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Sexuality, Sexual Orientation, and Intellectual Developmental Disorder: A Parent's Perspective

Wendy Marie Kellon
Walden University

Walden University

College of Social and Behavioral Sciences

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Wendy Kellon

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Review Committee
Dr. Chet Lesniak, Committee Chairperson, Psychology Faculty
Dr. Kathryn Dardeck, Committee Member, Psychology Faculty
Dr. Donna Heretick, University Reviewer, Psychology Faculty

Chief Academic Officer
Eric Riedel, Ph.D.

Walden University
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Abstract

A consistent gap in previous studies was sexuality education and sexual orientation, as well as how to disseminate the sexual education material in a format that would be useful to individuals with IDD, parents, and caregivers. This biographical study addresses the understanding of sexuality and sexual orientation of an individual with intellectual developmental disorder (IDD), as reported by his parents. Data were collected through face-to-face interviews, documents, and social media sites belonging to the participants. The theoretical framework for this study was social constructivism; a thematic analysis was used for data analysis. The six themes that emerged from this research study include: lack of certainty and confusion about disability; early childhood peer interaction, sexual education, exploration and bullying; family communication and supportive family structure; coming out; and, social media, privacy, and safety. Theme identification indicated that parents, caretakers, and individuals with IDD need more information including scripted, detailed sexuality and sexual orientation education, support in understanding and navigating social media dating sites, and information on dating etiquette. Findings may contribute to social change by providing a foundation for sexual education curricula to support the needs of individuals diagnosed with IDD.

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Dedication

This dissertation is dedicated to my family for the unwavering support I received during this arduous process. Thank you to my husband, Brian, who spent countless hours tending to our children, their activities, and all of the household tasks while I worked endlessly on researching, writing, and editing this dissertation. To my children, John, Samantha, Kandace, and Brian II, and my grandson, Jeremiah, this dissertation belongs to you, too. You inspired me to do my very best and work hard, and you encouraged me with your love and support to finish the job. I am forever grateful.

Lastly, I dedicate this dissertation study to my brother TJ. I am forever grateful that you trusted me as your sister to share your life feelings, complications, and struggles. I know that throughout your life you were faced with stigmas and labels, always feeling marginalized and invalidated in a society that required an expected norm. Rest in peace. I will forever hold your memory dear. 2/24/71-12/3/15

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This dissertation would not be complete without my sincerest acknowledgement to my committee, Dr. Chet Lesniak, Dr. Kathryn Dardeck, and Dr. Donna Maria Heretick. The guidance I received from my committee throughout this process was steadfast. The observations, direction, critiques, and motivation came in each interaction with my committee. I appreciate your tutelage, your expectation of excellence, and your discipline in keeping this dissertation on track and using a keen eye to keep it from falling to the wayside. Thank you for always making time for me. I genuinely appreciate your personal dedication to my research study and to me. My sincerest gratitude and thanks to Dr. Lesniak, Dr. Dardeck, and Dr. Heretick.

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Chapter 1: Introduction to the Study

A Kentucky newspaper ran a story reporting two gay men diagnosed with intellectual developmental disorder (IDD) were attending a group outing and were asked to leave a public swimming pool (Garcia, 2011). The story stated that the men sat on each other’s lap and cuddled while sharing the same lawn chair. The Bible is the reason the official gave for removing the men from the pool. The news report stated that the swimming pool staff asked the men to leave the pool because gay people were not permitted to swim there. The staff accompanying the men on the outing informed the pool staff that what they were saying was discriminatory. The pool staffer advised the group that he was allowed to evict the group because he was following what was in the bible. Although, the group staff argued that they should be allowed to stay, they were forced to leave. The report stated the men left crying feeling embarrassed and disappointed that they were not allowed to swim at the pool (Garcia, 2011)

The Bethesda Institute (as cited in Anderson, Park, Monteleone, & Dabelko-Schoeny, 2014) estimated that approximately 4.6 million to 7.7 million adults have the diagnosis of IDD in the United States. The diagnosis of IDD must include three criteria, which include significant limitations in adaptive behavior, intellectual functioning, and the onset of these limitations before 18 years of age. Additionally, there may be limitations in practical skills, social skills, and conceptual skills (Schalock, Luckasson, & Shogren, 2007). Although limited data exists on how many individuals with IDD identify as gay, about 3.8% of the U.S. population identifies as lesbian, gay, bisexual, transgender, and questioning (LGBTQ) (Brault, 2012). This appears to be a consistent number used on support group sites dedicated to the gay IDD population (Allen, 2003).

Societal beliefs influence stereotypical views regarding sexuality among individuals diagnosed with IDD. Most initial stereotypes develop from individuals directly related to the person with IDD (Dupras & Dionne, 2013). Parents and caregivers most frequent responses or reactions include: (a) individuals with IDD are childlike and dependent, (b) individuals with IDD do not want sex, (c) individuals with IDD are oversexed and unable to control their sexual urges, and (d) individuals with IDD are deviant and sexually perverse (Dupras & Dionne, 2013).

Researchers, who study human development, describe individuals with IDD as sexual beings (Cheng & Udry, 2002; Parchomiuk, 2012). This suggests affection, intimacy, companionship, love, and acceptance exist as developing emotional characteristics with associated behaviors (Parchomiuk, 2012). Kijak (2013) concluded that biological maturity of the individual with IDD is likely to progress like other children, although their sexual development may be delayed by about three years, while the intellectual, social, and emotional maturity may lag behind even further (Walker-Hirsh 2010). Research indicates many caregivers ask children with IDD to respond socially and emotionally to developing biological changes (Walker-Hirsh, 2010). The individual with IDD possesses a limited mental ability (Walker-Hirsh, 2010).

Research indicates many parents of children have a restrictive or ambivalent attitude when it comes to sex and their child (Aunos & Feldman, 2002; Brantlinger 1992;

Dupras & Dionne, 2013). This often translates into withholding sexuality information from children and excluding them from mainstream sexuality education programs (Dupras & Dionne, 2013). My study presented an opportunity for parents to express their experience of raising a son diagnosed with IDD, as well as their perception of the development of his sexuality. Findings provided insight through analysis of the personal accounts of their parenting experience. Findings add to the literature by offering ways to educate parents, as well as individuals with IDD, to make them less vulnerable so they will know how to act in sexual situations and ensure sexual competence (Dupras & Dionne, 2013). Research indicates girls with IDD appear to receive more sexuality education information than boys (Aunos & Feldman, 2002). Other trends indicate parents frequently choose to avoid the subject of sexuality awareness (Dupras & Dionne, 2013; Picard, Morin, & De Mondehare, 2014).

Parents of IDD individuals report that special education programs lack information on sexuality education, and research findings have supported this observation over the past 30 years (Brantlinger 1985; Dupras & Dionne, 2013, Tharinger, Horton, & Millea, 1990). Individuals with IDD appear to have unique needs related to sex education (Cheng & Udry, 2002). According to Kijak (2013), individuals with IDD appear to have a need to understand the emotional aspect of sexuality at a much higher level. Kijak (2013) noted that, after experiencing their first sexual interaction around the age of 24, the individuals diagnosed with IDD experienced feelings of disappointment, shame, and that they had committed a sin. Most individuals with IDD learn differently. Even though biological maturation may progress normally, learning and knowledge development proceeds at a slower pace than the peer who is not intellectually disabled (Aunos & Feldman, 2002). The physical development and slower cognitive and emotional progress might require a sex education program that meets the applicable skill level of the individual with IDD (Rembis, 2010).

Researchers suggest adolescents with IDD may be more susceptible to abuse because they do not receive suitable information on sexuality (Euser, Alink, Tharner, Ijzedoom, & Bakermans-Kranenburg, 2015; Owen, Griffiths, Feldman, Sales, & Richards, 2000; Pownall, Jahoda, Hastings, & Kerr, 2011). Researchers found individuals with IDD were less knowledgeable regarding sexuality topics in comparison to others without disabilities (Edmonson & Wish, 1975; Kajik, 2013; McCabe & Cummings 1996; McCabe & Schreck 1992; Nichols & Blakely-Smith, 2010; Szollos & McCabe 1993). The obstacles for many individuals with IDD include social acceptance and social adjustment specific to sexuality, resulting in a high risk of exploitation (Mansell, Sobsey, & Moskal, 1998; Nichols & Blakely-Smith, 2010). The U.S. Census Bureau stated that roughly 5.2 million Americans 5 to 20 years old have a long-term emotional, physical, or mental disability (Brault, 2012). This fact suggests 5.2 million American youths lack awareness and education about sexuality or sexual orientation. Despite the advancement in the sexual rights for individuals with an IDD diagnosis, it appears that the current approach of sexuality education has not adjusted accordingly. (Young, Gore, & McCarthy, 2012).

Parchomiuk (2012) found that medical personnel and special education teachers agreed that teens with IDD should attend classroom instruction on sexuality education and family planning programs. However, there was a perceived fear from parents and caregivers that sexual education conversations may awaken dormant sexual feelings (Parchomiuk, 2012). Studies on sexuality and individuals with IDD outside of the United States are limited in scope, especially regarding sexual orientation (Dupras & Dionne, 2013; Kijak, 2013, Parchomiuk, 2012). I attempted to identify the obstacles the individual with IDD faces with respect to developing awareness and knowledge of sexuality and sexual orientation, through the perspective of the individual's parents. The information obtained through this study represents the parents' perspective, which may be different from the experience of the child. However, the investigation of the parents' perspective provides the only avenue for research of the IDD individual's experience because the United States defines IDD individuals as members of a protected population.

The chapter began with an explanation of the background of the study, followed by the problem statement, purpose, and research questions. It continued by detailing the theoretical framework, nature of the study, definitions, assumptions, scope and delimitations, limitations, and significance of the study. The chapter concludes with a summary of the current thoughts surrounding sexuality and the individual with IDD.

Background

Most IDD caregivers accept some sexual behaviors such as brief kissing, hugging, and masturbation (Cuskelly & Gilmore, 2007; Parchomiuk, 2012). A recent study that included medical students and medical personnel also indicated health care professionals accept some levels of intimate behavior among individuals with IDD (Parchomiuk, 2012). However, according to both studies, displeasure among people intensifies when the intimacy becomes greater (Owen et al., 2000; Parchomiuk, 2012). Owen et al. (2000) found that adults with intellectual disabilities believed intimate relations were wrong regardless of the intimate partner. Adults with IDD feel it is acceptable to show affection like kissing, hugging, and caressing a leg or arm, particularly with acquainted caregivers who are not their own (Kijak, 2013; Morales, Lopez, & Mullet, 2011).

Parchomiuk (2012) found 72% of caregivers felt limited heterosexual contact such as hugging or handholding was acceptable, but only 9% of those caregivers accepted intimate contact like sexual intercourse among individuals with IDD. Some research indicates administrators and caregivers respond more negatively to intimate sexuality between individuals with IDD (Owen et al., 2000). However, sexual intimacy among other physically disabled people appears more acceptable (Dupras, 2006; Kijak, 2013; Trudel & Desjardins, 1992). The consensus among direct caregivers seems to be individuals with IDD must be encouraged to refrain from having intimate sexual relations (Dupras & Dionne, 2013; McCabe, Cummins, & Deeks, 2000; Parchomiuk, 2012). In response to previous research findings, my study was conducted to explore knowledge and understanding of sexuality and sexual orientation of individuals with IDD. My findings may contribute to social change by expanding society’s acceptance of the sexuality of individuals with IDD, and in turn may improve the quality of life for these individuals.

Problem Statement

The words sexuality and intellectual developmental disorder appear to contradict each other (Fager, Hancox, Ely, Stenjem, & Gaylord, 2010). In most cases, these terms do not typically appear paired together (Fager et al., 2010). Sexuality is an inherent aspect of every person with or without a disability. To provide an adequate understanding of sexuality and sexual orientation of individuals with IDD, there must be a consideration of their life experiences related to sexuality. Currently, some sex education exists for mainstreamed youths diagnosed with IDD; however, there remains a gap in the knowledge and understanding of sexuality and sexual orientation of individuals with IDD (Fager et al., 2010). Parents of individuals with IDD participated in a focus group to gather information about disability and sexuality (Holmquist, 2010). The focus group was asked five questions. None of the questions addressed sexual orientation (Holmquist, 2010). Although the focus group coordinators responded to a request by parents and caregivers to develop curricula on puberty and sexuality for individuals diagnosed with IDD, the questions used to develop the curricula included five basic questions and excluded sexual orientation. The parent focus group questionnaire exemplifies the limited discussion about sexuality and people with IDD, along with other sexuality studies that excluded specific components of sexuality and sexual orientation (Dupras & Dionne, 2013). Parents report their children verbally expressed interest in sex, and parents described comments made by their children that they wanted and had a need for both love and sexual experiences (Dupras & Dionne, 2013). The parents confirmed that the social lives of their children were limited and access to socio-sexual encounters was reduced because of these limitations (Dupras & Dionne, 2013). The parents reported rejection and stigmatization when they tried to integrate their children diagnosed with IDD in social networking outside of IDD groups (Dupras & Dionne, 2013). The parents described vulnerability as the main weakness of their child diagnosed with IDD, and reported that their child needed protection (Dupras & Dionne, 2013). The parent participants stated their biggest concern was aberrant sexual behavior that would lead to greater marginalization of their children (Dupras & Dionne, 2013). Although the parents acknowledged that their children were sexual beings, they also understood that their children were considered deficient according to social expectations and standards (Dupras & Dionne, 2013). Although the focus group offered a preliminary understanding of the parents' perceptions in relation to sexuality and their child with IDD, the gap remained in understanding the sexual orientation experiences of their child (Dupras & Dionne, 2013). By investigating the lived experience of parents of a child with a diagnosis of IDD who identified as a gay man, my study will help close a gap and contribute to the knowledge base regarding resources for individuals with IDD and their parents and caregivers.

Purpose of the Study

The purpose of this study was to explore the parental perspective of sexuality, including sexual orientation, to understand how this information could support curricula for the heterosexual or gay individuals with IDD. The findings may contribute to the knowledge base of information for parents, teachers, and caregivers. Results may contribute to social change by increasing awareness of the parental perspective of sexuality and sexual orientation among individuals with IDD. Findings may encourage the development of sexual education curricula to include sexual orientation in the IDD community.

The results of this study may increase awareness of the sexuality and sexual orientation of individuals with IDD. Insights may enhance parents' and caregivers' understanding of individuals with IDD and their sexual development. Findings may also support the development of curricula to help parents understand the sexuality of their children with IDD including their children's sexual orientation. Sexuality education is an area of emerging research in the disabled community (Fager et al., 2010); however, researchers have rarely included sexual orientation as a variable of interest (Dupras & Dionne, 2013; Kijak, 2013; McCabe, 1999; McCabe, et al., 2000; Parchomiuk, 2012).

Research Questions

- The purpose of this qualitative study was to explore the parental perspective of a son's sexuality and sexual orientation in light of his diagnosis of

IDD. The following research questions were used in hierarchical order to guide the study:

- RQ1: How do the parents of a son with IDD describe his sexuality and sexual orientation?
- RQ2: How do the parents of a son with IDD describe how he learned about sexuality and sexual orientation? Was this through a school curriculum or other source? What information did the parents provide in terms of sexual education?
- RQ3: What areas of support do the parents feel were needed, or wished were available when their son was going through puberty and beyond?

Theoretical Framework

The theoretical framework for this study was social constructivism. Social constructivist theory proposes that context and culture support a person’s understanding of what occurs around him or her. Social constructivism leads to an understanding of how individuals construct societal norms (O’Donnell & King, 2014). Vygotsky (1930) emphasized the influence of cultural and societal contexts in the construction of knowledge. The assumption is that individuals construct meaning actively and continuously in a social context; patterns emerge interactions with people, and from those social experiences the contextual meaning continually changes (Vygotsky, as cited in Kanuka & Anderson, 2007). Vygotsky (1930) identified three assumptions related to social constructivism:

1. Knowledge is a product of human interaction.

2. The group socially and culturally constructs knowledge that becomes societal norms.
3. Learning is a social activity.

Social constructivist theory offered a framework for understanding the lived experiences related to sexuality and sexual orientation specific to individuals with IDD. This study built on previous studies by offering an analysis from the social constructivist lens, while producing new information and direction for upcoming studies in the areas of sexuality and sexual orientation among the IDD population.

Nature of the Study

I used a qualitative biographical design. A biographical study involves writing a life story of an individual using records, archives, and interviews with persons close to the individual (Creswell, 2012). Triangulation is a validity procedure that allows the researcher to combine different types of data to identify categories or themes (Creswell & Miller, 2000). This approach allows the story to unfold through questionnaires given to interviewees and the unique story told through the words of the participants. The intent was that this biographical study would yield insight into the life, sexuality, and sexual orientation experience of the individual with IDD.

Definitions

Definitions of terms related to the topic of the study are as follows:

Developmentally disabled: An individual with impaired general intellectual functioning; the IQ score is usually at or below 70 but can be as high as 75 (Kijak, 2013).

Disability: a specific diagnosis given to individuals with mental disabilities also known as developmental disabilities (Kijak, 2013).

Gay: Demonstrating sexual desire for a person of one's own gender (Noonan & Gomez, 2011).

Heterosexism: Prejudice or discrimination against gay people assuming heterosexuality is the normal sexual orientation (Szymanski & Ikizler, 2013).

Impairment: A type of abnormality physical or mental, either partial or full. in this study a type of mental disability (Wild, Kelly, Blackburn, & Ryan, 2014).

Intellectual developmental disability (IDD): An intellectual disability that originates before the age of 18 and is characterized by limitations in adaptive behavior and intellectual functioning (Schalock, Luckasson, & Shogren, 2007).

Sexuality: Societies understanding of the sexual concepts of a person's being, such as being straight, gay, bisexual, or transgendered (Noonan & Gomez, 2011).

Sexuality education: The constant practice of gaining information and establishing approaches, opinions, and standards. Sexuality education includes sexual growth, sexual and reproductive health, social relations, love, affection, body image, and sexual roles (Dupras & Dionne, 2013).

Sexual orientation: A person's sexuality uniqueness relative to the gender he is attracted to, in this case, another male. Specifically, being heterosexual, homosexual, or bisexual (Noonan & Gomez, 2011).

Assumptions

Assumptions include aspects of the study that are out of the researcher’s control as (Leedy & Ormrod, 2010). I assumed that the parents of the individual with IDD felt that sexuality was an area of importance for their child. I also assumed that because the participants were anonymous and all answers were confidential that the parents would answer truthfully and honestly (Creswell, 2012). Another assumption related to the research topic was that individuals with IDD deny their sexual feelings, and this is described in more detail in the literature review (Stoffelen, Kok, Hospers & Curfs, 2012). I also assumed that individuals with IDD did not participate in sexuality education classes. A final assumption was that individuals with IDD are led to believe that engaging in sexual experiences is bad (Topper & McLaughlin, 2010).

Scope and Delimitations

Recent international studies (Kijak, 2014; Stoffelen et al., 2012) included individuals with IDD. In the United States, Institutional Review Board (IRB) regulations prevent individuals with IDD from being used as participants in research. Although the international studies included individuals with IDD and sexuality, none included sexual orientation.

My initial intent for a participant was a gay man diagnosed with IDD. However, after further discussion with an IRB representative at Walden University, I was advised that I could not have a participant diagnosed with IDD. After learning of this decision and discussing the verdict with my committee, my methods chair encouraged me to locate potential sources for participants. We concluded that a parent's perspective would be equally important in the study. I looked for a parent support group for gay IDD in a Google search and found a program in a large city in the Midwest. I called the center using the phone number listed on the website. After discussing the study with the program director, she felt confident that she knew a couple who would be interested in participating; this presented an opportunity for researching both a mother's and a father's perspective. However, the findings in this study may not be generalizable to other parents of gay individuals with IDD. Additionally, the biographical design may present the opportunity for the parents to include only the positive experiences of the individual's life.

Limitations

The limitations for this study included data collection of one individual with IDD and his parents' perception of his lived experiences related to his sexuality and sexual orientation. This experience may not represent the entire IDD community as each person has his unique experience. Another limitation was finding parent participants of an individual with IDD; many adults with IDD live in group homes or institutions. They have often moved from the foster care system as children directly into an institutionalized adult care system. My experience working with individuals with IDD is that they are sometimes ostracized by family because of their mental disability or are put into homes when parents pass away or become too old to care for them. An additional limitation was my personal bias in relation to the life experiences of a gay IDD person. Although I took great care to keep my personal bias from influencing any portion of this research study, it is important to note that my personal involvement with my brother with IDD and his gay life experiences inspired this research study. Additionally, because the participants were parents of the IDD person, the participants may have tried to protect the IDD person by presenting only the positive experiences of their child.

Significance of the Study

This study may contribute to the research literature on individuals with IDD with respect to laying a foundation regarding their sexuality and sexual orientation. Findings may promote a better understanding of the need for sexual education in the IDD community. The outcome of the study may also help reduce the social stigma of sexuality and sexual orientation of the individual with IDD. This study has already been used to effect change within the community in which I live. When I began my preliminary research for my dissertation, I contacted the Cuyahoga County Department of Disabilities, as well as the LGBT Community Center of Greater Cleveland, to determine whether there were any parent support groups for individuals with IDD who identified as gay. These inquiries led to the establishment of two support groups, one for gay individuals with IDD and the other for their parents or caregivers. I then became the facilitator for the parent group.

The findings of this study may contribute to a better understanding of the sexuality and sexual orientation of males with IDD. Insights from this study may aid parents and caregivers in supporting individuals with IDD and their sexual development.

Findings may also support the development of curricula to help parents of males with IDD understand their sexuality, including their sexual orientation. This understanding could support policy change within school districts with special education programs incorporating sexuality and sexual orientation education in the curricula for individuals with IDD. Sexuality education is an emerging area of study in the disabled community (Fager et al., 2010); however, much of the research excludes sexual orientation.

Summary

In Chapter 1, I introduced the study of sexuality and sexual orientation of a male diagnosed with IDD as reported by his parents. The purpose of this study was to understand the sexual experiences of the individual with IDD. This study may help reduce the anxiety for parents and caregivers regarding sexual development, orientation, and expression (Ballan, 2001).

In Chapter 2, I address the gaps in peer-reviewed literature, while also identifying and analyzing the information found in previous studies on sexuality and individuals with IDD.

Chapter 2: Literature Review

The questionable approach of parents and caregivers in relation to sexuality and sexual orientation of individuals with IDD creates a need for improved understanding (Morales et al., 2011). Sexuality and sexual orientation of individuals with IDD often goes unrecognized or results in support through mainstream sexual education programs that are limited in content (Morales et al., 2011). The failure to properly present content on sexuality and sexual orientation limits the natural rights of individuals with IDD (Cuskelly & Gilmore, 2007). According to Cuskelly and Gilmore (2007), there is no human life without sexuality. This dissertation study described the sexuality and sexual orientation of an individual with IDD as reported by the parents. I sought to enhance awareness of sexuality and sexual orientation among persons with IDD and effect positive social change for the IDD population.

This literature review addresses the research associated with sexuality and sexual orientation among individuals with IDD. The consideration of relevant historical topics revealed gaps in IDD research, as well as essential themes of sexuality often overlooked among the IDD population. An evaluation of research strategies for this study includes a comprehensive analysis of relevant research topics: disability, impairment, developmentally disabled, history of intellectual disability, history of gay orientation, psychological perspective of gay people, problems of sexuality, sexual orientation of individuals with IDD, social problem of excluding individuals with IDD from sexual education, effects of sexuality education for individuals with IDD, sexual health barriers of intellectually disabled, and capacity to consent to a sexual relationship.

Literature Search Strategy

The multi-source literature searches commenced March 2012. The search included a broad scope of academic literature and peer-reviewed journal articles. For the purpose of this dissertation, an exhaustive literature search included topics in chronological order that support both the theory and context of sexuality and sexual orientation of individuals with IDD. The initial search of psychological databases included ProQuest, Sage Online, Science Direct, PsycARTICLES, PubMed, ERIC, PsycINFO, Medline, EBSCO host, and EPIC. The literature search included the following terms: *sexuality and disabled*, *parent's perspective of disability and sex*, and *sexuality and mental retardation* from 1980 to present. A number of search themes emerged from the initial search including *physical disability and sexuality*, *eugenics among disabled,* and *sexual aides for the disabled.* Since none of these met the need of the literature topic, I narrowed the review to a more specific search with terms including *gay or lesbian developmentally disabled* and *sexual orientation and developmental disabled*, published from 2000 to 2013. Additional key words included *mental retardation and sexuality*, *intellectual developmental disorder and sexuality*, *sex education,* and *disabilities.*

Limited results among psychological databases led to an additional focus on health science. Inquiries of health science databases included Health and Medical complete, BIOMED, Nursing and Allied Health Source, CINAHHL, MEDLINE, and EBSCOhost. The same search criteria generated many more peer-reviewed journal articles. Supplemental and independent manual searches were done to locate articles that were not available electronically. The Walden University library delivered those articles via the university's document delivery service.

During the initial URR review, my assigned URR chair, Dr. Heretick, made a comment about the use of outdated articles. This prompted an additional search for more recent journal articles that addressed individuals with IDD and sexuality. This search included a detailed examination with the Walden University librarian. We looked for more recent peer-reviewed journal articles related to sexuality and individuals with IDD. The emerging articles included solely international studies on sexuality and individuals with IDD (Kijak, 2013; Parchomiuk, 2012); none were U.S. studies that included individuals with IDD because they are a protected population. Several international studies were written in their native language and were not available for translation in English. The studies translated to English addressed individuals with IDD but did not include sexual orientation as a variable. Studies that addressed sexual orientation of individuals with IDD were not found. The lack of peer-reviewed articles in the Walden University databases led me to contact the disability history museum in Buffalo, New York. That effort produced articles not found in the previously noted databases.

This literature review highlights several important concepts specific to sexuality, sexual orientation, and IDD. Documents considered for use in this review included peer-reviewed journal articles, edited books, conference papers, archived government papers, and information noted on disability support websites. Older articles and reports included in this chapter provide the historic foundation of the topic. This review included more than 300 articles, abstracts, and documents for evaluation; however, only 139 of those supported this dissertation study. The 135 resources used were chosen according to the following inclusion criteria:

- peer-reviewed articles that focused on intellectual disability and sexuality,
- peer-reviewed articles that addressed historical perspectives of disability and sexuality,
- formative studies that related to sexual orientation and intellectual disability,
- studies of adults with intellectual disabilities, and
- studies of parents with IDD children and sexuality.

Articles not chosen met the following exclusion criteria:

- studies that did not address intellectual disabilities, and
- studies that focused on sexuality and physical disability.

I used a master Microsoft Word document and Microsoft Excel spreadsheet to organize the dissertation resources.

Theoretical Foundation

Social constructivism theory provided the framework for this study. Sexual expression or experience in modern times falls under the category of social constructivism (Anastasiou & Kaufman, 2011). Viewing sexuality and sexual orientation through the lens of social constructivism offered an understanding of how society understands sexuality and sexual orientation among people with intellectual developmental disorders (Anastasiou & Kaufman, 2011). Among social constructivists, it appears that a dispute exists regarding sexuality as a social construct. Whereas, sexuality produces ways of being, versus the historiographical position which advocates that sexual orientation is a product of cultural history (Anastasiou & Kaufman, 2011).

Essentialism is the view that some groups have a fundamental reality or true nature not understood in a direct observation but that gives identity and is responsible for the similarities the group members share (Gelman, 2004). The debate suggests that human social fluidity and sexual diversity support an essentialist position that acknowledges a heterosexual versus gay struggle (Brickell, 2006). Those who argue against a historiographical construct state that gays are abnormal and the accepted norm is heterosexuality (Brickell, 2006). Social constructivism theory states there is no natural sexuality, only sexual understandings mediated by cultural understandings (Anastasiou & Kaufman, 2011).

To illustrate this point, consider the situation in which an IDD gay couple entered a public recreation center in Hazard, Kentucky. When the men sat together on a pool chair and hugged, staff members told them they had to leave. The staff members described the action displayed as against the bible, and the pool rules stated no gays allowed. The men were with a group of other individuals with IDD, and even though the staff members from the facility hosting the group intervened, they were all ejected (Garcia, 2011). According to social constructivist theory, the interpretation of the men's sexual orientation appears to have been mediated by the pool staff's constructed understanding (Anastasiou & Kaufman, 2011).

Although many studies address IDD, sexuality, and sexual orientation through a social constructivist lens, few address sexuality and sexual orientation in relation to the IDD person. This study and its theoretical perspective of Vygotsky's social constructivist theory offered a framework for understanding the parent's perspective of sexuality and sexual orientation of the IDD individual. The parent's perspective of IDD sexuality and sexual orientation appears dramatically influenced by society norms. For example, in New Haven, Connecticut, the Rainbow Support Group (RSG) televised a segment highlighting support for adult LGBT IDD persons. During the television promotion of the program, the father of one of the members took issue that his son was in the promotion. He sent a letter to the program coordinator suggesting that if the program were truly there to help the members, they would do it quietly without celebrating homosexuality (Allen, 2003).

The father's position presents a typical belief in society that individuals who do not fit the social norm should remain quiet and out of the way (Allen, 2003). Understanding that individuals with IDD have sexual desires and urges is important, and denying these feelings can prevent the IDD individual from having a full and experienced life (Allen, 2003). Recognizing the current context of sexuality and sexual orientation in relation to the IDD individual aligns with Vygotsky’s (1930) assumption of social constructivism. According to Vygotsky, social constructivism includes three key principles. First, knowledge is a product of human interaction, the group, and environment. Second, socially and culturally constructed knowledge is influenced by society’s norms. Third, learning is a social activity (Vygotsky, 1930). Given this framework, the theoretical perspective of this study fit perfectly in the context of social constructivism as seen through the lens of societal norms.

The theoretical framework of social constructivism indicates societal belief that individual truth develops over time through exchanges in social settings (LeCompte, 1999). The theoretical framework offers a perspective that an individual constructs his or her own truth. In this study, I sought to learn how social constructivism could be used to understand the parental perspective. The framework provides a lens for understanding individuals with IDD like those belonging to the Rainbow Support Group.

Herek, Chopp, and Strohl (2007) hypothesized that sexual disgrace is a shared belief system of society, which considers gay individuals as invalid, discredited, and denigrated compared to heterosexual individuals. Many group home institutions also promote this belief system into a philosophy that strengthens shame and exploits power differences, a phenomenon labeled heterosexism (Herek et al., 2007). For example, several times during monthly support group meetings for LGBT individuals with IDD, three men from separate group homes questioned whether they should attend the support group meeting because the facilitator of the group home advised them that being gay is a sin. The challenge for most group homes or similar institutions is educating the staff that people with IDD can have a sexual orientation besides heterosexual (Allen, 2003). Ultimately, institutional awareness may encourage and acknowledge IDD entitlement of sexual expression, intimacy, and privacy (Allen, 2003).

Social constructivism theory is often cited as a way to explain how varied social interactions can create a concrete belief over time (Anastasiou & Kaufman, 2011). Social constructivists recognize sexuality and sexual orientation in the same way. Society has an accepted norm of sexual conduct specific to opposite genders. The conveyance of these cultural norms transfers to the IDD community, including parents, caregivers, and institutions. This type of messaging is frequently not overt or intentional. It is often an indirect oversight; typically, no one educates or discusses the sexuality or sexual orientation of individuals with IDD (Rembis, 2010).

After broader theoretical review of other's studies (Allport, 1979; Goffman, 1963; Meyer, 2003; Scambler & Hopkins, 1986), the suggested social constructivism agenda combines institution and separate stages of examination, which helps to address the stigmatized minority and non-stigmatized majority. Although some of these studies are over 30 years old, the stigmatization of intellectual developmentally disabled appears to be about the same (Anastasiou & Kauffman, 2011).

Among other things, qualitative inquiry seeks to reconstruct and understand the experience of a subject, as told by those around him (Creswell, 2007). It also may help provide insight into that person's life experiences while identifying a phenomenon or narrating a biography (Creswell, 2007). In this study, the biographical narrative analysis will seek to realize, and reconstruct the male with IDD, his sexuality, and sexual orientation, as told by the parent experience with their son (Creswell, 2007).

Stigma historically refers to a condition that discredits individuals in social situations or across social settings (Werner, Corrigan, Ditchman, & Sokol, 2012). As with many minority groups, stigmatization of individuals with IDD happens because they are different. As defined, the societal benefits for individuals that fall into the stigmatized category compared to those that fall into the ordinary are distinct (Werner, et al., 2012). The stigmatized exist in an inferior status, have less power, and garner modest resource access compared to the so-called normal (Herek, Chopp & Strohl, 2007). The social reality of stigma is independent of an individual actor. The phenomenon develops, as a fragment of the belief, and this then becomes shared information between members of society, which ultimately justifies and rationalizes an ideology (Herek, Chopp & Strohl, 2007).

Sexual stigma links sexual orientation and society’s negative response to a non-heterosexual relationship, behavior, identity, or community (Herek, 2007). As in any stigma, sexual stigma generates community roles broadly shared by the members of the society. This study represents the social constructivism framework, supported by a narrative biographical design as told by the parents of the individual with IDD. This illuminates the rarely heard sexuality experience of the individual with IDD. In summary, the biographical narrative presented by parents helps offer the best opportunity to understand the person with IDD and his experience of sexuality and sexual orientation. This research study seeks to understand the issues concerning sexuality and the individual diagnosed with IDD. The next section explores known issues surrounding sexuality and sexual orientation.

Literature Review Related to Key Variables and/or Concepts

This literature review identifies nine major study areas as follows: Disability, impairment, and developmentally disabled, history of intellectual disability, history of gay orientation, psychological perspective of gay people, problems of sexuality and sexual orientation among individuals with IDD. The content of the literature review will also explore the social problems of excluding individuals with IDD from sexual education, the effects of sexuality education for individuals with IDD, the sexual health barriers of intellectually disabled, and the capacity to consent to sexual relations.

Disability, Impairment, and Developmentally Disabled

The most recent worldwide figures of the World Health Organization (WHO) identify that approximately one billion people experience a mental or physical disability (World Health Organization, 2012). Considering socioeconomic status (SES), disabled individuals often exist in the lower SES spectrum and tend to yield higher rates of poverty versus individuals who do not have disabilities (World Health Organization, 2012). This discrepancy presents the question of why inadequate services and misinterpretation of disability needs in health care, education, and employment appear so vastly skewed (World Health Organization, 2012).

Contemporary English describes the word *disabled* to define those who possess impairments, which are either mental or physical (World Health Organization, 2012). Similarly, the World Health Organization (WHO) maintains that the term *disability* covers impairments, limitations, and restrictions to an individual's physical participation (World Health Organization, 2012). While disability denotes an individual characteristic, impairment details the body part or function, which has limited intended use or purpose (World Health Organization, 2012). Ultimately, impairment identifies the imposing restriction to the individual when executing a task or action (World Health Organization, 2012). The World Health Organization seeks to convey and position disability as the general term for incomplete, partial, or non-functioning body components, while identifying impairment of the specific active physical limitation (World Health Organization, 2012).

Expanding upon these foundational concepts, the term developmentally disabled properly identifies individuals with both intellectual and physical disabilities (World Health Organization, 2012). As an example, an individual may possess a physical disability such as sight or hearing impairment along with an intellectual disability such as Down syndrome.

The focus of this study will be specific to intellectual disability only. As described above, these foundational concepts identify how any disability exists in a continuum of complexity. The next section will discuss the societal impact of intellectually disabled persons through a historic examination of treatment of disabled persons.

History of Intellectual Disability

The earliest accounts of intellectual disability suggested that such individuals were part of the wicked and mysterious (Pfeiffer, 1994). The Salem Witch Trials often described the unintelligent, insane, or uneducated individuals as witches (Pfeiffer, 1994). This label led to fear, anxiety, and ultimately individual elimination through hanging (Pfeiffer, 1994).

World laws began to change in relation to disabled individuals around the turn of the twentieth century (Bayton, 2013). Virginia was the first state to open a hospital specific to the treatment of developmentally disabled persons, in the United States (Braddock, & Parish, 2001). Medical advancements helped to create a better understanding for individuals with intellectual disabilities. Many cities in the United States began opening schools to accommodate physical disabilities for school-aged children, followed by schools particular to intellectual disabilities (Braddock, & Parish, 2001). These efforts lead to establishing mental institutions across the United States (Gollaher, 2011). Hervey Wilbur created an educational system for the unintelligent. Adopted by many states, his system was to train children to work on farms or as domestic help. These specific types of training were the first to demonstrate marked improvements for students once institutionalized (Osgood, 1999).

In Europe, Esquirol, a French psychiatrist, credited with classifying mental disabilities and distinguishing between mental retardation and mental illness, was one of the first to combine mental descriptions with a mental illness (Masten & Curtis, 2000).

The continued studies of the mentally ill began to bring about changes in training and educating mentally disabled individuals (Masten & Curtis, 2000). Seguin opened the first school in France for severely developmentally disabled persons in 1839 (Carlson, 2009). Seguin establish a sensory method technique to train individuals to learn communication skills, a method still widely used today (Carlson, 2009).

Continued research helped identify and define new mental disorders. This new identification effectively categorized disorders such as Down syndrome from other intellectual or physical disabilities. These differentiators allowed for further advocacy for all disabled individuals (Moss, Emerson, Bouras, & Holland, 1997).

Although progress offered better treatment, most disabled individuals lived in deplorable institutions. Society perceived disabled people as outcasts and rejects. As advocacy forged new laws, opponents looked for ways to control procreation of disabled individuals as a means to maintain the purity of society (Moss, Emerson, Bouras, & Holland, 1997). Many states adopted eugenic procedures detailing sterilization methods used to control reproduction among disabled individuals (Pfeiffer, 1994). This type of control was an acceptable norm of society and passed into law by many states in the early 1900s (Pfeiffer, 1994).

Societal awareness grew to reject the poor treatment of individuals in institutions. This promotion of change continued through the twentieth century. Advancements in vaccination and technology forged new areas of study and assessment tools including the development of intelligence testing (Wing & Gould, 1979). Changes to the mental health system identified new psychological classifications for early infantile autism and instituted specific groupings of mental conditions (Jolliffe, & Baron-Cohen, 1997). Public law 176, introduced during *National Employ the Handicap Week,* promoted employment awareness for handicapped persons (Wing & Gould, 1979). Discriminatory acts propelled marches within the civil rights movement. Sit-ins demanding accessibility to public transportation, lawsuits on behalf of institutionalized individuals, and full societal participation and equality emphasized the changes needed during the 70s, 80s, 90s, and continue through to today (Burgdorf & Burgdorf, 1974).

People with IDD have achieved significant advancements in many aspects of their lives (Baynton, 2013). As detailed above, advancements in disability services enable individuals to lead lives that very much resemble most of society. One component that appears an issue for most people diagnosed with IDD includes the element of their lives in relation to sexuality.

There is little information about people with IDD and sexuality. A review of the literature found limited information to help explain or enable disabled person to explore sexuality and his sexual orientation (Anderson, & Kitchen, 2000). The newest emerging research is based on international studies and continue to exclude sexual orientation within the research paradigm (Durpras & Dionne, 2013; Kijak, 2013; Morales et al., 2011; Parchomiuk, 2012). Community-based sex education programs or programs established at institutions dedicated to helping individuals with IDD with sexual development or sexuality appear limited or do not exist (Dupras & Dionne, 2013). This lack of information for parents, caregivers, and guardians results in an unmet need on how to help the person with IDD explore the natural development of their sexual urges or engagement of sexual relationships when appropriate (Dupras & Dionne, 2013). Morales et al., (2011) report that both men and women in the IDD community state they have a need and desire for sexual exploration.

History of Gay Orientation

The historical aspect of gay identity appears to argue both natural and cultural reasons for men and women developing attraction to the same gender (Halperin, 1990). However, the ability to interpret and express sexuality remains as a universal human sexual experience in some cultures. The differing aspects of gay identity may be a constructed force of sexual categories and personal identities emphasizing the social creation of sexual expression and experience (Halperin, 1995).

The ancient Greeks did not have social positions that designated gay and heterosexual. It appears that regional acceptance of same sex ‘eros’ was both approved and often celebrated types of relationships (Halperin, 1990). The distinction in sexual relations in Greek society was between the active or passive partner during sexual engagement. The role of passive partner was only acceptable to those of inferior status such as male youths not yet citizens, slaves, or women. Therefore, the social characterization of a same-sex relationship was between a 20-30-year-old man, known as the *erastes*, and an adolescent boy, the *eromenos* or *paidika* (Dover, 1989).

Status was important when choosing a sexual partner. Specifically, women, and male slaves were only acceptable sexual collaborates available for free men, since they were the only ones who had full status. As a result, sex among free men was socially challenging and could affect the status of both men (Dover, 1989). In such a relationship, gifts such as roosters were part of the courtship ritual. The *erastes* had to demonstrate that he had a more noble interest and not just sexual desire for the boy. The boy's role was not to succumb effortlessly to the desires of the older man, and if pursued by more than one man at the same time, the expectation of the boy was to demonstrate discretion and pick the nobler one. Other evidence indicates that the two shared an intercrural sexual experience, which abstained from any direct penetration. The entire relationship was temporary and typically ended when the boy reached adulthood (Dover, 1989).

Romans also accepted same sex attraction similarly to the Greeks. A male in good standing meant that he was the active partner and could choose sexual interaction with any free male, or female, slave, prostitute, or wife; it made little difference (Beaulieu-Prévost, & Fortin 2014). During this period, individuals responded to erotic behavior based on attraction, taste, or preference; such behavior was not a moral issue (Greenberg, 1988).

During the Empire period, society began to develop negative views of homosexuality. Attributed to social and economic turmoil, this negative view appears well before the influence of Christianity (Beaulieu-Prévost, & Fortin 2014). Most historians agree that the intolerance of sex began at the rise of the Roman Empire. Except for procreation by marriage, sexual expression of any type was sinful. Limited awareness and rationale for same gender partners did not foster Roman society acceptance. Instead, Roman society proclaimed same gender acts forbidden (Beaulieu-Prévost, & Fortin 2014).

Following the decline of the Roman Empire, new barbarian kingdoms had a general tolerance of same sex partners (Greenberg, 1988). Widespread acceptance of same sex attraction, however, remained class dependent. The middle class held a very narrow view, while the nobility and aristocratic class demonstrated a universal acceptance of same sex attraction, as well as the public expression, and display of same gender behavior (Greenberg, 1988).

The intolerance of heretics, Muslims, Jews, and homosexuals gave rise during the latter part of the twelfth to the fourteenth century (Greenberg, 1988). This intolerance appears to be a result of the class conflict between the Catholic Church and Gregorian reform movement. The Catholic Church began to implement expectations for of morality, and forbade non-procreative sex, masturbation within marriage, and any form of homosexual sex (Greenberg, Bystryn, & Fund, 1982). Secular interpretation became a core argument against attraction of the same sex. The overt religious agenda no longer controlled the dialogue of same-sex attraction (Greenberg, Bystryn, & Fund, 1982).

During this same period, medical and psychological fields further defined gender specific roles in sexuality. Trans-generational contact including sex, decreased, thus, sex among people about the same age became the standard (Greenberg, 1988). The medical field continued exploring the human body as a natural phenomenon. The application of sexuality as biologically driven became the foundation of automatic action (Greenberg, 1988).

By the 20th century, medical research further addressed the individual's physical and mental makeup (Greenberg, 1988). That research afforded credibility for the physiological explanations of sexual orientation (Greenberg, 1988). As society expressed negative sentiment that being gay was pathological and a diseased mental condition, homosexuality became less incriminating and more widely accepted (Greenberg, 1988). Medical and psychiatric fields lead campaigns to repeal the criminalization of consensual sodomy. Doctors and psychiatrists sought techniques to rehabilitate homosexuals (Greenberg, 1988).

Mid-20th century society began accepting premarital intercourse for the sake of pleasure. The argument against same sex relationships proved difficult, as many in society attributed gay sex as a perverse sexual pleasure (Dean Sinclair, 2009). This trend often referred to as the beginning of the gay liberation movement continued into the 1960s (Dean Sinclair, 2009).

Gay and lesbian right groups existed for many decades. The Mattachine society, founded by Harry Hay in the 1950s, formed a social justice group for gay men. The Daughters of Bilitis, founded by Del Martin and Phyllis Lyon, in 1955, formed a social justice group for gay women. Both social groups had a low-key approach to gay rights and thus did not gain much ground for gay equality throughout modern 20th century society (Dean Sinclair, 2009).

In June 1969, the customers of the Stonewell Inn, a gay bar in Greenwich Village, clashed with police. This event triggered lesbian and gay groups to organize in major cities and college campus across the country. The aftermath of this event prompted the removal of homosexuality from the American Psychiatric Association's Diagnostic Statistical Manual as a noted mental disorder (Dean Sinclair, 2009).

The post Stonewall era marked the prominence of lesbians and gays as a permanent feature of American society, notwithstanding serious obstacles of the AIDS epidemic and broad anti-gay counterattack (Dean Sinclair, 2009). Acceptance of gay and lesbian equality in Western European countries helped repeal anti-sodomy laws throughout Europe (Dean Sinclair, 2009). When homosexuality identified as a mental illness, the treatment of choice was conversion therapy. Although homosexuality became declassified, efforts to convert lesbians and gay men continued (Haldeman, 1994). Given an advanced awareness of historical gay orientation, the next section seeks to incorporate core fundamentals supporting a detailed theoretical foundation.

Psychological Perspective of Gay People

Hostility toward gay people began taking root in the final half of the 12th century. Non-procreative and gay sexual behavior was often condemned and believed unnatural (Boswell, 1980). Although the hostile sentiment of gay people was frequently the rhetoric of religious objection, core ideology changed during the latter 19th century. Psychiatry and medicine were successfully challenging both law and religion to acknowledge pathology versus crime or sin as the dominant sexual influence (Duberman, Vicinus, & Chauncey, 1990). However, the belief that being gay was pathological was not a universal one. Ellis believed homosexuality was not pathological but was inborn (Robinson, 2001). Freud shared a similar view, proclaiming humans were born bisexual until a life experience help to resolve whether the individual was heterosexual or homosexual (Robinson, 2001).

Academics from other disciplines were more tolerant toward homosexuality. Kinsey discovered many of his research participants experienced sexual orgasm after age 16 while engaging in gay conduct (Kinsey, Pomeroy, & Martin, 1948; Kinsey, 1953). Additionally, Kinsey states two to six percent of females and 10 percent of males engaged in gay behavior between the ages of 16-55 for about three years (Kinsey, Pomeroy, Martin, & Gebhard, 1953). Although some questioned the studies reliability, it appears more adults engaged in gay sexual behavior or experienced same-sex fantasies than previously recognized. Ultimately, the study calls into question the idea only a select few social misfits practiced gay sex (Herek, 2012).

Ford and Beach (1951) established gay behavior was prevalent amongst many species, as well as human societies. They found that gay behavior was socially acceptable for 64% of the 76 societies sampled. Although this was a nonprobability sample, Ford and Beach demonstrate that more societies accept homosexual behavior than condemn it (Bobrow, & Bailey, 2001).

Hooker (1957) offered a pioneering study attempting to identify a psychological adjustment difference between homosexuals and heterosexuals. Hooker used a procedure to research the modification of males without information of his sexual orientation. This technique helped to dispel bias, a controversial aspect of many sexualities and sexual orientation studies (Hooker, 1957).

Hooker used the three projective tests, Make-A-Picture-Story (MAPS), Thematic Apperception Test (TAT), and the Rorschach. A community organization recruited participants for the study. He used a sample size of 30 gay males and 30 heterosexual males. Both groups matched for IQ, education, and age (Hooker, 1957). During the study, the participants were not under psychological or psychiatric care (Hooker, 1957). Participant sexual orientation was unknown; Rorschach experts assessed the men’s adjustment independent of the study, using a five-point scale (Hooker, 1957). The results determined two-thirds of the gay men, and two-thirds of the heterosexual men met the three highest categories of adjustment (Hooker, 1957). The expert was unable to determine which Rorschach protocol came from the heterosexual or gay participant (Hooker, 1957). Additionally, the expert was unable to distinguish the sexual orientation by participant response at any level better than chance. Neither of the other two projective tests administered suggested a difference in adjustment amongst the gay or heterosexual participants (Herek, 2012). From this study, Hooker concluded gay is not pathological and should not be a clinical diagnosis.

Gonsiorek (1982) determined gays and heterosexuals continually score within the normal range and do not meet the criteria of maladjustment, or psychological disorder, “Homosexuals as a group are not more psychologically disturbed on account of their homosexuality" (Gonsiorek, 1982, p. 74).

In the 1970s, psychologists and psychiatrists began changing their views toward gay people, given the review of the empirical evidence and evolving social views (Drescher, 2008). During this post-Stonewall era, in 1973, social norms changed, and gay communities established more political activism than before Stonewall. Empirical data mounted, creating an atmosphere of change, resulting in the removal of homosexuality from the DSM (Drescher, 2008). Opposition to this act influenced a petition requesting a membership vote. A vote was taken, and the decision was ratified in 1974 (Drescher, 2008).

Consequently, in 1980, a new diagnosis, ego-dystonic homosexuality supplements the DSM third edition. Ego-dystonic homosexuality criteria included (1) an insistent absence of heterosexual arousal, and (2) persistent anguish from a continuous pattern of unwelcome homosexual arousal (Spitzer, 1981). Mental health specialists disapproved of this new diagnostic grouping, thinking it was a partial concession to appease psychiatrists, specifically those still insisting homosexuality as pathology (American Psychiatric Association, 1987). Psychologist argued that symptoms related to ego-dystonic homosexuality remain categorized and treated under existing diagnoses. Psychologists also feared the diagnosis might perpetuate anti-gay stigma.

By 1986, the ego-dystonic homosexuality diagnosis did not exist in the DSM. Ego-dystonic homosexuality, briefly detailed under Sexual Disorders Not Otherwise Specified (NOS), includes insistent and noticeable anguish about one's sexuality (American Psychiatric Association, 1987). The American Psychological Association (APA) quickly recognized the clinicians' actions, and subsequently worked to remove the degradation traditionally related with homosexual orientation (APA, 1987).

In 1973, the American Psychological Association declassified homosexuality as a mental disorder. However, it appears that clinicians continued to misunderstand treatment and assessment protocols when treating individuals with LGBT sexual orientation. In 1985, the American Psychological Association established Division 44 known as the Society for the Psychological Study of Lesbian, gay, and bisexual (LGBT). The division developed guidelines to help support assessment and treatment of LGBT sexually oriented individuals. The guidelines represent specifics for psychologists when working with LGBT individuals. The guidelines intend to help remind the clinician how life experiences often manifest an environmental aspect of the person. These psychological components denote a varied discrepancy on the existing interactive models among IDD LGBT individuals. The next section will assess the effects of capacity on formulating a well-formed sexual relationship.

Problem of Sexuality and Sexual Orientation Among Individuals With IDD

Absoud & Wariyar (2008) state the word sexuality can trigger a powerful range of emotion when presented as a discussion topic in the disabled community. Sexuality in our society, culture, and religion offers a vast assortment of interpretations (Baxter, 2008). Sexuality issues often generate debate, prompting dialogue about what is and is not acceptable behavior, and the debate tensions worsen given the additional exceptions like disability or gay (Parchomiuk, 2012).

The society offers individuals with IDD the opportunity to make residential, vocational, and social choices (Allen, 2003). However, there appears to be a preconception that people with IDD do not have the intellectual capacity to interpret the complexities of sexual relationships or the ability to understand his or her sexual orientation (Allen, 2003; Dupras & Dionne, 2013). Often individuals who attend LGBT IDD support groups report an overwhelming sense of loneliness and isolation. Considering the lived experience demonstrates and details how the individuals manage the combination of sexual and developmental disability stigma (Allen, 2003).

Morales et al., (2011) state individuals with IDD require interpersonal relationships, love, and affection in the same way as any other person may expect. As with any population, individuals with IDD also have varying responses to sexual interest, response, and reproductive ability (Morales et al., 2013). Although sexual expression of IDD persons identifies a fundamental human desire, denial, rejection, and absent-minded regard denote the typical responses from caregivers, healthcare providers, and parents (Parchomiuk, 2012). Given the studies conducted in the United States (Jacobson, 1982, Lund, 1992), over the years. The more recent international studies (Dupras & Dionne, 2013; Kijak, 2013; Morales et al., 2013; Parchomiuk, 2012) which include developmentally disabled individuals, most researchers overlook the fundamental human right of sexual expression and sexual identity, when researching the developmentally disabled population.

Anderson & Kitchin (2000), note most cultures hold the belief that persons with disabilities are sexless. The notion suggests a person with disabilities is asexual, does not have a sex drive, and, therefore, would not participate in sexual experiences. Furthermore, many believe the individual with IDD lacks the ability to behave in a socially responsible way because he lacks social judgment (Parchomiuk, 2012).

The lack of research contributes to negative attitudes and continues to marginalize and isolate sexuality among individuals with disabilities (Cuskelly & Gilmore, 2007). As a result, this marginalization severely limits the availability of sex education material able to fulfill the requirements of the individual with IDD. Material content differs from mainstream sex education information and may need to include detailed support for situational and social appropriate sexual expression (Hingsburger & Tough, 2002). Current, IDD sex education information yields an often-inaccurate view, which influences a negative overtone to dissuade sexual interest to the IDD person (Pownall, et al., 2011).

An important point detailed by Hingsburger & Tough, (2002) suggests individuals with IDD often live in a group home or with caregivers and lack privacy to explore sexual curiosity. The individual with IDD, while often accused of not having social judgment, ideally suffers from a lack of privacy to discover sexuality (Hingsburger &

Tough, 2002). Researchers agree many factors contribute to erroneous sexuality awareness, sexual orientation and the individual with IDD (Hingsburger & Tough, 2002; Siebelink, de Jong, M., Taal, E., Roelvink, L., & Taylor, S., 2006). These circumstances ultimately outline the social problems created by the education gap. I review these social issues and implications next.

Social Problem of Excluding Individuals With IDD From Sex Education

Uncertainty, anxiety, and mythology are among some of the attitudes noted when describing information concerning sexuality and individuals with IDD (Dupras & Dionne, 2013). The research identifies the sentiment among many in society that appear to be disapproving of people with IDD engaging in any sexual behaviors (Morales et al., 2011; Parchomiuk, 2012). Researchers state special education administrators and teachers further reveal individuals with IDD do not have the aptitude to take part responsibly in sexual relations (Swango-Wilson, 2011). As this section of the literature review notes, involuntary sterilization of people deemed intellectually disabled was common. Eugenics was commonly the mandate or recommendation, as some states considered cognitive disabilities genetically inherited (Kampert & Goreczny, 2007). Although eugenics is not the norm today, procedures may occur for various justifiable reasons including, reduced likelihood the individual will contract a sexually transmitted disease, sterilization will lessen the chance of sexual exploitation, and unquestionably, the basic prevention of individual sexual expression. Nevertheless, researchers maintain the practice is unethical, and sterilization does not accomplish any reduction for the reasons noted above (Dupras& Dionne, 2013; Kampert & Goreczny, 2007).

The American Academy of Pediatrics policy statement concerning sterilizing minors with intellectual disabilities states, a first step should adequately assess developmental delay and concretely garner awareness of individual capacity to make reproduction decisions (Diekema, 2003). Researchers reveal a capacity issue occurs when individuals are ill-equipped to advocate or speak for themselves (Lyden, 2007; Nichols & Blakey-Smith, 2009). Individuals with intellectual disabilities may appear as perpetual children, regardless of age, formulating a perception of childlike innocence concerning sexuality (Dupras & Dionne, 2013; Hingsburger & Tough, 2002). Researchers maintain the individual with IDD finds managing adult sexual urge and the appropriate sexual response more challenging to address than for others (Morales et al., 2011). This potential imbalance ultimately raises the personal equality concern and capacity question. On the other hand, researchers argue inappropriate sexual expression is not a reflection of insufficient capacity, but more precisely a consequence of the person’s with IDD poor environment where sexual expression often lacks proper acknowledgment or acceptance (Esterle, Sastre, & Mullet, 2008; Hingsburger & Tough, 2002).

Further research reveals, the position taken when describing persons with IDD and inappropriate sexual behavior identifies only biological urges of basic sex acts. Basically excluding the emotional intimacies of love and care (Fredriksen-Goldsen, Kim, & Barkan, 2012). By excluding the emotional component of sexual expression, the individual with IDD believes they do not have consent or approval of appropriate sexual conduct (Dupras & Dionne, 2013). The research further demonstrates persons with intellectual disabilities appear to have the lowest level of knowledge about dating, intimacy, sexuality, and social, sexual expression (Morales et al., 2011).

Although attitudes about sexuality among caretakers have become more liberal, Saxe, & Flanagan, (2014) note that caregivers feel unqualified and untrained to discuss sexuality. Dupras & Dionne, (2013) details there are many parent group advocates for sex education of adolescents with intellectual disabilities. However, the groups do not appear to prepare children for socio-sexual experiences out of fear the children will exhibit inappropriate sexual behaviors, thus becoming targets of sexual abuse. This exploitation anxiety results in overprotection and denies the adolescence with IDD or young adult sexual freedom (Parchomiuk, 2012). A failure to prepare the person with IDD with sexual knowledge may erroneously set the stage for a hasty response given a sexual encounter or upon the advent opportunity of a sexual experience (Dupras & Dionne, 2013).

As with any person, individuals with IDD can learn about appropriate sexual relationships, safe places, and ways to meet people, and cultivate a full awareness to engaging safe sex (Allen, 2003). The person with IDD can learn how to navigate and advocate for his essential needs. However, individuals with IDD require special instruction about sexuality, learned behavior may develop at a much slower rate. While ordinary physical maturation transpires, delayed cognitive and emotional development requires a different tact or approach to sex education (Kijak, 2013).

There exist the assumption societal individuals with IDD are dependent and childlike (Kijak, 2013). This sentiment presents a demeaning and uninformed societal notion (Kijak, 2013). Societal discomfort surrounding sexuality affords this general position and further heightens subject sensitivity for the individual with IDD (Saxe & Flanagan, 2014). Society may more readily accept a person and his disability if revered as the eternal child. Unfortunately, this acceptance denies his natural rights as a sexual person (Saxe & Flanagan, 2014).

The sentiment of individuals with IDD engaging in sexuality is consistently met with commentary that if the individual is not an eternal child, and not asexual, he must have uncontrolled urges or be hypersexual (Parchomiuk, 2012). This misnomer often fuels the reluctance to provide sexual education to IDD youth (Parchomiuk, 2012).

Effects of Sexuality Education for Individuals With IDD

Most people learn about sexuality during sex education class sometime during elementary school. Most researchers' state parents should be a child's primary sexuality educator (Dupras & Dionne, 2013). However, many parents are either embarrassed or afraid to discuss sex with their children. Parents state a fear discussion may encourage the child to experiment. The parent feels ill-equipped to answer the child's questions, and some parents believe the child possesses sexual insights from school or peers (Dupras & Dionne, 2013). Parents of children with IDD exhibit these same fears, including added concerns the child may be exploited, or possibly unable to express sexual feelings (Dupras & Dionne, 2013). When considering further explanation, parental apprehension stems from discussion undesirably causing increased child or young adult anxiety (Dupras & Dionne, 2013).

Individuals who suffer from a disability can be vulnerable and protecting him from abuse is important. Some individuals with disabilities may be physically incapable of defending himself and should the individual have communication impairment he cannot converse his consent (Baxter, 2008). Once a child reaches adulthood, sexual awareness becomes a developed life skill. These skills allow the individual with IDD to help develop the necessary social capacity to possess a healthy sexual knowledge. Undoubtedly, the emphasis seeks to aid critical decisions, to possibly keep from taking sexual risks, and ideally counteract any potential sexual exploitation or abuse (Nichols, & Blakeley-Smith, 2010).

Sexual Health Barriers of the Intellectually Disabled

Groce (2003) reveals several issues known as systematic barriers that contribute to the sexual health of the individual with IDD. They include reduced access to sexual health information, lack of privacy, increased vulnerability to sexually transmitted disease, reduced access to sexual partners, increased chance of abuse and exploitation, and the consistent lack of sex education.

As noted previously many believe the myth that individuals with IDD are asexual (Cuskelly & Gilmore, 2007). This fallacy may cause a disadvantage to the person with

IDD concerning negotiating safe sex practices or preventing vulnerable exploitation (Cuskelly & Gilmore, 2007). Researchers note an additional concern of forming unstable relationships that come from the social marginalization of the individual with IDD (Pownall, Jahoda, Hastings & Kerr, 2011).

Some researchers suggest eight significant reasons that individuals with IDD are at risk of sexual exploitation. They include:

1. They must rely on others for care;
2. They feel rejected of individual rights, which cause feelings of helplessness;
3. The perpetrator thinks they will not be caught;
4. The perpetrator believes victim will not be believed;
5. The individual may have a deficiency of information, and teaching about proper and improper behavior;
6. There may be an increased risk of manipulation and social isolation;
7. The person is more susceptible in community places than in a protected environment;
8. Integration in community programs that may cause the inability to self-protect (Nosek, Foley, Hughes, & Howland, 2001).

Although statistics vary, Jones, Bellis, Wood, Hughes, McCoy, Eckley, & Officer, (2012) state that 12% of adolescent girls with IDD report they experienced forced sex, which is double that of teenage girls who do not have a disability. Furthermore, this study found higher amounts of sexual abuse of children with intellectual and physical disabilities than that of their non-disabled peers (Jones et al., 2012).

In the same study, Jones et al., (2012) state 36% to 52% of marginally to severe individuals with IDD report experiencing the act of sex. However, as mentioned above many adolescents with IDD do not have the same opportunities to learn about sexuality. The research shows characteristically sex education curriculum developed for adolescents without disabilities do not address the sex education requirements of the youth with IDD (Schwier & Hingsberger, 2000). Although basic information about sexual education and sexual health is essential, an additional component needed for the individual with IDD is social skills and relationship training (Schwier & Hingsberger, 2000).

Hingsberger & Tough (2002) report a lack of privacy is a serious concern for individuals with IDD wanting to express sexual urges, particularly those living in institutions or group homes. In both settings, many share sleeping accommodations, the staff is more watchful or vigilant, and sexual behavior is discouraged (Stoffelen, Kok, Hospers, & Curfs, 2013). This lack of privacy deprives the individual a safe living space to explore sexuality. Therefore, the person seeks another setting, which may include public places such as parks, and public restrooms to participate in sexual activity. This decision is often the argument most researchers disclose as an example of how an environment condition may drive inappropriate public sexual behavior. Researchers do not believe it is a lack of capacity that the person cannot conduct his sexual behavior in a responsible manner (Stoffelen, et al., 2013).

Ames & Samowitz, (1995) wrote an editorial comment to the American Association on Intellectual and Developmental Disabilities (AAIDD). The commentary blasted the field for ineffectively coping with the sexual necessities of individuals with IDD. The researchers stated that the majority of persons with IDD are deprived and lack the opportunity to progress and partake in social relations that include sexual experience. Although written over 20 years ago, the lack of sexuality progress for individuals with IDD appears to exist today. This barrier lies in the apprehensions and collective negative attitudes of the uninformed general public, family members, professionals and administrators (Werner, Corrigan, Ditchman, & Sokol, 2012). Furthermore, continued support of outdated laws and public policy denies individuals with IDD the ability to develop responsible sexual skills, social behavior, and ability to exercise choice and to have opportunities to meet and relate (Werner, Corrigan, Ditchman, & Sokol, 2012). The cumulative result of this repression is that most individuals with IDD abandon the hope of social or sexual self-actualization, or when probable seek instants of fulfillment in unsafe, degrading, and at times unlawful circumstances (Morales et al., 2011). In the next section, we will discuss the psychological perspective of being gay.

Capacity to Consent to a Sexual Relationship

Several research studies have uncovered high incidences of sexual exploitation and abuse of individuals with IDD (Jones, et al., 2012; McCarthy, 1999; Sobsey & Doe, 1991). Typically, vulnerability, cognitive and social deficiencies attribute to the exploitation. Jones et al., (2012) states that women with IDD are doubly plagued and sexually exploited because of disability and gender, while contending that discriminatory responses most typically come from agencies hired to assist the individual. Other researchers also found women with IDD are at risk of abuse. Mostly by males within their inner circle like male individuals with IDD, family members, neighbors, family friends, and staff (McCarthy, 1999; McCarthy and Thompson, 1997; Brown, Stein & Turk, 1995; Hard & Plumb, 1987; Stromsness, 1993). Furthermore, researchers suggest people with IDD have a higher occurrence of sexual assault and sexual abuse because society stigmatizes individuals with IDD as deviants with little value. The individuals often lack relationship experience, have poor decision-making skills, and lack power over resources (Hayes & Craddock, 1992: 75; Jones et al., 2012; Baladerian, 1991; Wilson, Nettlebeck, Razack, 1996).

In the last decade, there has been an increase in research related to the capacity of individuals with IDD. Specifically, those looking to enter into sexual relationships (Dupras & Dionne, 2013; Kijak, 2013; Kennedy and Niederbuhl, 2001; Lyden, 2007; Morales et al., 2011; Meaney-Tavares & Gavidia-Payne, 2012; Murphy and Clare, 2003). The goal is to empower the person to make sexual choices while determining if the individual with IDD possesses the ability to provide sexual consent to a sexual relationship, or a sexual act (Eastgate, 2008).

Murphy & Clare (2003) differentiated three broad approaches when assessing IDD capacity. First, an outcome plan states if an individual makes decisions different from most others, it becomes a question of capacity. Second, the diagnostic status approach considers an individual’s affiliation to a particular group, for example, race, gender, age, or sexual orientation. This method limits the decision-making of persons that receive treatment for mental disorders. Finally, a functional approach centers on proper functionality, ability, behavior, or capacity, and to which the function meets the demand of a situation within legal context (Grisso, Steinberg, Woolard, Cauffman, Scott, Graham, & Schwartz, 2003).

Myron, Gillespie, Swift, & Williamson (2008), maintain the functional approach is favored when evaluating capacity and making a recommendation to medical and psychological specialists to measure capacity. The technique ideally supports consideration for confirmation of additional education or support to offer and ultimately increase the functional ability of the individual before declaring incapacity (Murphy & Clare, 2003).

Summary

Chapter 2 starts with a discussion of the peer-reviewed journal articles and the search strategies related to this dissertation study. The theme of most of the peer-reviewed journal articles studied appears to incorporate minor details concerning individuals with IDD and sexuality. The studies that do include sexuality and the individual with IDD appear limited in content and no studies included an individual with IDD and sexual orientation. The information in the chapter goes on to review the historical aspects of both intellectual disabilities and gay orientation. An additional component of the section examines the psychological perspective of gay people and moves into the theoretical foundation and conceptual framework of the study. This proposed study will fill a gap in the research by revealing the lived sexual understandings of the gay individual with IDD, as told by the parent. This biographical perspective may shed light on the types of sexuality education support needed in the IDD and gay community. Finally, the chapter details the reasons this particular study is important and concludes with how this study can contribute to social change within the disabled and gay communities.

Chapter 3 spells out the construct of a qualitative biographical study. The chapter content includes why this type of study was chosen for the research topic. The role of the researcher is defined and explained and includes a discussion of relationship biases, conflicts of interest, and ethical responsibilities. The chapter continues with explanations of the methodology, including identifying the population was chosen, participant selection, and any procedures related to the participants. Finally, Chapter 3 concludes with a discussion of the instruments, recruitment methods, data analysis, and ethical procedures.

Chapter 3: Research Method

Numerous studies addressed individuals with intellectual developmental disability (IDD), behavioral problems, the prevalence of psychopathology, and developmentally disabled sex offenders (Hastings & Brown, 2002; Lindsay, 2002; Tremblay, Richer, Lachance, & Côté, 2010). However, it appears researchers did not address sexuality as a fundamental human right of the person with IDD (Morales et al., 2011). Although the deviant behavioral aspect of sexuality has been addressed in at least one study (Lindsay, Steptoe, & Quinn, 2014), studies focusing on sexual education and the person with IDD have been limited to focus group questionnaires containing sexual education and sexual orientation content (Fager et al., 2010). What appears to be missing are studies related to the individual with IDD and sexuality and sexual orientation. In this study, I explored the sexuality and sexual orientation of a person with IDD as reported by his parents. I sought to understand the context in which the individual received information about sexuality and sexual orientation. This research may enhance understanding of sexuality and sexual orientation of the person with IDD. I conducted a qualitative biographical study to document the story of one individual from this marginalized population. This chapter presents the purpose of the study, the research design, rationale, researcher’s role, and methodology. I also describe the study participants, instruments, participant selection, and ethical procedures.

Research Design and Rationale

I examined the parents' view of their son diagnosed with IDD and his lived experience related to sexuality and sexual orientation. I asked the parents to describe the sexuality and sexual orientation of their intellectually developmentally disabled son. Creswell (2007) stated inquiry is the tradition of a qualitative study. The design of this study was biographical. I sought to capture the human dimension as told by parents of an individual with IDD to create a biographical context of his sexual experience.

Biographical researchers explore the individual's job and home experience, racial or ethnic culture, and the context of time or place (Creswell, 2007). I investigated a delicate but important human rights issue of a gay male with IDD. The focus was narrowed to understand the lived experiences of sexuality in his life, as reported by his parents. Creswell (2007) stated that to follow a biographical design, a researcher collects data through interviews, documents, and other archival information to produce an exhaustive account of the lived experience of the individual. Because I was unable to collect data from the direct source, gathering data through his parents' interpretation appeared to be the most appropriate method for this study.

A biographical design is used to study an individual's lived experience as told to the researcher and found in archival material and documents. This model includes the collection of documents such as photographs or journals that indicate a turning point in an individual's life (Denzin & Lincoln, 2008). The biographical study is the written life story told by someone other than the person being studied (Denzin, 1989). My objective was to note the experiences of the person written in the chronological order according to when the individual first identified his sexuality and sexual orientation, as perceived by his parents (Denzin & Lincoln, 2008). I gathered life documents to develop the context of these life experiences through stories or narratives helping to recount the instances of the person's sexuality (Denzin & Lincoln, 2008).

The stories were organized around the sexual aspects of the life of the participants' son. This approach gave me the opportunity to explore the meaning of the stories. The parents helped provide the context. I looked into a larger structure to explain the meanings, such as historical content, social interactions in groups, cultural understandings, and ideologies. This context helped provide an interpretation of the lived experiences of the individual through a biographical design (Creswell, 2007). To interpret the data, I used the narrative analysis approach to identify the most important themes of the interview. Riessman (2008) stated the thematic approach is used to avoid fracturing the biographical account into thematic categories, as grounded theory researchers would do, but rather to interpret the data as a whole.

I asked the following research questions (RQs):

- RQ1: How do the parents of a son with IDD describe his sexuality and sexual orientation?
- RQ2: How do the parents of a son with IDD describe how he learned about sexuality and sexual orientation? Was this through a school curriculum or other source? What information did the parents provide in terms of sexual education?

- RQ3: What areas of support do the parents feel were needed, or wished were available when their son was going through puberty and beyond?

These research questions were open ended, non-directional, and evolving. Research Question 1 was the central question, and Research Questions 2 and 3 were the sub-questions to frame the investigation.

Role of the Researcher

In this biographical study, it was central to understand the researcher's role in terms of access to the individual or the negotiation or integration of the researcher in the life of the participant. According to LeCompte, Schensul, Weeks, and Singer (1999), the expectation was that I would remain neutral and set aside biases related to the study. However, it is impossible for any researcher to set aside all biases (Merriam, 2014). Bias typically happens because of the researcher's theoretical perspective, hunches, observations, personal interests, and preferences (Merriam, 2014). The essence of a qualitative study is to understand the participants' perspectives through engagement. Therefore, to have the participants engage fully in the study, I needed to empathize with their difficulties and joys and be authentic (LeCompte et al., 1999). The intention of this study was to understand each parent's perception of the sexual life of his or her son diagnosed with IDD. In this study, I had an etic role as an objective outside observer. Although this role can at times include being an insider, it appeared there was little variation to cause me to change from being an objective viewer (Punch, 2002). I understood my experience was not the same as the parent participants. I also understood that sexuality can be a complex issue, especially between parents and their children.

Schensul and LeCompte (1999) described the importance of self-reflection. Specifically, self-reflection through journals helped me stay cognizant of my potential biases, gaps, and errors in data collection. This reflection helped me understand when the participant censored his or her discussion or had any feelings specific to me as the researcher. It also created a level of transparency (Ortlipp, 2008).

I was an instrument of data collection, which necessitated that I described my biases, assumptions, experiences, and expectations (Denzin & Lincoln, 2003). Additionally, I qualified my ability to conduct the study by disclosing my professional and personal experiences as a researcher with the participants (Greenbank, 2003). It was important for me to keep a research journal to take note of my reflections and personal reactions during the data collection phase of the study (Denzin & Lincoln, 2008).

I used a narrative analysis, which focused on how the participants imposed an order specifically related to their respective experiences with their son, and how they made sense of actions and events they shared (Riessman, 2008). Narrative analysis preserves the integrity of the personal biography and the distinct features of the story (Riessman 2008). I used thematic analysis of the biographical story by classifying the story into general themes, which are discussed later in this chapter (Riessman, 2008). The following information added context to my professional and personal experiences. I hold multiple roles in the community including community volunteer, tutor, and board member of the local psychological association. As a volunteer to the gay, disabled community, I developed relationships with many caregivers, staff, and parents, which provided access to individual stories of sexuality and sexual orientation.

I have experience with the gay disabled community and, in particular, the personal experience of interacting with my now deceased brother who was diagnosed as intellectually developmental disabled and identified his sexual orientation as a gay male. My brother had been an integral part of my life. I shared many of his life experiences, which exposed me to some of his lived scenarios, many of which may be similar to the experiences of other gay individuals with IDD. However, it is important to note that I understand that my brother’s experiences are unique and may not be generalizable to other gay individuals diagnosed with IDD. Additionally, I have direct experience of my parents’ expectations and involvements with my brother. Finally, I recently completed my doctoral course work, practicum, and pre-doctoral internship as additional general psychological training. I am working under supervision in a private psychological practice. Lastly, I am a volunteer facilitator at LGBT Cleveland of a parent support group for LGBTQ intellectual developmentally disabled individuals.

The psychological code of ethics mandates that a psychologist should strive to benefit those with whom he or she works and to be careful to do no harm (American Psychological Association, 2014). With this in mind, I was careful to do no harm to the research participants. To keep from doing harm, I asked questions specific to the subject matter, I was careful that the questions did not alienate or offend the participants, and was careful to keep from exploiting the participant intentionally or unintentionally (Creswell, 2007).

I had been in contact with the program director of a support group in a major metropolitan area in the Midwest. I learned of this group after Googling parent support groups LGBT developmental disability. After reviewing the results of the Google search, I contacted the program director and left a message informing her that I was looking for parent participants for my study. She contacted me the following day and noted that she had parents of an IDD gay male whom she thought would want to participate in this study. She noted that this particular family was very involved in their son’s life and used to attend the parent support group until they moved. Schensul, Schensul, and LeCompte (1999) stated this type of recruitment procedure is called reputational case selection because the director already had a relationship with the parents, and she suggested that they may be the best informants for the study.

According to Creswell (2007), this is the first phase referred to as the data collection circle. To gain access to participants, it was important that I establish a field identity. I provided background information to introduce the proposed study to the identified research participants, after receiving IRB approval (Creswell, 2007). This introduction supplied the participants with information about me and an accurate portrayal of the planned study (LeCompte et al., 1999). Creswell (2007) stated the next step includes considering the appropriate vessel of data collection. Typically, this requires developing a protocol, such as written forms, and logistical information about recording the interview. In this study, I conducted a semi-structured interview (Appendix E), which was audio recorded. I stored the data on a password protected external hard drive. The hard disk is in a locked file cabinet for safekeeping.

There is a requirement that I am an astute, active listener, to emphasize the expectations of the qualitative inquiry. LeCompte, Schensul, Weeks, & Singer (1999) suggest researchers ask many questions. Focus on the conversation with the participant, use active listening, allow the participant to be the principle talker, write down what is being said to give the participant time to think while helping her to feel what she is saying is important. Finally, I expressed empathy that revealed my understanding and regard for any experience that is related. This genuine expression was intended to create a comfortable environment, ultimately establishing a relaxed atmosphere (LeCompte, et al., 1999).

Concerning the ethical standards for data collection, researchers are bound to protect participants in a study from emotional, physical, and financial harm (LeCompte, Schensul, 1999). I provided a small incentive via a gift card to compensate the participants for their time partaking in the study; however, this incentive was not used for recruitment of the study participants, as they did not know of this compensation for their time until they were chosen to participate.

Methodology

Great consideration went into determining the population for this study. The initial idea was to include an individual with the diagnosis of IDD who identifies his sexual orientation as a gay male. However, after further consideration of some of the ethical protections in place to protect individuals with IDD, I decided to focus on the parental point of view. A joint decision by my committee and I were that understanding the life experience from the parental point of view was just as valuable.

As previously noted, there are no known studies that include a gay individual with IDD in the United States, because of their protected status. This decision was an important element in determining the sample size. The consideration of a sampling size was specific to the type of study I chose to conduct. After review of the other types of qualitative inquiry, no other qualitative type appeared more suited to meet the needs of answering the research question than a biographical study of one gay male with IDD parents. For instance, a phenomenological study studies a phenomenon within a group or culture (Creswell, 2007). After review of the literature, there did not appear to be a phenomenon concerning sexuality and sexual orientation of individuals with IDD. The ethnographic study would explore people and culture from the subjects' point of view (Creswell, 2007). This type of study was rejected because it too did not appear the best choice to answer the research questions since I was not looking to study an entire group. Grounded theory looks to support an emerging philosophy from the study (Creswell, 2007). Although appealing this also did not appear to offer the best method of answering the research questions, as I was not looking to find a new theory. I considered a case study early on in the research process; however, I was not looking to explore every aspect of the person and his history (Creswell, 2007). I was specifically interested in studying his sexuality and sexual orientation. Thus, I rejected the case study.

Selecting parents from the Cleveland LGBT parent support group was also considered since I am a volunteer facilitator of the parent support group. However, after careful consideration and consultation with my committee, I agreed that it too closely resembled a dual relationship, and felt it best to find a participant from another source. The support group I contacted is an agency that offers group support for gay men and women with IDD, as well as support for parents and family. This type of program offers same opportunity to recruit participants willing to participate since the person with IDD already identifies his sexuality as gay, and the program director already had an established relationship with the parents she has identified.

This research study required one interview with the participants. I met separately with each parent to allow each person to share his or her experience without the bias of the other parent. The interview was a semi-structured audio-recorded interview (Appendix E).

Instrumentation

As noted by Denzin & Lincoln (2008), as the researcher I am an instrument of data collection in this study. Additional instruments used for this study included participants screening questionnaire (Appendix D), interview questions (Appendix E), and the study debriefing form (Appendix F). The following section describes the instrument details and their role related to this research study.

Procedures for the study

As required by Walden University, no data collection occurred until the Institutional Review Board (IRB) reviewed the research study and I received consent to proceed.

Interview Questions

The interview helped to ensure that each potential participant received the same questions related to the interview (Creswell, 1999). I conducted a semi-structured in-depth interview with each parent separately (Appendix E). The in-depth interview provided a primary advantage of gathering detailed information as opposed to other methods of collecting data such as surveys (Boyce & Neale, 2006). The interviews were conducted in a relaxed atmosphere for the participants, which offered a warm condition to allow a casual, conversational style interaction between the participants and me (Boyce & Neale, 2006). In a biographical study, the interview questions offer a structure, which provided a forum to the participant. This structure supported the participants' ability to reflect, collect a thought, or explore a conscious awareness by giving those who have not been heard a voice (Roberts, 2002). Individuals with IDD historically have lacked a medium for their voices to be heard.

As suggested by Miller (2000), the interview questions supported the narrative of a biographical study to provide the exploration of social construct. This description outlined the individual's unique story, by using family, life and the interplay between the participant and researcher in structuring his reality (Boyce & Neale, 2006).

This research study supported the investigation concerning IDD sexuality and sexual orientation, by using semi-structured questions (Appendix E) to conduct an in-depth interview to chronicle specific behaviors and verbalizations of a gay male with IDD, as reported by his parents. Collecting the data for this narrative analysis included videos, interviews, observations, and review of artifacts; none was mutually exclusive (Reissman, 2008). The semi-structured questions of the interview guide were adapted from social science researchers who developed interview questions specific to the semi-structured interview (Elo, Kääriäinen, Kanste, Pölkki, Utriainen, & Kyngäs, 2014). The guidelines include phrases and terms used in the interview, which were understandable to the participants. The length of the questions was minimal and allowed for further probing of the response (Schensul, et al., 1999). Terminology was appropriate to the characteristics of the participants (i.e. gender, age, culture). I refrained from leading questions to eliminate participant bias. Questions identifying negative or positive associations were not used (Schensul, et al., 1999). It was significant to ask one question at a time and to avoid questions worded with negative connotations, and not use questions asking the participants to rank and order. Schensul, et al., (1999) also suggest not to pose questions that ask participants to perform several tasks. Finally, it was significant to ask open-ended questions and to be sensitive to the social meanings or cultural context of the issues posed in the interview.

With this in mind, I developed the interview questions to establish a general concept of queries. I followed an order or sequencing to address a chronology of events from the past to present, simpler to complex topics, concrete to abstract topics, and from least to most sensitive (Schensul, et al., 1999).

The study sequence included a face-to-face interview with the participants. The face-to-face meeting was conducted and I audiotaped the semi-structured interview. The interviews included an initial phase of general conversation with the participant to be sure they were comfortable, to answer any questions and proceed with reiterating the nature of the study, and receive oral consent to proceed. The interview questions acted as a template to keep from veering off topic or away from the main subject of the study (Schensul, et al., 1999).

The interview with each participant was just shy of two hours to complete, including the consent phase as well as any questions or debriefing of the participants. An audiotaped recording occurred as described below.

Audiotape of Interviews

Audiotaping offered me the opportunity to capture the participants' emotions and words verbatim (Schensul, LeCompte, Nastasi & Borgatti, 1999). Handwritten field notes included my interview-related comments and thoughts (Creswell, 2007).

The audio tapes included verbal consent, the participants' answers to the interview questions, and the debriefing. Two audio devices served, as protection to capture the information without incident should one of the devices malfunction (Schensul, et al., 1999). The audio tape devices did not require physical tapes but stored the recordings in the instrument memory. A microphone recorded the participant in his or her normal speaking voice. An external plug was on hand should one of the devices need an additional battery charge. Schensul, LeCompte, Nastasi, & Borgatti (1999) suggest the researcher not rely solely on audiotaping as the only means of recording. Specifically, electronics can be undependable, and things can and do go wrong resulting in important data loss or missed opportunities. This study had two participants who are the parents of the same individual. The interview took place in a boardroom setting, which did not have background noise; therefore, no additional audio backup was required. I transcribed the full context of both interviews which provided a level of detail yielding repeated and close data analysis (Schensul, et al., 1999).

Study Debriefing Form

The purpose of creating a study debriefing form was to reduce any possibility of psychological harm to the participants. The debriefing form gave the participants the opportunity to inform me about his or her experience as a participant and to ask any follow-up questions after the interview. Although I believed there was little to no participant risk, the debriefing phase of the study offered follow-up information should either participant experience psychological distress (Onwuegbuzie, Leech, & Collins, 2008).

I provided the participants with a paper handout (Appendix, F), which included the contact information for me, my dissertation chair supervisor Dr. Chet Lesniak, and local mental health 24-hour hotline. The form also included an area for me and the participants to sign to confirm the participants were not in distress or need of mental health assistance. The form included a statement in which the participants acknowledge receipt of the $25.00 gift card for participating in the study after the interview.

Study Participants

I contacted several community resources via phone and email offering a brief description of the proposed study. Many of the contacts expressed interest in the study and a high level of desire to help find a participant. This networking put me in contact with the LGBT Community Center of Greater Cleveland. During a conversation with the community outreach director, I was put was brought in touch with the human sexuality educator of the Cuyahoga County Board of Developmental Disabilities. The human sexuality educator advised me of an open volunteer position at the LGBT Center for an education facilitator of a parent support group for gay individuals with IDD. I contacted the Ohio Board of Psychology to be sure that applying for this position would not pose a conflict of interest or violate any ethical procedures related to research. The board confirmed that there are no violations related to taking this position or recruiting a research participant from the members of the parent support group. Besides, I consulted with my committee as to the best method to better support my participant recruitment. That discussion resulted in the determination that interviewing a parent from a support group I facilitate could pose a potential dual relationship and potentially cause harm to the participant. Thus, finding another source to recruit a participant appeared to be the best option. This change allowed me to find another program that offered both parents to participate; having both the male and female perspective seemed to offer the opportunity for a more enriched research study.

To meet the federal expectations of ethical guidelines, the criteria to participate included; a) the parents were aware their son identifies as a gay man, b) the parents were under the age of 65, and c) the parents fluently spoke and read English.

To protect vulnerability of the participants the exclusions included; a) the participant cannot be over the age of 65, b) is not diagnosed with a mental disorder, as self-reported, c) is not currently experiencing emotional problems, or in psychotherapy, also self-reported (Creswell, 1998).

Creswell (1998) suggests two options for finding a participant for a biographical study: a) use a pragmatic approach where the participant emerges from a chance encounter or shows interest as a volunteer, b) identify a marginalized or ordinary person who provides an example of the subject matter of the study. In this biographical design, the participants were the parents of a gay male diagnosed with IDD and were identified by the Wingspan program director who then contacted them to see if they are interested in participating; the program director advised they might be interested. I contacted the parents directly once I gained permission from IRB (Schensul, Schensul & LeCompte, 1999).

Sampling Procedures

The sample for this study included parents of a gay male with IDD. The support group did not receive any compensation for referrals and did not coerce potential study participants. The support group director helped identify participants she thought met the inclusion and study exclusion criteria. Once I received approval from IRB to proceed with the study, I screened the potential applicants to deem if they were eligible to participate in the research study (see Appendix B). If the identified participants had not met the study criteria, I would have distributed the flyer among the parent support group members with other support groups (Appendix G). Once I received permission, I gave the participants more information about the study, and an invitation to participate (see Appendix A).

If the referral of the participants had been from a source other than the one as described above, I would have screened the participants again to be sure they met the study criteria (see Appendix B). If the participants do not meet the criteria in Appendix D, I would have explained the reason for exclusion to the participants as described. I would have thanked the participant for wanting to participate in the study, and would have no further contact with the person. If the participants had met the criteria, I would have scheduled a date and time to meet. Since this study only had one set of parent participants, once the participants were determined, the screening was complete.

Participant Screener

I created a participant-screening questionnaire (Appendix D) which was crucial to the research study to help assess individuals wishing to participate. The screener served as a way to determine if the participants met the study inclusion criteria. The screener took about 10 minutes to complete and helped to determine if the participants were eligible to participate in the research study.

Preliminary Participant Contact

Once the participants received the letter of invitation, which gave a brief description of the study, I contacted the participants and conducted the participant's screener phase, (Appendix, B, and D). The participants met the inclusion criteria, and we scheduled an agreed upon date and time for the face-to-face interview.

Procedures Related to Informed Consent

I conducted the interview within four weeks of initial contact of the participants, based off of availability of both the participants and me. I provided the informed consent form at the initial interview and clarified any questions from the participants before having them sign the document. The informed consent provided an important component of meeting ethical considerations of the research study. The paper included a description of how I was going to respect their autonomy. I ensured the parents' involvement was voluntary and acknowledged that they had been fully informed and had granted personal consent, to the instilled safeguards for them as participants. The informed consent confirmed that they would be treated with beneficence while avoiding maleficence, ultimately confirming the participants were treated fairly throughout the study process (Schensul, LeCompte, Trotter II, Cromley, & Singer, 1999).

Data Analysis Plan

Denzin (1989) suggests identifying an experience of the participant's life to begin an analysis. The chronological aspect of this analysis will develop from a story. It may also emerge from a journal entry or during a review of an artifact such as photo album (Creswell, 1998). I looked for biographical material that was concrete and looked for larger patterns and meanings in the data (Creswell, 1998). I reconstructed the biography and identified the factors that shaped the life of the individual with IDD (Creswell, 1998).

Boyatzis (1998) states thematic analysis is a process of encoding qualitative information. I developed words, codes or phrases that served as labels for the themes of the data. When reviewing the biographical information, I looked for themes related to the research question and sub-questions (Riessman, 2008), thematic analysis is flexible and allowed me to process the analysis in broad patterns, thus allowing me a deeper appreciation of the content of the data as told by the participants.

Participants (Interview) Data Collection

Qualitative research requires a triangulation of information, to address a corroboration of information from all data sources, (LeCompte & Schensul, 1999). This study used a variety of data sources from the parents including artifacts, diaries or journals, social media sites and the interview, to help create the themes as stated above.

Participants (Demographic) Data Collection

I conducted each interview in a private boardroom. The interview began with a brief explanation of the study. I asked each participant the questions formulated on the interview guide (Appendix E) while audiotaping the interview session and taking field notes.

Participants Debriefing and Compensation

After both interviews, I debriefed the participants. The debriefing gave the participants the opportunity to process emotional distress and receive information on where to seek help. The forms also acted as a final interaction with me at the conclusion of the study and provided a receipt of receiving the $25.00 gift card for participating in the study.

Transcription of the Audio Tape

I transcribed all of the audio recordings of the interviews. No identifying factors of the participants are present with the audio tapes to protect the identity of the research participants.

Data Analysis

Dependability is the qualitative study counterpart of reliability (Creswell, 2012). In this study, I used triangulation and an audit trail to establish the dependability of the study. Shenton (2004) states if the researcher repeats the study with the same participants, the same results will occur.

I established an audit trail as a way to support the dependability and actions of the research as chronicled in an audit trail through reports, field notes, and archives (Creswell, 2007). An audit trail is a clear explanation of my research steps from the start of a research project to the development and reporting of results. This verification includes records of what I did in the study. The audit checks how well I managed the methods for meeting the credibility and transferability standards of the research (Creswell, 2007). If I had not preserved an audit trail, it would have weakened the dependability and trustworthiness of the study (Creswell, 2007).

Issues of Trustworthiness

Creswell (2007) stated that trustworthiness in qualitative research involves credibility, transferability, dependability, and confirmability. This trustworthiness is equivalent to reliability, internal validity, external validity, and objectivity (Creswell, 2007). Credibility is a critical criterion of internal validity. I sought to ensure the study tests measured the actual intention of the study (Shenton, 2004). Credibility should help answer the question, “How congruent are the findings with reality (Shenton, 2004)?” The research must use the correct operational measure for the study, to support the credibility. I established familiarity with the culture before collecting any data. Data included a review of documents, or preliminary visits to establish the prolonged engagement between participants and myself.

For this study, I used a triangulation of data, and prolonged engagement. As noted previously, triangulation allows the story to unfold in a triangulation of information through documentation, questionnaires given to the interviewees, and the unique story told in the words, dialect, and experience of the participants. The hope is that this research and application of a biographical study will help yield insight into the life, sexuality, and sexual orientation experience of the individual with IDD (Creswell, 2012).

This data included documents, journals, photographs, social media sites and artifacts provided by the participants, as well as the interview itself.

Prolonged engagement with the participants' allowed me the opportunity to build trustworthiness by becoming oriented to the context of the research study. My interaction with the participants' also helped me detect a distortion in the data while blending into the research participants' personal experience enough so that the participants felt comfortable disclosing intimately detailed information about their son (Creswell, 2007).

Ethical Procedures

The ethical procedures related to this research study included an agreement to gain access to participate as noted in Appendix, C. As indicated by the Institutional Review Board (IRB) application, I could not recruit participants until gaining approval from the IRB review committee. Once approval was given, I used the outlined protocol to recruit study participants. Since participants were already identified, I invited the participants with the letter of invitation (Appendix, A).

The participants' screening tool (Appendix, B), used questions to screen the participants' to be sure they were eligible to participate, and all ethical guidelines relating to research participants were met. The consent form not only addressed consent to participate in the study, but it also addressed early withdrawal from the study. Outlined earlier in this chapter, the data collection protocol supported the ethical consideration of autonomy and confidentiality for the research participants.

Summary

Chapter 3 begins by restating the purpose and research questions of the study. I defined and identified the definition of the central themes and the tradition of the study. I provided a rationale for the chosen tradition, as well as defined and explained my role as observer. I revealed my personal and professional experiences and relationships concerning the research. I disclosed my biases and discussed ethical considerations of the study. In the methodology section of the chapter, I identified the population, justified the sampling strategy and stated the criterion used to select participants. I explained in detail the identification and recruitment of participants. I used the instrumentation area of the chapter to disclose the data collection and collection instruments. There is a description of how participants were able to exit the study and all follow-up procedures. The data collection segment of the chapter presented the connection of the data to the research question.

Issues of trustworthiness described the credibility, which in this study included triangulation of data and prolonged contact. The ethical procedures were described including gaining access to the participants, the human treatment of the participants, IRB approvals, and ethical considerations related to the collection of data. The chapter concluded with a summary of the information. The next chapter will review the interpretation and analysis of the research relating to sexuality and sexual orientation of individuals diagnosed with IDD.

Chapter 4 Results

The purpose of this study was to understand the lived experiences of an individual diagnosed as intellectually developmentally disabled (IDD) who identified as a gay male, as reported by his parents. I used a biographical qualitative design including a face-to-face interview with the participants. I collected data using open-ended questions, field notes, and artifacts from the study participants. I used an audio recorder to tape the participants' responses. I used a field journal to document my feelings and used handwritten notes during the interview to document those accounts. I asked the participants to bring mementos related to their son's life experiences such as journals, diaries, photos, and ticket stubs to complete the triangulation of data (Creswell, 2012).

Social constructivism was the theory used in this research study. The following research questions were answered:

- RQ1: How do the parents of a son with IDD describe his sexuality and sexual orientation?
- RQ2: How do the parents of a son with IDD describe how he learned about sexuality and sexual orientation? Was this through a school curriculum or other source? What information did the parents provide in terms of sexual education?
- RQ3: What areas of support do the parents feel were needed, or wished were available when their son was going through puberty and beyond?

This chapter presents the research findings and results. I describe the study setting, demographics of the participants, data collection, trustworthiness of the data analysis, and the themes and subthemes that emerged.

Setting

The setting for this study was a boardroom in a local hotel. I chose this setting because it was a convenient location for my study participants. The site also offered autonomy as I reserved the room in my name and did not have to provide any details about the purpose of the reservation. The furnishings in the room included a large boardroom table and comfortable boardroom chairs. The lighting was soft and the décor was pleasant. I offered coffee, tea, water, and a bowl of mints on the table. I was the sole interviewer. The boardroom door was closed during the interview process. There were no outside interruptions or distractions. Neither participant became upset due to his or her involvement in the discussion. Both participants commented on how good they felt after the interview, relieved that they were able to share their son’s experiences. To my knowledge, neither participant contacted the crisis hotline that I provided. Lastly, there were no unexpected occurrences during or after the interview that may have influenced the data interpretation.

Demographics

I used the study participant screening questionnaire (Appendix D) to confirm that the participants met the inclusion criteria for my study. The inclusion criteria required that the participants (a) be under the age of 65; (b) be parents of a son diagnosed with intellectual developmental disorder; (c) have a son identified as a gay man; (d) have a son not living at home with them; (e) be willing to share their parenting experiences about their son, specifically related to his sexuality and sexual orientation; and f) could read and write English fluently. The participants were 56 years old. Both were Caucasian and had master's degrees. Both participants were employed in their respective fields (see Table 1).

Table 1

Demographic Characteristics of Study Participants (N = 2)

	N = 2
Age	
P1	*56*
P2	*56*
Ethnicity	
P1	Caucasian
P2	Caucasian
Education	
P1	Masters Music Therapy
P2	Masters Civil Engineering
Occupation	
P1	Early Childhood Music Educator
P2	Engineer
Number of Children	
P1	2
P2	2

Creswell (2007) suggested creating a biographical sketch of the study participants as a starting point. Both study participants were assigned identification codes and pseudonyms (P1, Christine; P2, Raoul) to ensure their confidentiality. The biographical sketch of the participants includes both their strengths and concerns in relationship to sexuality and sexual orientation (Creswell, 2007). The participants were the parents of the same adoptive son. The first participant (Christine) reported working in a career that she felt included a more diverse population so that she had more interaction with individuals who openly identified as LGBTQ. The second participant (Raoul) reported that he worked in a career that he felt was more conservative. He felt that he had less experience working with individuals who openly identified as LGBTQ. The participants lived in a city that they believed had progressive views regarding the LGBTQ community.

Participant 1: Christine

Christine is a 56-year-old Caucasian female married for 33 years to her husband, Raoul. She is the adoptive mother of an intellectually developmentally disabled son who identifies as a gay male. Christine has a Master’s degree in music therapy and an additional Master’s degree in early childhood education. She currently works as an early childhood educator and music teacher. Christine reported that she grew up with both of her parents and a sister. Her religious orientation is Lutheran. Christine reported that she spent a year in the Netherlands as a teenager. The experience was a turning point for her as her very conservative view of sexuality shifted to a more liberal one. Christine reported that she initially had very limited information about sexuality from her parents. Christine suspected a great uncle was gay although he never disclosed this. She has never asked him about it out of respect for his privacy. She stated that there was never any conversation about homosexuality or gay people while growing up. Christine reported that most of her information about sexuality came from her peer group in college.

Participant 2: Raoul

Raoul is a 56-year-old Caucasian male married for 33 years to his wife, Christine. He is the adoptive father of a gay, intellectually developmentally disabled son. Raoul has a Master's degree in civil engineering. He currently works as an engineer. Raoul reported that he grew up with both of his parents. His religious orientation is Lutheran. Raoul stated that his belief is that one is born gay and that he accepts his son's sexual orientation. Raoul reported he did not know that there were gay people while he was growing up. The issue of sexual orientation was never discussed in his family and, to his knowledge, he did not know anyone who was gay. His first experience learning about gay people occurred while he was in college when some of his friends began to come out as gay. Raoul reported that his parents never talked to him about sex.

Participants' Son: Erik

Erik is a 23-year-old male and the adoptive son of the participants. He was diagnosed in 3rd grade with Asperger's disorder and a developmental disability. He identifies as gay and has been out since he was approximately 12 years old. Erik lives in a group quadplex that allows him to have an apartment with staff who live nearby. His parents are his legal guardians. Erik was adopted as an infant from Korea at 10.5 months. His ethnicity is Korean/African American. He has an older brother who is not a biological sibling and who is also adopted from Korea. The parents adopted the boys in two separate adoptions. Erik was adopted from an orphanage. His brother was adopted from a foster care program. Erik suffered night terrors as an infant, but they eventually subsided. His parents noticed some developmental delay in both gross and fine motor skills. Erik attended public school and had a normal start in his academic career. His parents became concerned about his behavior while he was in kindergarten. He was initially diagnosed with attention deficit disorder (ADD) based on his presenting symptoms. His symptoms continued unabated, and it became apparent that they were not consistent with a diagnosis of ADD. His parents advocated for further testing in 3rd grade. At that time Erik was diagnosed with Asperger’s disorder, as well as a developmental disability. Erik has always been a large child in height and weight. He exhibited violent outbursts and behavior. As a younger child he had severe temper tantrums. He continued to exhibit severe, violent, and destructive outbursts during adolescence into adulthood. While he was in high school, Erik attended a boarding school in another state to address better his developmental disability and violent behavior. Erik has had numerous admissions to inpatient psychiatric units. He currently has an open order for an inpatient admission should he need it due to his mental instability.

Data Collection

After receiving permission from the Institutional Review Board (IRB) of Walden University, IRB number 11-11-15-0119593, I contacted a community partner who identified the individuals who might want to participate. I then contacted them by phone and conducted the participant screening questionnaire (Appendix D). After confirming that they met the inclusion criteria and were interested in participating in the study, we agreed on a date to conduct the interviews. I flew to their city of residence and met them at a convenient hotel, where I had reserved a boardroom to conduct the interviews. When the participants arrived, we exchanged introductions and went into the boardroom. I suggested that we discuss the consent form and proceed with the individual interviews; they agreed, and signed the consent forms. Neither participant had any questions regarding the consent form. The form included permission to audiotape the interviews. I used two audiotape recorders with microphones. I informed each participant that I was giving him or her an ID code (P1, P2) and an alternative name (Raoul, Christine) to protect his or her identity. I also asked participants not to use their son’s name when answering the interview questions. However, I informed participants that if they did use his name, I would change it to “my son” when I transcribed the audio tape to protect their son’s identity.

At the end of each interview, I reviewed the debriefing form with each participant. I provided each participant a signed copy of the consent and debriefing forms, as well as a $25 gift card. The first interview lasted 115 minutes; the second interview lasted 120 minutes. I transcribed the audiotaped interviews. After transcribing the recordings, I checked the transcription against the audio recordings for accuracy. The audiotapes were erased after they were transcribed. The written transcription is saved on a password protected hard drive and stored in a locked filing cabinet in my office.

Data Analysis

The coding manual for qualitative research guided the coding process for data analysis (Saldaña, 2012). Coding in qualitative inquiry includes phrases or words that capture the essence of the interview. Coding the data is often done in two stages. During the first cycle of coding, I reviewed the transcript from each participant and chose a word, a full sentence, or sometimes an entire paragraph that captured the principle content and essence. One-word codes are descriptive codes that summarize the topic. When coding a direct sentence, I put the sentence in quotation marks, which is known as an in-vivo code. A repeated pattern is when a code or same codes continues to appear. During the first cycle, I accumulated 390 codes. The 390 codes were broken down into 10 one-word descriptive codes and five in-vivo codes per participant (Saldaña, 2012).

The second cycle of coding required me to reanalyze and reorganize the data that was coded in the first cycle. During this cycle, I was able to develop a comprehensive combination of the data corpus or full set of the data (Saldaña, 2012). Lewins and Silver (2007) stated that before establishing categories, recoding may need to take place to make more precise word choices or phrases. Some codes are theoretically similar and may need to merge, while other times assessing special codes for usefulness in the research may require recoding. Finally, some codes may need to be dropped because they are redundant or negligible. My primary goal for second cycle coding was to establish a conceptual, theoretical, and thematic organization of the first cycle of coding (Saldaña, 2012).

I reviewed the initial 390 first cycle codes and used the above guidelines to establish categories relating to each of the three research questions. During this process, the lived experience of the biographical data was established and themes began to emerge from the interviews and artifact collection. The themes that emerged from this study formed an embedded topic. When analyzing the data corpus, my goal was to explore and develop an overarching theme that weaved various themes together into an articulated biographical account (Saldaña, 2012). Accounts that were irrelevant to the research study and did not embody the goal of the study were excluded from the data analysis. For example, one statement that was excluded as irrelevant was "Our older son is having some difficulties in life too, he is very smart but does not seem to know how to get his act together" (Christine).

Evidence of Trustworthiness

Creswell (2007) stated that trustworthiness in qualitative research involves credibility, transferability, dependability, and confirmability. Credibility is a fundamental criterion of internal validity. To ensure credibility, I followed Creswell's (2007) recommendation and chose the correct operational measure by establishing familiarity with the culture before collecting the data. I did this by volunteering as a facilitator at the Cleveland intellectual developmental disability LGBT REDI group, and have volunteered with this program for about a year. Stake (2010) states no study observes all of the above-noted standards, however the more that standards are addressed the more likely that the inquiry will be credible and significant.

Transferability

A think description of the context helps to enhance transferability as well as provides assumptions that were central to the research. I achieved this by providing a detailed account in the description of the study process. Whether or not the results can be transferred then becomes the responsibility of the individual who chooses to transfer the results in another context. Should this be the case, the intended setting must be similar to this research context to better identify those similarities. This more alike, the more probable that the findings will be transferable (Lincoln & Guba, 1985)

Dependability

Dependability is synonymous to repeatability and assumes the study can be replicated (Lincoln & Guba, 1985). Essentially, would the same results be obtained if we conducted the study twice? If, however, we measure the same thing twice, by definition we principally measure two different things (Lincoln & Guba, 1985). Thus, the surer the researcher has been in the research method, the more trustworthy the results (Creswell, 2012). One way to assess dependability is with an audit trail. I conducted an audit trail by recording all activities relating to the research. I kept field notes and reviewed the audiotapes, presented artifacts and transcripts. I met the standards of transferability by being accountable to the audit trail as I provided an explicit description of the research procedures from the start of the study through to documentation of the study in this dissertation. (Lincoln & Guba, 1989).

Confirmability

The confirmability standard refers to the quality of data and whether the participants provided quality results. Qualitative research often assumes that researchers bring an exclusive viewpoint to the study. Confirmability refers to the degree by which the outcomes can be validated or confirmed by others. The following strategies were used to enhance the confirmability of this study. I referenced literature and other study findings that confirmed my interpretations. I also used reflexivity by keeping a personal journal that I used to examine the filters I may use to see the world. I also reflected on how I might learn, understand, and explore the topic and how those thoughts might influence my inquiry concerning the research (Lincoln & Guba, 1989).

Credibility

To establish credibility, Lincoln, & Guba (1989) recommend using one of the following criteria: Member checking; negative case analysis; prolonged engagement; triangulation; persistent observation; peer debriefing; or progressive subjectivity checks. I chose triangulation and prolonged engagement to verify my findings. To achieve the triangulation of data, I reviewed peer-reviewed research literature sources. Those literature selections described in detail in Chapter 2. I chose multiple methods of data collection which included audiotaped interviews. I took field notes, and I reviewed artifacts provided by the study participants. The study participants presented artifacts at the interview that included videos, shown to me on one of the participant's smartphones, audio recordings, social media sites including Facebook and Myspace, which additionally provided other video artifacts related to their son's lived experiences. The data from these artifacts were incorporated as raw data and then incorporated into each theme. I acquired the same data from both participants. As hoped, the triangulation of data allowed the story to unfold as a biographical account which afforded insight into the life, sexuality, and sexual orientation of an individual with IDD (Creswell, 2012).

Prolonged engagement with the participants allowed me to build trustworthiness by adapting to the context of the research study (Creswell, 2012). My interaction with the participants over a course of a couple of months, as well as my experience as an LGBT facilitator helped me detect any misrepresentation in the data. This prolonged engagement with the participants and culture also supported a more comfortable setting for disclosing intimately detailed information about their son (Creswell, 2007).

Results

I interviewed the parents of an individual diagnosed as intellectually developmentally disabled (IDD) who identifies as a gay male. The semi-structured interview questions created for this study were made with the following research questions in mind: “How do the parents of a son with IDD describe his sexuality and sexual orientation?”; “How do the parents of a son with IDD describe how he learned about sexuality and sexual orientation? Was this through a school curriculum or other source? What information did the parents provide in terms of sexual education?”; and “What are the areas of support do the parents feel were needed or wished they had when their son was going through puberty and beyond?”

The following section will detail the analysis of each developing theme and subtheme. The analysis will include excerpts that will illustrate examples of emergent themes; themes which will contextualize and explain the research as an analytical narrative (Braun & Clarke, 2013). The following themes are described as they emerged from the interview transcripts. Appendix H presents the full list of themes and subthemes.

Theme 1: Lack of Certainty and Confusion About Disability

Each participant was directed to tell a little about themselves. This information was used to answer the question related to demographics. The second question asked each participant to describe their son's early childhood. Their responses exposed three subthemes lack of certainty, confusion over physical or mental disability, and intelligence.

Subtheme 1: Lack of certainty. Both participants reported experiencing feelings of uncertainty when they first adopted their son. They reported that they were unsure and somewhat confused as they wondered if they were dealing with physical or mental disabilities, or if his behavior was typical baby behavior or as the result of the adoption. "He was about 10.5 months old when we adopted him. He was, was difficult right from the start. He had night terrors and …um…that was challenging, but then those ended and um we knew something was different, a little unusual I guess." (Raoul)

"Our son was 10.5 months when we adopted him… he was in an orphanage not like my other son…I knew there might be some issues, and there were…and um so anyway um he needed physical therapy because of um his motor skills… [I would] put my son in the crib. Every night was a routine every night he would get up and scream [sic]." (Christine).

Subtheme 2: Confusion over physical or mental disability. One of the participants (Christine) worried about physical disabilities because she was aware that the children in the orphanage were not often allowed to crawl around or have floor time.

"There were two domains, that his gross motor and his fine motor, but you know speech and language, it's big [it] is a really big thing in cognition those two areas and you know he had we didn't know if it was the adjustment to being adopted [sic]."

Subtheme 3: Intelligence. Both participants reported feeling that their son was highly intelligent. They described feelings encouraged by the kindergarten teacher who recommended that their son be put in the gifted and talented program at school.

"He was um very intelligent. After kindergarten the teacher recommended that he go into the gifted and talented program because he was quite fluent, he was reading, you know, he seemed to be quite intelligent." (Raoul)

"So school for him when he was younger he was identified as gifted and talented his scores were very high because he was a good reader, so it is really hard to get services." (Christine)

Theme 2: Early Childhood Peer Interaction

The participants were asked to describe their son's educational experience. Their responses revealed three subthemes - early elementary school (K-3) peer interaction, middle school peer interaction, and mixed messages concerning diagnosis.

Subtheme 1: Early elementary school peer interaction (K-3). Both participants described some form of parent advocacy when describing their experience with their son's early elementary school participation. Specifically, they reported being concerned that something was amiss in relation to their son's learning style and behavior.

"Kindergarten was no problem for him. he was invited to every birthday party everybody loved him, he was even engaged to one of his classmates…in the third grade, because again he was a great reader, but the learning, sort of his learning, he had huge temper tantrums, just huge, and so then when I brought him in [for assessments], it was kindergarten and they said he had ADHD that was the first, which he never had, so you know it's it's we kept going in [for more assessments] and wondering is this from the adoption, is this, there were all kinds of things [sic]." (Christine)

"Probably in first, second grade, especially third grade we noticed that um he had difficulty um doing the work, not understanding it but actually doing it. So we kind of noticed there was something there something not quite right… we had him in for testing and you know psychologist and things like that. He had an initial diagnosis of ADHD." (Raoul)

Subtheme 2: Middle school peer interaction. Both participants described a stark change in peer and family relationships starting in middle school and escalating into high school.

"During middle school where he really, sixth, seventh, and eighth it was all the peer relations he would always come home and say they are bulling me they say I am gay! That is when that all started." (Christine)

“His relationship with his brother growing up was just awful; it was the two, just would fight all of the time. Almost violently, it was very difficult…Well just his behaviors, his extreme aggressive behaviors at school and home.” (Raoul)

Subtheme 3: Mixed messages concerning diagnosis. Both participants reported feeling relieved that they finally had a diagnosis that fit some of the behaviors they observed in their son.

“So in third grade, finally, that is when he was identified having Asperger’s and developmental disabilities.” (Christine)

“After further testing, it was Asperger’s and developmental disability.” (Raoul)

Theme 3: Sexual Education, Exploration, and Bullying

The participants were asked to describe how their son acquired sexual education. The response from that question revealed three subthemes - sexuality education, sexual exploration, and bullying.

Subtheme 1: Sexual education. One participant (Christine) discussed having an open dialogue with their son about sexuality. The other parent allowed his son to self-discover sexuality in the same way he himself learned about sexuality.

“We talked about sex really early on, I did with the boys, because my parents did not… I do remember my mom; my mom would really embarrass me about sex… we never had that talk about sex. I asked her once about it, and I remember she told me a story about this as I got my period, and I did not know what was happening, I was horrified, and so she made a story about how there’s a nest, that little birds sit in the nest, and I was like, What! So I thought, it starts early so I would talk to um the boys about lots of things and I know that irritated my, my mom, because my son would say, yep grandma has a vagina! … So I grew up in a home, and my husband said the same things they never talked [about sex], it is just when he was in college his dad told him, keep it covered… so I just said if you have sex you have to protect yourself…well, you buy condoms, and you fit them around your penis. And that will protect you, you need protection. … he attended sex education at school; you know, he went and then we would talk about it at home, and we would go through the worksheets and everything" (Christine)

"I do not think I talked to him about sex, or why his body was changing, no, I do not think I did…. I do not know, I do not remember, No, I do not remember if he had sex education classes…" (Raoul)

Subtheme 2: Sexual exploration. Both participants expressed a similar understanding their son's sexuality. Both reported feeling that he engaged in typical teen sexual exploration.

"When he was 12 he was in a play he was the king and the person that was the prince that he said when he would come over, I remember when he would come over, and he said they would make out in the basement. So we did notice that our son would have boys over and that he would, they would be making out in the basement." (Christine)

'When he was probably 14 or 15 he would have friends over, and they would go downstairs to play video games or to watch movies or something and I would always be a little suspect about you know can I trust what's going on down there [sic]." (Raoul)

Subtheme 3: Bullying. One participant (Christine) described her son as being bullied because he was gay. There were two particular instances of bullying that she recalled.

“In sixth grade he was teased about being gay, he was teased about a lot of things, but I do remember him talking about being teased that he was gay and I do remember I do remember and I do remember that, and I don’t I know, I talked to his special education teacher about being teased and harassed and that he felt that way, but they would always say well we’re always around and we never see that but also with autism you perceive like he’d see someone and think they didn’t like him so I mean I don’t know how much of a victim he was in that circumstance he really felt he was, I took it seriously, it was his perception I wanted him to feel safe, I was right in pulling him out you know.” (Christine)

“School was hell for him. It started becoming hell, and he broke down a lot, and he started cutting himself. And um, out and that is what all that started…[in] Elementary school he was very popular and then about six grade … my son is Korean/African-American and where he went to school, there were some rough kids who would make fun of him call him Blasian or some actually gang kids that were really mean to him calling him gay because he was always singing. He was in the musical, he had a star role in the musical, he was the king, and um you know they you know kids pick on kids so that all happened in sixth, seventh, grade.” (Christine)

Christine presented several memes' as artifacts noted on her son's Facebook page that included commentary about being bullied in middle school.

Theme 4: Family Communication and Supportive Family Structure

Both participants (Christine, Raoul) described steps they took to protect their son and make sure he was safe in school and home. The answers revealed two subthemes - school changes, home life change.

Subtheme 1: School change. Both participants described feeling that their son's school environment became much too hostile such that keeping their son safe became a priority.

"By the time he was in eighth grade, I had him pulled out for half the day, He had a private therapeutic classroom. Then we had a meeting in high school at the start of 9th grade. Then were like he cannot tolerate, I mean they had wonderful music programs, we would have loved that, but it just, we um asked that he go to a school that it was smaller that had more support for him. He did, he went to a really great school that had mental health piece, and that was um an intermediate district that he had he went there for high school (9-12)." (Christine)

"We met with the high school staff, we didn't feel they could really give him the support that he needed, we had to think about an alternative for him, which was the intermediate district." (Raoul)

Subtheme 2: Home life change. Both participants reported that as their son aged his violent behavior increased. His violent outbursts were often followed by a stay in a psychiatric hospital for evaluation.

"His behavior became increasingly violent, to a point that we had to have him hospitalized, several times. He would tear doors off the hinges; he is a big guy; it was very scary. He went to school in another state, and it was very good for him." (Christine)

"He did not live with us for a period. His behavior was just awful, we had to make some changes, he went away to school, that was good, for him and us." (Raoul)

Theme 4: Coming Out

The participants' response to interview questions regarding their understanding of their son's sexual orientation revealed several subthemes; their moment of epiphany, negative responses to sexuality, suicidal ideation, integrating into the adult gay community, and dating.

Subtheme 1: The moment of epiphany. Both participants described the moment of epiphany when they realized their son was gay and how they learned their son was gay.

"Well he even went to jazz camp and what was really great is like he would say I think I am gay, he was about 12, and I said that is fine, I mean I never made a big deal about it because maybe he was. I do not know...I didn't explore that with him because I just thought I do not want him to have any judgment about it for people [sic]. So, that they are good people that are gay and a lot of musicians are gay. I told him, Tchaikovsky, who wrote the Nutcracker, he was gay, so you know. So, I was like, you know, I think he was feeling bad because he was being bullied at school, he was being called, the, he was gay [sic] um you know, anyway, he he loved his jazz music." (Christine) Christine played an audio recording as an artifact of her son singing his rendition of the little drummer boy. "It's one of his favorite songs, he just has a great voice, he just loves to sing!" (Christine)

"Um, I suspected because I would catch him on gay porn sites on the computer, I was upset that he was on porn sites…gay or otherwise. I mean there wasn't any one moment, you know, I do not really remember when, you know either he figured it out or I figured it out, I don't really remember. We had so much to deal with behaviorally that sexuality and the gay thing was not really important." (Raoul)

Subtheme 2: Negative responses to sexuality. One participant (Christine) reported feeling that her son's treatment was influenced by the negative bias that people with IDD should not engage in sex.

"He was at a friend's house once, and the mother opened the door they were having oral sex. She was really upset and blamed my son, and I am just like well, they were both, I think they were both 15, she was really angry about it. Yes, she said, "I do not ever want him to contact my son again!" She blamed him and then because, so that that was really nasty, I thought, I was really upset about that, and she called me, and said, my son is "terrible", and I just said, "well it takes two!", I just said it takes two, so, and I felt so bad for my son. I just, well they had known each other, and they ended up going to another camp that he went to, and so she was like what happened at that camp? Blah, blah, blah, and then she told me that they had pulled their son out of a group home because of him having oral sex with other people. So, who knows, I mean, so, I was like, that was the first time that I thought or knew of that my son had oral sex so. What I really want people to understand, is that that um regardless of if you have a disability or not, human beings are sexual. That it is really important to be accepting of where people are at and not to be afraid [sic]. That there is support out there and that it is important for families if they aren't comfortable with, you know...I am just hoping that more people are accepting of the fact that people with disabilities are sexual." (Christine)

Subtheme 3: Suicidal ideation. One participant described her son's history of suicidal ideation and the impact of being bullied because he was gay.

"He had other issues; he wanted to kill himself. He was angry, he was depressed… He has been suicidal many times! Cutting himself. When my mother died, that night when we got home from the hospital, he went downstairs, and shut the door and locked it. I thought I better go downstairs, and he had a cord wrapped around his neck, so my husband then took him to the hospital because I just couldn't. I was with my mom when she died, you know, that was traumatic enough for me, but that is how he dealt with his pain. I know in the hospital he would talk about being gay, a lot, he felt he was not accepted by society, even though we accept him at home. So…He was at one group home where he was told he would go to hell because he was gay. (Christine).

Subtheme 4: Social boundaries. Both participants described their son's limitations in his social boundaries with others.

"Well and then there was some concern about him. I mean we have not had any issues with him, but there's there is, I mean he, we wanted to be sure, you know, when he would go to the locker rooms with younger boys he would say, "Hey you are hot!" And that, so we have really been working on understanding boundaries. And he doesn't always understand that. Another instance, he used to roll down the window and see guys with their shirts off and shout "Oh you are hot! I love your body, you are hot!" You know, and us telling him, I would not like that if someone yelled out at me. That is considered harassment, you cannot talk that way at work, you cannot talk that way, some people will take that, so that is not typical, that is not typical he does not have that filter, we are trying to break that habit [sic]." (Christine)

"We'll be sitting in a restaurant, and he'll say the waiter is really cute. And then we say son you cannot say that that is inappropriate for you to say it. It is okay to think it, but saying it is inappropriate. I tell him, I do not say that if I see an attractive woman, I do not blurt out hey I think she is really pretty. You know it is just not something you do…" (Raoul)

Subtheme 5: Integrating into the adult gay community. Both participants described their son's desire to and difficulty with integrating into the adult gay community.

“Um the first time he went to the gay pride festival in our city, I took him. And Um and his social workers both of [his] social workers told me do not do it. Don’t bring him up there. And they are both gay…I did not understand why, they just said they do not recommend that he go. So, but um I think it was a real good thing [sic]. Because we walked around and we were together, um I did not see anything that was bad, or you know, I was looking for red flags, because of what the social workers had said, you know, most of the people looked pretty darn normal to me, you know” (Raoul).

“He goes to the fur meeting its kind of another GBLT. They like different furry animals, like the rainbow horse, and they get together once a month. They go out to eat at Perkins, and they dress up um they have an animal that they characterized themselves with, and his is the Fox that’s gay so he has a rainbow um thing that he wears um a rainbow tail. [sic]” (Christine)

Christine shared her son’s face book page to show me her son’s wall paper that included the fury animals. She presented the data on her smartphone and scrolled through his Facebook photo’s as artifacts that support his experience participating in the fur meets as well as sharing his photo’s documenting his gay pride.

Subtheme 6: Dating. Both participants described some common and not so common themes as they described their son’s experience with dating.

“The First relationship was when he was 18, it was like a typical teen relationship, they would go to the movies or go out on dates, or grab a burger…they both lived in group homes, so when they did things together it was always staff supervised, they were never ever alone together. I felt kind of bad in a way because any type of intimacy was not allowed… I think a lot of the non-acceptance is ignorance so. Basically, I think it is, its ignorance and um probably past stereotypes and not understanding. ” (Raoul)

“Our son met an older brother of a friend who lived in a group home; he too was diagnosed IDD and gay. They met, and they dated. This was like two years ago, so he was like 20, okay, and he [his boyfriend] came over for his birthday party. He came over once for dinner too with his parents. He does not live with his parents, but they are very supportive of him, and he’s very artistic, and he is in this theater group that my son wants to go into but this this other person cheated on my son, so it was horrible. But anyway, they came over for dinner and our boys, I mean our sons, they are no longer boys, our sons, and my son said that they were engaged! I said that is great! I mean you do not know. So they came over [for] dinner we got to know his family, and then the one [boyfriend] cheated on my son, he was devastated, and then they got back together, and then they broke up for good, and now they are friends again. So that is good, and I said this can happen you might be serious in relationships and then you know you need a breathing time you know [sic].” (Christine)

Theme 6: Social Media, Privacy, and Safety

The participants’ response to interview questions regarding areas of support or needs that were not specifically queried during the interview revealed three subthemes - the Internet and social media, privacy, and safety.

Subtheme 1: The Internet and social media. Both participants described feeling rather limited in trying to teach their son about the nuances of social media.

“I just told him everything is trackable and traceable. And I told him you can’t download things looking at pictures and videos is one thing but downloading is another. Um, he you know he would have a cell phone, his DS you know and you can store stuff it. And anything that could have pictures or videos stored on he would they would be full of pictures and videos. And I told him and I tried to explain and it was hard because he didn’t want to hear it. But I said, “What I ultimately told him okay what if you’re at your grandmother’s house and you wanted to show your grandmother a picture of your latest frog and you call up and you know you’re going through pictures of your frog and then whoops there was a picture, you know, how would you feel knowing that your grandmother saw it?” and um he listened and I think it sunk in, I said you can’t have you can’t have these pictures you can’t carry things around with you with these pictures because it’s, it might be against the law.” (Raoul)

Subtheme 2: Privacy. One participant (Raoul) described concerns about his privacy in terms of meeting people via social sites.

“And to protect him… I’ve I’ve told him that you do not know who and where that is going, you do not share your address I said on these sites, and I told him you do not know who’s on the other end.” (Raoul)

Subtheme 3: Safety. Both participants described concerns about his safety meeting people online.

“Our last name is very easy to track down and I said, “don’t put your last name”. So we have had some of those, safety talks, about that you know. You don’t know who, when its online somebody could be out there it could be some 80-year-old man that is saying they are a 23-year-old you don’t know.” (Christine)

“I do not know what the law is, I do not if it is okay to take a picture of my body and send it to someone, or to take a photo of my penis and send it to another person I don’t know what it is. I know to a minor absolutely that’s no! But if it is to a consenting adult I I do not know. I have told him not to because anything that you send could get out on to the whole media. You know another example about safety, this past Saturday he mentioned that he was going to one of his fur meets and this guy had offered to pick him up and take him and then drop him off after. Our son said, “He lives real close by so it is not real out of his way”, and I said okay. Um, and I talked to staff too, and I just said, "I do not think it is a good idea this time", and I explained that I would like to meet this person first or at a minimum talk to them on the phone. He bought into that; he was fine with that.” (Raoul)

After reviewing the interview transcripts, some topics surfaced that were not noteworthy to the findings of this research study. However, they did offer an additional context of information about the lived experience of this individual. Rather than referring to these items as discrepant data, I have chosen to refer to these things as additional findings, which would fit more appropriately with a biographical research study.

Additional Findings

Some information that was meaningful to one or both participants in relationship to their son but did not represent information relevant to answering the research question about sexuality and sexual orientation note in this area as additional findings. This data contributed to the biographical nature of the study and presented stunning examples of the lived experience of the participant's son's life. Other findings include the report that her son is an amazing musician, and plays piano and saxophone (Christine). That their son has typical autistic traits such as narrowed interest, he loves musicals and has an obsession with the Phantom of the Opera (Christine & Raoul). Christine shared her son's Myspace page as an artifact that was filled with photos of the Phantom of the Opera, included photos of him dressed up as the main character. Both participants talked about giving him an opportunity to have positive role models in the community. He has sung in an all men's gay choir and recently sang the national anthem at a special Olympics event (Christine & Raoul). He participates in special Olympics in both bowling and ice hockey (Christine)

Amazing musician. In sharing her experience of bonding with her son, Christine states that music was a bonding element in their relationship.

"I saw with our older son how music was so important for [to] bond not just bonding but attachment learning so he had, and you heard him sing. He is an amazing, amazing musician amazing musician it just it's amazing to me. That's another link that we have he loves music, just like me. um, one day just went and sat at the piano and started playing a song. This was in [I] think he was three. He started to play jingle bells on his own. Now today he is an amazing piano player, does everything by ear, he is not a note reader but he wanted to play the saxophone, and so he started private lessons."

Narrowed interest. During the discussion about their son's diagnosis both participants Christine and Raoul report their son's obsession with the Phantom of the Opera and Broadway musicals.

"He loved musicals so much when he was three I went to the Phantom of the Opera, and I brought home the cassette. I played it for him, and he listened to it over and over again. When you are on the spectrum, you have a fixed interest narrow interest phantom was his, big! He [would] be the Phantom for Halloween, he would want the Phantom ornament at Christmas, and everything was. [sic] I had the piano music he would read he knows the entire play he goes every time they're playing we go with our family has Broadway tickets. He loves Broadway musicals, and he loves Rent, he loves to sing seasons of love, loves Rent he loves um Oh we just saw Kinky Boots. …It is so great… great, and the message is so positive. So and when we saw Jesus Christ Superstar, he loves all of the musicals of Andrew Lloyd Weber. [He] Had to have them, we had to have Cats, so we have those on DVD to listen to. [sic]"

Positive role models in the community. Both participants discussed how important it was to give their son positive role models in both the gay and disabled community, “When he was singing in the men’s gay choir, that was no disability, he was the only one with a disability, that I knew of in the choir. And so there were some very good role models there, and I am hoping someday he will go back and be part of that.”

Participant in Special Olympics and community events. Christine reported that her son has a rich life and is deeply involved in his community.

“Special Olympics so he is doing bowling, and he is doing hockey in his he loves people I took both my boys with me everywhere. Church all the time, we went to the nature center he loves, really identified with nature, we would always go to the nature center. um loves toads, and frogs, we had tons of them at our house. He saved up his money; he wanted to buy a Russian tortoise, and he did! And he named him Vladimir after one of the hunters from Peter and the Wolf.” Christine produced an artifact of her son singings the national anthem before a special Olympics bowling event.

Summary

This chapter began by introducing the study and presented that the data analysis and thematic findings came from the in-person interviews with both parents of a gay male, diagnosed with an intellectual developmental disorder. A description of the setting presented a way for the reader to have a described visualization of the study atmosphere. The demographic section gave the reader an understanding of the participants’ characteristics. The data collection section presented the process taken to collect the data. The data analysis section introduced the coding cycle of the study. In the section of evidence of trustworthiness, I discussed the attributes of transferability, dependability, confirmability, and credibility. The results section gives the reader a detailed analysis of the interview conducted by using semi-structured open-ended questions. The format presented included the deliberate understanding of the process and procedures of first cycle coding, second cycle coding, and thematic analysis. This analysis produced six themes; (a) lack of certainty and confusion about disability; (b) early childhood peer interaction; (c) sexual education, exploration and bullying; (d) family communication and supportive family structure; (e) coming out; and (f) social media, privacy, and safety. Within the central themes 20 subthemes also emerged. 1) lack of certainty; 2) confusion over physical or mental disability; 3) intelligence; 4) early elementary school peer interaction (K-3); 5) middle school peer interaction; 6) Mixed messages concerning diagnosis; 7) sexual education; 8) sexual exploration; 9) bullying; 10) school change; 11) home life change; 12) the moment of epiphany; 13) negative responses to sexuality; 14) suicidal ideation; 15) social boundaries; 16) integrating into the adult gay community; 17) dating; 18) the Internet and social media; 19) privacy; and 20) safety. The emerged themes are verbatim as told to me by the participants. These themes and subthemes provided answers to the following research questions: “How do the parents of a son with IDD describe his sexuality and sexual orientation?”; “How do the parents of a son with IDD describe how he learned about sexuality and sexual orientation? Was this through a school curriculum or other source? What information did the parents provide concerning sexual education?”; and “What are the areas of support do the parents feel were needed or wished they had when their son was going through puberty and beyond?” Through this description, the authentic story began to unfold and through the process a chronological biographical design emerged.

The implication for social change may be in helping to shift the social acceptance and perception of sexuality and sexual orientation among individuals with IDD, while additionally improving and bettering the quality of life for the person. An interpretation of the findings, limitations of the study, recommendations, implications, and the conclusion follows in Chapter 5.

Chapter 5

In this chapter, I summarize and discuss the findings presented in this qualitative biographical study designed to explore the lived experiences of the individual diagnosed as intellectually developmentally disabled (IDD), as reported by his parents. While reviewing journal articles for chapter 2, I noted a significant gap in the research relating to individuals diagnosed with an intellectual developmental disability, and their sexuality and sexual orientation. I collected data through face-to-face interviews with both parents on December 6, 2015. The participants shared their account of their son’s lived experiences. The analysis of the data captured the human dimension of the participants’ son, which yielded a biographical narrative of his sexuality and sexual orientation life experiences. This chapter includes an analysis of the findings based on the key themes and concepts of the literature review discussed in Chapter 2.

I used reputational case selection to recruit participants. A community program director of a support group for LGBT individuals with IDD suggested two informants for the study. The participants met the inclusion criteria as they were both under the age of 65, they were parents of a male child diagnosed with an intellectual developmental disorder, their son identified his sexual orientation as gay, and their son lived outside of their home. The participants were willing to engage in the study and wanted to share their parenting experiences related to their son’s sexuality and sexual orientation. Data were collected using face-to-face interviews with open-ended semi-structured interview questions (Appendix E). The data analysis revealed six themes and 20 subthemes. The six themes included (a) lack of certainty and confusion about disability; (b) early childhood peer interaction; (c) sexual education, exploration, and bullying; (d) family communication and supportive family structure; (e) coming out; and (f) social media, privacy, and safety. A full list of the themes and subthemes is presented in Appendix H.

Interpretation of the Findings

I analyzed themes and subthemes through the lens of social constructivism, which provided the framework for understanding societal norms relating to sexuality and sexual orientation in the IDD community. As confirmed throughout the vignettes offered by the participants, cultural and societal contexts influenced the knowledge of sexuality and sexual orientation of their son (O’Donnell & King, 2014).

Theme 1: Lack of Certainty and Confusion About Disability

Researchers in the area of disability often focused on the individual with the disability. A component of research that has often been left out is unknown aspects of disability that the family may face. Such components include stigmatization, poor or inadequate services, social isolation of the family and the individual, financial burdens, and the quality of family life (Home, 2012). Goldberg, Moyer, Kinkler, and Richardson (2012) concluded that additional uncertainties for adoptive parents include waiting for a child to be placed and the legal uncertainty of that placement. In some instances, according to Goldberg et al., (2012), there is some degree of legal risk because it is unknown whether the child is available for legal adoption. The participants in this research study did not discuss the issues raised above. However, both participants experienced a level of uncertainty and confusion about the type of disability they were facing. This theme led to the emergence of three subthemes: lack of certainty, confusion over physical or mental disability, and contradictions about their son's intellectual cognition.

Subtheme 1: Lack of certainty. Both participants discussed a lack of certainty about what might be different about their son's development as an infant and toddler. As Raoul stated, "He had night terrors and um that was challenging, but then those ended and um we knew something was different, a little unusual I guess." Christine noted, "So anyway um he needed physical therapy because of um his motor skills… [I would] put my son in the crib. Every night was a routine every night he would get up and scream [sic].…Even as a toddler he would have just terrible temper tantrums, they were just so outrageous." The depiction of those events was important to note as a theme because it indicated that there were early signs of uncertainty. However, when the participants first observed the early signs, they initially considered them to be a general aspect of baby behavior. As the parents developed a deeper understanding of their new son's behavioral difficulties, they began to suspect that they may be dealing with a developmental disability. Ivey and Ward (2010) noted parents often suspect developmental delays and differences during early childhood. In light of the participant's initial uncertainty and as additional symptoms began to surface, the parents sought further assessment to understand the challenges their son faced.

Subtheme 2: Confusion about physical or mental disability. Both parents felt confused about whether they were facing a physical or mental disability with their son. There was evidence of some gross and fine motor skill problems suggesting a physical handicap. However, there was also evidence that included behavioral problems and night terrors suggesting a developmental disability. Christine described the issues that their son experienced with gross and fine motor skills that suggested physical disability: “So anyway um he needed physical therapy because um his motor skills and in Korea a lot of babies are held all the time. Child rearing is different in Korea from here [babies are] not put on the floor to play that’s kind of a different child rearing practice. I knew that my son was probably laid in a crib probably. His gross motor and his fine motor, but you know speech and language is a big is a really big thing in cognition those two areas, and you know he had we didn’t know if it was the adjustment to being adopted [sic].”

Christine and Raoul described the problems their son experienced that suggested developmental disability, starting with night terrors, as well as outrageous temper tantrums. “He was very difficult to parent, he would get very angry, lots of temper tantrums he had huge temper tantrums, just huge” (Christine). The behaviors were unlike any experiences they had had with their first child. The parents report that they felt confused about what type of disability their newly adopted son might be experiencing. To add to the confusion, the parents described feeling at a loss because they were unclear of their son’s biological history. Although they had adopted a child from Korea only a year and a half earlier, their experience with their newly adopted child was starkly different, which led them to believe that the adoption was not a contributing factor of his behavior.

Subtheme 3: Intelligence. In addition to the parents' observations of their son's problem behaviors, what also added to their confusion was the fact that their son appeared to be "quite intelligent." Despite his earlier behavioral issues, Christine reported that by kindergarten their son was "reading fluently... had a lot of friends, and was well liked by his peers." Raoul stated, "It was really quite exciting; the kindergarten teacher was recommending that he be put in the gifted program." However, something continued to appear to be amiss, and both parents continued to seek guidance and push for answers from the school and support staff. The diagnosis their son was initially given was attention deficit disorder (ADD). However, his symptoms did not appear to meet all of the criteria for ADD, the parents report that they requested additional testing in third grade. The additional assessment generated a diagnosis of Asperger's syndrome and a learning disorder not otherwise specified.

The Asperger's Syndrome Coalition of the United States (as cited in Ivey & Ward, 2010) reported that recognition of Asperger's syndrome (AS) typically occurs later than autism. An Asperger's diagnosis is often given after the age of 3, with most children diagnosed between the ages of 5 and 9 (Ivey & Ward, 2010). Children with Asperger's do not usually present with language or cognitive delays (Ivey & Ward, 2010). The associated social deficits of Asperger's often appear around the time the child starts school, but the deficits are just below the typical range of the social norm, and are not as apparent (Ivey & Ward, 2010). As these children develop, their lack of social skills becomes more apparent to others, especially to their peers. As a result, children end up never truly fitting in to their respective peer group (Ivey & Ward, 2010).

Volkmar, Klin, Schultz, Rubin, and Bronen, (2014) noted that the gap between functional ability and intellectual ability for the individual diagnosed with Asperger's is complicated for the person as well as for the parents. Parents and teachers often see a talented and intelligent individual, yet they have trouble comprehending why the individual struggles with social and organizational experiences. This gap between functional ability and intellectual ability is one of the frustrations of the child with an Asperger diagnosis. The frustration comes from understanding things intellectually, but not fitting in socially. As noted during the interview, the son appeared very smart, could read before his peers, and played music by ear. As reported by the parents, the child appeared brilliant. He had excellent memorization and high verbal skills. "He is an amazing, amazing musician, amazing musician it just it's amazing to me…he loves really identified with nature. We would always go to the nature center um loves toads and frogs we had tons of them at our house...he loves all of the musicals of Andrew Lloyd Weber, he does not read music, he plays everything by ear, he just memorizes everything" (Christine). Socially the boy fit in in early elementary school where his lack of social skills was less noticeable. "The boy was five years old in kindergarten [it] was no problem for him. He was invited to every birthday party everybody loved him he could already read…he was popular in school. In elementary school, he was very popular"

(Christine). However, by upper elementary school and middle school, his social disparities were more apparent, and things began to change within his peer group. “School was hell for him. It started becoming hell, and he broke down a lot, and he started cutting himself, and um, …that’s when all that began before he was popular in school, elementary school. During middle school where he really, sixth, seventh, and eighth it was all the peer relations, he would always come home and say they’re bulling me they say I’m gay! That when that all started” (Christine).

Theme 2: Early Childhood Peer Interaction

Both parents describe their son’s behavioral disturbances from the time they adopted him, in particular, night terrors and severe temper tantrums. Sansosti (2012) describes that a behavior cycle exists with most individuals diagnosed with Asperger’s. The three stages of the behavior cycle typically start with rumbling, move into a rage, and finally ends with the recovery of calm. The first stage often noted as rumbling can include minor infractions such as name-calling, fidgeting, or refusing to comply with directions or instructions. Although, these behaviors can appear annoying, to those around the individual. It may not be clear to a parent or caregiver that the behavior is a precursor to a more intense behavior forthcoming. During the rage cycle, some individuals with Asperger’s syndrome may engage in threatening behaviors, appear impulsive and volatile. They may hit, kick, bite or act destructively. These behaviors are not purposeful. They are a result of an absence of emotional regulation, and a misunderstanding of the social world. This behavior usually leads to uncontrolled anxiety and increased stress. After the outburst, individuals with Asperger's syndrome enter the final stage of recovery of calm. Some individual's with Asperger's syndrome may deny that they had the inappropriate behavior, he may want to sleep after the episode, he may apologize or may become quiet and appear sullen (Sansosti, 2012).

Recent studies relating to peer interactions in early childhood education suggest social skills interventions including buddy skills, networking skills, peer imitation skills, and peer training skills for children diagnosed with Autism Spectrum Disorder (ASD) (Camargo, Rispoli, Ganz, Hong, Davis, & Mason, (2014). The participants in this study were aware that something was amiss with their son. However, peer interaction was not initially an issue according to the participants of this study, and ASD was not as commonly diagnosed when their son was a child.

The three subthemes that emerged within Theme 2: Subtheme 1; Early elementary school peer interaction (k-3), Subtheme 2; Middle school peer interaction, and Subtheme 3; Mixed messages concerning diagnosis.

Subtheme 1: Early elementary school peer interaction (K-3). Both participants describe continued behavioral issues with their son during his elementary school years. Although, they report positive peer interactions from kindergarten to about third grade. They recall seeing the initial behavioral changes in their son around first grade. “Probably in first, second grade especially in third grade we noticed that um he had difficulty um doing the work not understanding it but actually doing it. So then we kinda noticed there was something, there something not quite right.” (Raoul). Some of the symptoms the parents described such as impulsivity, and inattention overlap with criteria specific to Attention Deficit Hyper-Activity Disorder (ADHD). Thus, it is reasonable to understand that the initial diagnosis for their son was ADHD. Yee & Millichap (2015) state indications of ADHD may eclipse the symptoms of Autism Spectrum Disorder (ASD).

Subtheme 2: Middle school peer interaction. The participant's report that middle school was about the time they noticed extreme behavioral changes in their son. They report that some of the behavior could have been an attribute to adolescence and puberty. However, the difference was significant and more violent than what they witnessed at younger ages. "Our son has always been large for his age, and his tantrums often resulted in extreme violent behavior, like pulling doors off the hinges" (Raoul). The parents report that much of the new behavior was new territory and unbeknownst to them at the time, met the above-noted characteristics of the cycle behavior of Asperger's syndrome (Sansosti, 2012).

The parents report during this same period their son came out as being gay, after returning from jazz camp. The parents report that their son was struggling to fit in with his peers. Christine stated, "middle school was hell for him. He was bullied and often called gay".

Adolescence is an age of childhood and adulthood when the teenager grows in both physical and sexual maturation (World Health Organization, 2015). The parents report that they began to notice that their son was seeking to understand his biological urges and participate in sexual experimentation. “when he was 12 he was in a play at school. He was the king and the person that was the prince…he said when he would come over, I remember, when he would come over, he stated that they would make out in the basement. So we did notice that our son would have boys over and that he would, they would be making out in the basement." (Christine)

Subtheme 3: Mixed messages concerning diagnosis. Both parents report that the misdiagnosis of their son was tough. They were told he had ADHD because of what appeared to be symptoms of ADHD and state they tried to accommodate his needs accordingly. They report that the persisting symptoms that continued to surface were disruptive to the family. They continued to ask questions and seek help from school administration and mental health professionals. In third grade, they received a diagnosis that was consistent with their son's symptoms. "So in third grade, finally, that is when he was identified having Asperger's and developmental disabilities." (Christine) "After further testing, it was Asperger's and developmental disability." (Raoul) Emerging research notes children with ADHD as an initial diagnosis are 30 times more likely to receive an ASD diagnosis after the age of 6 (Yee & Millichap, 2015), which is consistent with what happened in this family.

Theme 3: Sexual Education, Exploration, and Bullying

Sex education is important, but is often inadequately addressed as a topic for individuals on the autism spectrum or identified with a developmental disability (Loftin & Hartlage, 2015). Sexual education programs often fail to consider the limitations of individuals with all types of intellectual developmental disabilities. A simplistic understanding means that the explanation of the subject matter cannot be overly complex or abstract. Otherwise, it will lead to confusion (Loftin & Hartlage, 2015).

The participants in this study stated this topic was significantly important to them. The parents in this study felt that the sex education curriculum fell short of meeting the needs of their son, for his autism and developmental disability diagnoses. Specifically, the parents noted that some of the sexual education concepts presented were euphemisms. The participants report that by using a euphemistic concept to describe sex, their son was at times confused about the information he was receiving in the class. Christine explained how her son would bring home worksheets relating to his sex education class. "We would review the worksheets together and talk about them until I felt he understood the content. We talked very openly about sex with our boys. We answered their questions and made sure they understood."

As described in this study, and confirmed through Wilson, & Frawley, (2016) support staff often provide social and sexual education to the individuals in their care, however, the support staff often report feeling underprepared and rely on their values to guide the sexuality information they provide.

The three subthemes that emerged; sexuality education, sexual exploration, and bullying.

Subtheme 1: Sexual education. One of the participants in this study noted that her son received sex education as standard curriculum in the public middle school he attended. The other participant could not recall if he participated in a sex education program. Christine stated that the sexual education information was often inadequate and to her knowledge there was no information presented about sexual orientation. The World Health Organization (2006) recommends seven specific points relating to sexual health, physical well-being about sexuality, emotional and mental well-being, social welfare, the absence of disease, dysfunction or infirmity, pleasurable and safe sexual experiences that is free from coercion, violence, and discrimination. Sex education designed specifically for individuals with IDD may be vital to safeguarding sexual health according to the WHO guidelines (Loftin & Hartlage, 2015).

The importance on the parent's role in providing sex education to the individual with IDD is significant. Pownall, Jahoda, & Hastings, (2012) state as the child navigates into adulthood, there is an increased dependence on the family for support. Many individuals with IDD age out of foster care or at home living and move into group home settings (Christian, Stinson, & Dotson, 2001). Group home providers usually do not have a sexuality policy and leave the decision-making to unqualified staff (Christian, Stinson, & Dotson, 2001). Often the staff relies on their personal views and values of sexuality and disability, or even on their experiences to provide support or direction to individuals with IDD (Christian, Stinson, & Dotson, 2001).

The parents report that they educated their son about both sexuality and sexual orientation. Aunos & Feldman (2002) report that many parents of children with disabilities take an uncertain approach when it comes to sex and their child. This uncertain approach, unfortunately, means the parents hold back information relating to sexuality and often asks schools to exclude the child from sexuality education programs (Dupras & Dionne, 2013).

Both participants in this study describe feeling very comfortable discussing education, questions, and concerns relating to sexuality. However, at the same time, they also felt some limitations when it came to answering questions relating specifically to gay sex. Though the parents were proactive in helping their son find a resource that would better handle these matters for him. They also report that they made themselves available to attend his appointments with him at the sexual health clinic. Both parents expressed gratitude that the city in which they live is progressive concerning sexual orientation. They report that having resources available to them as parents, and to their son have helped him to know how to interact in sexual situations, as well as ensure sexual competency (Dupras & Dionne, 2013).

Subtheme 2: Sexual exploration. Individuals with IDD have sexual wants and needs (Dupras & Dionne, 2013). The distinction in this study compared to others is that the parents openly accepted that sexuality is a fundamental human right and that their son should experience a rich and full life which includes sexuality. As the biographical narrative began to take shape and themes and subthemes began to emerge, the biases and stigmatization of their son's lived sexual exploration started to unfold. The parents report several denouncements their child encountered when learning and exploring his sexuality. Christine stated “One parent blamed our son when she caught our young adult boys engaged in oral sex. I told her it takes two, and she still forbade her son from ever having any interaction with our son.” Raoul reports “I knew that he was downstairs in our basement with a friend and they were probably making out. I think the other parents found out, and they would not allow their son to come over to our house again.” Christine stated, “In one of the group homes our son lived in, one of his support staff told him he was going to hell for being gay.” This discrimination came from parents, caregivers, and the gay community. “Both of our son’s social workers are gay. One is male the other is female. They both tried to dissuade me from taking my son to the pride festival.” (Raoul) This stigmatization is similar to findings reported in former studies (Allen, 2003; Anastasiou & Kauffman, 2011; Baladerian, 1991; Dupras & Dionne, 2013; Hayes & Craddock, 1992: 75; Herek, 2007; Jones et al., 2012; Werner, Corrigan, Ditchman, & Sokol, 2012; Wilson, Nettlebeck, & Razack, 1994).

Subtheme 3: Bullying. One of the participants reported that the bullying of her son was dramatic and often unrelenting. Christine stated. “The toll the bullying took on our son was at a breaking point when it was time for him to enter high school.” The participant discussed what a difficult decision it was to keep him in a school environment that academically offered an enriching music and drama curriculum or removing him for his safety and the safety of others. “The kids were just awful. They would call him gay and pick on him constantly. His explosive behavior was putting him in the psychiatric hospital often, and he would openly talk about being bullied for being gay during his hospitalizations.” (Christine). Twyman, Saylor, Saia, Macias, Taylor, & Spratt, (2010) state that children with IDD, attention deficit hyperactivity disorder, and learning disabilities showed substantial victimization scores on the Bully-Victimization Scale, compared to children without IDD.

Theme 4: Family Communication and Supportive Family Structure

Christine stated, “we had constant communication with our boys. We talked to them about everything. It was really, really important to us that we have the communication with the boys. I wanted to be sure our son knew that what he was wanting and dreaming about involving relationships was normal. I remember being a little girl and dreaming of getting married and having children.” Dupras & Dionne, (2013) note that some parents and caregivers often see sexuality and individuals with IDD in one of four ways, as child-like and dependent, not wanting to have sex, oversexed and out of control of their urges, and even deviates or sexually perverse. Unfortunately, these ambiguities denote similar experiences described by the parents in this study concerning some caregivers and other parents. “I told another mom about this study, and uh, and that I was going to be a participant. She too has a child with developmental disabilities, and she said. “I am glad I will never have to worry about sex with my child.” I said, “what do you mean?” and she said, “He is never going to have sex! I was like what? In my mind, I feel so very bad for her that she feels that way. Why would she want to deny that for her son?” (Christine)

Baynton (2013) reports that individuals with IDD have advanced considerably in many aspects of their lives, which is also noted by the parents in this study. The participants report their son had many typical life experiences, such as leads in school plays, attending birthday parties, and having playdates. They also report the enormous amount of stress caring for their son put on the family structure. Christine stated, “We had counselors come to our home and work with us. The family therapy was very helpful, and gave us the support we needed to work through all of the behaviors that were going on, um, with both boys. We have a really strong, and supportive family structure!”. Stress is a detriment to most parents caring for individuals with IDD. The contributing factors include the individual's social difficulties, noncompliance, cognitive impairment, behavior problems, internal distress, emotional dysregulation. As well as, dependence, lack of self-care, low functioning, learning disability, limitations on family function, need for care across the lifespan, inappropriate sexual expression, language deficits, and a high likelihood of remaining in the home (Karst, & Van Hecke, 2012). Woodman, Smith, Greenberg, & Mailick, (2015) conclude that an active maternal experience and a quality parent–child interaction forecasts positive adaptation into adulthood for individuals diagnosed with ASD and IDD. Additional empirical data from this same study suggest that having family processes support the child-family interaction also predict favorable outcomes for people with IDD through the life course. As noted throughout the vignettes both participants played an active role raising their son through supportive, interactive life experiences. The two subthemes that emerged; school change, and home life change.

Subtheme 1: School change. The participants report that the persistent issues concerning bullying were one of the mitigating factors when choosing to send their son to an out of state boarding school. Although they were also dealing with the outrageous behavioral outburst of their son, they felt that the day in and out bullying was a contributing factor to some of that extreme behavior. According to Beck, Egalite, & Maranto (2014), it is more likely for parents of special education students to mention that issues with behavior influence their decision to choose to send their child to new or alternate schools.

Subtheme 2: Home life change. Both participant's report that the increase in violent tendencies and irregularity of emotional outburst were not safe for their son or the family. The participants report choosing to move him from the family home into a supported, community-based residence was an important step in assisting his ability to be independent and to help him explore his relationships and sexuality. The change from traditional settings to smaller group home environments appear to offer individuals with IDD independence, by providing privacy, the option of choosing a roommate or living alone, and improving social experiences, including friendships and relationships (Wiesel, Laragy, Gendera, Fisher, Jenkinson, Hill, & Bridge, 2015).

Theme 5: Coming Out

One participant describes the moment of coming out when her son came home from jazz camp around the age of 12 and commented that he was gay. "He just blurted it out! "I think I am gay!", I did not want to make him feel any way about it, so I just said, that is fine, I mean I never made a big deal about it because maybe he was. I don't know? I didn't explore that with him because I just thought I don't want him to have any judgment about it for people you know so that they're good people that are gay, and a lot of musicians are gay, and I told him Tchaikovsky who wrote the Nutcracker he was gay." (Christine)

Similar to most adolescent's sexual development of individuals with IDD is an indicator of his development to adulthood. This development also has an effect on his sense of well-being, as well as his identity (Pownall, Jahoda, & Hastings, 2012). "So you know so I was like you know I think he was feeling bad because he was being bullied at school he was being called the...was gay um you know anyway he he loved his jazz music." [sic] (Christine)

Having a marginalized position as an individual in society increases the dependence of the person on his family, thus requiring assistance with understanding sexuality and sexual orientation (Pownall, Jahoda, & Hastings, 2012). Christine stated, "Well you know what I I would just say you know in middle school they always you know people use that word [gay] incorrectly people who are gay they love each other. But it's two dad's or two moms a boy and a boy and a girl and a girl, and if they think it's meaning sad or sick, they would all say that. I said neither is right because gay people are good…they're people. And I would say, your great uncle is gay, and he is a good person!" Vaughn, McEntee, Schoen, & McGrady, (2015) comment that coming out as gay and having a disability can feel like double jeopardy. There is stigmatization of the individual for both the disability and for being gay. There are few situations where a person is associated with multiple minority groups and feels accepted by both the culture and sub-culture of that group. Typically, the person is stigmatized further due to oppression amongst the internal group members. Although this noted study only included Lesbians, the information provided by the study participants of this research study indicates similar experiences for their son. The six subthemes that emerged; the moment of epiphany, negative responses to sexuality, suicidal ideation, social boundaries, integrating into the adult gay community, and dating.

Subtheme 1: The moment of epiphany. The parents report that the actual moment of epiphany for their son was when he went away to jazz camp and came home and exclaimed that he was gay. Christine described that moment as rather ordinary and did not want to alarm her son or make him feel that being gay was wrong or evil, and tried to be nonchalant to her child's declaration. As noted by Denzin (1989) the instant of epiphany is a significant moment of the lived experience identified as a turning point in understanding an individual’s relationship to the world. “Once we understood that he was gay, we wanted to support him and give him experiences that were healthy. I attend pride festivals with him, he participated in a gay men’s choir and had wonderful role models in that group.” (Raoul)

Subtheme 2: Negative responses to sexuality. Attitudes towards sexuality and gay individuals with IDD remain negative and often adversely influence competency of the individual, by dissuading the individual to have sexual experiences (Aunos, & Feldman, 2002). The participants report early negative responses from other parents, later from caregivers at the group homes and more recently from the gay community. Christine reports “Our son would have friends over, and they would go downstairs to the basement to watch movies and make out, some of the boys must have gone home and told their parents because they would not be allowed to come over again, or the mom would avoid my calls."

Wilson & Frawley (2016) state that group home staff often provide social and sex education, but often report being underprepared and that they rely on their own value system as guidance. Christine shared an incident at one group home, when a staff member learned that her son was gay "he was at one home where he was told he would go to hell by a worker because he was gay!"

Research suggests that individuals with IDD may experience resistance from both the gay and disabled communities (Vaughn, Schoen, McEntee, & McGrady, 2015). Raoul stated, "I talked to his social workers about taking him to the pride festival in our city, they are both gay, one is a woman and the other a man. Their response surprised me. Um the first time he went to the gay pride festival in Minneapolis I took him... and Um and his social workers both of [his] social workers told me don't do it. Don't bring him up there. And they are both gay!" (Raoul)

Subtheme 3: Suicidal ideation. Children and adolescents with intellectual disabilities (IDD), often diagnosed with co-morbid psychiatric disorders, are a vulnerable population who may be at risk for developing suicidal thoughts and behaviors (Ludi, Ballard, Greenbaum, Bridge, Reynolds, & Horowitz, 2012). Christine stated, "He tried to commit suicide many times! Cutting himself often. When my mother died, that night when we got home from the hospital, he went downstairs and shut the door and locked it, I thought, I better go downstairs, and he had a cord wrapped around his neck, so my husband then took him to the hospital."

Subtheme 4: Social boundaries. Social skills are specific verbal and non-verbal behaviors used in effective communication. Some examples are smiling, making eye contact during conversation, asking questions and appropriately responding when asked. Social boundaries are informal rules of behavior (Rao, Beidel, & Murray, 2008). Christine and Raoul report that teaching social skills and understanding social boundaries is an ongoing task with their son. They report that even though they have integrated him into many social situations, he still struggles with appropriate social boundaries relating to the community. Walton & Ingersoll (2013) report that social boundary skills are necessary, but few treatments are available for adolescents and adults with ASD, who also have an intellectual disability. The participants described several situations that their son overstepped social boundaries. "He does not realize that if you see a good looking person, you cannot just yell hey you are hot!"(Christine)

S***ubtheme 5: Integrating into the adult gay community.*** The participants describe the intricacies of their son's experience integrating into the adult gay community. They report that some caretakers in a previous group home tried dissuading their son from attending pride festivals, and criticized their son when he tried dating.

Many lesbian, gay, bisexual, and transgender (LGBT) people with IDD have unique sexual health needs that are not met, such as having access to condoms or having access to a private area to be intimate. Excluding access to condoms and privacy often leads to conduct that is deemed deviant or problematic (Dupras & Dionne, 2013). Raoul recalled a time he attended a doctor's visit with his son at the sexual health clinic. "Well in the sexual health clinic I went in and he saw two people there a [medical] doctor and a psychologist. And I would go in with him, when he saw the doctor, and he would talk about his problems. So I got to listen in on that, and things like that…well the problem was um erection, having & keeping an erection, that's when I found out that you know he was really trying to be able to masturbate, so the doctor gave him tips, tried to explain how the whole procedure works the scientific version how the penis operates and all of that."

Subtheme 6: Dating. One of the participants Raoul described both common and not so common scenarios specific to their son's dating experience. "So his first relationship he had when he was 18, was like the regular typical teen relationship where they would go to the movies or go out of dates or go grab a burger. They both lived in group homes, so when they did get together it was always staff supervised they were never ever alone together. I felt kind of bad in a way because any type of intimacy wasn't allowed, they were even engaged at one point"

Individuals with IDD often have limited dating knowledge, and, even more, limitations relating to sexual expression, intimacy and social interaction (Morales, Lopez, & Mullet, 2011). "He was recently seeing this guy from the support group, and he asked me about it. He was saying I am troubled by what's going on here and I don't, and he was wanting to break off the relationship, but he felt bad because he didn’t want to hurt this guy’s feelings. So he kinda asked what do I do?” (Raoul)

Theme 6: Social Media, Privacy, and Safety

Both participants shared concerns about social media, privacy and safety specifically that they too have some limitations in understanding the laws governing social sites. Both parents report that looking for a companion can be difficult and for individuals with IDD it can feel impossible.

Thomas (2013) states, something that has become a societal norm for many people is online dating or social group sites. However, there are few resources for individuals with IDD outside of the small in-person social networks. Meeting companions can be difficult, and the social networking groups for persons with IDD can be small, and the individuals can vary in the degree of mental ability, thus making it hard for individuals with IDD to find a special someone in person that they can relate to in a cognitive, romantic and personal level. Although, online dating sites can help eliminate some of the social anxiety of meeting in person, as well as expanding the pool of eligible people to choose from, there are risks.

Christine states, “our son is already using technology to communicate with my husband and me, and our extended family, we text and use social media sites. He posts his songs and music online to share with friends and relatives. But the online dating is new to us, we didn’t have that when we were growing up, and we have concerns about who is on the other end of the computer, you know, that our son is communicating with, we told him do not share personal information.” An international study out of the United Kingdom used a thematic analysis to review social media and individuals with IDD. The study confirmed that individuals with IDD can have positive experiences with social media, including gaining friendships, creating a social identity and an increased level of self-esteem. The international study also found issues with accessibility, difficulties with cyber-language and etiquette, along with literacy communication on cyber sites. However, the review also confirmed that individuals with IDD are susceptible to the same concerns found in this research study which included safety issues, and protection of privacy concerns (Caton, & Chapman, 2016).

Subtheme 1: The Internet and social media. Christine and Raoul both shared concerns of their son’s use of the Internet and social media. Raoul stated, "I have genuine concerns relating to our son downloading pornographic photos and videos to devices that he carries around, such as his phone or DS. I don’t know what the law is, I don’t if it’s okay to take a picture of my body and send it to someone, or to take a photo of my penis and send it to another person I don’t know what it is. I know to a minor absolutely that’s no but if it’s to a consenting adult I I don’t know. I have told him not to because anything that you send could get out on to the whole media. And to protect him."

As electronic media continues to develop and change so does the concern from parents regarding privacy and security (Cecere, Le Guel, & Soulié, 2015). Pornography, and sexting and other displays of risky behavior on social media sites impact individuals with IDD too (Strasburger, 2012). Sexting in early adulthood does not carry the same legal dangers of retaining sexual photographs if you are underage. However, recent research suggests viewing pornography presents a higher risk of sexual health behavior threats, including unprotected sex, sexually transmitted infections, and sex with multiple partners (Benotsch, Snipes, Martin, & Bull, 2013). Raoul stated, "I told him, and I tried to explain, and it was hard because he didn’t want to hear it. But I said, what I ultimately told him okay what if you’re at your grandmother’s house. And you wanted to show your grandmother a picture of your latest frog. And you call up, and you know you're going through pictures of your frog and then whoops there was a [pornographic] picture, you know how would you feel knowing that your grandmother saw it. And um he listened, and I think it sunk in, I said you can't have you can't have these pictures you can’t carry things around with you with these pictures because it’s it might be against the law."

The participants’ narratives suggest that parental support played a pivotal role in helping their son navigate the experience of going through puberty and young adulthood. The area that both parents felt a higher level of need for support came from the social media aspect of relationship navigation. Both participants elaborated on the significance social media and the Internet played in the reality of sexuality for their son. The participants report that he has access to people through the Internet that he otherwise might not have. Christine stated, “the whole Internet thing is really tricky, he has the ability to meet other people that are into the same things he is into, for instance, he goes to fur meets, like every other Saturday night and I think it was last night he went to that. It’s a group of people that identify themselves with animals. Okay yeah and so he goes to that they meet people there, and they go to a public place. They go to Perkins restaurant, and I think a lot of the people are probably gay, he [our son] said that he said not all of them are gay, and they go, and they have dinner and talk and share whatever stories, and conversation. They dress up in the fur animal they like. He is a gay fox. He wears a rainbow tail." The parents state they still feel compelled to continue to teach about the dangers of meeting people on social networking sites, as well as, not sharing personal information such as a home address or even a last name.

Subtheme 2: Privacy. Jahoda & Pownall (2014) report individuals with IDD were less selective when including people in their immediate social circle on social media sites, than individual that do not have IDD. They also express significant misunderstandings about sexuality and sexual health (Jahoda & Pownall, 2014). The participants in this study reported some challenges in helping their son navigate media dating sites, although the participants feel quite comfortable helping their son understand safety issues and concerns relating to social media. Social network sites have access to private information, leading to an increase in concern about privacy (Cecere, Le Guel, & Soulié, 2015). The participants report a huge concern in keeping their son's privacy in an online environment. Raoul stated, “I have told him, he has to be careful, you don't know who you are really talking to at the other end of your online chat. It might be someone with ill intentions and you think you are talking to another 20-year-old guy! You can't give out your name, address, or any other private information about yourself. You have to be safe.”

Subtheme 3: Safety. Christine and Raoul shared valid concerns when talking about social sites and safety, as they noted, there is a concern for their son that he does not interact with a predator or with an individual that has ill intent. Raoul stated, “I’ve I’ve told him that you don’t know who and where that is going. You don’t share your address I said on these sites, and I told him you don’t know who’s on the other end, and our last name is very easy to track down and I said don’t put your last name. So we have had some of those, safety talks, about that you know. You don’t know who when its online somebody could be out there it could be some 80-year-old man that is saying they are a 23-year-old you don’t know, they're enough stock photos out there somebody out there, and they could use someone else’s photograph.”

Individuals with intellectual disabilities often have poor insight and judgment, and may be at risk for Internet dangers, such as unwanted exposure to sexual material and sexual solicitation (Buijs, Boot, Shugar, Fung, & Bassett, 2016). The participants feel this is new territory for them and their son. They feel that providing constant teaching and training is a must. The participants report they have a constant dialogue with their son about the Internet and safety. They report that they direct him to remove or edit information that he shares online, they give him guidance about people that he meets, and they have a safety plan in place at his group home that he must gain their permission to have someone pick him up at his home address.

Limitations of the Study

The information provided by the participants add to the literature. However, the interpreted findings of this study should proceed with caution. Specifically, there are some noted limitations to this study. The sample was small, and the experience of the participants in this study may not represent the experience of the broader population. For instance, the participants in this study felt that they live in a city with progressive views relating to LBGTQ, participants in another city that may have more limiting views might have a different lived experience. Another example is that the participants in this study are parents of a male son, the experience of parents of a female daughter may be different. Future work should seek to understand the views of a larger sample of parents. A larger participant pool would allow more details and examination of some of above noted key factors of this study, such as gender. The decision to purposefully limit the participants to the parents of one gay male with IDD is in a preceding chapter of this study. This small sample was used to ascertain preliminary information since no other United States studies were found to include individuals with IDD who identify as gay (Creswell, 2007).

An additional limitation of this study is that parents of individuals with IDD often describe vulnerability as a weakness of their son diagnosed with IDD, this typically leads to a feeling of protection (Dupras & Dionne, 2013). It is possible that the participants in this study felt the need to protect their son and may have presented a positive light on the life experience of their child. Sexuality is a very sensitive topic to address with parents.

East & Orchard (2014) state most parents rarely talk about sex openly, is only comfortable sharing small bits of information on sex and often stress over the talk when they do talk about sexuality with their children. The participants in this study were very open about their experience of sexuality and sexual orientation as it related to their son. As highlighted in the findings of this study, the parents were the first source to discuss and answer questions related to sexuality and sexual orientation for their son. The participants in this study were quite progressive in their views about sex and looked forward to seeing their son in a loving, committed relationship.

Recommendations

After review of the findings from this research study, including the interviews and resulting themes and subthemes. Recommendations for further examination should be for the following interventions. The first proposal should include more concise information regarding sexuality education curriculum for individuals with IDD. As reported on the findings of this research study, the curriculum should include practical ways to explore and develop relationships, including discussions on sexual orientation, and sexual health. As noted in the vignette, Parent 1 reviewed the sexuality education material with her son when he worked on worksheets as homework assignments, but stayed true to the curriculum presented because she did not know better. This opportunity appears appropriate to additionally include parents, and caregiver in sexual education classes that would teach proper ways to talk about sex and sexual orientation. The class curriculum should also include information on social media, dating sites and sex. Future research may consider developing an interactive curriculum that would allow for parents and caregivers along with the individual to participate in a sexual education curriculum together. This curriculum would address and intervene in real time, questions and comments thereby allowing the person with IDD to feel empowered about his sexual aptitude in the face of parents and caregivers. Thus taking away the protective role of both parties. This type of intervention may reduce the victimization rate for individuals with IDD.

The second recommendation is for group home agencies to require all personnel to attend sexuality and sexual education programs to understand better that people with IDD are sexual beings and that they too should be allowed to participate in the fundamental human right of having relationships, including sexual intimacy in that relationship. As reported on the findings of this research study, biases and personal opinions often direct group home coordinators to dissuade individuals with IDD from having intimate relationships. Thus future research may include home group facilitators be part of the participant pool.

The third recommendation is for future research with mental health professionals to have a broader understanding of sexuality and sexual orientation of individuals with IDD. The results of further knowledge may help impact the social stigma on intimate relationships and intimate sex as a way of having a fulfilled life for individuals with IDD.

This qualitative biographical study generated future questions related to sexuality and sexual orientation with persons with IDD, and they include: How should sexuality and sexual orientation curriculum differ from the intellectual developmental disabled community? How can sexual education curriculum meet the needs of those differences for individuals with IDD? Does sexual knowledge decrease the risk of sexual abuse and exploitation? How can sex education programs for people with developmental disability be evaluated? How can adding social media content to sexual education curriculum help individuals with IDD better navigate current trends of meeting people and dating?

Implications

The findings of this study provide and contribute to positive social change by supporting families and caregivers at the most practical level of sexuality education information. Offering the availability of information in a proactive way to discuss sexuality and sexual orientation with individuals with IDD, would not only fill the gaps in knowledge about sexuality and sexual orientation. It will also help to thwart any misconceptions on behalf of the parents, caregivers, and the individuals.

According to the results of this study, the current sexual education curriculum appears to be influenced by biases and misconceptions. The additional factors which seem to complicate this information are the missing component that individuals with IDD are sexless and do not wish to have intimate relationships. The recommendation is for more research to include people with IDD in these areas on a broader scale which would offer further understanding to the needs and benefits of sexuality education and sexual orientation information. The results of additional research would help to serve better the IDD community, their parents and caregivers. The finding of this study concur with

(Brantlinger 1985; Dupras & Dionne, 2013, Tharinger, et al., 1990) not much has changed in 30 years. The parents of individuals with IDD feel that special education programs lack the appropriate curriculum on sexuality education and sexual orientation, as evidenced by the above-noted vignettes and participants accounts.

Conclusion

As mentioned throughout this dissertation study there is no statistical data supporting how many individuals with IDD identify as LGBT. However, studies cite that using the same formula relating to the general population seems about right. That means that the findings of this study may impact 3.8 percent of individuals with IDD. As reported, support in relationship and understanding sexuality and sexual orientation is often outdated or nonexistent within the developmental disability community (Dupras & Dionne, 2013). Add in societal misconceptions and stereotypical beliefs that individuals with IDD should refrain from sexual experiences and the results translate to a misaligned misunderstood group of marginalized citizens in our society (Dupras & Dionne, 2013). Despite the fact that numerous research studies suggest that individuals with IDD experience feelings of wanting, acceptance, love, companionship, and intimacy (Parchomiuk, 2012; Dupras & Dionne, 2013; Kijak, 2013).

Furthermore, individuals with IDD have unique sexual health needs not met. Specifically, the denial to experience sexuality and intimacy by heightened external control of parents and caregivers. This control often limits the individual in his experience of intimacy resulting in the person having sex in inappropriate places and taking risks with his sexual health (Allen, 2012).

Updating the sexuality education resources available to parents and caregivers will offer current information about sexuality and sexual orientation that will help guide the sexuality discussion and interaction with their child (Picard & Morin, & De Mondehare, 2014; Dupras & Dionne, 2013). As noted in the theory of social constructivism, the experience of sexuality and sexual orientation is socially constructed by society’s views, and acceptance of intimacy among individuals with IDD is considered taboo (Cuskelly & Gilmore, 2007; Parchomiuk, 2012). This type of acceptance is not limited to the public, but also transcends from parents, caregivers and health care workers (Parchomiuk, 2012). Displeasure appears to intensify among the care people if the intimacy deepens (Owen et al., 2000; Parchomiuk, 2012). This displeasure is passed on to the individual with IDD and often results in the person feeling ashamed for wanting to kiss, hug and have an intimate sexual experience. (Owen et al., 2000). Some adults with IDD feel that some affection is acceptable, but anything more is wrong (Kijak, 2013; Morales, Lopez, & Mullet, 2011).

The experiences shared by the research study participants provided valuable information which may help support better information in sexuality and sexual orientation education. While that is important, the true essence of this study is that individuals with IDD want the same opportunity to experience love including a relationship that embraces intimacy. They want society to know that they are sexual beings and can experience sex and intimacy in the same way as the general population. Based on these research study results individuals with IDD may have that experience, through awareness, and opportunity, to explore their sexuality and sexual orientation as a fundamental human right.

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Appendix A: Letter of Invitation

Hello,

My name is I am a doctoral candidate at Walden University. I would like to invite you to be a part of a study relating to intellectual developmental disabilities and LGBTQ. The following information is provided for you to decide whether you wish to participate. You are free to decide not to participate or to withdraw at any time

The purpose of this study is to understand your sons lived experiences in relation to sexuality and sexual orientation, from your perspective. The procedure will be a single, biographical study design. Data will be collected at the first interview, including journal entries made by the researcher, audio material, interviews, and field notes, as well as artifacts that I will ask you to bring such as journals, photographers and mementos of your son. The study will require a commitment from you to meet with me at two separate interview times. The second interview will give you the opportunity to review the transcript of the audio tape recording, review it for accuracy, and ask questions. As a token of appreciation for participating in the study, you will receive a $25.00 gift card for each interview, as a thank you for participating in the study. Since the study will require a commitment from you to meet with me at two separate interview times, you will receive two (2) gift cards, one for each session. There are no known risks associated with the study.

Do not hesitate to ask questions about the study before, or during your participation. This study may help other parents, caregivers, and mental health clinician's better support curriculum for sexuality and sexual orientation education for intellectually and developmentally disabled individuals.

If you decide to participate in this study, you will meet in person with me, the researcher for a face-to-face interview. The first interview will take approximately two hours and the second interview will be approximately one hour, 4-6 weeks after the first interview.
During the first interview, you will be asked to bring artifacts, mementos, photos, diaries, or journals in relation to your son. This information will help the researcher collaborate your son's life experience through artifacts, as an additional form of data along with your biographical account of your son. The interview will be audio taped with your written permission. No information including your name will be associated with the research findings in any way, and only the researcher and research team members, which include my dissertation chairperson and committee member will know your identity as participants.

The expected benefits associated with your participation would help identify areas of need in sexuality education curriculum for intellectual developmental disabled individuals. If you would like to participate in this research study, please contact me at

Appendix B

IDD Sexuality Parent Participants Screener

Recruiting goals:
- The participants shall be a parent of an IDD gay male under the age of 65.
- The participants must be able to read and speak English
- The participants must be aware of their son’s sexual orientation
- Recruit for one participants, for a biographical design.

Scheduling
- The schedule: (Tentative)
- Saturday: ☐ 9:00 a.m.-11:00 a.m. ☐ 12:00 p.m. – 2:00 p.m. ☐ 3:00 p.m. – 5:00 p.m.
- Sunday: ☐ 12:00 p.m. – 2:00 p.m. ☐ 3:00 p.m. – 5:00 p.m.

Incentive
- Participants will receive a $25 gift cards for participation in the study interview.

Appendix D: Participants Screening Questionnaire

Hello, my name is I am a PhD student from Walden University. I am conducting a research study on sexuality and sexual orientation of intellectually developmentally disordered gay males from the parent's perspective. I will need to ask you some questions to be sure you are eligible to participate in this study. It will take about 10 minutes.

1. How old are you? ____years old
☐ If over 65 *Terminate-ineligible*
☐ If under 65 *Continue*

2. What is your race? *(Mark X one or more boxes) -- continue for all*
☐ White
☐ Black, African American
☐ American Indian or Alaska Native
☐ Asian,
☐ Multiracial
____
____

3. Are you a parent of a male child diagnosed with Intellectual Developmental Disorder?
___Yes *Continue*
__ No *Terminate-ineligible*

4. Does your son identify his sexual orientation as a gay male?
___Yes *Continue*
__No or ____Don't know *Terminate-ineligible*

5. Does your son live at home with you?
___No *Continue*
___Yes *Terminate-ineligible*

6. Would you be willing to share your experiences about your son, his sexuality, and sexual orientation?
____Yes *Continue*
____No *Terminate-ineligible*

9. Do you currently attend a parent support group at Rainbow Support Group?
___No *Continue*
___Yes *Terminate-ineligible*

10. Do you feel you are emotionally stable at this time?
On a scale of 1-10, where 1 is not stable at all and 10 you are feeling very stable?
___ 10-5 *Continue*
___ 4-0 Terminate-*ineligible*

11. Can you speak and read English fluently?
___Yes *Continue*
___No *Terminate-ineligible*

Terminate-ineligible:
Thank you for taking the time to talk with me today and for answering my questions. The research I am conducting requires the participants to fit in a particular category. The information you provided does not meet the criteria of the research study. Thank you again for your time and wanting to participate in this research study.

Eligible:
That is all of the questions I have for you today, thank you. Do you have any questions for me?

You have met the criteria for participating in my research study. The study would require that we meet face to face two times; the first time will be the actual interview and will last about two hours. The second time will be about 4-6 weeks later to review our first interview. You will be paid for your time at the end of each interview with a $25.00 gift card.

Do you have any questions about what I have shared so far?
Would you like to participate in this research study?
___Yes *Continue*
___No *Terminate-ineligible*

If yes, Schedule interview:
Does Saturdays or Sundays work best for you?

- Saturday: ☐ 9:00 a.m.-11:00 a.m. ☐ 12:00 p.m. – 2:00 p.m. ☐ 3:00 p.m. – 5:00 p.m.
- Sunday: ☐ 12:00 p.m. – 2:00 p.m. ☐ 3:00 p.m. – 5:00 p.m.

If for any reason you are unable to keep your appointment, please contact me at
If you change your mind and decide you do not want to participate, please contact me at a suitable time so I can find another study participant.

I would like to confirm our appointment a day or two before we meet. May I have a way to contact you?

Phone: ______________________

E-mail: _______________________

Appendix E: Interview Questions

Interviewee Code: ______ Date: _____ Interview 1 of 2

Estimated total interview time: 120 minutes

Introduction

1. Tell me about yourself (e.g., age, marital status, children, and education).
2. Tell me about your son's life during his early childhood?
3. Tell me about your son's education experience? (e.g., Did he attend public schools, or a school specific to developmentally delayed children).
4. Describe for me when your son learned about sexuality education?
5. Can you share with me what you taught him about sexuality?
6. How did the information affect him?
7. Can you recall a time your son shared with you any questions about sexuality?
8. About how old was he when he asked these questions?
9. Did your son come to you to share his understanding of his sexual orientation? If Yes, when? If No, how did you learn your son was gay?
10. Tell me about your son's sexual relationship experience?
11. Is your son in a relationship now? Is this relationship accepted among other members of your family?
12. Has your son asked you questions directly related to his relationship?
13. Is there anything else you would like to share about your son that I might have missed?

Appendix F: Study Debriefing Form

You volunteered to participate in A study of sexuality, sexual orientation, and intellectual developmental disorder: A parent's perspective, which included an audiotaped interview. During your initial interview, you were advised that your participation also included a debriefing about the study. As you know, the purpose of this study was to understand your sons lived experience of sexuality and his sexual orientation, as told by you his parent.

I shared with you all of the details of the study, however, you may think of a question later. If so please contact me, or you may contact my committee. If you want to talk privately about your rights as a participant, you can call the Walden University Research Participants Advocate who can discuss this with you at
It is the expectation of the researcher that this research study should not cause any mental health distress to you. However, if you have experiences of distress as a result of your participation in this study, please contact the
You will receive a copy of this debrief form from the researcher after the first interview. You will also receive an additional copy following the second interview.

Date: ____________________________ Time: ______________________________

Participants Name: ___________________________________ Date_______________

Participants' Signature: ____

Researcher's Name:
Researcher's Signature: ____

Would you like to know the results and be kept informed about this research study?
__No __Yes

What is the best way to contact you? __email? ___ mail?

Please provide your email or mailing address for contact purposes of the results:

____

Please initial and date below to confirm you received a gift card for participating in the study.

First interview, ______ I have received a $25 gift card today (___/__/__) for my participation in this study.

Appendix G

VOLUNTEER NEEDED FOR
RESEARCH STUDY OF A PARENT OF A GAY MALE DIAGNOSED WITH INTELLECTUAL DEVELOPMENTAL DISABILITY

A Walden University researcher is looking for a parent volunteer to participate in a research study. This research is specific to a parent of a gay male diagnosed with intellectual developmental disability.

As a participant in this study, you will be asked:

- To meet privately for two interviews with a researcher, the first interview will take about 2 hours, the second interview (about 2 weeks later) will take about an hour.
- Be willing to be audiotaped during the interview

If you are interested in this opportunity:

- You must be between the ages of 18-65
- You must speak and read English
- You must be a parent of a son that identifies his sexual orientation as a gay male and has been diagnosed with intellectual developmental disorder
- Your participation in this research will meet all confidentiality and privacy rules under the American Psychological Association ethics guidelines.

Although there may be no direct benefit for participating in the study, you may find your participation will help aid in developing curricula related to sexuality and sexual orientation for people with IDD. Should you choose to participate in the study you will receive a $25.00 gift card after each interview as a small token of appreciation for your time participating. If you are interested in taking part in this, study or have questions, please contact

This study has been reviewed and approved by the
Institutional Review Board, Walden University

Appendix H: Themes and Subthemes

Themes	Subthemes	Participant Pseudonyms
Lack of certainty and confusion about disability		
	Lack of certainty	Christine, Raoul
	Confusion over physical or mental disability	Christine
	Intelligence	Christine, Raoul
Early Childhood Peer Interaction		
	Early elementary school peer interaction (K-3)	Christine, Raoul
	Middle school peer interaction	Christine, Raoul
	Mixed messages concerning Diagnosis	Christine, Raoul
Sexual education, exploration and bullying		
	Sexual Education	Christine
	Sexual Exploration	Christine, Raoul
	Bullying	Christine
	Facebook artifact	Chrisitine, Raoul
Family communication and supportive family structure		
	School change	Christine, Raoul
	Home life change	Christine, Raoul
Coming Out		
	The moment of epiphany	Christine, Raoul
	Negative responses to sexuality	Christine

	Suicidal ideation	Christine
	Social boundaries	Christine, Raoul
	Integrating into the adult gay community	Christine, Raoul
	Facebook artifact	Christine, Raoul
	Dating	Christine, Raoul
Social media, privacy and safety		
	The Internet and social media	Christine, Raoul
	Myspace, Facebook	Christine, Raoul
	Privacy	Raoul
	Safety	Christine, Raoul
Additional Findings		
	Amazing Musician	Christine
	Narrowed Interest	Christine, Raoul
	Positive role models in the community	Christine, Raoul
	Participant in Special Olympics and community events	Christine