual chatrooms. She said, "he has poor social skills, but you can click…and find sexuality so he may not be able to get a girl to go out with him on a date but he can

go online and watch this." It is important to note that each individual with DD reported

desiring a future relationship and wanting to work towards that as a goal, even if he

wasn't ready to pursue one at this time.

Level of Parent Preparation and Ability to
Engage in Education of Child with Disability

Both parents and PWDD interviewed indicated another risk as the lack of

adequate resources and training for parents on how to talk about and manage maturation,

sexual education, and PSB in the home. PWDD consistently reported that the information

they received from parents on sexuality was vague and often provided expected

boundaries around behaviors but did not address reasons or context. Doug explained that

at a young age he was taught that sexuality is something special that should be done with

one other person, but he did not know what that meant. "I didn't know what should be

done with that one other person, as far as I knew we were talking about, like, never draw

with someone unless you're married to them!" Teaching values in the home is something

that most parents feel comfortable with, it is when it comes down to navigating the

complexity of hormones, maturation, changing bodies, disability, and sexuality that they

feel they need additional resources and supports. Debbie explained that they did not talk

about sexual behaviors because she did not know there were any PSB going on to talk

about, but they did talk about sex in terms of it being for marriage. This is an example of

the value-based education most parents are comfortable and confident in teaching in the

home.

Parents that were interviewed also talked about how they didn't know how to talk

about sexual topics. Brady explained "We don't have the tools to explain everything in the detail [needed]. We wouldn't have been able to give that to him…," he then added "Maybe we needed more guidance as far as their changing emotional status as they got older. It really hit us hard when they starting hitting puberty." Other concerns parents expressed was dealing specifically with children who are vulnerable. Brady also added to this stating, "we did the best we could under the circumstances but we didn't realize the magnitude of his vulnerability."

Gary reported additional barriers in his home, where he was consistently put off by his parents. He stated that he remembers getting in trouble for saying something and then trying to ask why and to get greater detail about what made it wrong and at that point his mother disengaged from the conversation. The appearance of so much secrecy around sexual topics led to him feeling shame for even thinking about it. He reported that his family was very religious and conservative and he felt this contributed to their lack of openness in discussing these topics. Other participants also reported not feeling comfortable talking to or asking their parents questions. However, Caleb stated that he felt comfortable talking to his mom and dad, but he just never really did ask them any questions. Based on these statements it seems important for parents to feel comfortable creating an environment where their children with DD feel like they can ask questions, get real answers, and have opportunities for discussion.

Another specific area for which parents felt they were inadequately prepared, and that they could have used additional training and information was in knowing what technological devices needed parental blocks, and the process for implementing those

blocks. Putting up effective parental blocks to avoid early or unwanted exposure or access to pornographic materials was mentioned by all parents as being important. However, all of the parents interviewed were also able to point out at least one device within the home that they hadn't been aware their child could access materials from. "I wish I was more educated on technology," Fiona reported, "I think that if I knew how to block things on the router or manage that darn TV, that could have prevented his exposure to pornography then maybe he would have to go to us and say 'hey, what's yxz?'"

Parents also reported that as sexual behaviors emerged they experienced additional social factors themselves that impacted their support network, and consequently their ability to respond to their child's needs. Parents reported that after their child's PSB was discovered they often experienced loss of friendships and felt isolated or shame for what was happening. These factors may make it difficult for parents to talk about the problem or seek help. Amy stated "I was new to this whole sexual piece. It was shocking to me and it was hard to talk about..I didn't feel there was support because it was such an embarrassing problem…it was just kind of isolating." Debbie reported that when things came out her previous friends began to blame her "they blamed me…I 'wasn't watching my kids close enough'." These experiences of social isolation can further limit a parent's ability to access and utilize support and resources.

Complexity of Disability-Related Activity

The final factor contributing to risk that was identified is one that was closely interacts with several other contributing factors, but that also emerged as its own,

independent factor as well. Complexity of disability-related activity refers to the complexity that is introduced in general with a child with a DD. The needs, demands, treatments, behaviors, interventions, programs, and skill development that go along with having a child with a DD require simultaneous navigation. In the midst of all of these disability-related factors, sexuality can easily become overlooked. In many cases, it is missed entirely. "You're looking at other things like how to deal with life and you never think this [PSB] is going to be a problem" Brady said. Beth further expanded on this by stating that "we're on a journey without special needs kids... you're dealing with a lot of physical issues, emotional issues, and you don't know what's important and what's not necessarily." Erika explained it well when she said "it's really difficult enough to grasp the issues without the sexuality, just now to deal with his moods or his neurological issues or etcetera." This seemed to have a particularly strong influence on the level of parent preparedness for discussing and talking about sexual topics. Their focus was often so divided and needed in other areas, that discussions on sexual topics were not a priority.

In addition, PWDDs often recognize that they are having different experiences than their peers, and may feel further isolated and disconnected as a result. PWDD were often prevented from engaging in normative developmental events and activities because they were doing so many other specialized interventions. Gary described this experience by saying "so much effort done towards helping me that I felt outcasted to some level." He explained that you either went mainstream with classes where you got very little help or things went to the opposite extreme where you were involved in "every IEP class, every tutoring session, every isolating event throughout your school day and therefore

after the school day." Gary said that he wanted to be social but that he had so many doctors' appointments, therapists, IEP meetings, psychiatrists, balances of meds, etc. that he was isolated in every area of his life. Two of the participants specifically reported that their child with DD was in a specialized school for autism as a result of their other behaviors of concern. This specialized placement limited their access to various sources of information and social learning opportunities.

**Functional Limitations/Developmental
Influences**

As was outlined in the literature review, there were several areas of functional limitations that were confirmed to interact with the development of PSB. These functional limitations and developmental influences included impulsivity, fixation, obsessions, difficulty experiencing and developing empathy, and rigid thinking. These were specifically referenced as playing a role in continuation of PSB even after there have been negative consequences.

Adolescents are prone to being impulsive overall, but when DD are present, participants felt that it became an extra challenge to think through choices. One mother mentioned that executive functioning is closely tied to impulsivity and that her son has always struggled with thinking through consequences. Candice stated, "The impulsivity from ADHD, the obsessions with OCD and the fixating thing with Asperger's all comes together…" Erika added "It's difficult because of the Asperger's piece. Once he gets his mind set on something, you know…it plays a lot into him getting kind of suck in these issues.." Brady also determined that this seemed to play a role with his son when he said,

"he has impulsivity, I think he lacks the ability to check himself, so-to-speak." One PWDD explained that urges just felt like they built up and that if he didn't act on them he would burst.

Fixations and obsessions are difficult to separate and seemed to be used interchangeably throughout the interviews. In both cases participants were referring to the strong preoccupation and focus on certain behaviors. Fixations and obsessive urges were often described as taking on a compulsive element as individuals felt like they lost their ability to control their actions. At times this was referred to as an addiction process with Caleb stating "even though I have a sexual addiction that doesn't mean that I don't know what I'm doing is bad." He then went on to explain how he feels like he cannot easily control his urges and impulses, or get sexual ideas and topics off is mind. Erika talked about having to cut visits with her son short because he was so obsessed with engaging in his PSB that he "couldn't control himself." Rigid thinking was problematic because it makes it challenging to differentiate differences in when and how sexual behaviors are appropriate. Brett explained that after viewing pornography he thought that must be how it works for everyone. Then, once he had learned about consent and sexual laws he found it challenging to understand why there were certain situations where certain laws do not seem to apply, such as when someone who is 18 can be dating someone under 18. This rigid thinking highlights the importance of context when teaching principles, particularly in terms of helping the PWDD to apply their learning.

As a result of continued PSB, all participants continued to experience negative consequences. Three participant's limitations on independent living were specifically

mentioned. Candice explained how her son has been unable to maintain a job, and has been expelled from school. "There is something in his brain saying I still have to do this even though I know it's wrong and that I can get in trouble." Amy reported that in the process of bouncing between different treatment programs trying to address the complex range of problematic behaviors, he displayed behaviors indicative of becoming institutionalized. "It's very hard for him to live in the real world and that is probably the most heartbreaking piece of all of this…I feel like he didn't get everything he needed…the damage has been done. He's instutionalized." Erika also reported that as a result of his behaviors, her son cannot maintain employment since he is unable to manage his impulses.

The final potential factor to consider that was brought up is the power of language. By giving individuals with DD a label either related to their disability or their PSB it may be integrated as just "part of who I am." Erika explained this by stating "once he was labeled as 'this is my fetish' it was almost like it became a part of him." She goes on to say that the same thing happens when being labeled as ADD, Asperger's, or any diagnoses or label, "it became something he owned as part of his behaviors." Labels may have power to influence self-concept as well as willingness to engage in PSB.

Summary

The purpose of this study was to explore the experience and contributing factors that contribute to the development of PSB among individuals with DD. Although participants came from varied backgrounds, and had engaged in a wide range of

behaviors, a model was able to be established. This model establishes four primary

components that emerged as being critical for developing PSB. These were exposure,

motivation, deficits in sexual education, and opportunity. Additionally, nine contributing

factors were identified that increase the likelihood that a PWDD will engage in PSB.

These were: abuse, trauma, viewing pornography, attitudes towards disability, access to

sexual education, barriers to appropriate help/treatment, social isolation, level of parent

preparation and ability to engage in education with the child with a disability, and the

complexity of disability-related activity. The following chapter will outline the

implications these findings have for future research as well as the potential implications

for families of PWDD, practitioners, and educators working with adolescents with DD.

CHAPTER V

SUMMARY AND IMPLICATIONS

The purpose of this study was to develop a model to explain the process that individuals with DD go through in developing PSB. The model outlines four key components leading to PSB; exposure, motivation, deficits in sexual education, and opportunity and contributing factors that likely increase the potential of engaging in PSB. The nine contributing factors identified were abuse, trauma, viewing pornography, attitudes towards disability, access to sexual education, barriers to appropriate help/ treatment, social isolation, level of parent preparation, and ability to engage in education with child with disability, and complexity of disability-related activity. This chapter will outline the potential utility of this model as it is applied by families of PWDD, service providers, and educators working with adolescents with DD. Implications for future research and practice, as well as the limitations of the study, will also be addressed.

Model Utility and Application

The data from this study were used to develop a model to describe the experience and contributing factors that contribute to individuals with DD engaging in PSB. Models are useful in that they are intended to help predict action by proposing if-then logic, and explaining how and/or why something is happening by stating its causes (Saldaña, 2012). The purpose of this particular theoretical model is to help describe the factors that *if* they occur, *then* there is increased likelihood of engagement in PSB. Once this is understood, then action can be taken to try to predict or change outcomes, engage in additional

research to gain clarity and depth of understanding of specific phenomena, and design interventions. However, it is important to note that models must be continually flexible to allow for additional elaboration and amendment with additional research (Glaser & Strauss, 1967).

While there are a few existing models that explain the experience of adolescents who engage in PSB, or that describe the process of sexual addiction, no models exist that specifically address the experience of PWDD who engage in PSB. This gap makes research of this nature of particular importance. Without the identification of disability-specific contributing factors, PWDD are left without adequate resources for prevention and intervention. It is clear from the data that the presence of DD adds complexity to the experience of engaging in PSB. Thus, this model was developed to fill this gap and provide potential guidance to families, service and treatment providers, and educators in their decision making regarding efforts to help lower the risk of engagement in PSB.

Factors that contribute to risk for adolescents without DD engaging in PSB have been identified in the literature. These were then supported by this data, included trauma or abuse (Hall, 2012; Maniglio, 2009), and viewing of pornography (Alexy et al., 2009; Mancini et al., 2014). One factor that was identified as a potential barrier to education in the litertuare but that was more specifically identified as a contributing factor of overall risk in this study was attitudes towards disability, including perception of PWDD as innocent or in need of protection (Tarnai, 2006; R. Young et al., 2012). Additional axial codes were created and resulted in the identification of an additional five contributing factors. These were (1) access to sexual education, (2) barriers to appropriate

help/treatment, (3) social isolation, (4) level of parent preparation and ability to engage in

education with child with disability, and (5) complexity of disability-related activity.

These additional contributing factors illustrate the added layers of complexity introduced

as a direct result of the presence of a developmental disability. If an adolescent has a

developmental disability all of these factors that are potential contributors to risk must be

considered. It is important to note that the range of type and severity of PSB that were

reported by participants in this study adds support to the significance of the

commonalities within each participants experiences. Also of interest was the willingness

of parents to discuss a broad range of PSB, including those behaviors that were more

severe, while PWDD were more likely to discuss their pornography use rather than

engage in discussion regarding the more severe PSB. Regardless of the severity of the

PSB and differences in each individual's experiences, the themes and emerging factors

were clearly evident. The implications of this newly developed model will now be

explored for families, service providers, and educators.

Implications for Families of Persons
with Developmental Disabilities

Parents within this study discussed their fears of potential consequences of their

child's engagement in PSB, including loss of independence, potential criminal charges,

inability to maintain employment, and potential barriers to being able to engage in future

relationships. This model helps parents in two primary ways. The first way is through

prevention. The second is by providing a depth of understanding that may be of

assistance if PSB issues arise.

Parents expressed a general lack of knowledge regarding what to do when a child with DD begins to go through puberty, and again when a child with DD begins to engage in PSB. Based on the data collected and the contributing factors identified, families can determine what steps they may desire to take to prepare for these situations. To address the contributing factor of level of parent preparation, families may proactively seek to build the skills requisite to effectively engage in education of sexual topics, with the child with DD. Within their homes, families can proactively engage in discussions around sexual topics and encourage dialogue with their child around these topics. This can help create a foundation of comfort in discussing sexual topics. Additionally, when looking at the contributing factor of complexity of disability related activities, families can seek education and resources in advance to learn about how to navigate the complex needs of their child with a DD as he/she navigates maturation, exposure to sexual materials, and the desire to have social interactions. This can prepare against overlooking sexual topics in the midst of all the other disability related needs and behaviors being addressed. Families can also seek and develop resources to better protect against the contributing factor of viewing pornography. This may include learning about the electronic devices in their home, and learning how to utilize safety blocks to minimize opportunity to view pornography. Families may also look to the contributing factors of abuse, trauma, and social isolation and seek to pay increased attention to the interactions and desires of the child with DD. Creating opportunities to foster positive social connection, and to facilitating appropriate social modeling, may be good ways to mitigate these risks.

This model provides increased depth of understanding that may be of assistance

for parents of families of adolescents who begin to engage in challenging or problematic sexual behaviors. In most cases parents are surprised at the discovery of PSB in their child, particularly if that child has a DD. Referencing this model may assist parents and families in being able to contextualize their experience and to gain insight and understanding into what factors may have led to their child engaging in these behaviors. This may then also guide the way that they respond to the PSB. Specifically, this model may assist in understanding the complexity of the child's experience, and the various considerations that should be made related to treatment and education. Parents may also be able to identify areas of communication that may need improvement, especially those related to empathy development and the pursuit of healthy social and relationship outlets. Referencing this model may also help parents and families to feel less isolated through a difficult experience. Knowing that others have been in similar situations and being able to learn from their experiences can be of great value.

Implications for Service Providers

There are two primary implications for service providers highlighted by this study. First is understanding what this model requires directly related to treatment provisions. Second, is understanding the need for training and preparation among service providers.

Data from this study indicated that there are several areas of treatment that were considered to be of importance when addressing PSB among PWDD. These areas included addressing what are and are not appropriate sexual behaviors, training in empathy and understanding impact of PSB on others, urge management and control, and

understanding healthy relationship development. Meeting these objectives becomes more complex when disability is present. The DD may impact an individauls' ability to understand the concepts, or to make the connection to application in daily life The DD may make understanding of nuance and exceptions to social rules challenging. All participants indicated that it was only once they were in treatment that they felt they gained understanding regarding appropriate behaviors. This would indicate that service providers are essential for helping to address PSB. The work of service providers is critical for enabling a PWDD who has engaged in PSB to be able to have an opportunity to live a healthy and safe life. Unfortunately, data from this study indicate that few services providers have adequate training to be able to meet this need. Even fewer have training on how to adjust treatment interventions to account for the functional limitations introduced by disability.

The most common barrier that families experience in finding appropriate treatment was locating service providers who were comfortable and competent in addressing both the disability aspect of care, as well as the sexual behaviors. There seems to be a shortage of service providers in the areas of disability and sexuality, which increases when the two needs are combined. The individuals with DD who engage in PSB frequenrly fall between the cracks of professional expertise. Service providers who are trained in disability rarely have training or expertise in sexual behaviors. Likewise, providers with experience and training in sexual areas rarely receive training in disability.

Participants reported that providers often failed to address the PSB from the multiple perspectives required when DD is introduced. For example, when addressing

DD there may be a need to view PSB as the result of fixations and compulsions as well as a result of addictive processes. All of the parents interviewed reported concerns that at one point or another service providers who were not adequately trained or prepared may have inadvertently done harm rather than good by trying to minimize sexual behaviors, or address them in an inappropriate manner. This may be the result of general attitudes towards disability, such as the professional not thinking of PWDD as sexual, or perhaps it is a limitation of their scope of practice. Whatever the cause, it is important that there be opportunities for training among service providers.

By fully recognizing the risks associated with inappropriate services, treatment providers can make an educated choice regarding if they feel comfortable or qualified to work with individuals with DD who have engaged in PSB. They also may proactively seek education and training around sexual topics and issues, so that they might better meet the needs of these individuals. This includes understanding how to address the potential contributing factors that may include a history of abuse, social isolation, or trauma. Service providers who are competent in these areas may consider providing professional development and training to other professionals in the field. Also, as access to pornography and other sexual materials increase, it may be an important for educators of service providers to consider including instruction and training on these topics in their general curriculum.

Implications for Educators

There are two primary areas of consideration for educators based on the results of this study. First, is the question of what sexual educational content is appropriate and/or

necessary to teach PWDD. Second, is the question of how this curriculum should be taught. There may be many factors that impact educator's ability to determine what sexual education content to teach, as well as how it can be taught. One such factor is the way that the education system is structured in their particular location, and the extent and scope of the sexual education content in general. This is often influenced by community values and may vary across different regions and locations.

The results of this study indicated that recommended content areas for sexual education courses include maturation, understanding of sexual impulses and urges, differences in male and female development and sex drive, safe-sex practices, knowledge of what to do to recognize and respond to situations of abuse, and understanding sexual consent.

While schools and programs may be limited in their ability to have flexibility in the sexual education course content, there may be other ways to address some of these topics. Participants indicated that many of these topic areas could be successfully and appropriately integrated in social skills training classes. Many individuals with DD are provided with social skills training. It was recommended that topics of consideration for social skills classes include healthy relationship development, empathy and impact on others, consent, and communication around dating and sexual relationships. Educators may be able to utilize social skills classes. as well as other opportunities, to provide students with DD with positive mentor, and opportunities for positive social interactions.

Educators can also take steps to ensure that students with DD are receiving equal access to the sexual education that is being provided in their school. Sexual education

that is provided in general classrooms may not be delivered in a manner that is appropriate for PWDD. However, in many cases self-contained or segregated classrooms which may be able to provide content in a more accessible manner may not be providing any sexual education at all. Once again, this dichotomy creates a situation where PWDD may fall through the gaps for appropriate education provision. Methods for increasing the accessibility of sexual education materials include being clear and blunt, providing repetition of information, including context for application, and applying academic accommodations that the student is qualified for to sexual education classes. While it may be challenging to gear the content and delivery of sexual education content to be appropriate for PWDD it is a necessary step in ensuring PWDD are equipped with both the knowledge and skills they need.

Implications for Future Research

While this study resulted in the development of a model to explain the contributing factors and experience of engagement in PSB for PWDD, there were many questions that also emerged. Research in this area is extremely limited, and there are many opportunities for exploration of each risk area as a topic. Some of the topics that emerged as potential areas of study will now be outlined.

The field would benefit from exploring the role of appropriate sexual education as a mitigating factors for engaging in PSB. While previous literature, as well as participants in this study, speculate that improved access to sexual education will decrease the risk of engaging in PSB, the data from this study is limited in addressing this question.

Understanding the methods and implemtation of sexual education for PWDD may enable proactive actions that may avoid potentially life-changing PSB. Some participants reported engaging in PSB as a means of feeling power and control in their own lives. This is of particular in cases of sexual abuse are often associated with having power and control over another person rather than power over one's own life. Additional research exploring if increasing opportunities for autonomy and empowerment in the lives of PWDD would decrease or alleviate some of the motivation to engage in PSB would be valuable. Exploration of other mitigating factors, such as appropriate social interactions, presence of positive role models, exposure to healthy relationship training, and other potential factors related to each risk area, would also be of interest.

Another topic of future investigation that arose as a result of this study is examining social isolation as a contributing factor. Each participant reported some level of desire to have social connection. Research addressing the extent to which level of desire for social relationships impacts the level of risk for engagement in PSB would be of value. This could determine if the contributing factor of social isolation is more about being isolated socially, or if it has more to do with being blocked from a desired social connection. Without that desire there may or may not be any increased risk to development of PSB. This is of particular interest as the contributing factor related to social isolation emerged completely as a result of every participant specifically mentioning it, despite the fact that no questions in the semistructured interview specifically asked about the desire for social connections. The voluntary and spontaneous generation of this factor across all participants clearly indicate how important and

overlooked an area this is, there are many assumptions that are projected onto the experience and desires of PWDD and further delineating the role social desires and connections influence engagement in PSB.

This study established the existence of factors contributing to risk, but it is beyond the scope of this data to determine which, if any, of these factors carry greater weight or more heavily influence the development of PSB among PWDD. Research investigating the extent to which each contributing factor influences PSB would also be of great value. It is unclear from this research if each factor is weighted equally or if some contribute more to risk than others.

Additional research into the experience of female adolescents with DD who engage in PSB would also be of great interest. Information and data available on the experiences of females is extremely limited. This may be the result of fewer resource and treatment options for females who engage in PSB. It is unknown if the motivations and risk areas for engagement would differ for this population. For example, it would be interesting to explore if women rely on different sources for information regarding sexuality (such as magazines like Cosmo or other media sources), and if this has any influence related to risk. Additionally, the nature and type of PSB may differ. This is a largely unexplored area that would benefit from investigation. Studies exploring appropriate and effective treatment options would add great value to the field and to those who are involved in PWDD who engage in PSB. This is of particular importance as the potential consequences of continued engagement in PSB for PWDD are potentially life altering. Providers are charged with meeting the needs of their clients with beneicience

and malificnse and may be unable to do so in cases of PSB among PWDD without additional education and training. There is little information available to guide the choices and decisions of treatment providers at this time. Outcome studies related to specific interventions would be of great benefit in the future.

Limitations

The primary limitation of this study is in the level of diversity in participants. While there was evidence of some diversity among participants in areas such as religious affiliation and region of the U.S, it was clear that the participants in this sample who reported race were all Caucasian ($n = 4$). A sample with greater diversity may reveal additional codes and themes. This model may also be limited in its ability to explain the experiences of females with DD who engage in PSB as there were no female participants. Future studies that explore the experience of females would be helpful for comparison, as well as to attempt to generate a model that more completely encompasses the experiences of more individuals with DD.

Another potential limitation is the shared background of participants of the same residential treatment center. This may play a large role in the development of their perception and interpretation of their PSB. For example, if the program they went to had a certain value system regarding its view of the role of pornography, then it is possible that participants agreed on this as a contributing factor as a result of this being taught to them in treatment. Thus, more diversity in terms of where participants received treatment would be of benefit. Closely connected to this is the limitation introduced through the use

of self-recall as a data source. When relying on self-report and self-recollection there is an inherent inability to verify the veracity of the reported experiences. In addition, it is difficult to determine in what way the therapeutic process the participant engaged in while in treatment may have shaped the way that events and experiences were recalled or interpreted.

It is also important to note that it was not possible with this data set to break out contributing factors that are more relevant related to a specific disability, as all participants had multiple diagnoses. A shared diagnosis across all participants was autism. Better understanding the role that autism plays across each experience and gaining better insight into how PSB interacts with the different types and severities of DD would be beneficial as well. A final challenge in this study was the quality of the recordings and subsequent transcrtiptions of the interviews. There were several instances in which the transcripts were inaccurate and the original recordings had to be consulted to determine what was said by the participant. During the interviews every attempt was made to repeat back what participants had stated to ensure accuracy of responses and quality of the recording, but in some instances it was still difficult to determine exactly what was said by participants. However, while specific phrasing was at times difficult to determine, meanings were clear and were clarified through the validation checks of this study.

Summary

Individuals with DD undergo regular maturation and development, complete with

hormones and sexual desires (Attwood, 2008). While it is likely true that most adolescents with DD do not engage in PSB, it is known that some PWDD do engage in PSB and are at risk of limiting their future opportunities. In order to be able to address the needs of this population in terms of prevention of PSB, and the provision of effective treatment after PSB has begun, more understanding regarding this experience is needed.

It is with this in mind that this study was designed with the purpose of exploring the experiences of adolescents with DD who have engaged in sexually problematic behaviors, including compulsive or addictive patterns of behavior, and to explore the contributing factors for engaging in these behaviors. The research questions addressed were:

RQ1: What is the experience of individuals with DD who have engaged in problematic sexual behaviors?

RQ2: What are some of the potential risk factors that may contribute to individuals with DD developing problematic sexual behaviors?

To address these questions, a grounded theory approach with a directed analysis component was used. Eleven participants, including PWDD and parents, were interviewed regarding the experiences of seven different individuals with DD who have engaged in PSB. Results of this study led to the creation of a model that explains the overall process of engaging in PSB as requiring exposure, motivation, deficits in sexual education, and opportunity. In addition, nine different risk factors were identified that increase the risk that an individual with DD may engage in PSB.

This study attempted to begin to bridge the gaps that exist in identifying and addressing the needs of PWDD who engage in PSB. These gaps exist in the provision of sexual education as well as in the availability of service providers who are adequately

trained and prepared to address PSB among PWDD. Understanding risk factors exist for PWDD that may not exist for individuals without DD facilitates the use of proactive education and resources, rather than depending on reactive attempts at intervention. This study has demonstrated that the introduction of DD adds additional risks and complexity that make it difficult to provide adequate education and treatment opportunities for PWDD who engage in PSB.

Increasing our understanding of the process and risk factors experienced by PWDD who engage in PSB will greatly improve the ability of families, service providers, and educators to address their needs. In addition, this study has highlighted many relevant and important areas of research needed in this field. Continued engagement in this research, and improved efforts at intervention will enhance our ability to improve the lives of PWDD and their families.

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APPENDICES

Appendix A

Informed Consent

OFFICE
of RESEARCH and
GRADUATE STUDIES
UtahStateUniversity
INSTITUTIONAL REVIEW BOARD

Full Accreditation

Informed Consent

A qualitative analysis exploring the development of problematic sexual behaviors in adolescent males with developmental disabilities

Purpose
You are invited to participate in a research study conducted by Maria Watters, a doctoral student in the Department of Special Education and Rehabilitation at Utah State University. The purpose of this research is to understand the experience of adolescents who have engaged in problematic sexual behaviors from both their own perspective as well as through that of their caregivers, and to learn more about what things may have played a role in the development of those behaviors.

This form includes detailed information on the research to help you decide whether to participate in this research. Please read it carefully and ask any questions you have before you agree to participate.

Procedures
Your participation will involve an interview that will be conducted either in person, over the phone, or using video conferencing. This interview is expected to be approximately one hour in duration. There are likely to be one or two brief follow-up interviews to ensure that your responses are accurately interpreted and represented, these would approximately 10 minutes. No information will be collected outside of the interviews. We anticipate that at least 6 student and caregiver pairings will participate in this research study.

Risks
This is a minimal risk research study. That means that the risks of participating are no more likely or serious than those you encounter in everyday activities. The foreseeable risks include potential for some discomfort related to the topics being discussed, and potential loss of confidentiality. In order to minimize those risks, the researchers will be available to consult with your current therapist, if you would like, to ensure you have opportunity to discuss any concerns or discomforts both before and after your interview. There will also be an opportunity at the end of your interview to process through your concerns and discomfort with the researcher. In addition, all information you share in the interview will be de-identified while it is being transcribed to remove details of your identity and story that may make you easily identifiable to people who know you. Also during this process your name will be removed from all transcribed copies and will be replaced with a code. This code is to allow us to be able to re-contact you to ask any clarifying questions or to confirm we appropriately understood your answers. After this research is completed your original interview files as well as all coding lists will be destroyed.

If you have a bad research-related experience during your participation, please contact the principal investigator, Dr. Jared Schultz of Utah State University, right away at 435.797.3478 or jared.schultz@usu.edu.

Benefits
There is no direct benefit to you for participating in this research study. More broadly, this study will help the researchers learn more about the way that problematic sexual behaviors develop and may help us to be able to better provide resources, services, and interventions for others in the future to prevent or provide earlier intervention for people who may have similar experiences or problems.

Confidentiality
The researchers will make every effort to ensure that the information you provide as part of this study remains confidential. Minimal demographic information will be collected and your identity will not be revealed in any publications, presentations, or reports resulting from this research study. And while every effort will be made to

de-identify your information (such as removing details related to where you live, specifics of behaviors or situation, etc.) it may be possible for someone to recognize your particular story.

We will collect your information through an interview that will be audio recorded and then transcribed. This information will be securely stored in a restricted-access folder on Box.com, an encrypted, cloud-based storage system and/or in a locked drawer in a restricted-access location. Following the completion of this study both original audio recordings as well as coded identifiers will be destroyed within 30 days. This form will be kept for three years after the study is complete, and then it will be destroyed.

It is unlikely, but possible, that Utah State University may require us to share the information you give us from the study to ensure that the research was conducted safely and appropriately. We will only share your information if law or policy requires us to do so. If the researchers learn that you are engaging in abusive or self harm behaviors, or have intent to harm another individual state law requires that the researcher report this to the authorities. No reports of abuse that were reported during your time at Oxbow Academy will be re-reported.

Voluntary Participation & Withdrawal

Your participation in this research is completely voluntary. If you agree to participate now and change your mind later, you may withdraw at any time by notifying Maria Watters. If you choose to withdraw after we have already collected information this information will then be destroyed and no further contact related to this study will be made. The researchers may choose to terminate your participation in this research study if it is determined that it would be unsafe to have your son participate in interviews due to aggressive or violent behaviors and/or stability of current disability. If this occurs you will be notified personally by Maria Watters.

IRB Review

The Institutional Review Board (IRB) for the protection of human research participants at Utah State University has reviewed and approved this study. If you have questions about the research study itself, please contact the Principal Investigator, Jared Schultz, at 435.797.3478 or jared.schultz@usu.edu. Or you may contact the graduate researcher, Maria Watters at 801.885.7371 or at maria.watters00@gmail.com. If you have questions about your rights or would simply like to speak with someone other than the research team about questions or concerns, please contact the IRB Director at (435) 797-0567 or irb@usu.edu.

Jared Schultz, PhD
Principal Investigator
(435) 797-3478; jared.schultz@usu.edu

Maria Watters, PhD Candidate
Student Investigator
(801) 885-7371; maria.watters00@gmail.com

Informed Consent

By signing below, you agree to participate in this study. You indicate that you understand the risks and benefits of participation, and that you know what you will be asked to do. You also agree that you have asked any questions you might have, and are clear on how to stop your participation in the study if you choose to do so. Please be sure to retain a copy of this form for your records.

_____   _____   _____

Participant's Signature   Participant's Name, Printed   Date

A qualitative analysis exploring the development of problematic sexual behaviors in adolescent males with developmental disabilities

Purpose

Your child has been invited to participate in a research study conducted by Maria Watters, a doctoral student in the Department of Special Education and Rehabilitation at Utah State University. The purpose of this research is to understand the experience of adolescents who have engaged in problematic sexual behaviors from both their own perspective as well as through that of their caregivers and to learn more about what things may have played a role in the development of those behaviors.

This form includes detailed information on the research to help you decide whether to allow your child to participate in this research. Please read it carefully and ask any questions you have before you agree to his participation.

Procedures

Your child's participation will involve an interview that will be conducted either in person, over the phone, or using video conferencing. This interview is expected to be approximately one hour in duration. Your child may choose to have his parent/guardian or his therapist present during his interview. There is likely to be one or two brief follow-up interviews to ensure that responses are accurately interpreted and represented, these would be approximately 10 minutes. No information will be collected outside of the interviews. We anticipate that 6 student and caregiver pairings will participate in this research study.

Risks

This is a minimal risk research study. That means that the risks of participating are no more likely or serious than those encountered in everyday activities. The foreseeable risks include potential for some discomfort related to the topics being discussed and potential loss of confidentiality. In order to minimize those risks, the researchers will be available to consult with your current therapist, if you would like, to ensure you have opportunity to discuss any concerns or discomforts both before and after your interview. Additionally, processing time will be available at the end of the interview to discuss any concerns or discomforts you are experiencing. All information you share in the interview will be de-identified while it is being transcribed to remove details of your identity and story that may make your family easily identifiable. Also during this process, your and your child's name will be removed from all transcribed copies and will be replaced with a code. This code is to allow us to be able to re-contact him to ask any clarifying questions or to confirm we appropriately understood your answers. After this research is completed your original interview files as well as all coding lists will be destroyed.

If you have a bad research-related experience, please contact the principal investigator, Dr. Jared Schultz of Utah State University, right away at 435.797.3478 or jared.schultz@usu.edu.

Benefits

There is no direct benefit for participating in this research study. More broadly, this study will help the researchers learn more about the way that problematic sexual behaviors develop and may help us to be able to better provide resources, services, and interventions for others in the future to prevent or provide earlier intervention for people who may have similar experiences or problems.

Confidentiality

The researchers will make every effort to ensure that the information your child provides as part of this study remains confidential. Minimal demographic information will be collected and his identity will not be revealed in any publications, presentations, or reports resulting from this research study. And while every effort will be made to

de-identify your information (such as removing details related to where you live, specifics of behaviors or situation, etc.) it may be possible for someone to recognize this particular story.

We will collect information through an interview that will be audio recorded and then transcribed. This information will be securely stored in a restricted-access folder on Box.com, an encrypted, cloud-based storage system and/or in a locked drawer in a restricted-access location. Following the completion of this study both original audio recordings as well as coded identifiers will be destroyed within 30 days. This form will be kept for three years after the study is complete, and then it will be destroyed.

It is unlikely, but possible, that Utah State University may require us to share the information you give us from the study to ensure that the research was conducted safely and appropriately. We will only share your information if law or policy requires us to do so. If the researchers learn that your son is engaging in abusive or self harm behaviors, is being abused, or has intent to harm another individual, state law requires that the researcher report this to the authorities.

Voluntary Participation, Withdrawal
Your family's participation in this research is completely voluntary. If you agree to participate now and change your mind later, you may withdraw at any time by notifying Maria Watters. If you choose to withdraw after we have already collected information about your family, this information will then be destroyed and no further contact related to this study will be made. The researchers may choose to terminate your participation in this research study if it is determined that it would be unsafe to have your son participate in interviews due to behavioral concerns and/or stability of current disability. If this occurs you will be notified personally by Maria Watters.

IRB Review
The Institutional Review Board (IRB) for the protection of human research participants at Utah State University has reviewed and approved this study. If you have questions about the research study itself, please contact the Principal Investigator, Jared Schultz, at 435.797.3478 or jared.schultz@usu.edu. Or you may contact the graduate researcher, Maria Watters at 801.885.7371 or at maria.watters00@gmail.com. If you have questions about your rights or would simply like to speak with someone other than the research team about questions or concerns, please contact the IRB Director at (435) 797-0567 or irb@usu.edu.

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Informed Consent

By signing below, you agree to participate in this study. You indicate that you understand the risks and benefits associated with your son's participation, and that you know what he will be asked to do. You also agree that you have asked any questions you might have, and are clear on how to stop his participation in the study if you choose to do so. Please be sure to retain a copy of this form for your records.

_____   _____   _____
Parent/Guardian Signature   Parent/Guardian name, Printed   Date

Youth Assent

We are doing a research study about understanding sex and what leads to problems in sexual behaviors. Research studies help us learn more about people. If you would like to be a part of this research study, you will participate in an interview, you can have a parent or caregiver or your therapist if you have one present for this interview. It will be about 1 hour long. There may be a few questions after this interview that we may want to ask, any follow-ups would be approximately 10 minutes.

Before you agree to do these things, we need to tell you a little more. First, when the researcher interviews you, you may feel uncomfortable answering some of the questions or you may be worried about other people finding out about what you said. We will do all that we can to make sure that nobody can determine it was you we interviewed and we will not share your information with anyone else. However, if you say things that show that you or other people may be in danger we may share these things with your parents or other authorities as necessary.

Not everyone who is a part of research studies receives a something good from it. In this study, nothing directly good will happen to you, but you may help us learn more about people. Also, we will tell other people about what we learned from doing this study with you and the other people who are in the study, but we won't tell anyone your name or that you were in the study.

If this sounds like something you would like to do, we will ask you to say that you understand what we talked about, and that you do want to participate. You do not have to be in this study if you do not want to be. If you decide to stop after we begin you can tell yourparent or caregiver, or the researcher that you don't want to, that's okay, too. No one will be upset if you don't want to do this, or change your mind later. During your interview you also can choose not to answer any questions you don't want to.

You can ask any questions you have, now or later. Your parents know about this research study, and they have said you can participate, if you want.

If you would like to be in this study, please sign your name and write the date.

NAME _____   Date_____

Appendix B

Semistructured Interview

Semistructured Interview

Student Interview

1. What diagnoses do you have? What does this mean for you in everyday life?

2. When do you first remember seeing, hearing, or learning about anything sexual?

3. What were your thoughts and feelings when you heard/saw/learned these things?

4. What kind of conversations about sexual things have you had with others before coming into treatment (parents/siblings/peers/friends/teachers, etc)?

5. What kind of things do you remember your parents telling you about sex or your sexual behaviors before treatment?

6. What kind of things do you remember learning about at school or from your teachers about sex or about your sexual behaviors?

7. Has anyone ever hurt or abused you? If yes, in what way?

8. Do you remember anything really bad or frightening happening to you before you started having PSB?

9. What was your first time seeing pornography (how, when, etc)?

10. What was your use of pornography like after you first saw it?

11. What things do you think influenced you to show the sexual behaviors you did?

12. What kept you going back to your problematic sexual behaviors after people told you it wasn't ok?

13. Explain to me what you think are and are not appropriate sexual behaviors for you? Where did you learn this information?

14. What do you feel has helped you learn about what makes sexual behaviors appropriate or not?

15. Do you think anything could have helped you not engage in these behaviors? If so, what?

16. How do you feel about one day having a relationship with someone, like being attached and in a committed relationship? Do you want this?

Parent/Guardian Interview

1. What diagnoses does your child have? How have you observed this impacting him in everyday life? Has this impacted your communication with him?

2. When do you first remember your child seeing, hearing, or learning about anything sexual?

3. What were your thoughts and feelings when you heard/saw/learned that he had learned these things?

4. What kind of conversations about sexual things have you or others had with your son others prior to him coming into treatment?

5. What kind of things do you remember telling your son about sex or his sexual behaviors prior to entering treatment?

6. What kind of things do you remember being taught to your child in school about sex or about sexual behaviors?

7. Has anyone that you are aware of ever hurt or abused your child? If yes, in what way?

8. Do you remember anything really bad or traumatic happening to your child before he started having PSB?

9. What was his first time seeing pornography that you are aware of? Do you know how, what or how old he was?

10. What was his regular use of pornography like after his initial exposure?

11. What things do you think influenced him to display the sexual behaviors he did?

12. What do you think kept him going back to his problematic sexual behaviors after people told him it wasn't ok?

13. Explain to me where you think he learned about what are and are not appropriate sexual behaviors?

14. Do you think anything could have helped your child not engage in these behaviors? If so, what?

15. How do you feel about your child one day having a relationship with someone, like being attached and in a committed relationship?

16. When did you first start noticing sexual behaviors in your child?

17. What made you start to think that maybe there was a problem?

18. What did you do in response to seeing behaviors that worried you?

19. Did you seek supports in your community or from professionals? If so, what kind of information/messages did you get from these individuals?

20. Do you think there is anything that could have been done that would have prevented these PSB from developing if you had had the knowledge or resources to do them? Please explain.

CURRICULUM VITAE

MARIA J. WATTERS

Address: 412 W 14th Avenue
       Ellesnburg, WA 98926
Phone: (801) 885.7371
Email: maria.watters00@gmail.com

Current Position
Research Director, Oxbow Academy, RedCliff Ascent Companies

Research Interests

1) Integration and use of mindfulness-based approaches for individuals with disabilities, particularly in relation to management of emotional and behavioral reactivity and how these activities can help improve autonomy and independent living. 2) Evaluating the efficacy and effectiveness of incorporating experiential learning and treatment methods into therapeutic goals and objectives, with a specific focus on equine-assisted activities for individuals with disabilities. 3) Understanding the way that pornography and other behavioral addictions impact individuals with disabilities and identifying the most appropriate and effective interventions.

Education

    Utah State University
    Current Doctoral Candidate, Disability Disciplines- Rehabilitation Counseling
             Dr. Jared Schultz, Advisor and Major Professor
             Projected Graduation Date: March, 2018
    2011   Masters of Rehabilitation Counseling

    University of Nebraska-Lincoln
    2010   Bachelors of Science in Animal Science
            Minor in Psychology

Professional Memberships, Affiliations, and Credentials

    Credentials
    Licensed Clinical Mental Health Counselor (Utah), Number: 8935496-6004
         Expiration Date: Sep 30, 2018
    Certified Rehabilitation Counselor, Certification Number: 00116673

Expiration Date: September 30, 2022

Memberships/Affiliations
National Counsel on Rehabilitation Educators (NCRE), Student Member: 2012-
    Current
Utah Rehabilitation Association (URA) - Student Chapter: 2010-2014
Utah Transition Action Team (UTAT): 2012-2014

Professional Experience

Research Director	Oxbow Academy Mount Pleasant, UT: February 2014-Current Oversee research activities of a residential treatment center, including activities such as identifying and developing research projects and processes and collecting, analyzing, and reporting data. Disseminate research data and information both internally and externally through written manuscripts and presentations.
Central Access Administrator Lab, which	Central Washington University Ellensburg, WA: November 2016-February, 2018 Oversee all administrative functions within the Central Access is a part of the Disability Services department. Central Access Lab is responsible for production of alternate format and accessible print materials for all CWU students as well as for external customers. Manage the documentation, budget, and daily functions of the lab including supervising two full-time staff as well as 12 or more student technicians. Engage in outreach and education on campus regarding disability and accessibility topics.
Mental Health Counselor	Oxbow Academy Mount Pleasant, UT: February 2014-July, 2016 Provide individual, family, and group therapy for adolescent boys with disabilities who also struggle with inappropriate sexual behaviors such as pornography addiction, compulsive sexual habits, inappropriate interpersonal relations, etc. Engage in treatment planning, case documentation, case management, and experiential and equine-assisted therapy interventions.
EmployAbility Clinic Coordinator	Department of Special Education and Rehabilitation, Utah State University Logan, UT: January- 2012-January-2014 Coordinate services for individuals referred from Vocational Rehabilitation who had been identified as high risk for inability to

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successfully gain and maintain employment. Focus on developing work and social skills among individuals with disabilities, emphasizing those skills that lead to gainful employment. Engage in community and business outreach and with those involved in providing services for individuals with disabilities. Provide clinical supervision for Masters students working within the clinic. Manage case documentation, case management, professional outreach and development, and other business functions of the clinic.

Clinical-Focused Supervised Intern	St. Joseph's School for the Visually Impaired Dublin, Ireland: September 2011-December 2011 Assist in the provision of sensory-driven therapeutic interventions to improve attention, focus, and engagement of students with disabilities. Provide training to staff and students regarding service provision to students in a transition program regarding employment skills, abilities, and opportunities. Assist in creation of therapeutic riding sensory trail. Create manualized approach to teaching social and work skills to transition-aged students.
Equine-Assisted Activities-Supervised Intern	**Festina Lente** Dublin, Ireland: September 2011-December 2011 Assist with development of treatment plans and individualized lessons for individuals seeking equine-assisted activities such as therapeutic riding and Hippotherapy under the supervision of an cccupational therapist. Collaborate in development and training of independent living skills for students with mental-health concerns or cognitive impairments within the transition program. Teach youth ages 6-10 basic horse care and safety.
Vocational Rehabilitation- Supervised Intern	Idaho Division of Vocational Rehabilitation Idaho Falls, Idaho: May 2011-September 2011 Participate in direct client services such as evaluation of applications, intake interviews, creation of individualized plans for employment, case documentation, and other generalized office services. Assist in various tasks and duties as assigned.

Teaching Experience

Summer 2017 Primary Instructor- Universal Design, Accessibility Studies Program
Fall 2017   (undergraduate level, online program), Central Washington University

Spring 2017   Primary Instructor- Rehabilitation Services and Resources (masters level, distance education), Utah State University

Spring 2015   Primary Instructor-Theories of Counseling Applied to Persons with Disabilities (masters level, distance education), Utah State University

Summer 2013 Co-Instructor- Rehabilitation Counseling Skill Development (masters level), Utah State University

Spring 2013   Instructor (supervised)- Theories of Counseling Applied to Persons with Disabilities (masters level, distance education), Utah State University

Fall 2012   Teaching Assistant- Ethical Decision Making in Counseling (masters level), Utah State University

Spring 2010   Teaching Assistant- Introduction to Equine Assisted Activities (undergraduate), University of Nebraska-Lincoln, actively involved in curriculum development for this course.

Fall 2009   Teaching Assistant-Companion Animal Nutrition (undergraduate), University of Nebraska-Lincoln

Fall 2008   Teaching Assistant-Deans Scholars in Experiential Leadership (undergraduate), University of Nebraska-Lincoln

Presentations

Peer Reviewed

Watters, M, Taylor, A., & DeMille, S. (2017, January). "How to Embrace Research and Help Your Program Do the Same: A Look at Research Through the Stages of Change Model". Concurrent Presentation. 2017 NATSAP Annual Conference, Tucson, Arizona.

Watters, M. (2016, September). "Understanding and Exploring Specific Treatment Needs of Individuals who Engage in Sexually Problematic Behaviors who have Developmental Disabilities." Concurrent Presentation. 2016 SASH Annual Conference. Austin, Texas.

DeMille, S., Huff, S., & Watters, M. (2016, February). "Using Research to Inform Clinical Practice: Methods for Integrating Data into Clinical Decision Making. Concurrent Presentation. 2016 NATSAP Annual Conference. La Jolla, California.

Lewis, M. (2015, April). "Bridging the Gap Between Disability and Treatment for Sexually Inappropriate Behavior: Rehabilitation Counselors Role". Concurrent Presentation. 15th Annual National Rehabilitation Educators Conference. Newport Beach, California

Lewis, M., & Alldredge, C. (2014, March). The USU EmployAbility Clinic: A Model for Education, Research, and Community Outreach. Poster Presentation. 14th Annual National Rehabilitation Educators Conference. Manhattan Beach, CA.

Lewis, M. (2013, April). Family systems intervention model that is viable within a rehabilitation context. 13th Annual National Rehabilitation Educators Conference. San Francisco, CA.

Invited

Southwick, J., Lewis, M., & Schultz, J. (2014, March). Technological Intoxication: Making Learning Strategies the Designated Driver in Rehabilitation Education. 14th Annual National Conference, Manhattan Beach, CA

Lewis, M. Employment opportunities for individuals with disabilities and an overview of the EmployAbility Clinic. Sam's Club Associate Training. Logan, UT (October, 2012).

Deseret Industries Staff Training. Logan, UT (Jan 2013).

Lewis, M. (December, 2012). Ethical decision making in vocational rehabilitation. Utah State Office of Rehabilitation. Logan, UT.

Lewis, M. (September, 2012). Employment opportunities for individuals with disabilities. Classroom lecture, Utah State University. Logan, UT.

Publications

Watters, M, & Schultz, J. (Pending Acceptance). Development of an instrument to track changes in emotional, social, and behavioral experience of students in residential treatment facilities.

Watters, M., & Spaulding, T. (2018). Sex addiction and adolescents. In Birchard, T., & Benfield, J (Eds.), *The Routledge International Handbook of Sexual Addiction.* New York, NY: Taylor and Francis

Watters, M., & Spaulding, T. (In preparation). Use of clinical polygraph as a therapeutic tool in treatment of adolescents with problematic sexual behaviors. *Sexual Addiction & Compulsivity: The Journal of Prevention & Treatment.*

Additional Experience

Certification: Certified in Basic Sand Tray Therapy- Oct. 2014

International Travel

  Rehabilitation Counseling Internship, Sep. 2011-Dec. 2011
  Dublin & Bray, Ireland

  Fisheries and Wildlife Study Abroad, May 2009
  Namibia, Africa

  Agriculture Study Abroad, March 2008
  Argentina

Crisis Line, Voices of Hope (Rape, Crisis, and Abuse Center), Oct. 2009-May 2010
  Provided general counseling, support, advocacy, and referral information for individuals using domestic violence and sexual assault crisis line.

Animal Science Ambassador, University of Nebraska-Lincoln, August 2009- May 2010. Assisted in recruitment activities and provide information and education regarding career opportunities and educational options available to potential students and families.

Sunrise EquiTherapy, Aug. 2008-Jan. 2009. Assisted facilitator in developing individualized lesson plans and providing safe, adaptive riding sessions for individuals with disabilities.

Products

2013   Assist on Grant Application under direction of Dr. Nancy Glomb for Institute for Educational Sciences Grant on bullying education and prevention in schools. Assist on Grant Application under direction of Dr. Jared Schultz and Dr. Tim Riesen for Rehabilitation Research and Training Center on effective employment outcomes

2013   Develop synchronous teaching materials and curriculum for Introduction to Addictions course at Utah State University (masters level)

2013   Research Internship-Provide consultation in development of program evaluation and tracking tool as well as provide statistical analyses for validation and reliability of this tool, called the Residential Emotional, Social, and Behavioral Assessment Tool (RESBA). RedCliff Ascent Troubled Teen Programs.

2012   Manual development: "Work and You," a model for engaging transition aged special education students in career building for the future.