PARENTAL ROLES AND ATTITUDES REGARDING SEXUALITY AND INTIMATE RELATIONSHIPS: COMPARING ADULT CHILDREN WITH AN INTELLECTUAL DISABILITY TO THEIR TYPICALLY DEVELOPING SIBLINGS

By

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A DISSERTATION

Submitted to
Michigan State University
in partial fulfillment of the requirements
for the degree of

Human Development and Family Studies—Doctor of Philosophy

2019

ABSTRACT

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Despite the known benefits of experiencing healthy intimate relationships in adulthood, adults with intellectual disabilities (ID) are often denied these experiences. This occurs because of deficits in their sexuality education, as well as restrictions placed on them from parents and caregivers-limiting opportunities for sexuality expression and intimate relationships. High rates of abuse and exploitation that occur within this population can lead parents to use tools such as guardianship to maintain control over the sexuality education they receive and the types of interpersonal relationships in which their adult child can engage. However, such restrictions do not deter adults with ID from desiring intimate relationship experiences. Instead, restrictions frequently lead to secretive relationships, which often include abuse and exploitation. Although we understand these patterns, there is still a gap in our understanding of the role parents specifically play in their adult child's experiences of romantic relationships.

The purpose of this research project was to examine the role that parents play in the creation and maintenance of intimate relationships, as well as their experiences responding to the sexuality expression for their adult with ID. This was done by examining parents who have an adult child with ID, as well as a typically developing (TD) adult child, and comparing parental experiences between these two adult children. This study used a mixed methods design was used within this study including an online survey with 50 parents nationwide, and follow-up phone/video conferencing interviews with a subset of 20 parents from the survey. Both the survey and interview demonstrate parental experiences and perceptions regarding sexuality education, expression, and intimate relationship experiences for both of their adult children.

Study 1 examined the parental role in overall sexuality education and sexuality expression for adult children with and without ID. Parents elaborated on educational methods, as well as how they help their adult children develop positive sexuality expression and manage sexual behaviors. Findings from this study indicate that parents are more involved with their adult child with ID and struggle to determine the appropriate level of sexuality education they should be providing to them. Study 2 examined the parental role of helping their adult children with ID create and maintain intimate relationships in comparison to their TD adult children. Parents struggled to determine the appropriate level of involvement they should have in the romantic relationships of their adult child with ID, and voiced a strong need for coaching and mentoring parents in these areas. Both studies contribute to the knowledge base of sexuality expression and intimate relationships among adults with ID by further exploring the parental role, and the educational and training needs for parents trying to navigate these experiences successfully.

ACKNOWLEDGEMENTS

While writing these acknowledgements, with my completed dissertation in hand, it still feels surreal that my time as a graduate student at MSU is coming to an end. I have grown as both a scholar and a human during these last five years and have so many people I want to acknowledge for helping me on this journey. First and foremost, my husband Levi, without whom none of this would have happened. Your constant support and love (and even your pushing, nagging, and drill instructor tactics) are exactly what I needed to help me succeed, and I am so grateful you "hitched yourself to the Becca train". I am also so appreciative of my dog Argos—the best late-night study buddy and listener a girl could ask for.

I want to thank my parents, Maribeth and Steve, for all their love and support throughout my life. You always told me I can do anything I set my mind to, and I am so grateful to have parents who never once doubted me and have been my biggest supporters. Alongside my parents, I want to acknowledge my sister Jenn for her constant motivation, you will always be the Murphy to my Connor. Also, my brother Joe, being in academic competition with you throughout our lives has always pushed me in the exact right way, and to my future sister-in-law Kayla who helped with data collection, even though she didn't have to, just because she's amazing.

I am so grateful to have had the amazing mentors and support system that I had here at MSU. My advisor Sarah, I have learned so much from you and am so happy I had such a wonderful advisor who was not only supportive on an academic level, but on a personal one as well. I will forever be grateful that I had you on my team throughout this process, and to know that you will always be there to help support me throughout my career. I am also grateful to the rest of my committee—Adrian, Megan, and Brooke—for guiding me through this process and

taking my wild, overly ambitious ideas and showing me how I can actually make a difference with my research.

Alongside my committee, I am also thankful for all of the HDFS faculty who have helped mentor me over the years, answering the many questions I had and giving advice and tips. Especially the CFT faculty who not only guided me academically, but also as a therapist. I am forever grateful for the amazing therapeutic training I received; it has helped me in so many ways outside of simply being a therapist. I truly appreciate the amazing cohort of CFT students I had (Adam, Erica R, Erica N, Heather & Travis), it has been such a blessing having an amazing and supportive group of people to connect with. I am also thankful for two amazing women who I definitely would never have been able to get through this program without—Meg, I love your face, and Gaby, me encanta tu cara tambien.

I would also like to acknowledge the wonderful support I have received from my in-laws, Jeff and Terry; I honestly could not have asked for a better and more supportive family to marry into. As well as the rest of the Kammes clan, you guys are the craziest, but I have never once doubted you all have my back. I also want to send a thank-you to Rhonda, who has mentored me and been such an amazing and supportive person, I’m so glad we found each other.

I want to give a special thank-you to Alanna, the most amazing undergraduate research assistant. I can honestly say that this dissertation would never have been completed if it wasn’t for your help and support. I also want to acknowledge and thank my participants for being willing to talk about a topic that is not always easy to discuss with strangers. I appreciate your openness in sharing with me your struggles and stories. Finally, I would like to acknowledge the Dissertation Completion Fellowship I received from the College of Social Sciences that allowed me to conduct this research.

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CHAPTER 1: INTRODUCTION

Background of the Problem

The term intellectual disabilities (ID) refers to disabilities characterized by significant limitations both in intellectual functioning (reasoning, learning, problem solving) and in adaptive behavior, which covers a range of everyday social and practical skills, and originates before the age of 18 (AAIDD, 2019). An ID diagnosis is considered a life-long diagnosis as the individual tends to maintain overall limitations in functioning throughout their lifespan. In addressing the health and well-being of individuals with ID, social and romantic relationships, as well as healthy sexuality expression and experiences, are important yet often overlooked topics. Healthy interpersonal relationships in general provide economic benefits, physical health benefits, and psychological benefits such as decreased depression (Bates, Terry & Popple, 2016; Beckes & Coan, 2011; Moos, 2003; Robles, 2014). Individuals diagnosed with ID can also experience benefits from intimate and romantic relationships.

Intimate relationships and ID. Individuals with ID often face significant challenges developing and maintaining intimate and/or sexual relationships throughout their lifespan, which can lead to isolation, loneliness, and mental health challenges (Fulford & Cobigo, 2018; Koller, Le Pouesard & Anneke Rummens, 2018; Lafferty, McConkey & Taggert, 2013; Murray & Greenberg, 2006). Developing close relationships becomes even more difficult in adulthood as many of the support services received during childhood and adolescence disappear, along with the safety net of a school setting that provides built-in social experiences (Esbensen, Bishop, Seltzer, Greenberg & Taylor, 2010; Fulford & Cobigo, 2018; McGillivray & McCabe, 2007).

Adults with ID may also experience impoverished intimate relationships due to restrictions placed on them by others (English, Tickle, & dasNair 2018; Fulford & Cobigo, 2018;

Whittle & Butler, 2018). These restrictions often come from rules imposed within supported living environments (Fitzgerald & Withers, 2011; Hollomotz & The Speakup Committee, 2008; Kelly, Crowley & Hamilton, 2009), rules enforced by parents, caregivers, and legal guardians (Rushbrooke, Murray & Townsend, 2014; Sullivan, Bowden, McKenzie & Quayle, 2013; Sullivan, Bowden, McKenzie & Quayle, 2016; Turner & Crane, 2016), or social norms and restrictions from society as a whole (Bernert, 2011; Bernert & Ogletree, 2013; Healy, McGuire, Evans & Carley, 2009; Johnson, Minogue & Hopklins, 2014). Research has noted that parents and guardians especially tend to place limitations on the type and amount of social experiences for adults with ID (Azzopardi-Lane & Callus, 2015; Stoffelen, Kok, Hospers & Curfs, 2013). In a study by Yacoub and Hall (2009), adults with ID reported that limits placed on them by parents and guardians impacted their social experiences the most. This impact can be especially profound in influencing their access to intimate and romantic relationships. This is largely because the social networks of adults with ID consist mostly of family, staff, and the networks that those individuals bring with them (Esbensen, et al., 2010; Fulford & Cobigo, 2018; Petner-Arrey, Howell-Moneta & Lysaght, 2016). Parents and caregivers play a large role in the social networks of these adults, so any restrictions often lead to deficiencies in intimate and romantic relationships.

Restrictions within intimate relationships. Parents and other legal guardians not only place restrictions on the actual experiences the adult may have, but often restrict the individual's knowledge and awareness related to intimate relationships as well (English et al, 2018; Whittle & Butler, 2018). If an adult with ID does not have guardianship of themselves, it is often the biological or adoptive parent who has guardianship. Sometimes another family member or a court appointed carer may have guardianship (Millar, 2007). However, biological or adoptive parents most commonly have guardianship, so the term parent is used to designate those with guardianship throughout this study. Many parents avoid discussions of sexuality and romantic relationships with their children with ID due to a lack of appropriate resources (Greydanus & Omar, 2008), the belief that if they do not discuss the topic that their child will not engage in sexual practices (Pownall, Jahoda, Hasting & Kerr, 2011), or the belief that their child's disability limits their desire to participate in sexual or romantic relationships (Lund & Johnson, 2015). Parents may also restrict access to knowledge about intimate relationships and sexuality by restricting other caregivers from engaging in conversations with adults with ID regarding these topics (Brown & Pirtle, 2008). This often leads to a large gap in sexuality and romantic relationship knowledge on the part of the individual with ID, which can influence adult experiences. Foley (2012) emphasized this phenomenon when he noted that parents of adults with ID often describe themselves as "reluctant jailors" who feel a responsibility to restrict the social relationships of adults with ID in order to shield them from negative experiences.

Despite these overt boundaries that limit intimate and sexual experiences and knowledge for adults with ID, many still express a desire to have intimate relationships (Healy et al., 2009; Kelly et al., 2009; Rushbrooke et al., 2014; Turner & Crane, 2016). However, the conflict between their desire and imposed restrictions from parents often leads to secretive relationships (Fitzgerald & Withers, 2011; Healy et al., 2009; Hollomotz & The Speakup Committee, 2008; Rushbrooke et al., 2014). Unfortunately, these secretive relationships are frequently inappropriate and exploitative (Hollomotz & The Speakup Committee, 2008). As a result, adults with ID, especially women, experience higher rates of sexual abuse, sexual exploitation, and intimate partner violence (Stavis, 1991; Ward, Bosek & Trimble, 2010; Yacoub & Hall, 2008). This risk is exacerbated by the lack of knowledge adults with ID have of healthy and unhealthy relationships, and a fear of punishment if they discuss experiences with others (Bernert, 2011; Bernert & Ogletree, 2013; Johnson et al., 2014).

The role of parents. Because parents play such a key role in the lives of individuals with ID, they have the greatest influence in restricting the intimate relationship experiences and knowledge. Often adults with ID require support and supervision in multiple facets of their lives that go beyond those required by typically developing (TD) adults (Lunsky, Robinson, Blinkhorn & Ouellette-Kuntz, 2017; Rowbotham, Carroll & Cuskelly, 2011; Yoong & Koritsas, 2012). Supports might be required in the areas of employment, transportation, and daily living (Lunsky et al., 2017; Rowbotham et al., 2011). As such, parents play a greater role in the lives of their adult children with ID than TD adult children. This may be especially true regarding sexuality education and intimate relationships, in which parents often serve as supervisors of knowledge and experiences (Foley, 2012).

Because of the increased impact parents have in the lives of adults with ID, there is a pressing need to train parents and other primary caregivers in strategies that can support adults with ID in intimate relationship experiences (Berkson & Romer, 1980; Berkson, 1981). Newton and colleagues (1994) suggested a model for how service providers and caregivers can help adults with ID improve their social lives by introducing them to friends and teaching social skills alongside more traditional health and safety skills. Some programs have already begun to engage in providing these supports and initial results are positive. For example, Ward and colleagues (2013) created a program aimed at teaching healthy social and romantic relationships to adults with ID. Their program increased the size of the adults' social networks and decreased the number of violent interpersonal incidents.

Purpose of the Study

Although parents are crucial to ensuring positive intimate relationship experiences for adults with ID, little is known about the role they play in the intimate relationships of their adult family members with ID. Further, little is known about how parent attitudes and opinions impact these intimate relationship experiences. One way to examine this impact directly is to explore the experiences parents have with their adult with ID and compare these to their experiences with a TD adult sibling to see how they differ. Therefore, the goal of these studies is to explore the parental role in creating and maintaining intimate relationships for adult children and explore how parental attitudes regarding intimate relationships and sexuality impacts the parental role and the communication parents have with adults with ID compared to TD adults.

Theoretical Perspectives Guiding the Study

Three theoretical perspectives on the role that parents play in the development of sexuality expression and romantic relationships for adults with ID inform these studies. The social model of disability (Oliver, 1983) provides an understanding of disability in a social context and within social relationships. The parental straddling theory (Johnson, 2000) offers insight into how parents of children with disabilities perceive their role living in both the world of “normality” and the world of “disability”. Systems theory (Whitchurch & Constantine, 1993) examines the family unit and how relationships between family members impact individual development and experiences.

The social model of disability. This theory originally developed out of human rights activism, as a counter to the medical model of disability (Oliver, 1983), which examines disability solely as a medical issue and therefore relies on an individualistic approach. Conversely, the social model of disability focuses on societal labels of disability, and the social oppression and exclusion that results when one has a disability label (Anastasiou & Kauffman, 2013; Berghs, Atkin, Graham, Hatton & Thomas, 2016; Hughes, 2010). The theory emphasizes how social and environmental factors impose limitations upon individuals with disabilities, rather than simply focusing on the physical or cognitive limitations of the individual (Hughes, 2010; Oliver, 1983; Oliver, 2013). Disability, therefore, is viewed through society's social constructs with the aim of examining how ideas, values, and judgments about disability are passed down through generations and lead to oppression and prejudice about the social desires and capabilities of adults with ID (Anastasiou & Kauffman, 2013; Hughes, 2010). The conceptual framework focuses on how individuals with disabilities can find and engage allies—those who help fight the stereotypes and oppression of individuals with disabilities in society—within support systems (Campbell & Oliver, 1996), and support the inclusion of individuals with ID in all aspects of life (Berghs et al., 2016; Kattari, Lavery & Hasche, 2017).

The social model of disability aids in the understanding of intimate relationship experience for adults with ID because of its focus on social and environmental factors (Kattari et al., 2017). Social and romantic relationships rely on the ability to experience relationships and adult life in ways akin to TD adults (Berghs et al., 2016; Goering, 2015; Kattari et al., 2017). As the theory posits, individuals with ID are capable of experiencing social and romantic relationships but are often denied the experience due to familial and societal restrictions (Burchardt, 2004; Kinn, 2016). Although societal factors do influence intimate relationship experiences for TD adults, their experiences are often more individualized and self-controlled. In contrast, the social model of disability posits that social relationships and experiences for adults with ID, including sexuality and intimate relationships, are impacted by the individual's experience of their disability, their identity in society, and by other environmental factors.

Parents are thought to largely influence these experiences because their involvement influences the intimate relationship experiences for adults with ID. Parents may not only serve as an advocate for the intimate experiences of their family member, they may also play a different role within those relationships compared to TD adults. Parents have likely experienced the societal and environmental barriers their adults with ID face. Understanding of these barriers will help guide discussion of the role parents play in creating and maintaining these experiences.

The parental straddling theory. This parenting theory originally developed to aid in understanding the parenting experiences of mothers who have a child with a disability (Johnson, 2000). The theory places emphasis on the parenting feeling of "straddling" two different worlds: the world of "normality" and the world of "disability". Straddling occurs on three levels (Johnson, 2000). In the first level, parents straddle living simultaneously in the past *and* the present. Individuals with disabilities tend to develop differently than TD peers, and parents find themselves celebrating milestones they were unsure their child would ever meet. At the same time as the child continues to develop and grow, the parent must always remain in the present dealing with current responsibilities and developmental concerns. This leads to parents straddling their recollections and celebrations of previous developmental milestones, while also struggling with current lingering concerns. In the second level parents straddle thinking of their child as "normal" and trying to help the child live "typically", all while remaining keenly aware of their child's disability and actively pursuing special services for their child. In the third level, parents straddle attending to their child's issues and feelings, while simultaneously attending to their own increased stress and emotions that come from parenting a child with a disability.

Although the parental straddling theory was originally created with mothers of young children in mind, it is a useful way to conceptualize parents of adults with ID as they often serve as lifelong caregivers and continue to experience the three levels of straddling. For example, within sexuality expression and intimate relationship experiences of adults with ID, parents may experience all these levels of straddling. The straddling experience of living in the past and the present might include a recognition of their child's status as an adult with a remembrance of the struggle their child faced to reach developmental milestones. This may lead to protective feelings and instincts. This can also be impacted by the fact that the adult's development of sexuality and intimate relationship interest, knowledge, and desire may be delayed. If this development occurs later than expected for TD adults, it may be difficult for parents to continuously alter their perception of their adult child. Within the second level of straddling, parents might be striving to view the adult with ID as "normal", wanting them to have typical intimate relationship experiences, but also recognizing the label of "disability" and restricting these experiences for fear of negative encounters. In the third level of straddling parents may understand the emotions, experiences, and desires of their adult with ID related to sexuality and romantic experiences, while simultaneously understanding their own feelings and stress of wanting to protect their child, and balancing the pressure they feel to help facilitate these experiences for the adult with ID.

Systems theory. This theory examines systems and how they interact with one another (Whitchurch & Constantine, 1993). This theory has commonly been applied to the family system, providing an understanding of the functioning of a family as a unit, and examining how that unit also impacts individual development (Smith-Acuña, 2011). Systems theory offers an understanding of the processes that families experience and how those processes impact each member of the family (Taylor Sutphin, McDonough & Schrenkel, 2013; Whitchurch & Constantine, 1993). Adults with disabilities are more enmeshed within their family of origin, and family members play larger roles in support and care (Hill-Weld, 2011). This includes parents and caregivers, siblings, and often times extended family such as grandparents. It is important to fully understand the family system and conduct research systemically to make lasting change for adults with ID (Swango-Wilson, 2010).

When applied to families, systems theory helps provide a way to examine the unique relationships that occur when a family member has ID, and how adaptions in one part of the family system impacts the entire system (Hill-Weld, 2011; Swango-Wilson, 2010; Whitchurch & Constantine, 1993). In the case of families with a family member who has ID, the family system often shifts specifically to accommodate the needs of that family member (Hill-Weld, 2011; Swango-Wilson, 2010; Whitchurch & Constantine, 1993). Parents may need to be more involved in the lives of the individual with ID, and this can impact their relationships with other family members, especially siblings of the individual with ID. Given the focus of this study specifically on examining differing parental roles and attitudes regarding adult children with ID compared to TD adult children, systems theory provides a unique understanding of how these relationships differ across multiple domains. Parents may have experienced these unique family dynamics and the ways in which they have adjusted to their role as caregiver of an individual with ID will likely impact how they interact with other adult children, including the level of involvement they have in their lives, and their understanding of sexual and intimate relationship experiences.

Chapter Summary

It is clear that parents play a much larger role in the daily lives of their adult child with ID. This is especially apparent when examining the social and romantic relationships and experiences of these individuals. However, there is a need to understand the type and level of involvement parents have in supporting adults with ID as they create and maintain intimate relationships. There is also a need to explore how the parental attitudes and opinions impact these experiences. Such understanding can help inform interventions and strategies to ensure individuals with ID have healthy intimate relationship experiences. Therefore, Study 1 (Chapter 2) will examine the parental role in overall sexuality education and sexuality expression for adults with ID by comparing experiences for parents who have an adult child with ID and a TD adult child. Study 2 (Chapter 3) will examine the parental role in helping adults with ID create and maintain romantic relationships by comparing experiences for parents who have an adult child with ID and a TD adult child.

Using a convergent mixed methods research design, each study provides further exploration of the role of the parent within sexuality and romantic relationship development for adults with ID, with an aim to inform sexuality education practices for these individuals. Specifically, Study 1 identifies the role that parents play in providing sexuality education to adults with ID, and what methods parents have found most impactful. It will also explore how parents help individuals with ID develop positive sexuality expression, and the parental role in managing sexual behaviors and expression individually and within relationships for adults with ID. Study 2 explores interpersonal relationship experiences and identifies how parents help adults with ID create intimate and romantic relationship opportunities, coach them through relationship experiences, and help maintain these relationships. Further, it examines the barriers parents feel adults with ID face related to romantic relationships, and how issues of sexual abuse and vulnerability impact relationship experiences. Together, these studies contribute to increasing our awareness of the lived experiences of adults with ID and the important impact that parents have. They highlight the gaps in parent knowledge and training, which can inform the creation and implementation of sexuality and intimate relationship education for adults with ID.

CHAPTER 2: PARENT PERCEPTIONS AND SUPPORT FOR SEXUALITY EDUCATION AND EXPRESSION FOR ADULTS WITH AN INTELLECTUAL DISABILITY

Abstract

When referring to the health and well-being of adults with intellectual disabilities (ID), their sexuality expression and experiences are often ignored. Adults with ID often have deficits in their sexuality education, and experience restrictions from parents and caregivers exploring their sexuality. The control parents exert often stems from fear of the high rates of exploitation that occur within this population. However, parental control does not deter adults with ID from desiring sexual experiences, and instead often leads to secretive and potentially exploitative relationships. While this pattern is recognizable, we lack an understanding of the impact of parental attitudes on sexuality education and expression for adults with ID. The current study examines parental experiences attending to sexuality education and sexuality expression for adults with ID. This was done by comparing experiences of parents who have an adult child with ID and a typically developing (TD) adult child. A mixed methods design was used within this study including an online survey with 50 parents nationwide, and follow-up phone/video conferencing interviews with a subset of 20 parents. Findings from this study indicate that parents are more involved with adults with ID and struggle to determine the appropriate level of sexuality education they should be providing to individuals with ID. Findings add to our understanding of the important role of the parent, and provides insight into training to support parents as they navigate these experiences.

Introduction

In addressing the health and well-being of adults with intellectual disabilities (ID), healthy sexuality expression and sexual experiences are important yet often overlooked subjects (Fulford & Cobigo, 2018; Koller et al., 2017; Lafferty et al., 2013; Murray & Greenberg, 2006). Gaining sexuality knowledge and education, as well as having the ability to express individual sexuality in a healthy way, is an important part of adult life. Unfortunately, most adults with ID significantly lack proper sexuality education and are often restricted from having these experiences or from any form of sexuality expression. Sexuality expression refers to any way in which an individual expresses their sexual knowledge or feelings. This could include topics such as an individual expressing to whom they feel sexually attracted, masturbation, and sexual practices within a relationship. Sexuality expression is strongly influenced by a lack of understanding of the sexuality of individuals with ID (Gardiner & Braddon, 2009; McCarthy, 2011), as well as societal concerns around vulnerability and protection of individuals with ID (Ward et al., 2010). Despite these concerns, individuals with ID can gain physical health, mental health, and interpersonal relationship benefits from proper sexuality education and instruction on healthy sexuality expression.

Arguably the most important people in the lives of adults with ID are their parents (Pownall, Jahoda & Hastings, 2012). Parents play a significant role in the daily routines of adults with ID, especially related to discussions around sexuality education and expression. Parents are often the main sources of support for adults with ID (Foley, Bourke, Leonard & Girdler, 2014), and have the most input into the types of experiences in which adults with ID can participate. Unfortunately, many parents restrict experiences related to sexuality expression, and place restrictions on the individual’s knowledge and awareness related to sexuality (English et al, 2018; Whittle & Butler, 2018). This avoidance may occur because of a lack of appropriate resources (Greydanus & Omar, 2008), the belief that a lack of sexuality discussion for individuals with ID will result in a reduced desire to engage in sexual practices (Pownall et al., 2011), or the misguided belief that their child's disability limits their sexual needs or desires (Lund & Johnson, 2014). These parental beliefs and behaviors often lead to a large gap in sexuality knowledge as the child with ID enters adulthood.

Despite overt boundaries parents may place that limit sexual experiences and knowledge for adults with ID, most of these individuals still have sexual needs and desire the ability to explore their own sexuality expression, either interpersonally or individually (Healy et al., 2009; Kelly et al., 2009; Rushbrooke et al., 2014; Turner & Crane, 2016). Unfortunately, this struggle between their desire for experiences and restrictions or lack of information from parents can lead to secretive relationships which are often inappropriate and abusive (Hollomotz & The Speakup Committee, 2008). As a result, adults with ID, especially women, experience higher rates of sexual abuse and exploitation (Stavis, 1991; Ward et al., 2010; Yacoub & Hall, 2008). This risk is exacerbated by the lack of knowledge adults with ID have regarding healthy sexuality expression and education, and a fear of punishment if they discuss their desires and experiences with others (Bernert, 2011; Bernert & Ogletree, 2013; Johnson et al., 2014).

Because of the significant role of parents, both as sexuality educators for their children and the role they play in the daily lives of adults with ID, there is a distinct need to further understand how parents view their role in the continued sexuality education of their adult with ID, as well as their role in helping them explore and manage their own sexuality expression.

Overview of Sexuality Education for Adults with ID

Sexuality plays a unique and fundamental role in adult experiences and is considered an important factor in leading a healthy life (Diamond & Huebner, 2012). Despite the known benefits that sexual health education has on both individual health and future interpersonal relationships (Tolman & McClleland, 2011), there is a lack of proper education and information within the general population (Barr et al., 2014). However, for individuals with ID this is amplified as sexuality education is often skipped or minimally covered in special education curricula (Brown & McCann, 2018). Many students with ID leave high school without receiving any type of sexual health education (Kelly et al., 2009; McCabe, 1999; Tarnai, 2006). This has extended ramifications as individuals with ID transition into adulthood. When adults with ID share their sexual education experiences, most individuals express dissatisfaction with their previous education and sexual knowledge. Gil-Llario and colleagues (2018) found that among 360 adults with ID, 89.4% desired more sexuality knowledge and conversations around sexuality. Despite increased vocational and adaptive behavior programs aimed at expanding previously unmastered skills, there is still a distinct lack of sexual health education for adults with ID (Chrastina & Vecerova, 2018; Graff et al., 2018; Richards, Miodrag & Watson, 2006).

Stakeholders involved in teaching about sexuality. One of the reasons sexual health education may not occur for individuals with ID is that stakeholders (e.g. parents, educators, therapists) often believe that other stakeholders should be responsible for such discussion. It is most often thought that parents should be the primary source of sexuality education, however parents report a lack of knowledge and expertise to do so (Ballan, 2004; Greydanus & Omar, 2008) and feel unsupported by teachers in this area (Nichols & Blakeley-Smith, 2009). Furthermore, parents, teachers, and carers often avoid the topic of sexuality until an issue occurs, such as a potential abuse situation or inappropriate behaviors on the part of the individual with ID (Schaafsma, Kok, Stoffelen, Van Doorn & Curfs, 2014). Lack of training and education for parents and other carers on how to discuss sexuality with their child with ID is cited as the primary reason parents avoid these discussion (Chrastina & Vecerova, 2018; Dupras & Dionne, 2014). Parents also indicate not knowing which professionals they should contact for support, or how to best reach out to them to meet their child's needs (Nichols & Blakeley-Smith, 2009).

Despite hesitancy, parents recognize their role in the sexuality education of their child with ID. Pownall and colleagues (2012) highlighted that mothers recognize this responsibility, but lack confidence and feel unprepared to fulfill this role. Isler and colleagues (2009) found that among 40 parents of young adults with ID, the majority felt they did not have the education or training needed to teach their child about sexuality, and this caused them to avoid the topic. Furthermore, parents have shared that they did not know how to tailor sexuality education based on their child's needs (Dupras & Dionne, 2014; Pownall et al., 2012) something with which parents of typically developing (TD) children also struggle (DiIorio, Pluhar & Belcher, 2003). Other research highlights the challenges parents of children with Autism Spectrum Disorder (ASD) face in communicating with their child around sexuality when significant behavioral concerns are present (Holmes, Himle & Strassberg, 2016).

Both parents and the adolescent find it hard to discuss sexual matters together (Pownall et al., 2011). These discussions between parents and children are often difficult and emotional (Pownall et al., 2012). Parents tend to focus on biological components of sexuality education (e.g. puberty) and avoid topics related to relationships (e.g. safe sex and intimacy; Pownall et al., 2012). As a result, many individuals with ID, especially women, report gaining sexuality education from their own experiences and from other women with ID, despite the same lack of education and gaps in knowledge (Gomez, 2012).

Societal attitudes and assumptions regarding sexuality. Another cause of inappropriate or lacking sexual health education for individuals with ID comes from societal attitudes, especially attitudes from those living and working with these individuals. Berman and colleagues (1999) report that when it comes to sexuality education for individuals with a disability, negative societal attitudes can be a bigger barrier than the disability itself. Myths and prejudices related to individuals with ID still exist within society and continue to influence access to appropriate education (Gardiner & Braddon, 2009; McCarthy, 2011). This has resulted in a culture in which many parents of individuals with ID avoid topics of sexuality or ascribe to abstinence only approaches, believing that discussions of sexuality will only increase interest and participation in sexual activities (Berman et al., 1999; Cheng & Udry, 2002; Evans, McGuire, Healy, & Carley, 2009; Sinclair, Unruh, Lindstrom & Scanlon, 2015; Swango-Wilson, 2009).

Even when sexuality education is provided to individuals with ID, it is often inappropriate and not comprehensive (e.g., focus on biological factors only; Murphy & Elias, 2006; Pownall et al., 2012). Conversely, sexuality education for TD individuals is often done with the assumption that sex and intimate relationships are important and normative for development (Tolman & McClelland, 2011). Historically, individuals with ID have been viewed as “eternal children”, “different”, and “other”, and have therefore been separated from the mainstream and often denied sexual rights (Swango-Wilson, 2010; Wilson, Parmenter, Stancliffe & Shuttleworth, 2011). These individuals have been consistently sexually repressed and ignored because of fear of the different ways in which they understand the world around them, especially how they process, learn, and experience sexuality (Gomez, 2012; Richards et al., 2006).

When it comes to sexuality, an individual with ID is often seen in one of two ways: 1) as a social threat that must be segregated, or 2) as a socially vulnerable individual with no skills to survive on their own (Block, 2000). Often it is believed that these individuals cannot have the same experiences as those without ID because of their cognitive capabilities (Gomez, 2012). Furthermore, because of assumptions that individuals with ID do not fully understand sexual feelings and expression, they are often taught that sexual exploration, even if done in private, is "wrong" (Tarnai, 2006). Individuals with ID are looked at as "conditionally sexual" (Wilson et al., 2011) meaning that due to the developmental capacity of the individual the body's basic hormones and processes are what drive their sexual nature, not a cognitive and emotional understanding of sexuality or sensuality. The general belief is that if the topic of sexuality is avoided or repressed with these "conditionally sexual" beings, they will not experience problems with sexuality (Wilson et al., 2011).

Sexual education curriculum for individuals with ID. The focus of most curricula for younger individuals with ID tends to be on anatomy, personal sexual health, and hygiene. In adulthood, the focus often shifts to avoidance of abuse and exploitation (Blanchett & Wolfe, 2002; Frawley & Wilson, 2016; Kelly et al., 2009; Richards et al., 2006; Yau, Ng, Lau, Chan & Chan, 2009). Despite the knowledge that sexuality education is most effective when done in the context of human relationships (SIECUS, 2004), there is a distinct lack of relationship education and discussion within sexuality education programs, which increases the risk of harm for individuals with ID (Shakespeare, 2000; Swango-Wilson, 2011). Martinello (2014) discusses how significant gaps in sexual knowledge for children with ID put them at a higher risk, and states that these risks continue into adulthood. In a study examining the outcomes of sexual health education for individuals both with and without ID, Baines and colleagues (2018) followed a group of young adults from the age of 13 to 20 who had received sexuality education through school. They found that the individuals with ID were less likely than their TD peers to have had sex by the age of 20, but those that did were more likely to engage in unsafe sex due to lack of knowledge of safe sexual practices. Despite the low rates of sexual experiences, females with ID had higher rates of unwanted pregnancies than their TD peers. Furthermore, sexual abuse, exploitation, and intimate partner violence has been found to be related to a lack of proper sexual health education including discussion of interpersonal relationships (Ward et al., 2010).

The Role of Parents and Primary Caregivers in Adulthood

Parents and primary caregivers play a critical role in the lives of adults with ID. Often, the individual with a disability is more dependent on the parent and other family members and dependent for far longer than their TD peers or siblings (Pownall et al., 2012). As such, parents of children with ID are considered “lifelong caregivers” because their parental duties do not lessen as their child moves into adulthood. Parents of individuals with ID are often responsible for helping their adult child find gainful employment, lead social lives, and conduct everyday tasks such as driving to work and doing laundry (Cheak-Zamora, Teti & First, 2015). When asked about the role their parents play in their lives, adults with ID describe relying on them as their main source of physical, emotional, and social support (Foley et al., 2014).

The role of parents compared to TD adult children. The impact of family, especially parents, has been shown to be much greater for adults with ID than a TD population (Evans et al., 2009; Healy et al., 2009). When comparing the experiences parents have with their children with ID to the experience of a parent with a TD child, one of the most obvious differences in adulthood is guardianship. In most cases parents maintain legal rights for adults with ID (Millar, 2007). For their TD siblings, however, parental guardianship ends at 18 and these individuals gain their own legal rights. Guardianship provides parents of individuals with ID with the legal right to control their individual's life including finances, employment, and living arrangements (Stancliffe, Abery, Springborg & Elkin, 2000). While there are differing levels of guardianship, most parents of adult children with mild to moderate ID maintain full guardianship (Millar, 2008). Even in instances where an adult with ID lives in a group home or other assisted living outside of the parental home, parents retain control over the social activities in which adults with ID can participate, as staff are unable to take individuals outside of the home without guardian permission (Azzopardi-Lane & Callus, 2015; Stoffelen et al., 2013; Yacoub & Hall, 2009).

Parents are involved with adult children with ID differently than TD adults. This is true not only in terms of how much control they retain due to guardianship, but also the types of activities in which they are involved. For example, a parent may help a TD adult child search for a job by looking for job postings with them or editing their resume. For an adult child with ID, the parent may call employers to see if they work with individuals with disabilities, attend employment interviews, and/or advocate for the individual with ID if they require accommodations in the workplace (Rowbotham et al., 2011). Another area where differences are noted is in parental involvement in social and intimate relationships. While most TD adults in U.S. and European cultures tend to form friendships and romantic relationships without the involvement of their parents, adults with ID often need support from parents to facilitate these relationships (Cheak-Zamora et al., 2015).

Parents as supervisors of sexual and intimate relationship experiences. When it comes to sexual health education for any population, parents are considered the best educators for their child (Gossart, 2002; Shtarkshall, Santelli & Hirsch, 2007; SIECUS, 2004). This is especially true for parents of individuals with ID. Although siblings and peers could play a role in the social teaching of sexuality for an individual with a disability, this is often thought of as a burden to those individuals (East & Orchard, 2014; Jahoda & Pownall, 2014). In addition, parents worry about their child with ID learning about sexuality from someone who does not know how to tailor the message based on their child's needs, and individuals with ID often lack the types of peer relationships that would provide social forms of sexuality education. This, coupled with insufficient sexuality education in school, leads to parents as the main source of sexuality knowledge (Swango-Wilson, 2010).

Aside from being the main source of sexuality knowledge, parents of adults with ID are also more involved in the intimate relationship experiences of the individual (Chrastina & Vecerova, 2018; Foley, 2012). Much of this can be attributed to the level of control guardianship affords to parents (Azzopardi-Lane & Callus, 2015; Stoffelen et al., 2013; Yacoub & Hall, 2009), and parental views on how an ID diagnosis impacts an individual's ability to engage successfully and safely in sexual experiences (Brown & McCann, 2018; Cuskelly & Bryde, 2004). Parents are often able to make decisions on the dating activities in which the individual can participate (Azzopardi-Lane & Callus, 2015; Fitzgerald & Withers, 2011; Johnson et al, 2014; Kelly et al., 2009; Rushbrooke et al., 2014), what level of privacy they can have with others (Healy et al., 2009; Hollomotz & The Speakup Committee, 2008; Rojas, Haya & Lázaro-Visa, 2016), and when and what types of contraceptives they can use (Frawley & Wilson, 2016; Kelly et al., 2009). In these ways' parents of individuals with ID act as the supervisor to their child's sexual life, and have ultimate say on their exposure to different experiences (Foley, 2012).

In their role as a supervisor, too often parents withhold sexuality education or unsupervised social contact for fear of abuse and as a means to protect their child (Brown &

McCann, 2018; Murphy & Elias, 2006; Pownall et al., 2012). Increased inclusion in the community, increased levels of independence, and more prominent visibility due to integration can also have the adverse effect of amplifying the vulnerability of a person with ID and result in increased rates of abuse and exploitation within this population (Bernert, 2011; Swango-Wilson, 2009; Ward et al., 2010). Parents recognize this, and work to avoid these experiences for their child with ID by placing heavy restrictions on their experiences (Healy et al., 2009; Löfgren-Mårtenson, 2004; Murphy & Elias, 2006). While avoidance of abusive experiences is an important consideration, placing heavy restrictions without input from the individual ultimately impacts the self-determination and independence of adults with ID regarding sexuality expression (Brown & McCann, 2018).

Research Questions

Given the challenges that individuals with ID face related to sexuality and the important role of parents in their lives, this study aimed to examine how parental attitudes and experiences towards sexuality differ between their adult child with ID and their adult child without ID. The following research questions were posed:

1. How do parent attitudes towards sexuality education and expression differ in relation to their adult child with ID and without ID?
2. How does communication around sexuality differ for parents of individuals with ID and without ID, including type and amount of communication?
3. What barriers do parents perceive for adults with ID in experiencing healthy sexuality education and expression?

Methods

A convergent mixed methods research approach (Creswell & Creswell, 2018; Greene, 2007) was selected for this study to provide an in-depth understanding of the experiences and attitudes of parents towards the sexuality education and sexuality expression of their adult child with ID. Through this design, data were collected using two different measures (i.e. quantitative survey, qualitative interview), analyzed separately, and then merged together for the purposes of development and complementarity (see Figure 2.1; Creswell & Creswell, 2018; Greene, 2007). In a mixed methods design, both quantitative and qualitative methods are used because of their complementary strengths and non-overlapping weaknesses (Creswell & Creswell, 2018). The use of both quantitative and qualitative methods helps amplify the voices of participants and allows for a deeper exploration of lived experiences (Creswell & Plano-Clark, 2011; Greene, 2007).

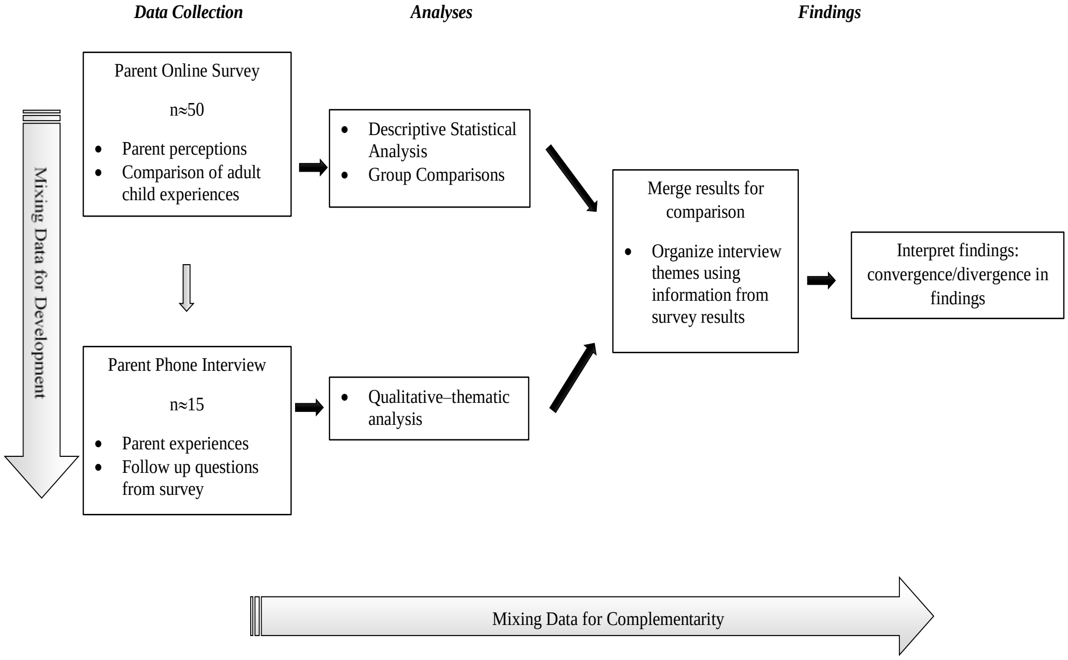

Figure 1.1 Data Collection, Analysis, and Interpretation Procedures

Participants

Recruitment. Following Institutional Review Board (IRB) approval, potential parent/caregiver participants were identified through contact with national and local agencies and organizations that support adults with ID. Listservs, along with partner agencies, were sent an email with a flyer that provided an overview of the study, participation requirements, and a link to the online survey. Organizations were asked to share the flyer with eligible parents. The flyer can be found in Appendix A.

Interview participants were gathered through the online survey. Parents who indicated a willingness to be interviewed in their survey were contacted via phone or email. The researcher explained the interview process and research questions (e.g. length of interview, types of questions in the interview guide), the consent and confidentiality process (e.g. audio recordings, connection of interview to survey answers), and gave participants a chance to ask questions. If they were still willing to be interviewed, the researcher set up a date, time, and method (i.e. phone or video conference) for the interview.

Inclusion and exclusion criteria. Parents/caregivers were eligible to participate if they were the: 1) biological parent or legal primary caregiver to an adult with an ID diagnosis between the ages of 18-35; and 2) biological parent or previous legal primary caregiver to an adult without an ID diagnosis between the ages of 18-35. Parents/caregivers were excluded from participation in the study if they: 1) had a diagnosis of an ID; 2) did not speak/understand English fluently; and 3) did not currently reside within the United States.

Study Measures

Data collected from this study answered parallel research questions and were collected simultaneously (Creswell & Plano-Clark, 2011). Quantitative data included an online survey with parents and/or primary caregivers of an adult with ID, and a second adult child with no ID diagnosis. The survey was used to understand the differences in parental attitudes and experiences between the two adult children. Three sections of the survey were adapted from Cuskelly and Bryde's (2004) Attitudes to Sexuality Questionnaire—Individuals with an Intellectual Disability (ASQ-ID). The measure was originally developed to ask about attitudes regarding sexuality for adults with ID (see Appendix B for a copy of the original questionnaire). The adapted version of the ASQ-ID used in this study included rewording to allow parents to make comparisons between their adult children with and without ID. The remaining sections of the survey included demographic questions about the participants and the adult children they are referring to within responses, questions regarding parent communication around sexuality for both adult children, and questions regarding parental attitudes towards sexuality for adults with ID. The survey was created based on a review of the literature discussing the role of parents in the lives of adults with ID (Cuskelly & Bryde, 2004; English et al., 2018; Fulford & Cobigo, 2018; Whittle & Butler, 2018) and was guided by the following theories: the social model of disability (Oliver, 1983), parental straddling theory (Johnson, 2000), and systems theory (Whitchurch & Constantine, 1993). A table detailing how the theories were used to create study measures is provided in Appendix C.

Qualitative data were collected using semi-structured phone/video conferencing interviews with a subset of parents who completed the online survey. The interviews were conducted individually with each parent and were designed to further explore parental attitudes and experiences teaching and discussing sexuality and intimate relationships with their adult child with ID. An interview protocol was created to guide the interview, with several participant-specific questions based on online survey responses. The interview protocol was created using the social model of disability, parental straddling theory, and family systems theory, as well as a review of the literature discussing the role of parents in the lives of adults with ID (Lunsky et al., 2017; Rowbotham et al., 2011; Yoong & Koritsas, 2012; See Appendix C). Probing questions were provided to be used as necessary, but the interview was guided primarily by participant responses in an effort to minimize bias (Legard, Keegan, & Ward, 2003; Willig, 2001).

Pilot study. Prior to distributing the survey, a pilot study was conducted to inform adaptations to the original ASQ-ID measure and ensure the survey would be appropriate for adults without ID. The following procedures were used. First, 7 of the original 33 questionnaire items were excluded from the pilot survey as they were questions specifically aimed at adults with ID and did not apply to TD adults (e.g. questions regarding sterilization). Next, in order to avoid confusion for participants, 8 of the remaining 26 items were excluded based on their similarity to other items. The remaining 18 questions were placed in an online survey with the adapted phrasing of “my child” instead of “adult with an intellectual disability”. In the pilot study, participants were asked: “Does this question apply to my child?” and “If not, why?” after each question.

The pilot study was conducted with parents who had at least one TD child between the ages of 16-30 and who did not have a child with ID. This pilot study had two goals: 1) to ensure the questions were applicable to parents of TD children; and 2) to determine if the questions were applicable to parents of adolescent and adult TD children (aged 16-35,) or if these questions were only applicable to adults (aged 18-35). Participants were recruited through a series of social media posts on Facebook.

A total of 33 parents participated in the online pilot study survey (3 males, 29 females, 1 did not disclose), and reported about their children (5 males, 17 females, 1 did not disclose) ranging in age from 16-28 (M = 20, SD = 3.72). Among the parents of children under 18, 40% of questions were rated as not applying to their child and the reason given was because they were too young. From this information, it was determined that participants would only be eligible to participate in the final survey if they had adult children aged 18-35. Participants reported that the remaining survey questions were applicable to their TD children but indicated confusing wording in seven of the questions. These questions were revised for the final survey.

Sexuality is a topic that many parents find difficult to discuss, and this is very often the case for parents of children with disabilities (Foley, 2012). Thus, the second part of the pilot study included a material review by two parents of adult children with ID and an expert in the field of disability and sexuality to ensure materials were appropriate. Based on their feedback, the Likert scaled questions in several sections were adjusted to include short answer space after each question to allow parents to elaborate on their responses as necessary.

Online survey. Appendix D provides a sample of the survey in its entirety as it was used in the study. The survey included eight sections. The first three sections include demographic data of the parent, the adult child with ID who they were reporting on, and the TD adult child who they were reporting on. Sections four and five were the adapted ASQ-ID questions. Section four was the set of questions for the adult child with ID, and section five included the same questions for the TD adult child. To reduce the likelihood that the responses for one adult child influenced responses for the other adult child, these questions were presented separately for each adult child, and each participant was randomly presented with either section four or section five first. Section seven included the remaining seven questions from the original ASQ-ID survey that were not included earlier since they were not applicable to TD adult children.

The remaining sections included questions to parents about the support they provide their child relative to sexuality and romantic relationships with each of their two children. In section six Likert scaled questions were posed where parents were asked how frequently they communicated with their adult child around sexuality (never to always), and how well they felt they communicated about sexuality (not well to very well) for each adult child separately. Questions surrounding parent/child communication were asked based on literature that suggests parents often struggle with discussing sexuality with their children, even though parents of children with ID often need to be more involved that parents of TD children (Cuskelly & Bryde, 2004; Foley, 2012). Finally, using a checklist, parents were asked to indicate the expected social experiences for each of the adult children reported in the survey (i.e. friendships, romantic/dating, marriage, and sexual/physical intimacy).

The last section of the survey asked parents to use a Likert scale (not at all to very much) to rate how particular factors serve as a barrier to their adult child with ID experiencing sexuality and intimate relationships. There were eight factors listed (i.e. age, gender, adaptive functioning level, cognitive level, rules within place of residence, staff perceptions, societal factors, and other). These factors were chosen based on a literature review of relationship experiences for adults with ID (English et al., 2018; Fulford & Cobigo, 2018; Whittle & Butler, 2018). Parents were asked to rate the perceived level of impact each factor had on the adult child's life. The survey concluded by asking parents to provide contact information if they were willing to participate in a follow-up interview.

Parent interviews. Participants who agreed to conduct a follow-up interview were contacted to determine a mutually convenient date/time and method for the interview (i.e., via phone or video conferencing). Prior to the interview, online survey results for the participant were analyzed, using descriptive statistics, to determine personalized follow-up questions for the interview. Interviews were conducted by the primary researcher and a research assistant who was the sibling of an adult with ID and had experience working with adults with ID. The research assistant was trained by the primary researcher prior to conducting interviews. This included instruction on conducting interviews, as well as role play of an interview with coaching from the primary researcher.

Prior to beginning the interview, the interviewer gave a brief introduction of the study and talked informally to build rapport with the participant (Gale & Dolbin-MacNab, 2014). See Appendix E for the interview guide, including the verbal consent form, interview script, and outline of questions that was used for each interview. The interviewer began by discussing the objectives of the study and the interview process. Next, they carefully discussed the consent procedures and answered any participant questions. The interviewer was sure to emphasize the participant's right to skip any question or withdraw from the interview at any time without penalty. The participants were also informed that the interview was audio recorded for later transcription. Once consent was obtained, the interview began. No demographic information was collected during the interview as this information was already collected from the participant's survey and data were connected using a participant code.

Data Analyses

Analyses from both the survey and the interviews were conducted using the seven-stage mixed methods data analysis process (Johnson & Onwuegbuzie, 2004). These stages include: 1) data reduction where themes were identified in the qualitative data and quantitative data were analyzed using statistical methods; 2) data display where data were illustrated to create an understanding of the findings; 3) data transformation where the qualitative data were quantified and quantitative results were transformed into descriptive themes for comparison; 4) data correlation between the two data sets; 5) data consolidation where the two data sets were combined; 6) data comparison where the two data sets were compared for points of convergence and divergence; and 7) data integration where both data sets were integrated together to form a cohesive understanding of the results. The merging of both data sets allowed for further interpretation and a deeper understanding of parent perceptions and support in sexuality education and expression for their adult children with ID.

Surveys. After survey data collection was complete, data were exported from Qualtrics (2005) and examined for accuracy, missing data, and incomplete responses. The statistical analysis program SPSS was used for all quantitative data analyses (IBM Corp., 2017). Following data preparation, descriptive statistics (i.e. mean, range, and frequencies) were run on all participant demographic information from the survey.

Parental attitudes towards sexuality for adult with ID. Parents were asked to rank their agreement with statements pertaining to sexuality and intimate relationship experiences specifically focused on adults with ID. Frequencies were conducted to examine areas of highest concern for parents. For questions in which there was substantial variability in rankings, frequencies were compared based on demographic information including family approximate annual income and parental relationship status, as well as gender, diagnosis, living arrangements, and guardianship for the adult with ID.

Comparing parental attitudes. Parents were asked to rank their agreement with statements pertaining to sexuality for both their adult child with ID and their TD adult child. An exploratory factor analysis was run to examine any potential underlying relationships between questions in these sections of the survey. No relationship was found, so a paired-samples t-test was conducted on each question comparing the parent’s answer for their adult child with ID to their answer for their TD adult child.

Comparing parental communication and expectations. Parents were asked to rank how often they communicated about sexuality with each adult child, and how well they felt they communicated about sexuality with each adult child. Frequencies were conducted on these questions and examined for trends. Parents were also asked to indicate what types of social and romantic experiences they expected of their two adult children. Frequencies were conducted to determine their expected experiences for each adult child.

Interviews. Data collected from the interviews were analyzed using a thematic analysis (Braun & Clarke, 2006). This included six phases: 1) familiarization of the data through data transcription and initial reading of each transcript; 2) generating initial codes; 3) searching for themes; 4) reviewing themes; 5) defining and naming themes; and 6) producing a final report. Codes and themes were created using two levels of analysis and following a constructionist thematic analysis approach (Boyatsiz, 1998). First, data were analyzed at the semantic or explicit level to create initial codes. Next, data were analyzed at the latent level of analysis using underlying ideas and conceptualizations to inform the semantic level of analysis. A detailed audit trail was kept in order to reflect the different levels of analysis.

Trustworthiness. Trustworthiness in qualitative data analysis refers to demonstrating that the findings are a result of rigorous methodological procedures, and that they describe participant experiences accurately. In order to demonstrate trustworthiness, qualitative research studies must achieve four criteria: credibility, dependability, confirmability, and transferability (Lincoln & Guba, 1985; Morrow, 2005).

Credibility refers to the degree to which qualitative results represent clearly the reality and lived experiences of the participants (Morrow, 2005). To demonstrate credibility of this study's results, a member check was conducted with each interview participant (Lincoln & Guba, 1985). Participants were sent a summary of the main findings and provided with an opportunity to confirm the findings and/or provide additional feedback/information about their experiences. Half of participants responded to the member check and indicated the summary accurately reflected their interview.

Dependability and confirmability are related concepts that both aim at ensuring qualitative results were derived using rigorous and reliable methodology (Lincoln & Guba, 1985; Merriam, 2009). To ensure dependability and confirmability of this study, an audit trail of data analysis was conducted where emerging codes and themes, the timeline of the analysis, frequency of codes, and development of themes were all documented. The audit trail also included information concerning other research activities, potential issues with recruitment or data collection, and overall data analysis that could also impact the qualitative data results.

Transferability refers to the ability of findings to be applicable to other contexts (Morrow, 2005). Transferability for this study was achieved using reflexive journaling. Through reflexive journaling the contexts in which qualitative data were gathered were documented, as well as what contexts influenced data analyses. Journals were reflected upon throughout the data analysis process as a component of trustworthiness.

Merging and interpreting the data. Data from the quantitative and qualitative strands of data collection were merged together using a transformative merging process (Creswell & Plano Clark, 2011; Greene, 2007). Quantitative data was transformed into descriptive themes using data reduction, and then compared with qualitative results using visual data mapping

(Creswell & Plano Clark, 2011). Qualitative results were also quantified to allow for thorough comparison. The two sets of results were integrated and examined for areas of convergence and divergence to provide a more realistic and meaningful representation of participant attitudes and experiences (Greene, 2007).

Participants

Online survey. Fifty parents (46 mothers, 4 fathers) completed the online survey. All were parents of an adult with ID, as well as a TD adult. Parents were representative of all regions of the United States. Parents were aged 40-76 (M = 62, SD = 9) The majority of parents were Caucasian (92%) and were currently married (74%). Parents also indicated they had an average of 3 kids total (SD = 0.68) with ages ranging from 8 to 53 (M = 24.61, SD = 7.47). Further description of parent demographics can be found in Table 1.1.

Table 1.1
Parent (Survey) Demographics (n = 50)

Characteristics	**% (n)**	**Characteristics**	**% (n)**
Race/Ethnicity			
White	92 (46)		
Black, African American	4 (2)		
Hispanic, Latino, or Spanish Origin	2 (1)	*Relationship Status*	
Not Reported	2 (1)	Married	74 (37)
		Widowed	2 (1)
Approximate Family Income		Divorced	16 (8)
Less than $40,000/year	14 (7)	Separated	2 (1)
$40,000-$80,000/year	38 (19)	Living Together	2 (1)
More than $80,000/year	46 (23)	Single	2 (1)
Not Reported	2 (1)	Not Reported	2 (1)
Highest Education Level		*Region of the U.S.*	
High School Degree	4 (2)	Northeast	10 (5)
Some College	12 (6)	Midwest	50 (25)
Associate Degree	18 (9)	South	18 (9)
Bachelor’s Degree	28 (14)	West (incl. HI & AK)	22 (11)
Graduate Degree	34 (17)		
Not Reported	4 (2)		

Parents reported demographics for two adult children in the study (one with and one without ID). Table 1.2 provides a visual comparison of the demographics of the TD adult children and the adult children with ID. There were 30 male and 20 female adults with ID aged 18-33 (M = 23.86, SD = 3.68) reported about in the survey. The majority lived at home (70%) and were not currently employed (50%). Parents indicated that the majority (66%) were not currently in a relationship. When asked about diagnoses, 34% of parents indicated that their adult child had more than one disability diagnosis. Most parents (62%) had guardianship of the adult with ID. See Table 1.3 for further information on diagnoses and guardianship.

Table 1.2

Adult Children (Survey) Demographic Comparison (n = 50)

Characteristics	**Adult w/ID % (n)**	**TD Adult %(n)**
Highest Education Level		
High School Degree	78 (39)	18 (9)
Some College	16 (8)	32 (16)
Associate Degree	2 (1)	12 (6)
Bachelor's Degree	--	22 (11)
Graduate Degree	--	14 (7)
Not Reported	4 (2)	2 (1)
Current Residence		
At home with parent	70 (35)	22 (11)
In the community independently	6 (3)	68 (34)
In the community with minimal support or college living	10 (5)	10 (5)
Group home or supported living	14 (7)	--
Employment Status		
Full-time	8 (4)	54 (27)
Part-time	30 (15)	16 (8)
Not currently employed	50 (25)	10 (5)
Full-time student	10 (5)	18 (9)
Not Reported	2 (1)	2 (1)
Currently in a Romantic Relationship		
Yes	30 (15)	62 (31)
No	66 (33)	30 (15)
Parent is Unsure	4 (2)	8 (4)

Table 1.3

Adult with ID (Survey) Diagnosis and Guardianship (n = 50)

Characteristics	**% (n)**
Diagnosis[1]	
Down Syndrome	32 (16)
ASD[2]	36 (18)
General ID	24 (12)
Other[3]	50 (25)
Parent Has Guardianship	
Yes	62 (31)
No	38 (19)

Note. [1]Many adults were reported as having multiple diagnosis and are placed in more than 1 category. [2]All adults with ASD also had an ID diagnosis. [3]Other diagnosis included Williams Syndrome, PDD/NOS, significant health conditions, genetic disorders, mental health diagnosis, speech disorders, and neurodegenerative disorders.

Of the 50 TD adult children, 38 were male and 12 were female aged 18-33 (M = 24.66, SD = 5.24). The majority lived independently in the community (68%) and were employed full-time (54%). Parents indicated that the majority (62%) were currently in a relationship.

Interviews. A subset of 20 parents (19 mothers, 1 father) who completed the survey also participated in the interview. Demographics of parent interview participants can be found in Table 1.4, and demographic details of the children they reported on can be found in Table 1.5. Further information on diagnoses and guardianship for the adults with ID can be found in Table 1.6. Demographic details of parents who were interviewed and the adult children they reported on were similar to those who completed the survey.

Table 1.4

Parent (Interview) Demographics (n = 20)

Characteristics	**% (n)**	**Characteristics**	**% (n)**
Gender			
Male	5 (1)		
Female	95 (19)		
		Highest Education Level	
Age		Some College	15 (3)
40-50	25 (5)	Associate Degree	15 (3)
51-60	45 (9)	Bachelor's Degree	40 (8)
Above 60	25 (5)	Graduate Degree	25 (5)
Not Reported	5 (1)	Not Reported	5 (1)

Table 1.4 (cont’d)

Race/Ethnicity		*Approximate Family Income*	
White	90 (18)	$40,000-$80,000/year	55 (11)
Black, African American	5 (1)	More than $80,000/year	45 (9)
Hispanic, Latino, or Spanish Origin	5 (1)		
		Relationship Status	
Region of the U.S.		Married	80 (16)
Northeast	--	Divorced	20 (4)
Midwest	60 (12)		
South	20 (4)		
West (incl. HI & AK)	20 (4)		

Table 1.5

Adult Children (Interview) Demographic Comparison (n = 20)

Characteristics	**Adult w/ID % (n)**	**TD Adult %(n)**
Gender		
Male	65 (13)	25 (5)
Female	35 (7)	75 (15)
Age		
18-22	40 (8)	35 (7)
23-27	30 (6)	50 (10)
28-32	30 (6)	15 (3)
Highest Education Level		
High School Degree	75 (15)	10 (2)
Some College	15 (3)	40 (8)
Associate Degree	5 (1)	10 (2)
Bachelor’s Degree	--	30 (6)
Graduate Degree	--	10 (2)
Not Reported	5 (1)	--
Current Residence		
At home with parent	80 (16)	10 (2)
In the community independently	--	80 (16)
In the community with minimal support or college living	15 (3)	10 (2)
Group home or supported living	5 (1)	--
Employment Status		
Full-time	--	45 (9)
Part-time	25 (5)	35 (7)

Table 1.5 (cont'd)

Not currently employed	55 (11)	--
Full-time student	15 (3)	15 (3)
Not Reported	5 (1)	5 (1)
Currently in a Romantic Relationship		
Yes	25 (5)	60 (12)
No	75 (15)	35 (7)
Parent is Unsure	--	5 (1)

Table 1.6

Adult with ID (Interview) Diagnosis and Guardianship (n = 20)

Characteristics	**% (n)**
Diagnosis[1]	
Down Syndrome	30 (6)
ASD[2]	35 (7)
General ID	25 (5)
Other[3]	55 (11)
Parent Has Guardianship	
Yes	45 (9)
No	55 (11)

Note. [1]Many adults were reported as having multiple diagnosis and are placed in more than 1 category. [2]All adults with ASD also had an ID diagnosis. [3]Other diagnosis included Williams Syndrome, PDD/NOS, significant health conditions, genetic disorders, mental health diagnosis, speech disorders, and neurodegenerative disorders.

Results

The results from this study provide details about parent perceptions and experiences in the sexuality education and sexuality expression experiences of their adult children with ID, and how those differ from their TD adult children. Results will be presented across two main themes: 1) the parental role in sexuality education; and 2) the parental role in sexuality expression. Each theme contains illustrative subthemes and represents the merged data from both the online survey and interviews.

Parental Role in Sexuality Education

One of the main themes that emerged from this study is the importance of the parental role in sexuality education for both of their children. Parents discussed this in terms of education they provided when their adult son or daughter was a child, as well as the ways they have continued to provide information on sexuality as their child entered adulthood. Parents discussed this in terms of their role in comparison to the role of others, and how their role differed between their adult child with and without ID.

Overall poor sexuality education in school. Parents indicated that both their adult children received poor sexuality education in school. When one mother was asked about sexuality education for her children, she stated,

> "the schools do a very minimum level. It's very disappointing."

The impact was slightly more amplified for individuals with ID. Most parents indicated that their child with ID received little sexuality education if any, while the TD child often received at least one to two classes throughout their education. Parents commonly discussed how the TD child, even though they received little or poor sexuality education, was still more capable of understanding and integrating that information than their child with ID. Many parents discuss feeling the need to supplement any sexuality education their child with ID received at school, as it was often not enough. One parent described this saying,

> "they kind of did their own thing (sexual health class) in the special ed classroom…I would answer any questions or supplement anything she'd need because it still just wasn't a lot of information"

However, for the TD child parents indicated they felt they had to supplement less because that child received information from peers and other sources that increased their knowledge. One parent described her TD daughter as having had

> "a very good social circle, so she was around her peers which makes a huge difference, obviously you learn a lot, and all that not necessarily good, but you still learn."

When comparing experiences between the two adult children, another parent said it simply,

> "my other kids were going to hear it through the grapevine."

Parent as best sexuality educator. Parents indicated that they were the best person to provide sexuality education for their children. While many of them mentioned this for both children when they were school-aged, they indicated that their role changed for their TD child as they moved into adulthood because the parent became further removed from providing any sexuality education outside of relationship advice, and was often not involved in any aspect of sexuality expression for their TD adult child. However, this change of role did not occur for their adult child with ID. Parents indicated that they continued to be the main sexuality education provider for their adult with ID as they often had the most daily connection and knew how to tailor messages to their child. One mother described her process in talking to her son with ID:

> “I probably tend to reiterate just because of his learning disability. I know that he needs to hear that same information a couple of times before he absorbs it.”

Parents also described themselves as needing to be the main sexuality education provider for their adult with ID because the individual with ID often lacked the peer group that the TD adult had that enabled them to learn socially about sexuality issues. When describing the issue of lack of peers for her daughter with ID, one mother said,

> “you know that’s always the problem with people with disabilities is the friends and usually it’s friends with disabilities, so yeah. So no, she didn’t have friends to go to.”

Another parent described how she felt knowing her son with ID has so few friends to talk to:

> “the fact that he has to come to his mom to talk about this, it kills me if I think about it too much…There is not a single person at school, there is not a single person in his social circle that he can talk to.”

Many parents indicated they felt as if it was important for them to be the main provider of sexuality education for their children as it was important for them to be able to instill their own values into their child’s learning. For example, parents discussed needing to emphasize to their child that sex should only occur within marriage or a committed relationship, as well as emphasizing their views on when or if pornography should be viewed. While this was indicated as important for both children, it was emphasized more often for the adult with ID. Parents related this back to the issue with a lack of a peer group for the adult with ID, stating that the TD adult often created their own sexual understanding based on experiences and what they learned from others, whereas the adult with ID often only had their parent as a resource. Parents indicated that instilling values into their adult with ID was important to help ensure they seek out and engage in healthy sexual experiences and understand sexuality similar to the parents' own understanding. When discussing sexuality education specifically for her son with ID, one mother stated that the school's

> "role is to reinforce what I'm doing. It has to go back to the values and norms of the family."

Differences in teaching sexuality to adult with ID. When it came to the teaching of sexuality education to their adult children, parent reports were very different between the survey results and the results of the interviews. When asked in the survey how often they talked to each child about sexuality, 51% of parents indicated they talked the same amount with both children. When asked how well they felt they communicated around these issues with each child, 54% of parents indicated they felt they communicated the same with both adult children. However, through interviews the parents discussed drastic differences between conversations with their adult with ID and their TD adult child. One of the main areas of differences was on topics that were covered. Parents tended to focus on the basics of sexuality (e.g. anatomy, sexual hygiene) as well as avoiding abuse and exploitation with their adult with ID. With their TD adult, while some conversation still covered the basics of sexuality when necessary, more often parents discussed relationship-based sexuality topics (e.g. safe sex practices). A major area of difference that parents of female adult children with ID noted was around the topic of birth control. Often, they felt that was a topic that needed to be covered with their TD adult but struggled with whether they should discuss it with their adult with ID and what level of information they should be given. In interviews three parents discussed the birth control of their adult daughter with ID but indicated that they felt she did not truly understand the connection of birth control to sexuality. One parent stated,

> “She’s on birth control, mainly for hygiene…she knows she’s on birth control pills but I don’t think she knows exactly why or what it even means.”

Many of the noted differences in topics highlighted the differing parental expectations for TD adults (e.g. an expectation of sexual experiences) and adults with ID (e.g. limited expectations of sexual experiences). One parent stated,

> “the conversations are different too. Because (TD adult son) is engaged in sex, and (adult son with ID) just hasn’t had sex yet.”

Another difference between the two adult children was in the method that parents used to present the information. Often, parents discussed how they would wait for their adult with ID to have questions or an experience that needed to be explained to them before the parent would approach the topic. When one parent was asked about which sexuality topics they discussed with their adult with ID she explained,

> “as far as sex with another person…that hasn’t really come up yet. We haven’t talked about it because he hasn’t shown any interest.”

Parents indicted that their TD adult asked different and more directly applicable questions, so it was easier to address those issues as they came up. These differences were also impacted by concerns that their adult with ID would not be able to integrate knowledge if the parents covered something with which their child did not have a concrete experience. Unfortunately, sometimes this would mean that parents waited until their adult with ID experienced some form of abuse or exploitation before sexuality topics were discussed. One parent shared a story about how her adult son with ID had been sexually abused by an older male from work. She discussed how she had talked to him when he was younger about “saying no to strangers” but had avoided other topics of sexuality because they made her uncomfortable. She stated,

> “I just avoided it…I didn’t want to talk about it and neither did his dad...I just feel like I have an ability in some regards to prevent him from being in those situations, so I didn’t need to talk about it.”

She went on to explain that she also avoided the topic of sexuality for her TD daughter with no negative consequences as she learned on her own, and that made it easier to avoid the topic with her son with ID. Then when her son was taken advantage of, she realized it actually had been harmful for her to avoid those topics. During the interview the parent became visibly upset, crying and stating,

> “Looking back, I just didn’t get as in-depth as I should have…I didn’t have a clue, not even an inkling. And that was probably very naïve.”

Overall, parents reported waiting longer to talk about sexuality with their adult with ID than for their TD adult child. Parents felt that waiting until puberty to discuss issues of sexuality with their child with ID (M = 2.59, SD = 1.57) was significantly more important than waiting until puberty for their TD child (M = 1.94, SD = 1.07), t (49) = 3.36, p = .002. Parents most often cited concerns over their child with ID’s ability to understand and integrate information due to their ID as the main reason for waiting. As one parent described it,

> “(TD adult daughter) can analyze it and can come to better decision making than I feel like (son with ID) can and it’s definitely because of his intellectual disability and those concerns.”

Parents wanted to approach and teach the topic at a time they were more certain that their adult with ID would be able to integrate and apply the knowledge. As they moved further into adulthood, parents discussed one of the main differences related to conversations about sexuality between children was how often the conversation occurred. For their adult with ID, these conversations occurred more often and needed to be more concrete. As one parent described:

> "I definitely have to go over things with her a number of times and just talk about it and kind of repeat myself because that's how she learns is with the repetition."

Another parent reflected on this constant process saying,

> "it's ongoing for me, for her. There's never a point where everything is going to be solved."

With their TD adult, conversations included scaffolding of knowledge and building on previous conversations. For their adult with ID, conversations often involved repetition and re-teaching.

When it came to the different way parents communicated and taught issues of sexuality to their two adult children, parents often expressed worry about uncertainty if they were engaging in these conversations in the "correct" way for their adult with ID. One parent expressed her frustration saying,

> "there is no handbook for this kind of thing."

This worry was not prevalent for their TD adult. Despite the commonalities discussed in previous paragraphs regarding discussing sexuality with their adult with ID, there were many different methods of discussion that parents mentioned using, such as photos or videos to help them discuss topics, simple verbal discussions, or even purchasing sexuality education programs designed specifically for adults with ID. The majority of parents reported feeling unsure of how they should be discussing sexuality. This concern was amplified for them as their child entered adulthood, and uncertainty grew even larger when conversations began to look different from those they had with their TD adult children.

Parental Role in Sexuality Expression

The second overarching theme that emerged in the study related to the parental role in sexuality expression. Parents indicated a large role in sexuality expression for their adult with ID, including teaching and then subsequently monitoring practices. Many parents indicated that while they wished that there would be others to help them in this area, they felt as if they were most responsible. This is an area in which parents felt stark differences between their adult children. Parents felt that they played little to no role in this area for their TD adult. One parent discussed the conversations they had regarding masturbation with their adult child with ID and then comparing that to how they talked with their TD adult child stating,

> "I didn't have any discussion or there was never a conversation with me and (TD adult son) on masturbation or how to masturbate beyond it's ok to do it. There was none on how to at all. There was with (adult son with ID)."

Differences in potential sexuality practices. Within the survey results, parents felt it was more important for sexual intercourse to be discouraged for their adult with ID (M = 2.98, SD = 1.61), than it was to discourage that sexual practice for their TD adult (M = 2.39, SD = 1.77), t (46) = 2.08, p = .043. They also viewed the availability of advice on contraception for their adult with ID (M = 5.51, SD = .804) as less important that the availability of that information for their TD adult (M = 5.72, SD = .540), t (46) = -2.12, p = .040. Within the qualitative comments regarding these survey questions, parents indicated that they worried their adult with ID would not fully understand these practices, and if they provided information to them before they were fully ready it would increase their child's chances of engaging in these practices in a negative way.

Within the survey parents indicated the types of relationships they expected their adult children to have (i.e. friendships, romantic/dating, marriage, and sexual/physical intimacy). For friendships and romantic/dating relationships, 96% of parents indicated they expected both children with and without ID to have friendships and 82% of parents indicated that they expected both children with and without ID to experience romantic/dating relationships. There were higher levels of variability related to marriage and sexual/physical intimacy. For parents who reported differences, 46% of parents expected their TD adult child would get married but their child with ID would not, and 34% expected their TD adult child would have a sexual/physically intimate relationship while their adult child with ID would not. The interviews further illuminated these differences. Parents indicated that theoretically they felt their adult children should have similar sexuality expression experiences. But in reality, they struggled because they would have to monitor and help their adult with ID more in this area and they felt unprepared to do so. One parent stated,

> “I wish I felt the same. But it’s very worrisome because he (adult son with ID) does not possess the ability all of the time to discern what’s real and what’s not.”

Barriers to sexual experiences. When thinking about barriers their adult with ID faced to having healthy sexuality expression and sexual experiences, parents first discussed their concerns related to vulnerability. Within the concept of vulnerability for adults with ID, parents commonly cited their adult’s cognitive and adaptive functioning level as a barrier. In the survey parents were asked to rank potential barriers in whether they perceived that barrier as not a barrier, a minor barrier, a moderate barrier, or a large barrier. Of the 50 parents who completed the survey, 64% ranked cognitive level as either a moderate or large barrier, and 62% ranked adaptive functioning as either a moderate or large barrier. Most parents viewed their adult child’s inability to integrate sexuality knowledge with their experiences, coupled with their lack of daily adaptive behaviors, as substantial barriers to healthy sexual experiences.

Along with concerns related to their disability diagnosis, parents also saw society as a barrier to their adult with ID having these experiences. In their ranking of potential barriers, 66% of parents ranked societal factors as either a moderate or large barrier. Another component of society as a barrier is concerns with the lack of acceptance of adults with ID as sexual beings. Many parents felt part of their job is to help eliminate some of these barriers by working towards normalizing sexuality for their adult with ID, both for the adult themselves and for society.

Parental monitoring. Parents indicated that monitoring sexuality expression and sexual practices for their adult with ID was often one of their major responsibilities. Monitoring included verbal check-ins with the individual, check-ins with staff or therapists working with them, and constant observation and surveillance. One parent described a situation in which her son with ID had discussed masturbation with her at length, then when the family was at a party the following day, she followed her son around monitoring him because she was worried he would start masturbating inappropriately while at the party. One of the reasons parents felt they needed to monitor was to ensure their adult with ID was integrating sexual knowledge in an appropriate and applicable way. One parent described the process as,

> “we talk about it calmly and just ‘you understand what happens when this happens?’ and then she says ‘yes’ and then you know, we just walk through the steps as often as we need to.”

Many parents expressed concern about their adult inappropriately acting on a sexual desire or misinterpreting a potential sexual interaction with someone. Often, this monitoring was done on the part of the parent to help their adult with ID avoid potentially abusive or exploitative situations and avoid being the perpetrator of harassment or abuse. Parents were often impacted by the stories they heard about adults with ID being taken advantage as well as the alarming statistics surrounding abuse and exploitation. This caused parents to monitor their adult with ID more closely to help them avoid these situations. One parent stated simply,

> “I have to be more protective of (daughter with ID), I just have to.”

Parents also worried about their adult child potentially engaging in an inappropriate sexual practice. The most common worry for parents was that their adult with ID would engage in inappropriate (e.g. public) masturbation. One parent described this constant struggle with her adult son with ID:

> “he stills has a hard time, when he feels the need to attend to it, it’s like constantly ‘(son with ID) you can’t always do it whenever, when you want to you have to do it upstairs in your bedroom with the door closed’ and it’s a worry, what he might do if I’m not there to catch him.”

Inappropriate sexuality expression could result in their adult being labeled as a predator, and parents felt they must monitor sexual practices to avoid that situation.

Parents also struggled with the reality of recognizing their adult child’s status as a vulnerable individual due to their ID, while also recognizing that they have the same sexual drives and desires as everyone else. When comparing the conversations they had with their adult with ID to those they had with their TD adult, one parent stated,

> “It’s a different kind of protect yourself conversation.”

Another parent described,

> “I worry much more about (daughter with ID) …but it’s hard to get her to understand how vulnerable she is.”

When asked if adults with ID have fewer sexual interests than adults without ID, 93% of parents disagreed. Parents often found it difficult to balance their role of allowing their adult child to have sexual experiences, while also protecting them.

Caretaking and sexual behaviors. An area that parents mentioned as a major concern for them was in overall caretaking and managing sexual behaviors for their adult with ID. This was the most prominent area in which parents noticed a difference in how they interacted with their TD adult child compared to their adult child with ID. This often occurred in the form of monitoring for inappropriate behaviors both in the home and out in public. When an inappropriate behavior or situation did occur, many parents described having to teach and/or re-teach their adult with ID regarding more appropriate behaviors, as well as potentially coach them through the situation if it arose again. One of the driving reasons behind this was concerns that the adult with ID would not be able to distinguish between sexual thoughts and sexual behaviors. Parents indicated they felt that their adult with ID (M = 3.93, SD = 1.47) was significantly less likely to make the distinction between sexual thoughts and sexual actions than their TD adult (M = 5.67, SD = .739), t (44) = -6.904, p = .000. This concern caused parents to monitor situations closely to ensure their adult does not engage in inappropriate sexual behaviors, and ensure they understand the difference between sexual thoughts and actions.

When asked if sexual behavior represents a major problem area in management and caring for adults with an intellectual disability, approximately half (49%) of parents agreed. However, for those who had an adult with ID living outside the home, only 27% indicated they agreed, while 58% of those whose adult lived with them indicated that this was a major problem area. Potentially, parents whose adult lived with them would have more direct experiences with managing sexual behavior than those whose adult lived outside the home.

When examining the potential impact of socioeconomic status, of families who reported an annual family income of $40,000 or less/year 57% agreed that sexual behaviors are a major problem area. This is in comparison to 56% of parents who have a family income above

$40,000/year and who indicated that managing sexual behaviors is not a problem area. These differences could be impacted by the fact that those families with a lower yearly income may have less access to caretaking resources for their adult with ID. There were also minimal but important differences between parents who were married or living with a partner (50% agreed it was a problem area) compared to those who were divorced, separated, widowed, or single (56% agreed). This may be due in part to the help and support parents felt they had in dealing with these issues. A final area of difference was in the diagnosis of the adult with ID. For parents of adults with Down syndrome, 56% agreed this was a problem area, while only 44% of those with ASD and 42% of those with a general intellectual disability or other diagnosis agreed. This may be impacted by parent and society misconceptions that adults with Down syndrome are more sexual than those with other diagnoses.

Parents blocking experiences. Whether purposeful or inadvertent, parents often found themselves blocking potential sexual experiences for their adult with ID. Some parents blocked experiences intentionally, due to concerns with their adult child's perceived level of vulnerability. One parent discussed how adults with ID are not "allowed" to date as often because

> "there's so much fear among parents, so much worry."

When reflecting on their anxiety with previous experiences leaving their adult with ID alone on a date, another parent said,

> "this situation honestly brings out the worst in me because there are times I just felt completely, completely and totally freaked out about it."

Parents often felt that their adult could not mentally comprehend the situation or experience, and so avoided potential situations or stopped them from happening. Sometimes they recognized the role they would have to play in monitoring these situations or experiences and avoided them due to the extra stress and pressure it would place on them. One parent described this saying,

> “parents can’t do it all, so I think that’s what you find among special needs parents is there is too much to do and this is kind of the thing that you are like ‘oh, I’ll worry about that later’.”

In other situations, parents blocked these experiences unintentionally. This was often because parents felt unsure about their role, or because of potential misconceptions they had about sexuality and disability that led them to avoid the topic altogether. When reflecting on their own avoidance of the topic, one parent stated,

> “sometimes often now, I’m thinking I might have my head in the sand.”

Another parent reflected,

> “it’s really about parents not avoiding this topic, I just see parents limit their child so much more than what their children are actually capable of.”

Parents also shared the expectation that while their TD adult child would engage in sexual experiences, their adult child with ID most likely would not. When asked about whether or not she had taken her adult son with ID out in the community to find a potential dating partner, one mother reflected that she knew this was going to be her responsibility but stated,

> “I wouldn’t even know where to begin. Things like that, I am just emotionally, like, just the thought of it makes me want to hyperventilate. I just don’t even know.”

Parents expressed that they felt insecure in knowing how to handle situations, because they did not have to play this role with their TD adult child, and their parents did not play this role in their own lives, so they felt they had no example to model after. Many parents expressed the desire to be mentored by a parent who has gone through these experiences before, or to have a training and further information to help them navigate these experiences.

Discussion

The purpose of this study was to examine the parental role in sexuality education and sexuality expression for adults with ID as compared to TD adults. The findings of this study demonstrate that due to poor in-school sexuality education and the important role of the parent in the lives of adults with ID, parents feel they are their child's best sexuality educator. Findings also highlight that parents play a more significant role in monitoring and management of sexuality expression for adults with ID compared to TD adults. The findings of this study emphasize the role of negative stigma and safety concerns and how that influences parent perceptions of the sexual development of their adult with ID.

Parents Struggle with Feeling Unprepared

Overall, parents described having a much larger role in sexuality education and expression for their adult child with ID, especially when compared to their role with their TD adult child. While parents reported these roles as more similar in the survey, when asked to elaborate in the interview they often realized they actually had significantly different roles. They discussed how this is impacted because teaching sexuality education to adults with ID requires different methods and often multiple repetitions of information due to their disability. Parents recognize that they are uniquely situated to provide information in this way, as they are often the person who spends the most time with the adult with ID, and they know how to deliver information in the way that will be most impactful. Adults with ID also lack peer groups with which to discuss these topics, leaving the conversations up to the parents (Evans et al., 2009; Healy et al., 2009). Despite this recognition of their role, parents still felt unprepared to discuss these topics. Parents felt unprepared because they lacked the sexuality knowledge and background to know what they should discuss with their child when (Nichols & Blakeley-Smith, 2009). They also felt unprepared because they worried about providing too much or too little information in any conversation and how that might impact learning for the adult with ID. This is a valid concern for parents as individuals with ID often struggle with abstract concepts that are difficult to define yet important to interpersonal relationships (e.g. respect, trust, reciprocity) as well as struggling with generalizing concepts especially in regard to social related concepts such as sexuality and intimacy (MacFarland & Fisher, 2019). Parents worried about providing an inappropriate amount of information when their child needed it and hindering their sexuality development and knowledge even further. These conversations also looked different with their TD adult children. Parents were able to take more of a “hands-off” approach with their TD adult children, so when they need to have sexuality discussions with their adult with ID, they often felt unprepared because the role was unfamiliar. Parental anxiety around feeling unprepared and unsure of their role may ultimately lead to parents avoiding the topics of sexuality altogether. This can have a large impact on the adult with ID, as they may not receive that information elsewhere (Gomez, 2012).

As mentioned in the participant descriptions, the majority of adults with ID in this study also had multiple diagnoses, often including significant medical or mental health concerns. This is common for adults with ID (Tonge, 2007) and can impact parents’ ability to feel prepared to discuss sexuality, as multiple diagnoses and conditions could impact what information is pertinent to the individual and how it may need to be adapted to accommodate any particular conditions. Parents also felt extremely overwhelmed dealing with the “compound caregiving” responsibilities and juggling these roles along with other duties they may have for other family members and their household (Perkins, 2010). Concerns regarding sexuality education may be an area parents feel they have the least amount of information and impact, so they avoid these topics for as long as they can.

Stepping Out of Their Comfort Zone

Many parents of children with ID discussed how they had to be a very different person and parent for their child with ID. As found in other research (Rowbotham et al., 2011) parents in this study indicated that they were more involved in everyday life and had to advocate more often for their child to receive services and engage in particular experiences. Parents also noted that this role continued into adulthood, because they are lifelong caregivers (Cheak-Zamora et al., 2015). Parents have to step out of their comfort zone in order to advocate and help their child’s development but are often used to this role by the time their child reaches adulthood. However, sexuality expression is an area where parents continue to struggle (Brown & McCann, 2018) a fact that was reiterated by parents in this study. Goals for TD individuals as they enter adulthood often includes developing their own sexuality, understanding how they express their sexuality, and monitoring their own sexual behaviors (Sharpe, 2003). During this time, the parental involvement significantly lessens. Although adults with ID may develop sexuality and sexuality expression at a somewhat slower pace than their TD siblings, these developments will occur. However, the parental level of involvement does not lessen as this sexual development occurs, as it does for TD individuals. For adults with ID there is a need for parents to engage in more descriptive conversations regarding sexual practices and monitor to ensure safe and appropriate sexual practices. Parents often do not need to have these conversations with their TD adult children, as well as not having to monitor them in the same way. This can be an issue for parents who already struggle discussing sexuality as a topic. Sexuality is still a very prohibited topic in general society, and this is even more so for discussions between parents and children

(Nichols & Blakeley-Smith, 2009). Parents in these situations must learn how to juggle stepping out of their own comfort zone with the understanding that they are often the best person to engage in this topic with their adult with ID. While TD siblings may be able to help with these conversations and may be a natural choice due to their closeness in age, parents often avoid asking siblings to help and sometimes even directly stop them from discussing the topic due to concerns with over-burdening the sibling and lack of control over the message the adult with ID may receive (East & Orchard, 2014; Jahoda & Pownall, 2014).

Parents in this study also expressed a need to step out of their comfort zone and deal with potential anxieties by confronting stigmas themselves and others have around the sexuality of adults with ID. Parents may have different expectations for the potential sexuality experiences of adults with ID in comparison to TD adults, namely that they will never experience sexual intercourse or romantic and dating relationships. Most parents do not question the reality that their TD adult will have sexuality experiences. However, they often feel their adult with ID *might* have those experiences but need to reach certain milestones before such experiences can happen. Parents in the study indicated that these feelings were strongly impacted by concerns about the ability of their adult with ID to fully comprehend and integrate sexuality knowledge. This again may be amplified for parents if they feel insecure in discussing the topic of sexuality in general. These concerns with cognitive and adaptive abilities also impact the way that society views the sexuality and sexual development of individuals with ID. Negative stigmas within society, such as individuals with ID being either asexual or over-sexed (Block, 2000; Miligan & Neufeldt, 2001), may hinder sexuality expression. Parents themselves noted particular issues such as their need to monitor individuals with ID due to safety concerns, as well as the extra stress that monitoring inappropriate sexual behaviors places on the parent. Parents constantly struggle with facilitating independence for their adult with ID, while still protecting them. These negative experiences and concerns add to already high levels of parental stress that can cause parents to avoid the topic of sexuality with adults with ID, serving as a further barrier to sexual experiences.

The Need for Coaching and Guidance

The struggle parents had in this study feeling unprepared to teach sexuality education, coupled with the fact that the topic of sexuality forces many parents to step out of their comfort zone, indicates a strong need to help parents better navigate these experiences with adults with ID. Many parents in this study mentioned the positive impact that further education and coaching on the topic of sexuality could have for them. Parents of adults with ID often discuss feeling isolated and lacking groups of friends and mentors they can go to with questions (Marsack & Perry, 2018). This leaves many parents having to navigate the situations on their own. And often, the only previous experience they had, if any, is with their TD children. Parents in this study often described not knowing what information their adult with ID needed, and as a result waited until their child asked questions, or it became apparent they needed some level of sexuality education. On one hand, parents wanted to teach at the correct level for the adult with ID and not give them too much information that they would not be able to integrate or apply. On the other hand, they also had increased anxiety around the topic. This resulted in parents avoiding the topic and inadvertently leaving their adult with ID open to potential abuse and exploitation due to lack of knowledge and awareness. Parents needed help understanding how these conversations should look for their adult with ID and what different information needs to be presented. They also need guidance in juggling their own anxieties with the needs of their adult child. Engaging in teaching and coaching, or simply having a peer mentor for parents, is a need.

Implications for Sexuality Education Practices

This study has important implications for sexuality education practices for adults with ID and their families. Based on the important role of the parent as a sexuality educator for their child with ID, there is a strong need to increase inclusion of parents within sexuality education programs. This includes providing more detailed information for them on how their child’s delayed development impacts their sexuality so that parents can understand when to discuss topics. Coaching should also be provided to parents to help them learn how to talk about specific topics, and how conversations might be different from those with their TD child. The coaching needs to be done in the context of their real, lived experiences in order to be most effective.

Further, parents still need training and coaching on how to manage sexual behaviors and the sexuality expression of their adults with ID. This is also most likely true for staff and others who work with these adults as well. Parents often find themselves engaging in situations and discussions they have never experienced with their TD adult child, and they feel unprepared to do so. Parents in this study often worried about providing the appropriate level of sexuality education for their adult with ID, as well as conducting appropriate levels of monitoring. With the concerns of the ability of adults with ID to integrate and generalize information, there is a need to provide information prior to an event or experience, while also helping coach and provide scaffolded information while they are going through an experience. More education and coaching to help manage these scenarios are needed for all individuals who work or live with adults with ID. This type of training should be an established component of all programs for adults with ID, their staff, and their caregivers.

A final implication of this study is that parents need a better way to connect with one another. Many parents feel as if they are struggling through these issues alone and would benefit from having interactions with other parents. Many helpful parental communities and support groups already exist, especially for parents who have young children recently diagnosed with ID. However, there is a significant lack of such groups for parents of adults with ID who are entering the dating world. There needs to be more intentional and accessible communities for these parents. This would give them the opportunity to learn from one another, and to share their stories and struggles with individuals who are experiencing similar situations.

Limitations

There are a few limitations to the current study. The first is that only 50 participants nationwide participated in the survey, and 20 parents participated in the interviews. While these numbers are typical of studies conducted with parents of adults with ID (Band-Winterstein & Avieli, 2017; Cheak-Zamora et al., 2015; Cuskelly & Bryde, 2004; Rowbotham et al., 2011; Stein, Kohut & Dillenburger, 2017), this limits the overall generalizability of the findings. Parents participant ages also varied widely and as such, generational parenting differences may have impacted the findings in this study. Future research should explore generational parenting differences for parents of individuals with ID to understand this issue more fully. Also, while all regions of the U.S. were represented in the sample, they were not represented evenly. Another limitation is that the survey was self-report and descriptive in nature. There was no direct measure of the specific sexuality education the adults with ID or parent received, only parent report and perceptions. A third limitation is that the study asked only for parents with adult children aged 18-35, which may also have limited the sample and excluded some parents.

There are also limitations with lack of diversity of the sample of participants themselves. A large majority of the participants reported that they were Caucasian, married, with a family income of $40,000 or above and that their adult with ID was living at home with them.

Therefore, the results may not represent the experiences of families from lower socioeconomic levels or those who may not have access to as many resources as the participants in this study. The majority of participants for both the surveys and the interviews were also female (mothers). This limits generalization to the experiences of fathers. There also was no specific gender-matching done among participants and their adult children. This could have an impact on the study as discussions of sexuality between parents and their children can often be a topic heavily influenced by gender (DiIorio et al., 2003). This may have impacted some of the experiences that parents described in this study.

Future Directions

Future research should build on the findings in this study by investigating the parental role in sexuality expression and education experiences for adults with ID from the perspectives of the adults themselves. This will help provide further insight into how parent perceptions match up with their adult children, and further inform how sexuality discussions and education can be successfully integrated into adult programs. Using dyadic data collection methods to gather information from both parents and their adult child with ID together could help provide significant insight into the dynamics of this relationship around this issue (Caldwell, 2014). Future research should also explore what methods would be best for parent’s education and coaching around sexuality, and support creation of relevant sexuality education materials for adults with ID that address these concerns. The impact of gender on these discussions is also an area that would benefit from future research. Determining if mothers or fathers talk differently to their child with ID depending on gender would provide important information to inform interventions and would further expand the findings of this study.

Conclusion

This study examined the role that parents play in the sexuality education of their adult child with ID, as well as how parents manage sexuality expression. Findings provide important insights into the sexuality development and education for adults with ID and highlight critical gaps that need to be addressed in future research. Future research should continue to explore these gaps to ensure that individuals with ID and their parents are provided with the supports they need to develop healthy sexual understanding and experiences.

CHAPTER 3: PARENT PERCEPTIONS OF INTIMATE RELATIONSHIP EXPERIENCES OF ADULTS WITH INTELLECTUAL DISABILITIES: COMPARISONS WITH TYPICALLY DEVELOPING SIBLINGS

Abstract

Although there are vast benefits of experiencing healthy intimate relationships in adulthood, adults with intellectual disabilities (ID) are often denied these experiences. This is due to restrictions placed on them from parents and other caregivers. However, these restrictions do not deter adults with ID from desiring intimate relationship experiences, leading to many of them engaging in secretive and often exploitative relationships. Despite this known pattern, there is still a gap in understanding the role parents specifically play in their adult child's experiences of romantic relationships. The current study examines the role that parents play in the creation and maintenance of intimate relationships for their adult child with ID. This was done by asking parents who have an adult child with ID, as well as a typically developing (TD) adult child, to compare their experiences between these two adult children. A mixed methods design including an online survey with 50 parents nationwide, as well as follow-up phone/video conferencing interviews with a subset of 20 parents was used. This study finds that parents struggle with determining the appropriate level of involvement they should have in the romantic relationships of their adult child with ID, and that there is a strong need for coaching and mentoring for parents to help them navigate these experiences successfully.

Introduction

Intimate and romantic relationships are an often-overlooked aspect of health and well-being for adults with intellectual disabilities (ID). Despite the known benefits of healthy interpersonal relationships (Beckes & Coan, 2011; Cacioppo & Patrick, 2008; Moos, 2003; Robles, 2014), adults with ID are often denied opportunities to create and maintain these types of relationships (English et al., 2018; Fulford & Cobigo, 2018; Whittle & Butler, 2018). This comes in the form of restrictions placed on them by others (Rushbrooke et al., 2014; Turner & Crane, 2016), and lack of proper sexuality education that includes content about healthy intimate relationships (Brown & Pirtle, 2008; Foley, 2012).

Despite these restrictions and limitations, many adults with ID express an overt longing to experience romantic and intimate relationships in a healthy way (Gil-Llario, Morell-Mengual, Ballester-Arnal & Diaz-Rodrigues, 2018; Healy et al., 2009; Kelly et al., 2009; Rushbrooke et al., 2014; Turner & Crane, 2016). Restrictions and lack of knowledge collide with this longing to create situations in which adults with ID become part of inappropriate and exploitative relationships and sexual situations (Hollomotz & The Speakup Committee, 2008; McDaniels & Fleming, 2016). As a population, individuals with ID have significantly higher rates of sexual abuse, exploitation, and intimate partner violence (Scherer, Snyder & Fisher, 2013; Scherer, Snyder & Fisher, 2016; Swango-Wilson, 2009). And unfortunately, those who have the most control over the social lives and experiences of adults with ID are not the adults themselves, but rather parents or legal guardians. Parents of adults with ID play a more significant role in the life of their child than parents of adult children without ID, and this is especially true for social and romantic relationship experiences (Lunsky et al., 2017; Rowbotham et al., 2011; Yoong & Koritsas, 2012). Because of the significant role parents play, there is a clear and palpable need to understand the nuances of parental roles specifically and how they impact intimate relationship experiences for adults with ID.

Background on Social Networks and Romantic Relationships

Social and romantic relationships are interrelated. When considering adults with ID, social relationships and social networks have more attention in the research than romantic relationships. However, research regarding social networks can enlighten our understanding of romantic relationships.

Impoverished networks. One of the key findings common across all social relationship studies is that adults with ID have impoverished social circles and networks. Impoverished networks and lack of social experiences in adulthood have been shown to have a negative impact on quality of life (Miller & Chan, 2008) and mental health (Gilmore & Cuskelly, 2014; Hartley, Hayes Lickel & MacLean, 2008; McGillivray & McCabe, 2007). The average network size of adults with ID, defined as total number of people in the network, has been reported to be in the range of 8.0-8.8 (Bigby, 2008; Hulbert-Williams, Hasting, Crowe & Pemberton, 2011; Krauss & Erickson, 1988; Rosen & Burchard, 1990). Those with profound or severe ID have even smaller networks, with an average of only 5.1 different social contacts throughout one year (Kamstra, van der Putten & Vlaskamp, 2015). Networks of adults with ID are smaller in size and density when compared to both a typically developing (TD) population (Rosen & Burchard, 1990) and adults with a physical disability and no accompanying ID (Lippold & Burns, 2009). Outside of family members and staff, adults with ID have few friends, engage in few social activities (Emerson & McVilly, 2004), and their friendships are often primarily composed of other adults with ID (Emerson & McVilly, 2004; Lippold & Burns, 2009; Rosen & Burchard, 1990).

Staff who work with adults with ID report that there is a significant absence of social support across all settings in the adult's life (Lunsky & Benson, 2001). Bigby (2008) described adults who moved from an institution into community living. In the first year they experienced an initial increase in average network size and level of support. However, after five years, social network and levels of support decreased back to levels similar to their time in an institution. This exemplifies the isolation of adults with ID even when they live in community settings (Hall et al., 2005). They often only have contact with staff and family member and rely on others to create, support, and maintain their social networks.

Restrictive social experiences. Another factor that impacts the size of social networks and experiences within social relationships is the restrictive nature of the lives of adults with ID. When asked to describe close relationships, participants named the "good mate" and "boyfriend/girlfriend" as important close relationships but stated that environmental barriers often prevent them from experiencing these relationships (Knox & Hickson, 2011). Unemployment and low pay, coupled with consistent transportation concerns serve as huge barriers to creating social lives (Abbott & McConkey, 2006). Furthermore, when adults with ID lack necessary social skills, their experiences are also restricted (Abbott & McConkey, 2006; Wilson, Jaques, Johnson & Brotherton, 2017). This results in atypical development of social identity, which leads to different social experiences—ones that often occur at the intersection of oppression, power, and discrimination (Meekosha & Shuttleworth, 2009). At the core of the barriers individuals with ID face is the attitudes of others. This is critical, considering the reliance of adults with ID on others for daily activities. Lack of family support along with adverse attitudes from others in the community when adults with ID engage in social interactions impacts the number of social opportunities and positive experiences of the individual (Abbott &

McConkey, 2006; Van Asselt, Buchanan & Peterson, 2015). The majority of relationships for adults with ID are formed through family members, religious commitments, humanitarian sentiments, and staff (Taylor & Bogdan, 1989). Most friendships of adults with ID, outside of family members, arise from a staff/client relationship (Lutfiyya, 1991).

One of the most restrictive aspects of the lives of adults with ID is their living and work settings. The level of community involvement in the lives of individuals with ID impacts their overall exposure to social opportunities. Emerson & McVilly (2004) found that the setting a person lives in is more predictive of having significant friendships than personal characteristics. Smaller community residences provide more opportunities for socialization, and more personal help from staff and family members (Emerson & McVilly, 2004; McCausland, McCallion, Brennan & McCarron, 2017; McVilly, Stancliffe, Parmenter & Burton-Smith, 2006). However, most adults tend to live with family or in larger community settings, adding restrictions to their experiences. Across all different types of living settings, adults with ID also report lack of privacy in these settings as a major barrier to forming intimate relationships and friendships (Brown & McCann, 2018).

Love and intimacy for adults with ID. When it comes to the discussion of intimate relationships for adults with ID, there exists a myth that these adults do not show interest in their own sexuality or the sexuality of others (Swango-Wilson, 2011). Historically individuals with ID were viewed as asexual—a lifelong, non-distressing lack of sexual desire for any gender (Lund & Johnson, 2015), and were thought to lack the capacity to understand love and intimacy, or that they do not have the same desire for romantic relationships as TD adults (Arias, Ovejero & Morentin, 2009; Mattila, Uusiautti and Määttä, 2017; Morales et al., 2014). However, it has been shown that adults with ID can assess and conceptualize love in the same manner as TD adults and can integrate information about intimacy and commitment in meaningful ways (Arias et al., 2009; Gil-Llario et al., 2018; Morales et al., 2014). Similar to TD adults, adults with ID describe falling in love as a sensation and include sharing experiences and having similar interests as components of being in love (Mattila et al., 2017).

Aside from interpreting love and intimacy as concepts, adults with ID are also capable of describing key components of these relationships. Lafferty and colleagues (2013) asked about the impact of romantic relationship experiences and found five main themes: the importance of comradeship, increases in social experiences overall, feeling happy because of their partner, mutual support, and having continuous commitment from the other. When discussing how they select partners, participants also provided specific criteria such as the impact of environment, personality of the other, companionship, physical attractiveness, and having similar expectations of the relationship (Bates et al., 2017). The impact of family acceptance and support is also noted and ranked as a high need within a relationship due to the increased reliance on family members within this population (Brown & McCann, 2018; Arias et al., 2009).

The desire for normalized romantic relationships. Overall there are lower rates of marriage among adults with ID, with most marriages occurring among adults with mild ID (Koller, Richardson & Katz, 1988; Lee & Oh, 2012). Adults with ID who are able to marry often find themselves with unique financial and legal concerns compared to their TD counterparts (Koller et al., 1988). They also experience higher rates of isolation in the community because of their marital status and in many cases extreme discrimination (Lee & Oh, 2012). Despite these challenges, individuals with ID express a desire to be in romantic relationships and to have intimate relationship experiences (Azzopardi-Lane & Callus, 2015; Bernert, 2011; Bernert & Ogletree, 2013; Froese, Richardson, Romer & Swank, 1999; Healy et al., 2009; Kelly et al., 2009; Rojas et al., 2016; Stoffelen et al., 2013, Yacoub & Hall, 2009). This may include a desire to get married or have a long-term relationship (Frawley & Wilson, 2016; Healy et al., 2009; Johnson et al., 2014; Turner & Crane, 2016;), engage in a sexual relationship (Azzopardi-Lane & Callus, 2015; Bernert, 2011; Turner & Crane, 2016; Yacoub & Hall, 2009), or have more opportunities to meet new and different people (Brown & McCann, 2018; Rushbrooke et al., 2014). Despite the common occurrence of negative experiences and multiple restrictions around romantic relationships for adults with ID, individuals still describe love as happy, enjoyable, and an experience that is a core component of independent adult life (Mattila et al., 2017).

The Role of Parents in Adulthood

Parents play a significant role in the daily lives of adults with ID. Often, these individuals depend on the parent and other family members for far longer than their TD peers or siblings (Pownall et al., 2012). Parental duties do not lessen as their child moves into adulthood, leaving parents of children with ID as "lifelong caregivers". These increased parental duties often include supporting their child in finding employment, socializing with others, and conducting daily living skills (Cheak-Zamora et al., 2015). Adults with ID describe relying on their parents to be their main sources of physical, emotional, and social support (Foley et al., 2014).

The role of parents when compared to TD adult children. Family members, and more specifically parents, have been shown to have a much greater influence in the lives of adults with ID than TD individuals (Evans et al., 2009; Healy et al., 2009). One of the main differences in their experiences is in the area of guardianship, which is when parents maintain legal rights to make decisions for an individual who is 18 or older. Most parents of adults with ID elect to maintain guardianship (Millar, 2007). For TD adults, parental guardianship ends when the individual turns 18 and gains legal autonomy. Guardianship provides parents of individuals with

ID the legal right to maintain control over decisions related to their adult child's life. This includes control over finances, employment, and living arrangements (Stancliffe et al., 2000). While there are differing levels of guardianship, most parents of adult children with a mild to moderate ID maintain full guardianship (Millar, 2008). When parents have guardianship, even if the individual with ID lives outside of their home, they are still able to retain control over their social activities. This occurs because parents maintain control over access to transportation and finances, and even when the individual is in a supportive living setting, staff cannot take the individual outside the residence without parental permission (Azzopardi-Lane & Callus, 2015; Stoffelen et al., 2013; Yacoub & Hall, 2009).

Parents are also involved in different types of activities for TD adults compared to adults with ID, such as having more involvement in helping manage daily living skills. This is also true of parental involvement in social relationships. While most TD adults in the United States and European cultures tend to form relationships without parental involvement, adults with ID require support from parents to facilitate these relationships (Cheak-Zamora et al., 2015).

Parental roles in social relationships. Family and staff are extremely important to the social networks of adults with ID, since they frequently make up the majority of the network (Krauss, & Erickson, 1988; Lippold & Burns, 2009; McCausland et al., 2017; Van Asselt-Goverts, Embregts & Hendriks, 2015a; Van Asselt-Goverts, Embregts, Hendriks, Wegman & Teunisse, 2015b). Family members and staff are the most frequent source of social and emotional support (Froese et al., 1999). Individuals with ID also report that close physical proximity and emotional connections to family positively impact interpersonal relationships (McCausland et al., 2017; Van Asselt-Goverts et al., 2015a; b). Additionally, family members frequently have the final say in the activities in which the individual participates (Emerson &

McVilly, 2004). Family members help adults with ID engage in friendship activities by providing transportation and creating social events (Emerson & McVilly, 2004; Wilson et al., 2017). Consequently, Newton and colleagues (1994) suggested a model for how service providers and caregivers can help adults with ID improve their social experiences by introducing them to friends and teaching social skills alongside traditional health and safety instruction.

Parents role in supervising intimate relationship experiences. Parents are often considered the best relationship educators for their child (Gossart, 2002; Shtarkshall et al., 2007; SIECUS, 2004). This is especially true for parents of individuals with ID. Although siblings or peers could potentially support relationship education for individuals with ID, most parents do not seek such support for fear that this the role would burden them (East & Orchard, 2014; Jahoda & Pownall, 2014). Parents also worry as to whether another individual would be able to tailor messages based on their child's specific needs. Aside from parental concerns, individuals with ID often lack the opportunity to gain an understanding of relationships from social experiences due to a lack of significant peer relationships. This, combined with insufficient relationship focused education in school, leads to parents being the main source of intimate relationship knowledge for their child (Swango-Wilson, 2010).

Parents of adults with ID are also extremely involved in the intimate relationship experiences of their child (Chrastina & Vecerova, 2018; Foley, 2012). Guardianship is a large factor in this level of involvement (Azzopardi-Lane & Callus, 2015; Stoffelen et al., 2013; Yacoub & Hall, 2009), as well as parental views on how ID impacts independent relationship skills (Brown & McCann, 2018; Cuskelly & Bryde, 2004). Because of these factors, parents often have influence over the dating activities in which the individual can participate (Azzopardi-Lane & Callus, 2015; Fitzgerald & Withers, 2011; Johnson et al, 2014; Kelly et al., 2009;

Rushbrooke et al., 2014), the level of privacy they are afforded (Healy et al., 2009; Hollomotz & The Speakup Committee, 2008; Rojas et al., 2016), as well as the types of contraceptives to which they have access (Frawley & Wilson, 2016; Kelly et al., 2009). As such, parents are able to supervise and manage their child's social and romantic life, and ultimately determine what exposure they have to different relationship experiences (Foley, 2012).

Unfortunately, within this managing and supervising role parents often withhold education relevant to intimate relationships or unsupervised social contact in an effort to protect the individual with ID from possible abuse (Brown & McCann, 2018; Murphy & Elias, 2006; Pownall et al., 2012). Increased inclusion, independence, and visibility in the community for adults can have the adverse effect of amplifying vulnerability and increasing rates of abuse and exploitation (Bernert, 2011; Swango-Wilson, 2009; Ward et al., 2010). Parents recognize this increased vulnerability, and often place restrictions on the individual's experiences to avoid potential consequences (Healy et al., 2009; Löfgren-Mårtenson, 2004; Murphy & Elias, 2006).

Secrecy and Deception Within Relationship Experiences.

Despite impoverished social relationships for individuals with ID, especially romantic or intimate relationships, they still express a desire to have frequent, healthy intimate relationship experiences (English et al., 2018). However, adults with ID often note parental restrictions as barrier to these relationships (Azzopardi-Lane & Callus, 2015; Rojas et al., 2016; Rushbrooke et al., 2014; Sullivan et al., 2013; Sullivan et al., 2016; Yau et al., 2016). When queried further, women with ID indicate that they are "old enough" to be in intimate relationships, and express frustration over the lack of legal autonomy to make these decisions (Bernert, 2011). Sexual autonomy as an adult is a large hindrance to quality of life (Bernert, 2011). A direct impact of restrictions around intimate relationships is that it often results in secrecy and deception

(Azzopardi-Lane & Callus, 2015; Fitzgerald & Withers, 2011; Sullivan et al., 2013; Sullivan et al., 2016). Despite restrictions, many adults with ID still seek out and engage in intimate and romantic relationships (Gil-Llario et al., 2018). When interviewing adults with ID, Healy and colleagues (2009) found that many participants discussed the need for deception in order to engage in romantic relationships. Deceptive behaviors were often used because the individual feared expressing sexuality too openly (Rushbrooke et al., 2014). Secrecy is such a common component of romantic relationships for adults with ID that it is often considered part of the experience (Johnson et al., 2014; Rushbrooke et al., 2014).

The connection between social restrictions and abuse experiences. However, feelings of secrecy also prevent individuals from discussing or reporting instances of sexual abuse or interpersonal violence, for fear of retribution for engaging in a forbidden relationship (Bernert, 2011; Bernert & Ogletree, 2013; Johnson et al., 2014; Ward et al., 2010). In fact, adults with ID are at an elevated risk of abuse experiences and victimization (Fisher, Baird, Currey & Hodapp, 2016; Gil-Llario et al., 2018). In their seminal paper on sexual abuse and exploitation among individuals with disabilities, Sobsey (1994) explained that the disability diagnosis is not what puts individuals at risk for abuse and exploitation, instead society's treatment and understanding of people with disabilities is what places them at risk. Yet, restrictions and control exerted by parents can impact intimate experiences for adults with ID (Azzopardi-Lane & Callus, 2015; Fitzgerald & Withers, 2011; Johnson et al., 2014; Rushbrooke et al., 2014). Indeed, adults with ID frequently report that others take advantage of secrecy and use this as a form of control within their sexual experiences (Fitzgerald & Withers, 2011; Johnson et al., 2014; Stoffelen et al., 2013; Sullivan et al. 2013; Sullivan et al., 2016; Yacoub & Hall, 2009). The need for secrecy due to parental restrictions, coupled with lack of proper relationship education, leads to abusive and exploitative experiences and high rates of abuse within the population, especially among women (Bernert, 2011; Bernert & Ogletree, 2013; Johnson et al., 2014; Ward et al., 2010).

The Impact of Parental Restrictions in Intimate Relationships.

Parents themselves are often the main initiators of these restrictive experiences (Bernert, 2011; Bernert & Ogletree, 2013; Healy et al., 2009; Hollomotz & The Speakup Committee, 2008; Kelly et al., 2009; Stoffelen et al., 2013; Yau et al., 2009). Parents who have guardianship can determine what type of relationships their family member is allowed to have and can terminate those relationships at any time by not allowing the individual access to resources such as transportation and money (Azzopardi-Lane & Callus, 2015; Bernert 2011; Bernert & Ogletree, 2013; Kelly et al., 2009; Yau et al., 2009). Often negative attitudes and an unwillingness to discuss intimate relationships leads caregivers to place strict boundaries around activities and censor free time (Löfgren-Mårtenson, 2004). These restrictions ultimately impact the self-determination and independence of adults with ID regarding romantic relationship experiences (Brown & McCann, 2018).

Despite reports of the positive impact love and intimacy has on happiness (Cacioppo & Patrick, 2008), and knowledge of the desire for intimate relationship experiences among adults with ID (Azzopardi-Lan & Callus, 2015; Bernert, 2011; Bernert & Ogletree, 2013; Healy et al., 2009), little research exists. We know that parents play a significant role in the adult lives of these individuals overall, especially as supervisors of relationship experiences (Foley, 2012). Therefore, it is important to know more about the barriers that parents face discussing intimate relationships with their adult child with ID, and what makes their role so unique in helping them create and maintain these relationships, so that we can work towards helping adults with ID have more positive experiences. This study seeks to address this significant gap in the literature by exploring parental attitudes regarding sexuality and intimate relationships for their adult child with ID, and their role in the creation and maintenance of those relationships.

Theoretical Frameworks

Two theoretical perspectives provide important insight into helping understand the role parents play in intimate relationship experiences for their adult child with ID. The social model of disability (Oliver, 1983) provides an understanding of disability in a social context and therefore within social and romantic relationships as well. The parental straddling theory (Johnson, 2000) offers insight into how parents of children with disabilities balance living in the world of “normality” and the world of “disability”.

The Social Model of Disability

This theory focuses on how society labels individuals with disabilities and how this impacts the social oppression and exclusion these individuals often experience (Anastasiou & Kauffman, 2013; Berghs et al., 2016; Hughes, 2010). This theory posits that social relationships and experiences for adults with ID, including relationships of a romantic or intimate nature, are impacted by the individual’s experience of their disability and their identity in society because of that label. The social model of disability allows for the examination of how ideas, values, and judgments about the label of “disability” and the experiences of these individuals are passed down through generations and between social groups. Through this examination the prejudices about the social desires and capabilities of adults with ID and the way in which they impact social and romantic experiences are able to be clarified (Anastasiou & Kauffman, 2013; Hughes, 2010; Kattari et al., 2017).

When it comes to social and intimate relationship experiences for adults with ID, parents have significant influence. Understanding how parents navigate these social experiences is important to further understand the experiences of adults with ID and work towards improving the experiences of these individuals. The social model of disability helps provide a backdrop by which we can interpret parent experiences with individuals with ID and can offer insight about the influence of societal expectations and labels.

The Parental Straddling Theory

This theory explores the experiences of parents of children with ID. Specifically, it focuses on the perpetual feeling of "straddling" two different worlds: the world of "normality" and the world of "disability" (Johnson, 2000). This includes times when the parent straddles between celebrating developmental milestones for their child while recognizing the need for continued work, straddles between helping the child live a "typical" life while also securing special services due to their disability, or straddles the need to address their child's anxiety while also attending to their own.

While this theory was originally created to describe the experiences of mothers of young children, it provides a useful framework to examine the experiences of parents of adults as well since they serve as lifelong caregivers. Parents of adults may also be straddling the worlds of "normality" and "disability" in multiple different ways, especially in relation to their experiences with intimate relationships. This could be especially true in parents striving to help their adult child have as "typical" experiences as possible, while recognizing the extra level of involvement and control they have over these experiences. This is especially apparent when compared to parents of TD adults. This theory can help provide an explanation of the contradictory experiences' parents may have as they help their adult with ID navigate intimate relationships.

Research Questions

Given the gaps within the existing literature, this study aimed to understand parent perceptions and experiences supporting intimate relationships for individuals with ID and compare these experiences to TD siblings. The following research questions guided the study:

1. How do parents perceive their role in creating and maintaining intimate relationships for individuals with ID compared to individuals without ID?
2. How do parent attitudes towards intimate relationships differ in relation to individuals with ID and without ID?
3. How does communication around intimate relationships differ for parents with individuals with ID and without ID, including type and amount of communication?
4. What barriers do parents perceive for individuals with ID in experiencing healthy and successful intimate relationship experiences?

Methods

This study used a convergent mixed methods design to provide a detailed understanding of the experiences and perceptions of parents regarding the intimate relationship experiences of individuals with ID. Both quantitative and qualitative methods were used within this design because of their complementary strengths and non-overlapping weaknesses (Creswell & Creswell, 2018), and to amplify the voices of participants themselves (Creswell & Plano-Clark, 2011; Greene, 2007). Data were collected using two different measures (i.e., quantitative survey, qualitative interview), analyzed separately, and then merged together for the purposes of development and complementarity (see Figure 3.1; Creswell & Creswell, 2018; Greene, 2007). The merging of data allowed the interpretation of final results to support the understanding of relationships between the data. Quantitative data included an online survey with parents of an individual with ID and an individual without ID. The survey was used to compare differences in parental attitudes between their adult children with and without ID. Parent responses on the survey were also explored further in the interviews. Qualitative data were collected using semi-structured interviews with a subset of parents who had completed the online survey. Interviews were used to further explore parent perceptions and experiences of intimate relationships for individuals with ID. Interviews were used to help substantiate and empower parents (Greene, 2007), and give voice to their experiences in supporting individuals with ID (Cheak-Zamora et al., 2015; Duggan & Linehan, 2013; Foley, 2012; Grey, Totsika & Hastings, 2017).

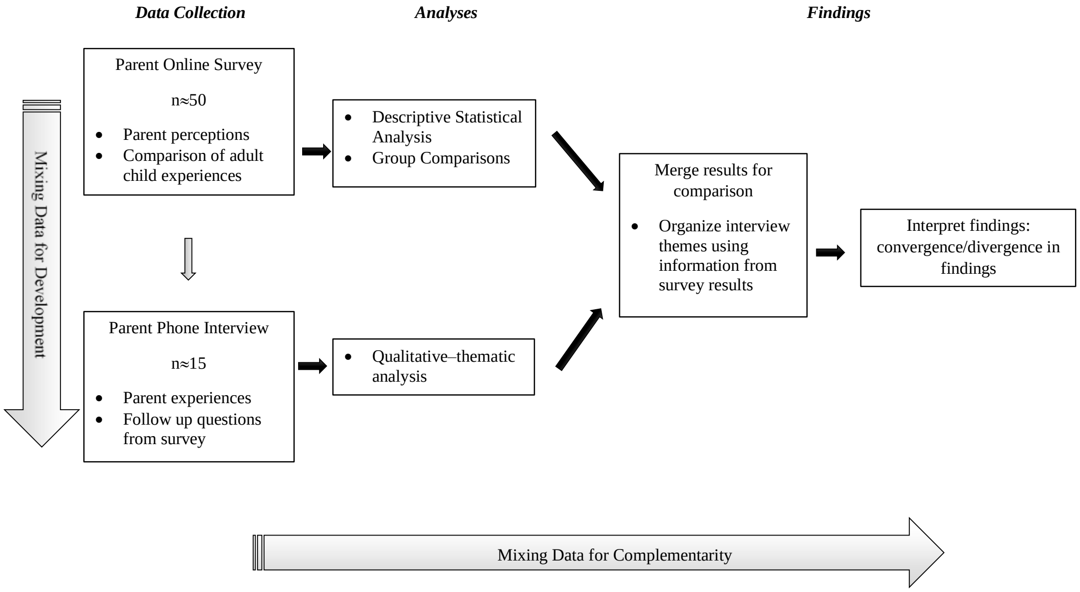

Figure 2.1 Data Collection, Analysis, and Interpretation Procedures

Participants

Recruitment. Participants were identified through agencies and organizations that support adults with ID. Following Institutional Review Board (IRB) approval, partner agencies and organizations across the U.S. were sent a flyer via email to distribute to the families they served. The flyer included an overview of the study, participation requirements, and a link to the online survey (see Appendix A).

A subset of survey participants was also interviewed. Parents were provided with a place on the survey where they could indicate interest in interview participation. All interested individuals were contacted via phone or email. During this contact the researcher explained the interview process including the research questions, the consent procedures and confidentiality process, and gave participants a chance to ask any questions. Participants who were still willing to be interviewed scheduled a date, time, and preferred method (i.e. phone or video conference) for the interview.

Inclusion and exclusion criteria. Parents/caregivers were eligible for participation if they were: 1) a biological parent or legal primary caregiver to an adult with ID between the ages of 18-35; and 2) a biological parent or previous legal primary caregiver to an adult without ID between the ages of 18-35. Parents/caregivers were excluded from participation in the study if they: 1) had an ID diagnosis; 2) did not speak/understand English fluently; and 3) did not currently reside within the United States.

Study Measures

As is common with convergent mixed methods research designs, quantitative and qualitative data were collected simultaneously and to answer parallel research questions (Creswell & Plano-Clark, 2011). An online survey was used to gather information from parents regarding their perceptions of intimate relationships with an aim to compare these experiences and perceptions between two of their adult children. Three of the sections in the survey were adapted from Cuskelly and Bryde's (2004) Attitudes to Sexuality Questionnaire—Individuals with an Intellectual Disability (ASQ-ID). See Appendix B for a copy of the original questionnaire. The ASQ-ID was originally intended to collect data regarding the attitudes around sexuality and romantic relationships for individuals with ID. The phrase "adults with an intellectual disability" was used within survey questions. In order to adjust the survey to allow comparison between adults with ID and TD adults, the adapted version of the ASQ-ID used in this study reworded this phrase to instead use the names of the adult children provided by the parent participant. This ensured parents reflected on their own experiences.

Survey pilot study. Before distribution of the survey, a pilot study was conducted to inform the adaptations of the original ASQ-ID measure. The pilot study had two goals: 1) to ensure the questions were applicable to parents of TD children; and 2) to determine if the questions were applicable to adolescent children (aged 16-18) or if the questions were more appropriate for adults (aged 18-35). The following procedures were used to adapt the ASQ-ID. First, 7 of the original 33 questionnaire items were placed in their own section of the survey due to their focus on disability-specific issues (e.g. questions about sterilization, questions about working with care staff). Next, 8 of the remaining 26 items were excluded based on their similarity to other items in order to avoid confusion for participants. The remaining 18 questions were placed in an online survey with the adapted phrasing of "my child" instead of "adult with an intellectual disability". Within the survey pilot, after each question participants were asked to answer yes or no to the question: "Does this question apply to my child?" and asked to respond to the follow up question "If not, why?" as applicable.

Participants were recruited through a series of social media posts. Thirty-three parents completed the online pilot study survey (3 males, 29 females, 1 did not disclose) and reported about their children (5 males, 17 females, 1 did not disclose) ranging in age from 16-28 (M = 20, SD = 3.72). Among the parents of children under 18, 40% of questions were rated as not applying to their child. Parents indicated this was because they were too young. Therefore, parents were asked to report only on their children who were over the age of 18 in the final survey. Parents also indicated that wording of seven of the questions was confusing. These questions were revised for clarity in the final survey.

Parents often find discussions about intimate relationships with their children difficult, especially if they have a child with ID (Foley, 2012). Therefore, the pilot study also included a review by a panel consisting of an expert in the field of disability and sexuality, and two parents of adult children with ID. The panel reviewed all materials before the study began to ensure they were appropriate and would not cause discomfort for parents in answering. Based on panel feedback, space was provided after each Likert scaled question to allow parents the option to elaborate on their responses.

Online survey. The final survey used within this study is provided in Appendix D. The adaptations of the ASQ-ID were used in the survey as well as questions created based on a review of the literature discussing the role of parents in the lives of adults with ID (Cuskelly & Bryde, 2004; English et al., 2018; Fulford & Cobigo, 2018; Whittle & Butler, 2018), and using the social model of disability (Oliver, 1983), and parental straddling theory (Johnson, 2000) to inform questions related to relationship topics. A table detailing the use of the different theories during the creation of study materials is provided in Appendix C.

The survey began with demographic data for the parent and the two children they were reporting on within the study (an individual with ID and without ID). The survey also included two sections that contained the adapted questions from the ASQ-ID—one area to respond about the individual with ID and one to respond about the individual without ID. These sections were presented separately and were randomly presented to participants to reduce the likelihood of biased responding. The remaining seven questions from the original ASQ-ID survey that were not applicable to TD adult children were included in a separate section. Participants were also asked to rate factors (i.e. age, gender, adaptive functioning level, cognitive level, rules within place of residence, staff perceptions, societal factors, and other) that serve as a barrier to their adult child with ID experiencing intimate relationships using a Likert scale (not at all to very much). The survey concluded by asking parents to provide contact information if they were willing to participate in a follow-up interview.

There were other sections of the survey designed to understand issues specific to sexuality education, sexuality expression, and parental communication around sexuality. These topics are not discussed in this manuscript due to the focus on intimate relationships. Therefore, these sections of the survey are not detailed here.

Interview creation. An interview protocol was created for the semi-structured interviews. The protocol included general questions for all participants, as well as several participant-specific questions based online survey responses from each participant. Interviews were conducted to allow: 1) further exploration of findings from online surveys; and 2) further examination of parental experiences and the role they play in supporting romantic relationships for adult children with ID. The protocol also included probing questions to be used as needed, however interviews were primarily guided by participant's responses in an effort to minimize bias (Legard et al., 2003; Willig, 2001). See Appendix E for the interview guide (i.e. the verbal consent form, interview script, and outline of questions used for each interview). The interview protocol was created using the social model of disability, parental straddling theory, as well as a review of literature discussing the role of parents in the lives of adults with ID (Lunsky et al., 2017; Rowbotham et al., 2011; Yoong & Koritsas, 2012). A table detailing the use of these theories in the creation of study materials can be found in Appendix C.

Interviews. Parents interested in participating in the follow-up interview were contacted to determine a mutually convenient date/time and method for the interview (i.e., via phone or video conferencing). Prior to conducting the interview, the participant's survey response was analyzed, using descriptive statistics, to create personalized questions for the interview. The primary researcher conducted interviews with support from a trained research assistant who was the sibling of an adult with ID and had experience working with adults with ID. Research assistant training included instruction on conducting interviews and practice interviews with coaching. At the start of each interview, the participant was oriented to the study and the participant and researcher talked informally to build rapport (Gale & Dolbin-MacNab, 2014). The interviewer then reviewed the objectives of the study and the procedures for the interview. Then the consent procedures were discussed, and any participant questions were answered. This process included explanation of the participant's right to skip any question or withdraw from the interview at any time without penalty. During this time participants were also informed that the interview was being audio recorded for later transcription. After obtaining participant consent, the interview proceeded. Demographic information was not collected for participants during the interview since this information was already collected within online surveys. Surveys and interview data were connected using a participant code.

Data Analyses

Data from the survey and the interviews were analyzed using the seven-stage mixed methods data analysis process (Johnson & Onwuegbuzie, 2004). This included each of the following steps: 1) data reduction where quantitative data were analyzed using statistical methods and themes were identified within qualitative data; 2) data display where data were illustrated visually to support understanding of the main findings; 3) data transformation where quantitative results were transformed into descriptive themes and qualitative data were quantified to aid in comparison; 4) data correlation between the two sets of data; 5) data consolidation where the data sets were combined; 6) data comparison where data sets were compared for points of convergence and divergence; and 7) data integration where data sets were integrated together to form a cohesive understanding of results. The merging of data sets allowed for a deeper understanding and interpretation of parent perceptions and support in the romantic relationships of their adult children with ID.

Survey analysis. After the completion of survey data collection, data were exported from Qualtrics (2005) and examined for incomplete responses, missing data, and accuracy. After preparation of the data, participant demographics were analyzed using descriptive statistics (i.e. mean, range, and frequencies). Descriptions of analyses for other questions on the survey follow. All quantitative analyses were completed using the program SPSS (IBM Corp., 2017).

Parental attitudes towards intimate relationships for adults with ID. To interpret results of the data related to parental attitudes a number of steps were taken as part of data analysis. First, frequencies were conducted to determine the areas of highest concern for parents related to their attitudes of intimate relationship for individuals with ID. Within questions where there was high variability in rankings, frequencies were further compared based on demographic information to provide additional insight into the potential reasons for the variability. Demographic data that were used within these comparisons included approximate annual household income, parental relationship status, gender, child diagnosis, living arrangements, and guardianship for the adult with ID.

Barriers to intimate relationships for adults with ID. To interpret results of the data related to barriers to intimate relationships for adults with ID the following steps were used.

First, frequencies were conducted to determine the most common barriers adults with ID face related to experiencing romantic relationships. Parent's short answer responses were also analyzed and categorized to identify additional barriers not included in the survey question.

Comparing parental attitudes. To understand how parental attitudes vary related to raising an individual with ID and without ID, the following steps were conducted for analysis. An exploratory factor analysis was conducted to examine if there were any potential underlying relationships between questions from these sections. No relationship was found using this analysis, so a paired-samples t-test was conducted for each question relating to parental attitudes to determine differences in responses for adult children with ID and those without ID.

Interviews. Interview data were analyzed using thematic analysis. Braun & Clarke's (2006) procedures were followed during analysis: 1) familiarization with the data through data transcription and initial reading of each transcript; 2) generation of initial codes; 3) search for themes; 4) review of themes; 5) definition and naming of themes; and 6) creation of a final report. Using a constructionist thematic analysis approach (Boyatsiz, 1998), two levels of analyses were used to create codes and themes. Data were first analyzed at the semantic or explicit level to create initial codes. After these initial codes were created, data were then analyzed at the latent level using underlying ideas and conceptualizations to inform the semantic level of analysis. A detailed audit trail was kept in order to reflect the different levels of analysis.

Trustworthiness. Trustworthiness within qualitative data analysis refers to validation of study findings to ensure they accurately represent participant experiences. In demonstrating trustworthiness, four criteria are assessed: credibility, dependability, confirmability, and transferability (Lincoln & Guba, 1985; Morrow, 2005).

Credibility implies that the results represent the lived experiences of the participants (Morrow, 2005). A member check (Lincoln & Guba, 1985) was conducted with each interview participant to ensure credibility of study results. Participants were sent a summary of their interview via email and asked to indicate if the summary was accurate and provide additional feedback/information if necessary. Half of participants in this study responded and indicated the summary accurately reflected their experiences.

Dependability and confirmability are interrelated concepts that aim at ensuring that a rigorous and reliable methodology was used to derive the qualitative results (Lincoln & Guba, 1985; Merriam, 2009). For this study, an audit trail was kept of the data analysis process. A timeline of the analysis, emerging codes and themes, and overall development of themes were all documented.

Transferability refers to the applicability of findings to other contexts (Morrow, 2005). Transferability was achieved in this study using reflexive journaling. The contexts of data collection were documented, as well as contexts that potentially influenced data analyses. These journals were referred to throughout the data analysis process.

Merging and interpreting the data. Analyses and results from both the quantitative and qualitative strands of data collection were merged together using a transformative merging process (Creswell & Plano Clark, 2011; Greene, 2007). Quantitative data were transformed into descriptive themes using a data reduction process, and then these data were compared with qualitative results using a visual data mapping process (Creswell & Plano Clark, 2011). Qualitative results were also quantified to allow for thorough comparison. Following data reduction, data sets were incorporated together and examined for areas of convergence and divergence to provide a more holistic and accurate representation of participant attitudes and experiences (Greene, 2007).

Participants

Online survey. Fifty parents (46 mothers, 4 fathers) participated in the online survey portion of this study. All participants were parents of an adult with ID, and a TD adult. Parents were representative of all regions of the United States. Parents were aged 40-76 (M = 62, SD = 9). The majority of parents were Caucasian (92%) and were currently married (74%). Most parents (84%) indicated they had an approximate annual family income of $40,000 or above. Parents also indicated they had an average of 3 kids total (SD = 0.68) with ages ranging from 8 to 53 (M = 24.61, SD = 7.47). Further breakdown of the demographics of parent participants can be found in Table 2.1.

Table 2.1
Parent (Survey) Demographics (n = 50)

Characteristics	**% (n)**	**Characteristics**	**% (n)**
Race/Ethnicity			
White	92 (46)		
Black, African American	4 (2)		
Hispanic, Latino, or Spanish Origin	2 (1)	*Relationship Status*	
Not Reported	2 (1)	Married	74 (37)
		Widowed	2 (1)
Approximate Family Income		Divorced	16 (8)
Less than $40,000/year	14 (7)	Separated	2 (1)
$40,000-$80,000/year	38 (19)	Living Together	2 (1)
More than $80,000/year	46 (23)	Single	2 (1)
Not Reported	2 (1)	Not Reported	2 (1)
Highest Education Level		*Region of the U.S.*	
High School Degree	4 (2)	Northeast	10 (5)
Some College	12 (6)	Midwest	50 (25)
Associate Degree	18 (9)	South	18 (9)
Bachelor’s Degree	28 (14)	West (incl. HI & AK)	22 (11)
Graduate Degree	34 (17)		
Not Reported	4 (2)		

Individuals with ID. Parents provided demographic information for both adult children reported on in the study. Table 2.2 provides a visual comparison of these demographics. There were 30 males and 20 females for individuals with ID aged 18-33 (M = 23.86, SD = 3.68). Most individuals with ID lived at home (70%) and were not currently employed (50%). Parents also indicated that most of these individuals (66%) were not currently in a relationship. When asked about diagnoses, 34% of parents indicated that their adult child had more than one disability diagnosis. The majority of parents (62%) reported that they had guardianship of this adult. See Table 2.3 for further information on diagnoses and guardianship for individuals with ID.

Table 2.2
Adult Children (Survey) Demographic Comparison (n = 50)

Characteristics	**Adult w/ID % (n)**	**TD Adult %(n)**
Highest Education Level		
High School Degree	78 (39)	18 (9)
Some College	16 (8)	32 (16)
Associate Degree	2 (1)	12 (6)
Bachelor’s Degree	--	22 (11)
Graduate Degree	--	14 (7)
Not Reported	4 (2)	2 (1)
Current Residence		
At home with parent	70 (35)	22 (11)
In the community independently	6 (3)	68 (34)
In the community with minimal support or college living	10 (5)	10 (5)
Group home or supported living	14 (7)	--
Employment Status		
Full-time	8 (4)	54 (27)
Part-time	30 (15)	16 (8)
Not currently employed	50 (25)	10 (5)
Full-time student	10 (5)	18 (9)
Not Reported	2 (1)	2 (1)
Currently in a Romantic Relationship		
Yes	30 (15)	62 (31)
No	66 (33)	30 (15)
Parent is Unsure	4 (2)	8 (4)

Table 2.3

Adult with ID (Survey) Diagnosis and Guardianship (n = 50)

Characteristics	**% (n)**
Diagnosis[1]	
Down Syndrome	32 (16)
ASD[2]	36 (18)
General ID	24 (12)
Other[3]	50 (25)
Parent Has Guardianship	
Yes	62 (31)
No	38 (19)

Note. [1]Many adults were reported as having multiple diagnosis and are placed in more than 1 category. [2]All adults with ASD also had an ID diagnosis. [3]Other diagnosis included Williams Syndrome, PDD/NOS, significant health conditions, genetic disorders, mental health diagnosis, speech disorders, and neurodegenerative disorders.

TD individuals. TD individuals included 38 males and 62 females aged 18-33 (M = 24.66, SD = 5.24). The majority of these individuals lived independently in the community (68%) and were employed full-time (54%). Parents also indicated that the majority of these adults (62%) were currently in a relationship.

Interviews. A group of 20 parents (19 mothers, 1 father) who completed the survey also participated in the interview. Demographics of parent interview participants can be found in Table 2.4. Demographic comparisons between the two children they reported on can be found in Table 2.5, and further information on diagnoses and guardianship for the individuals with ID can be found in Table 2.6. The demographic details of parents who were interviewed and the adult children they reported on were similar to those who completed the survey.

Table 2.4

Parent (Interview) Demographics (n = 20)

Characteristics	**% (n)**	**Characteristics**	**% (n)**
Gender			
Male	5 (1)		
Female	95 (19)		
		Highest Education Level	
Age		Some College	15 (3)
40-50	25 (5)	Associate Degree	15 (3)
51-60	45 (9)	Bachelor’s Degree	40 (8)
Above 60	25 (5)	Graduate Degree	25 (5)
Not Reported	5 (1)	Not Reported	5 (1)
Race/Ethnicity		*Approximate Family Income*	
White	90 (18)	$40,000-$80,000/year	55 (11)
Black, African American	5 (1)	More than $80,000/year	45 (9)
Hispanic, Latino, or Spanish Origin	5 (1)		
		Relationship Status	
Region of the U.S.		Married	80 (16)
Northeast	--	Divorced	20 (4)
Midwest	60 (12)		
South	20 (4)		
West (incl. HI & AK)	20 (4)		

Table 2.5

Adult Children (Interview) Demographic Comparison (n = 20)

Characteristics	**Adult w/ID % (n)**	**TD Adult %(n)**
Gender		
Male	65 (13)	25 (5)
Female	35 (7)	75 (15)
Age		
18-22	40 (8)	35 (7)
23-27	30 (6)	50 (10)
28-32	30 (6)	15 (3)
Highest Education Level		
High School Degree	75 (15)	10 (2)
Some College	15 (3)	40 (8)
Associate Degree	5 (1)	10 (2)
Bachelor’s Degree	--	30 (6)
Graduate Degree	--	10 (2)
Not Reported	5 (1)	--

Table 2.5 (cont'd)

Current Residence		
At home with parent	80 (16)	10 (2)
In the community independently	--	80 (16)
In the community with minimal support or college living	15 (3)	10 (2)
Group home or supported living	5 (1)	--
Employment Status		
Full-time	--	45 (9)
Part-time	25 (5)	35 (7)
Not currently employed	55 (11)	--
Full-time student	15 (3)	15 (3)
Not Reported	5 (1)	5 (1)
Currently in a Romantic Relationship		
Yes	25 (5)	60 (12)
No	75 (15)	35 (7)
Parent is Unsure	--	5 (1)

Table 2.6

Adult with ID (Interviews) Diagnosis and Guardianship (n = 20)

Characteristics	**% (n)**
Diagnosis[1]	
Down Syndrome	30 (6)
ASD[2]	35 (7)
General ID	25 (5)
Other[3]	55 (11)
Parent Has Guardianship	
Yes	45 (9)
No	55 (11)

Note. [1]Many adults were reported as having multiple diagnosis and are placed in more than 1 category. [2]All adults with ASD also had an ID diagnosis. [3]Other diagnosis included Williams Syndrome, PDD/NOS, significant health conditions, genetic disorders, mental health diagnosis, speech disorders, and neurodegenerative disorders.

Results

The results from this study provide insight into how parents perceive the intimate relationship experiences for individuals with ID, and how these perceptions and experiences differ from their TD adult children. Results are presented across five main themes including: 1) differing levels of parental involvement; 2) differing parental expectations; 3) differing parental roles; 4) parents as “gatekeepers” for intimate experiences of individuals with ID; and 5) barriers to romantic relationships for individuals with ID. Each theme contains descriptive subthemes with specific findings from the merged data from the online survey and interviews. Figure 3.2 provides a visual representation of the results and themes.

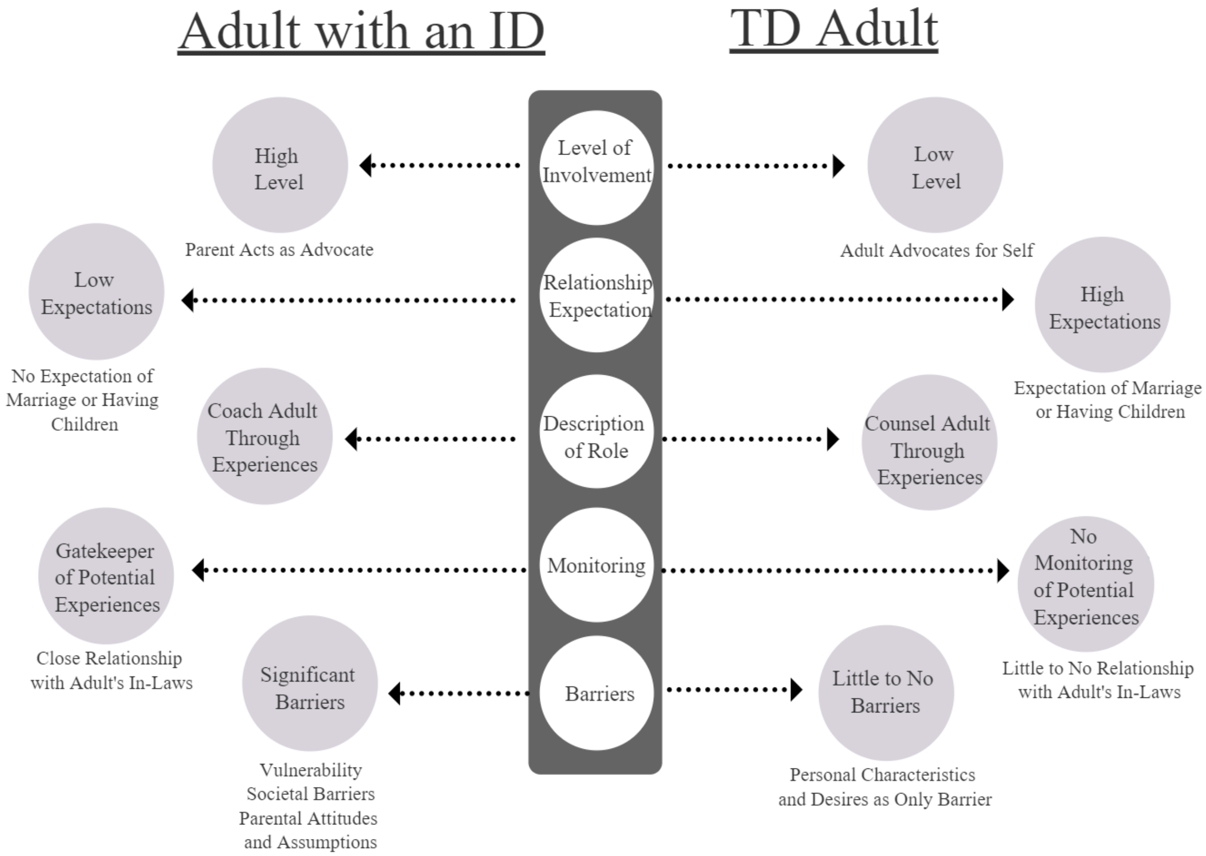

Figure 2.2 Results of Parental Role in Intimate Relationships

Differing Levels of Parental Involvement

Within the study parents noted that their involvement in the romantic lives of their adult children differed drastically with a much higher level of involvement expected for individuals with ID. Parents described involvement in the daily aspects of dating and having a relationship including facilitating and monitoring dates, and coaching their child through potential relationship issues or general experiences. One parent discussed a situation in which her son with

ID wanted to have sex with his girlfriend one night and the girlfriend did not. After overhearing the argument, the parents had to get involved and the mother explained,

> "we had to walk through that with him and explain and re-explain everything…that is not a conversation that I would've ever been involved with with my (TD) daughter."

Overall, parents discussed feeling as if the individual with ID was in need of more support to maintain a relationship than a TD individual. For example, one dad discussed the relationship of his son with ID and his son's girlfriend and rated his overall management and involvement in their relationship as an 8 out of 10—indicating a high level of involvement. When thinking about her daughter with ID potentially getting married in the future, another parent participant said:

> "if I have a house, they live either upstairs or they live downstairs and that makes, you know, an apartment or whatever, just so they have the ability to be able to be on their own, but yet where they're in a close area so that I will be able to help them if they do need our help."

Outside of daily management of the relationship, parents also discussed being more involved in other aspects of romantic relationships, such as helping their adult with ID find potential dating partners, engaging the family members of other individuals with ID to set their children up on dates, and potentially facilitating a break-up between individuals when necessary. When comparing the dating experiences of her daughter with ID to those of her TD adult daughter, one mother reflected,

> "you have to be there kind of facilitating the whole time, it's not a real natural process like it is with typical kids."

Another parent discussed her role in helping her adult son with ID date:

> "transportation is always an issue…The parents were always driving the kids somewhere and picking them up and dropping them off at each other's houses, more like dating was for (daughter with ID) in middle and high school."

One parent said that with her daughter with ID,

> "I would have to have like 90% involvement in everything."

Even if the individual with ID was not currently in a relationship, parents discussed expecting high levels of involvement for the same reasons as parents who were currently in these situations. Parents also discussed being involved more than any other person. One parent elaborated saying,

> "I'm his mom. I feel like I'm responsible for him in general…Maybe there would be other people that may be more appropriate coming from, but because it's been mainly me for so long, I think that I've just gotten into this habit that I'll do it, that's something I have to do."

Some of the people parents indicated they may receive help from were other family members (e.g. siblings, spouses), therapists the adult may be seeing, or staff working with their adult son or daughter. However, despite the help these individuals may provide, most parents felt as if they were the main facilitator of these relationships and experiences. This was true across different genders. For example, many mothers of sons with ID discussed wishing their child's father would provide more guidance, but recognized the responsibility fell mainly to them.

Parents as advocates. One of the most distinct aspects of parental involvement is the differing levels of advocacy. Parents often felt that they had to advocate for romantic relationship experiences for the individual with ID. TD adult children often sought out and engaged in these romantic relationship experiences with little or no help from parents. Advocating for the individual with ID most often included discussions with other parents or community providers to facilitate dating opportunities. Less commonly, this included education and advocacy among family and community members for the individual with ID to have the right to engage in romantic relationships. Parents discussed feeling the "need to" act as an advocate and be more involved because of social stigma and the lack of opportunities and education allowing individuals with ID to create these experiences independently.

Differing Parental Expectations

Another theme that emerged from parent surveys and interviews was the drastic difference in expectations that parents have regarding intimate relationship experiences. The majority of parents discussed wanting to believe their adult children will have similar experiences. However, they also expressed fear that in reality their TD adult child is much more likely to engage in intimate relationship experiences than the individual with ID. When asked in the survey if they expected their adult child to engage in a romantic relationship, parents answered similarly for both children. However, within the qualitative comments parents indicated there were many more stipulations that would need to be in place for this to happen for the individual with ID. Within the interviews, parents discussed how they would love for their adult child with ID to experience intimacy and a loving relationship, but fear challenges related to their disability will act as a barrier. One parent said about her son with ID:

> "I would love for him to meet someone he could be intimate with."

but then later stated she felt her son never would have this experience because

> "communication for him is his main barrier."

The disability-related issues parents discussed as barriers were often related to adaptive behaviors, societal issues such as not having places to meet someone, and concerns with finding "the right person".

While finding the "right person" is often something parents of both TD adults and adults with ID stated as a desire for their children, this term held a different meaning for the adult with ID. For their TD adult child, finding "the right person" included someone who was compatible with them in terms of personality, as well as someone with whom they were in love. For their adult child with ID, the "right person" included someone who was at a similar cognitive functioning level, whose adaptive behaviors were similar or complementary to their child's, and whose parents were accepting of their child and had similar views so they could work together to facilitate the relationship. Often, ideas of love or personality match held lower importance. In this way, the parents were looking for their individual with ID to have more of a "practical daily living match" as opposed to a "love match". Parents were also asked in the survey to check all the types of relationships they expected their adult children to have (i.e. friendships, romantic/dating, marriage, and sexual/physical intimacy). Approximately 96% of parents indicated they expected both of their children to have friendships, and 82% of parents indicated that they expected both children to experience romantic/dating relationships. While most parents still indicated the same expectations for both kids regarding sexual/physical intimacy and marriage, there were higher levels of variability. For these types of relationships, 34% had different expectations for their two children, expecting their TD adult child will have a sexual/physically intimate relationship while their adult child with ID will not. For expectations of marriage, 46% of parents had differing expectations between their two children, expecting that their TD adult child will get married but their child with ID will not.

Marriage. The most obvious area of difference in parental expectations was around the topic of marriage. Parents indicated that they felt marriage should be discouraged for their adult child with ID (M = 2.62, SD = 1.62) but not for their TD adult child (M = 1.87, SD = 1.73), t (46) = 2.16, p = .036. Parents also felt that their TD adult child had the right to marry (M = 5.72, SD = .807) while their adult with ID did not (M = 5.04, SD = 1.23), t (45) = -3.30, p = .002. The qualitative comments relating to these questions indicated that parents believed that overall, adults with ID should have the right to marry and should be encouraged to do so, however they each felt that their child should not marry due to individual characteristics. Parents saw marriage as an option for their TD adult child as long as that was something desirable for that individual. For their adult child with ID, parents had more concerns and indicated many things would need to be in place for this to happen. One parent described this as,

> "I think for (TD daughter)'s world I see a lot of different variations of what her life could be and if she wants to be married one day that's awesome. I wish I could say I have the same expectations for (daughter with ID), but I don't. I just don't see it."

Marriage was seen as too large of a commitment and contained too many variables for parents to envision this as a possibility for their adult with ID. For example, many parents worried about their adult with ID's ability to function in a marriage with daily living and relationship skills. One parent provided this description:

> "whether they could live along on their own, I don't think (daughter with ID) could, even with another person, because if that person would also be intellectual challenged it would be tough for them. They would have to have tons of support – parental support and community support and sibling support - for that to happen."

Parents often felt as if they would have to be much more involved in the daily lives of their child and their spouse. Parents were also concerned with the loss of social security related disability benefits that would occur if their child married. They did not have these same concerns for their TD adult child. One parent stated

> "people will ask me if (adult son with ID) will marry and I'll say 'I'm not against it'. I know that it would take a lot of work on our parents' part due to the issues with funding, with social security, with Medicaid, with Medicare especially."

Having children. The expectation of having children is another area in which there were drastic differences in parent views. What made the findings of this topic unique is that, compared to marriage, parents did not express a desire that their adult with ID have the experience of having children. When asked if adults with ID as a group should be discouraged from having children, 62% of parents from the survey agreed. Similar to the issues of marriage, parents felt that for their TD child, the choice to have children was up to them. For the individual with ID, parents strongly believed they should not have children. One mother described this situation in terms of the conversations related to having children with both of her adult children:

> “As (daughter with ID) got older we had to talk about children and about, you know, her not being able to handle children and her capabilities. I didn’t have to have that discussion with (TD son).”

When another parent compared her expectations between her two adult sons, she stated,

> “I don’t worry about (TD adult son). Because of (adult son with ID)’s developmental and intellectual level, I don’t think he is capable of all of the tiny pieces that go into parenting a child.”

When asked if they felt their child should be permitted to have children within marriage, parents disagreed for their adult with ID (M = 2.48, SD = 1.76), but agreed for their TD adult (M = 5.44, SD = 1.07), t (47) = -9.35, p = .000. The main concern for parents regarding their adult with ID having children is their inability to care for the child due to their disability. Parents felt their TD adult child would be capable of rearing well-adjusted children (M = 5.28, SD = 1.49) but did not feel this would be the case for their adult child with ID (M = 2.42, SD = 1.73), t (49) = -8.65, p = .000. Within interviews parents indicated that they knew their adult with ID talked about having children or being a parent one day but felt as if they did not fully understand what it meant to raise a child. When discussing her adult son with ID’s desire to be a father, one mother explained,

> “he is just getting to the point I think where he understands that he can’t handle that. Although for a very long time, possibly still a little bit, he wanted to, that was his dream.”

They also felt that their cognitive abilities and lack of adaptive behaviors would prevent them from being attentive parents. Parents indicated that if their adult with ID were to have a child, they would have to step-in and raise the child themselves. One parent stated,

> “If she (daughter with ID) had another person, I would be taking care of them 100%.”

Another parent reflected,

> "I mean, she has talked about having kids…and she thinks she can do everything, but in my head I know that I would be a caregiver."

A final concern a handful of parents brought up in their interviews was regarding whether or not if their adult with ID had a child, if that child would also inherit any potential disabilities as well. Most parents indicated if that was the case, their adult with ID would not be able to handle all of the complexities of raising a child with ID. However, if the child did not have ID, then there were concerns of what would happen when the child's intellectual and adaptive needs outgrew what their parent with ID could provide. One mother explained this succinctly saying,

> "you also then have to think about the child. So is the child disabled like the parents, and then there's no way they could handle that. Or is the child going to be smarter than the parents, and if that's the case, that's just no good."

Differing Parental Roles: Coaches vs. Counselors

Parents also played very different roles with their adult children regarding intimate relationship experiences. In the case of raising an individual with ID, parents often acted as coaches. Parents mentioned their role teaching their adult child about relationships (e.g. describing the difference between dating and being in a committed relationship) as well as teaching them the nuances of being in a relationship. This included instructing them on how they should act on a date, or what types of gifts they should buy for their partner for an anniversary. One parent described,

> "my role is often to be a facilitator for him with relationships, in terms of getting him to places, in terms of overall helping him, being a resource for him that he can talk to."

Parents also discussed how they have to help coach their adult with ID through romantic relationship situations. Coaching is different than teaching in that it is more specific to the situation their adult is experiencing. This includes situations such as working with them to understand and mend a potential argument they had with their partner or going along on a date with them to give them step-by-step coaching on actions they should take throughout the date. One parent described this as,

> "I need to just be supportive and help him to problem solve as much as he is capable of."

Another parent further explained this when discussing how she coached her daughter through a date with another person with ID stating,

> "you think you can just put them together and they know what to do, but they *don't*."

Parents also are the ones who helped involve the adult with ID in the community to find potential dating partners or engage in dating activities. One parent said,

> "I'm just exposing him to as much social opportunities as I can, where he might meet somebody."

Another parent reflected,

> "I know that if I'm not there to help her in these situations and coach her through them, they don't just arrive for her."

Parents were often the only form of transportation and managed finances for their adult with ID, which created more coaching opportunities. Acting as a coach within their relationship also included having more detailed and intimate discussions than they would with a TD adult child. For example, one parent discussed a situation in which her son with ID was displeased with a sexual situation with his girlfriend and this parent had to walk her son through the conversation he should be having with his girlfriend step-by-step to help him.

On the flip side, parents served in the role of counselor with their TD adult children. Parents felt as if their main responsibility was to give advice when their child needed it. That meant waiting until the individual came to the parent and asked for advice or input on their relationship. One mother described this as

> "the others (TD adult children), when they need, they come to me and ask questions. Whereas with (daughter with ID) I have to monitor, I have to bring it up."

Often times, parents felt as if they had little to no idea of what was occurring in their TD adult child's relationship until they came to them with questions and concerns. The main difference between "coaching" their adult with ID and "counseling" their TD adult was in the expectation of whether or not their input was going to be directly applied by that individual. Parents expected their adult with ID to follow their coaching because they are often their only source of information on the topic. They also felt more control over the situation and relationship for their adult with ID. For their TD adult, advice and information might come from peers, co-workers, or other family members. TD adults also have the ability to integrate knowledge from other sources and experiences to create their own understanding and make their own judgment. Parent advice was simply one piece of it. But for the adult with ID, there were concerns that they would not integrate information in this way, so parents felt they must guide and coach rather than counsel. A mother of an adult male with ID said,

> "But some of the things like this are difficult, like for him to call up and to set a date, and then to coordinate with the parents to get it all done. He can't do that…that is just not his skill set."

Due to these cognitive concerns, parents felt the "need" to be more involved in coaching their individual with ID.

Parents as Gatekeepers

Aside from just acting as a coach for their adult with ID, parents also noted the control they have over the intimate relationship experiences of the individual with ID. They acted as a gatekeeper of these experiences, determining what experiences and information was allowed for their child. One mother described how her daughter with ID does not date because,

> "she's just not there, she's not in situations where that could happen because we so carefully control her world."

Parents felt they had to constantly monitor the experiences and knowledge that their adult with ID is exposed to. One parent said:

> “with (daughter with ID), she’s never at a place or in a position where she’s on her own. Somebody is there watching her, taking care of her, always.”

This is something that parents did not feel is necessary for their TD adult child. There is the expectation that their TD adult will be capable of understanding and handling situations on their own. For their adult with ID, there were concerns with their ability to comprehend certain situations, as well as potential deficits in their adaptive functioning as having negative impacts on their experiences. One parent worried,

> “part of that is trying to give him his freedom, but also to understand that due to his intellectual disability he can’t always problem solve or recognize dangers.”

Parents felt as if they were constantly asking questions to gauge what information the individual with ID has, what they might need to supplement, and what information may have been received incorrectly. Added to these concerns was their child’s status as a vulnerable adult and knowledge of the high rates of sexual abuse and exploitation among adults with ID. Worries about their vulnerability caused parents to feel the need to closely monitor intimate relationship experiences. One parent simply stated,

> “it would be different if we lived in a different world and I didn’t have to worry about her being taken advantage of.”

Another parent described,

> “those (sexual assault) stats, they’re always there in the back of the head.”

Again, parents had a feeling of “needing to” act as their child’s gatekeeper. One parent said:

> “I don’t want to be overprotective, but, I’m in a position where I have to be at least somewhat protective.”

The importance of the "other mother". Parents also discussed the unique situations that arose when their adult with ID entered into a romantic relationship. In these situations, the other partner's mother became a factor within the relationship on the same level as the parent. With this the relationship became not only about the two adults dating but a relationship between the families. A few parents discussed the importance of both the partner's mother and father, however the mother was commonly the person mentioned as the most impactful. Many parents felt that this person, and their own relationship with this person, could make or break a relationship for their adult with ID. One dad described the impact he, his wife, and his son's girlfriend's parents have on the relationship:

> "if we weren't (as involved) and worked so well together, they would have broken up a long time ago, I think. But just because they wouldn't know what to do, not because they wanted to break up."

Parents relied on this person to help them monitor situations between their children and coach them when needed. One parent described,

> "We had made a pact that they would never be alone together. And we have always been with them, they never had an unsupported or unsupervised time."

Parents whose adult with ID is currently in a relationship talked about having frequent check-ins with this person. One parent described,

> "I had lunch with them a couple of weeks ago… and we sat down and sort of hacked out the details of, if they behave like this what is our reaction going to be? If they behave like that what is our reaction going to be?"

Parents also often reported becoming close friends with this other parent. One parent mentioned,

> "before they were dating, I didn't know her parents, but we have since become almost best friends."

Another parent elaborated on this idea describing,

> “we’re really good friends. We both are there to support each other. If she has an update, she texts me or I text her. Because, when you both have an adult with an intellectual disability, you bond and become friends. It’s almost like you were meant to be, you all fit together.”

One parent went even further and described this other parent as a “mentor”. Even parents whose adult was not currently in a relationship discussed how important other parents would become. When one parent was reflecting on a potential dating scenario for her son, she stated:

> “I would feel the need to get to know her, and to form a relationship with her parents or whoever were her caregivers. So hopefully we could work together, to either coordinate and facilitate their access to each other, as well as coordinate and facilitate kind of the fall out. When there are issues in the relationship, you know, how are we going to handle it? What can we do to support our kids? What can we do to make sure both our kids are protected?”

This relationship was discussed as being much closer and much more intimate than with the parents of a TD adult child’s partner. One parent, whose daughter with ID was married, described her relationship with her daughter’s mother and father in-law as “significantly closer” than relationships she has with her other children’s in-laws. Another parent, when imagining a future relationship for her adult daughter with ID, stated,

> “I definitely, definitely see the other family, I mean we’d have to be pretty aligned on everything. Like I would see meeting the parents and getting to know them. Obviously, I won’t be doing that in my other daughter’s relationships, that won’t be necessary.”

Barriers to Romantic Relationships for Individuals with ID

The final theme that emerged from the data is the barriers adults with ID face related to intimate and romantic relationships. Parents noted three main barriers: the vulnerability of their adult with ID, societal barriers, and barriers the parents themselves put up. All of these are barriers that are unique to individuals with ID that their TD siblings do not face.

Vulnerability. Parents noted many concerns with the individual with ID’s inability to comprehend and integrate knowledge, and the potential risk that posed. Not only did their vulnerability itself act as a barrier, but the parental worry about their vulnerability also caused parents to restrict potential experiences. One parent stated,

> "there is just a multitude of situations and possible bad experiences that could present themselves, and I'm just, I'm just not comfortable with that."

Within the survey, parents indicated they felt their adult child with ID should be living in same-gendered housing (M = 3.37, SD = 1.68), while this was not necessary for their TD adult child (M = 2.47, SD = 1.61), t (48) = 3.46, p =.001. The qualitative comments from this survey question indicated that parents worried about what could happen for their adult with ID if they lived in a mixed-gender household, but felt as if they did not have to worry about their TD adult in that living arrangement because they would be capable of handling situations that may arise.

Societal barriers. Another barrier that parents felt adults with ID faced were those from society. When asked to rank societal factors as a potential barrier for their adult with ID, 66% ranked it as either a moderate or large barrier. While their TD adult child had more independence and opportunities to meet people and date, adults with ID were often relatively invisible in their communities. One parent stated,

> "the opportunities are just not there for kids with disabilities, I think, to build relationships."

Another parent described,

> "she (adult daughter with ID) lived in a group home for a while, and the group home wouldn't take them anywhere, wouldn't bring her to meet people anywhere."

This is especially true when it comes to social outings that could potentially introduce romantic partners. Parents often mentioned how they felt that a major issue was that there was nowhere for adults with ID to meet people. One parent described,

> "if you're in school you meet people through school. He (TD adult son) works and so he may meet people through work, same here for me. But (adult son with ID), he doesn't have those outlets."

Along with the invisibility of adults with ID, parents also felt there were negative attitudes in society that impacted their ability to find and meet people. One parent mentioned,

> "society has a different view…when there is an individual, two individuals with a disability connecting, or one with and one without, society takes a certain negative view of that."

Another parent elaborated on the impact they felt societal views had stating,

> "I think those on the outside perceive it as much less emotionally involved than those who are undergoing it see it as, simply because of their disability."

One parent simply stated,

> "A lot of times, unfortunately, I don't think society is really ready for it."

Parents felt that people still hold very negative views of adults with ID as sexual and romantic beings, and this was a barrier they felt they had to help their adult child overcome.

Parents also mentioned negative attitudes and lack of knowledge on romantic relationships from staff and others who work with their adult with ID as a societal barrier. One parent recognized that providers often struggle because there is a lack of training for them on romantic relationships:

> "what would that look like? You know what I mean? And we don't know what that would look like so we can't tell them…we don't know, because unfortunately no one takes the time to get to know these couples."

Parents often felt as if the lack of staff knowledge on how to talk about the subject, or their negative attitudes towards adults with ID being in romantic relationships, hindered the experiences afforded to these adults. One mother who had an adult daughter with ID who was married and lived in a supported living environment discussed how providers attitudes towards their relationship was a huge barrier. She described,

> "It was providers that came into their home and don't respect them as a married couple…when providers look into the home, they look for everything that's wrong and not what's right."

This same parent further went on to discuss this issue with trained providers stating,

> "we have not been able to find a counselor or therapist that will work with them, someone who knows how to help them through their couple issues."

Parental barriers. While most parents do not intentionally place barriers in front of their children, parents discussed situations in which they inadvertently acted as a barrier to their child engaging in romantic relationship experiences. Sometimes this occurred by parents minimizing their child's relationship and experiences. Many parents would talk about their adult with ID's relationship as "not being a real relationship" or compare them to school-aged kids who label themselves as dating without truly understanding the meaning. For example, one parent described his son with ID's relationship as:

> "the way they interact with each other is almost like a couple of third graders, you know? And, 'oh, so-and-so said this to me at this dance that I went to' and 'I'm going to tell so-and-so' and blah blah blah. It's sort of this moronic, sort of gossipy thing that they do."

Another parent minimized her daughter's desire to have a relationship by stating,

> "she has an infantile impression of what boyfriend and girlfriend are, she doesn't even know what she wants."

Another parent mirrored this with her son with ID stating,

> "I think part of it is just to be able to say he has a girlfriend, because his other friends with disabilities have a boyfriend or girlfriend, and he just wants to be like them."

After one parent compared her adult son with ID's long-term relationship to that of a 4th grader, she further reflected,

> "that sounds mean, I know. That sounds harsh. But it makes it easier for me to minimize it. It makes it less work for me."

Parents also placed barriers because they felt overwhelmed or unsure how to help their adult child engage in these relationships. One parent described:

> "You get tired. I mean, after I worked all day, I'm ready to go home and put my pajamas on and do what I need to do at home versus go out and, you know, go try to pick up a

> girlfriend, you know, go get someone for him, take them out. Then what? Do I sit in the car? Do I eat at a different table? What do I do while they're doing their date?"

Another parent shared,

> "I mean, I don't know how to get her (adult with ID) those experiences. I really just don't even know where to begin."

This also led them to avoid discussions of these relationships or wait until their adult began asking to date. One parent stated,

> "I don't know, this is all uncharted territory for us. So I just wait to deal with it until I have to deal with it."

Another parent reflected on her experiences with fellow parents stating,

> "What I've seen with parents is that sometimes they're a bigger disability than the disability that their child has because they put more road blocks in front of their children than the disability does because of their fears and their misconceptions and how they feel about it, so they avoid it."

Another parent added to this concept stating,

> "parents can't do it all. So I think that's what you find among special needs parents is there is too much to do and this is the kind of thing that you are like 'oh, I'll worry about that later'."

A final way that parents placed barriers was in their potential misconceptions about intimate experiences for their adult with ID. This often took the form of the parent assuming they knew what their child desired without asking them, as well as an inability to visualize their adult child as a romantic person. After describing a dating situation with her TD adult son, a mother was asked if she saw her adult son with ID having the same experiences. She responded,

> "I mean, if something like that happened for him I would be accepting of that, but I know him pretty well at this point and I can't visualize that happening."

Another parent described this inability to visualize her adult son with ID in a relationship as,

> "I think I just can't picture it. There's just a cloud in the way. I can't picture it at all."

After further reflection on this subject, this same parent went on to say, “you know what, maybe I’m his barrier.”

Since parents play such a large role, their own feelings and misconceptions can hinder how much they help their adult with ID. And when they decrease their amount of involvement around this topic, that leads to the adult having less experiences and opportunities. Parents discussed feeling as if this was unfair, but also recognizing that this is simply another component of parenting an individual with ID. Parents discussed needing help managing these situations, and wishing they had others to talk to and help them manage their own emotions to feel more confident and capable in this area.

Discussion

The goal of this study was to examine the parental role in helping an adult with ID create and maintain romantic relationships, by comparing experiences for parents who have an adult child with ID and a TD adult child. The findings of this study demonstrate that parents are much more involved in the romantic lives of their adult with ID. They also maintain different expectations for the intimate relationship experiences of their adult with ID that influence how they interact with them around this topic, especially around the topics of marriage and having children. This study also demonstrates how parents view themselves as coaches for romantic relationships for their adult with ID, as well as gatekeepers of information and experiences in order to monitor and protect their adult with ID from potentially harmful situations. Finally, this highlights the barriers that parents see as impeding romantic relationships for their adult with ID, including concerns with vulnerability, societal barriers, and barriers from parents due to their reluctance and insecurity addressing the topic of intimate relationships.

Parental Straddling

Parents reported more involvement in the romantic lives of their adults with ID, often acting as a coach and gatekeeper of information and experiences. With most TD children, parents can lessen the role that they play as that child moves into adulthood. This is often not true for parents of adults with ID (Cheak-Zamora et al., 2015). While parents seem to be more accepting of this role as it relates to issues such as employment and general living skills, they struggle with it significantly when it comes to intimate relationship experiences. This is most likely due to the extra burden placed on them by having to straddle so many significantly different experiences.

Johnson (2000) describes the parental straddling theory for parents of young children, and how they constantly feel as if they are straddling the world of “normality” and the world of “disability”. For these parents of adults, this straddling continues but in different ways. One of these experiences manifests in parents having to juggle their own daily needs with those of their adult child. Parents experience stress in managing the daily life of their adult with ID as well as their own, this could include transportation to and from work as well as household chores. With the addition of feeling responsible for engaging their adult in social and romantic relationships, their level of stress increases. Parents may also be straddling their own desires and their child’s desires in these areas. Their adult with ID may desire a romantic relationship, but parents may worry about them having that experience due to vulnerability concerns. Another area in which a parent may straddle is in wanting their adult with ID to have more typical and “normal” relationship experiences, while struggling with their values around relationships. They may have to step out of their comfort zone in order to help their adult have those experiences. An example of this would be when a parent does not want their child to have any form of sexual intimacy outside of marriage but recognizes that their adult with ID may never get married and they need to adjust their values and involvement in those conversations accordingly. A final layer of parental straddling is in parents understanding the negative attitudes and other barriers that are in place to prevent these adults from having intimate relationships. Sometimes, these barriers are there because of the parent themselves. Parents must straddle their own avoidance of these barriers and the stress that brings, with wanting their adult to have these experiences and advocating for them as part of their role as a parent.

Defining Intimate Relationships for Adults with ID

The different roles that parents in this study described fulfilling for their adult with ID compared to their TD adult child, combined with their differing expectations and the specific barriers their adults with ID face, indicates that there is still a struggle with defining relationships for adults with ID. The social model of disability (Oliver, 1983) tells us that we should aim to define disability as a social experience and not a medical diagnosis, and to understand that the differing experiences that those with a disability have are not less than TD experiences, they are simply different. When it comes to social and romantic relationship experiences, we should not strive for the "same" as TD, but we should instead recognize that these relationships will look different (Foley, 2014). Usually, by the time their child with ID reaches adulthood, parents have had a lifetime of experiences in helping themselves and others recognize how harmful it is to constantly compare their children to other TD children. However, parents may still struggle with this when it comes to sexuality expression and intimate relationships. Part of this may be that often times, a parent's only other comparison experience is with their TD adult children, and they may not have many other parents of adults with ID with which they can discuss their experiences. While parents recognize that these experiences—and their role in these experiences—may be different, there is still a lack of understanding of exactly how these couples and their relationships are different from TD adult couples and that impacts parental anxiety around these issues.

Through this study, parents discussed the need to be more of a “coach” for their adult with ID, while acting as more of a “counselor” for their TD adult child. Parents played a more active role in the romantic relationships of their adult with ID, almost becoming part of the relationship themselves. For TD adults in the United States, it is expected that parents will be involved in very minimal ways in their intimate relationships (Sharpe, 2003). Because of this discrepancy, parents may negatively view their increased level of involvement in the relationship of their adult child with ID. However, by recognizing that parents play this vital role and helping normalize it, the stigma around it would decrease as would parental anxiety. The same is true for parents acting as “gatekeepers” of information and experiences for their adult with ID. Parents may view this role negatively since they do not need to do this for their TD adult children. However, this role can have a positive impact on safeguarding their adult with ID from potentially abusive or exploitative experiences, while also helping them engage more fully in the intimate relationship experiences they desire. Parents need help recognizing this important role and how to engage in a healthy way, again to lessen their anxiety and to develop a further understanding of romantic relationships for adults with ID.

A final area that is important for defining relationships for adults with ID is determining the importance of the relationship between the two parents of adults with ID who are engaging in an intimate relationship. Again, this relationship provides a different experience for parents, as most of them have little to no involvement with their TD adult children’s in-laws. However, this relationship is vitally important for the success of an intimate relationship for an adult with ID. Recognizing the importance of this relationship and working to understand it as part of the adult experience for individuals with ID, could also help lessen the anxiety of parents around these experiences. This relationship between the parents provides an example of how disability experiences need to be described from a social perspective and understood as different from TD adult experiences and not less than. The importance of this parental relationship is a component of healthy relationships for adults with ID, and the more that parents engage in this relationship the more effective they will be at navigating intimate relationships for their adult with ID.

The Need for Coaching and Mentoring of Parents

Parents struggle with their role as a caregiver of an adult with ID and straddling the desire to be less involved in their lives during adulthood while recognizing that they are lifelong caregivers and will always need to be more involved with these children than they are with their TD adult children. This understanding coupled with the feeling of being unsure what intimate relationships look like for their adult with ID and how they should be different than for TD adults, results in many parents struggling with these experiences. Many participants mentioned the positive impact that coaching and mentoring related to these experiences could have for them. Feelings of isolation and lack of friends is a common complaint among parents of adults with ID (Marsack & Perry, 2018). Many parents feel as if they must navigate these intimate relationship situations on their own with very little support. They often only have previous experiences related to their TD adult child to draw from, and these relationships and the parental level of involvement look very different. Parents in this study often described not knowing what their role should be, how involved they should be, and how the relationship for the adult with ID should and should resemble their TD siblings. Parents need further coaching and mentoring to help them navigate these experiences. This could include both specific training and coaching for parents, as well as help from clinicians and others who work with these families. This could also include ways for parents to connect with one another so they can provide community mentoring. Providing a more intentional community for these parents could help them normalize their experiences, and work towards further normalization of these couples in general society.

Implications for the Intimate Relationship Experiences of Adults with ID

The findings of this study have important implications for families who have an adult with ID. Parents are overall more involved in the lives of their adult with ID (Cheak-Zamora et al., 2015), and this is especially true for romantic and intimate relationships. These relationships often do not occur—or do not occur in a healthy way—unless the parent is significantly involved. Parents act as coaches and gatekeepers for adults with ID, yet they often feel as if they are unprepared for this role. Parents need more guidance and training in this area of managing adulthood with their adult with ID. This includes providing more detailed information on understanding what healthy relationships look like for adults with ID, and how these relationships differ from TD adult children. Also, helping parents learn how they can best advocate for their adult with ID to engage in these relationships. They are their son or daughter's main source of support, and they need help learning how to tear down the barriers they face in regard to these experiences. This need for advocacy is especially necessary regarding the topic of marriage. Adults with ID face a loss of funding when they get married and become a dual-earner household - funding that is often essential as adults with ID infrequently find positions that provide a living wage. Parents need to understand these factors that make couples with ID unique, and their role and addressing these barriers in order to best advocate. This also includes providing coaching and mentoring for parents on their role within these relationships. The coaching needs to be done in the context of their real, lived experiences in order to be most effective. Future research should explore the most effective methods for parents to receive information and coaching around their role in the romantic lives of their adult with ID, and how these relationships function in typical experiences. Mentoring from other parents is also desired from many parents. Parents need a more effective way to connect with one another in order to provide mentoring. This would help parents feel less isolated and be able to share their stories and struggles with individuals who are experiencing similar situations with their adults with ID.

A further implication of this study is the importance of the relationship between the mothers of the two adults with ID who are engaged in a romantic relationship. These mothers are vitally important to the success of the relationship. Whether or not they work well together can impact the ability of their adult children to engage in their desired relationship. These parents also can work together to arrange dates, and support relationships. This relationship between parents needs to be a focus of future research to gain further understanding of these relationships and how they can be fostered. Clinicians who work with these families need to be more aware of such dynamics and understand the important role of the “other mother” in order to best help these families through these relationships and experiences.

Limitations and Future Directions

There are specific limitations to the current study. A total of 50 participants nationwide participated in the study. While this number is typical of studies conducted with parents of adults with ID (Band-Winterstein & Avieli, 2017; Cheak-Zamora et al., 2015; Cuskelly & Bryde, 2004; Rowbotham et al., 2011; Stein et al., 2017), this limits the generalizability of the findings. Parent participant ages also varied widely, which could have impacted the findings due to generational parenting differences. Future research should explore generational parenting difference to better understand this phenomenon. Within the 50 participants all regions of the U.S. were represented, however they were not represented evenly. Future research would benefit from examining parental experiences in a more region-specific manner as social views on intimate relationships and access to resources may differ.

Additionally, the online survey in this study was self-report and descriptive in nature. There was no direct measure of what sexuality education the adult children or parent received, or a direct measure of relationship satisfaction for the adult with ID. Rather, the study relied on parent report and perceptions. Future research should investigate the views of adults with ID themselves on the role their parent or caregiver plays in their romantic relationships. This will help gain further insight into this relationship dynamic, and further inform what we know about healthy intimate relationships for adults with ID. Specifically, collecting dyadic data from both the parent and their adult with ID together could provide significant insight into how this parent/child relationship functions to impact other relationships for the adult with ID (Caldwell, 2014). Future research would also benefit from a closer look at how staff and clinicians who work with adults with ID impact their intimate relationships. This would help to determine their role in healthy relationships and how to effectively train them on this role.

As the topic of the survey was sexuality and intimate relationships, parents who are not open to these relationships for their adult son or daughter with ID and who believe they are not interested in these relationships may not have responded, biasing the sample. Another limitation is that both the survey and interview asked only for parents with adult children aged 18-35, which may also have limited the sample and make generalization to individuals outside of this age group more challenging.

The demographic make-up of the sample also presents a limitation. The sample of parents was not widely diverse, with a large majority of the participants being Caucasian, married, and with a family income of $40,000 or above/year. Therefore, the results of this study may not represent the experiences of families of a lower socioeconomic status who may not have access to as many resources as these participants. Also, the majority of participants had their adult with ID living at home with them. This could also limit the study as parents whose adult with ID lived outside the home may be less involved in their daily lives and may have different experiences than these participants. Future research should evaluate the impact of these demographic components on the experiences of intimate relationships for individuals with ID.

Lastly, most participants were female (mothers). As such the results from this study may not represent the experiences of fathers of adult children with ID. There also was no specific gender-matching done among participants and their adult children. This could have an impact on the study as teaching and coaching about romantic relationships between parents and their children can often be a topic heavily influenced by gender (DiIorio et al., 2003). The impact of gender on the different role of parents is also an area that would benefit from future research. Determining if mothers or fathers play a different role with their child with ID would provide further elaboration on the findings of this study.

Conclusion

This study examined the role that parents play in helping their adult child with ID create and maintain intimate relationships. Findings offer important insights into intimate relationship experiences for adults with ID and highlight critical areas that need to be explored in future research. Future research should continue to address these gaps to ensure that individuals with ID and their parents are provided with the supports they need to have healthy and appropriate intimate relationship experiences.

CHAPTER 4: INTEGRATED DISCUSSION

Introduction

This chapter provides an integrated discussion of the two studies to demonstrate how the findings collectively provide an understanding of the impact of parental attitudes and roles on the sexuality expression and intimate relationship experiences of their adult children with ID. These two studies provide important insight and information that can further illuminate the experiences of these families and determine how to better aid them in supporting their children in these areas. A summary of the overall findings from the studies is presented, followed by an integrated discussion of the entire body of research, limitations of the studies, and implications for practice and future research.

Summary of the Two Studies

The first study examined the parental role in the sexuality education of their adult child with ID, as well as how parents manage sexuality expression. Parents indicated they felt both adult children received poor sexuality education in school, which led to parents being the most important sexuality educator for their children. However, parents felt a much larger responsibility to be the main source of sexuality education for their adult with ID, as they also had to play a large role in managing this individual's sexuality expression by monitoring experiences and managing inappropriate sexual behaviors. This study found that parents struggle with feeling unprepared for this role, especially as the individual with ID enters adulthood. Parents often had to step out of their comfort zone and desired more coaching and guidance to manage these adult issues.

The second study examined more specifically the roles parents play in helping their adult child with ID create and maintain intimate relationships, and how this differs from their role with their TD adult. Findings from this study indicate that parents are significantly more involved overall in romantic relationships for their adult with ID. They also have very different expectations of romantic experiences for their two children. Parents felt as if they acted more as “coaches” for their adult with ID in relationships and were often the gatekeepers of romantic experiences for these adults. Parents also noted many barriers that adults with ID face in having successful romantic relationships. This study exemplified how parents struggle with constantly straddling the multiple roles they play in the lives of their adult with ID, especially when it comes to their involvement in romantic relationships. Parents struggled with defining what these relationships should look like, especially in comparison to their TD adult children. This study showed a strong need for coaching and mentoring for parents regarding romantic relationships in adulthood for their family member with ID.

Integration and Importance of the Entire Body of Research

Both studies provide a deeper exploration of the experiences of parents surrounding sexuality education and expression for their adult with ID, as well as their experiences in the romantic lives of their adult child. By comparing these experiences to those parents have with their TD adult children, the distinct differences in the roles that parents play and the level of involvement they have is apparent. Together, these two studies provide further insight into how parents manage the topic of sexuality and intimacy for child with ID, how this changes as their child enters adulthood, and how parental control impacts the experiences of adults with ID due to highs level of parental involvement.

The Juggling of Needs

Across both studies there was a common theme of parents constantly juggling their own needs with the needs of their adult child with ID. These included physical needs (e.g. daily transportation), social needs (e.g. connecting with peers), as well as individual needs (e.g. attending to personal anxiety concerns). Due to parents being significantly more involved in the daily lives of their adult with ID (Cheak-Zamora et al., 2015), managing these needs is often the sole responsibility of the parent. Parents must examine their needs and the needs of their adult child daily and make decisions about which needs are most pressing. Unfortunately, needs concerning sexuality expression and intimate relationships for adults with ID are often a low priority for these parents (Foley, 2012; Holmes et al., 2016).

Within sexuality education and expression, parents must balance the issue of wanting their adult with ID to be well-informed, while also feeling unprepared to provide sexuality education. For their TD adult, parents recognize the important role they play in laying a foundation for sexuality education, but also assume that child will gain further knowledge from their peers and their own experiences (Tolman & McClelland, 2011). For their adult with ID, parents recognize that type of social learning may never occur. Parents also more commonly deal with issues of inappropriate sexuality expression from their adult with ID, and juggle having to attend to these issues while balancing concerns of their ability to discuss and understand the topic. Similarly, in the area of intimate relationships parents must balance the knowledge that they will have to be more involved in order to help their adult with ID have romantic relationships with the anxiety that comes from their own lack of surety on how to best support their child in this area.

In the areas of sexuality education/expression and intimate relationships, parents work to balance wanting their adult with ID to experience a fulfilling life, while simultaneously protecting them. Sexuality expression and intimate relationship experiences are normal and natural for adults (Sharpe, 2003). Parents want their adult child with ID to have these experiences and be as fully included in society as possible. However, due to the high rates of abuse and exploitation within the population (Bernert, 2011; Swango-Wilson, 2009; Ward et al., 2010), parents constantly worry about their child's vulnerabilities within these experiences. Therefore, parents become more involved in the sexuality education and intimate relationships of their adult with ID, but struggle with understanding exactly what level of involvement is appropriate. Clarity is needed around what makes these couples with ID unique and the role parents should play to help their adult have a healthy relationship while still balancing their own needs and desires. Similar to past research, parents in these studies indicated feelings of isolation as their child with ID entered adulthood (Cheak-Zamora et al., 2015), indicating a need for parents to connect with each other to learn from their experiences (Grey et al., 2017).

The Impact of Parental Expectations

Another common theme between the two studies is the difference in parental expectations for sexuality expression and intimate relationships between their two adult children. This difference in expectations impacts the way that parents engage and interact with their adult children around these topics. Parents have different expectations for their adult children regarding sexuality and intimate relationships, mainly because they may struggle with viewing their adult child with ID as a "sexual being" (Gardiner & Braddon, 2009; McCarthy, 2011). Commonly, there is the misconception that adults with ID are either "asexual" and not interested in sex at all, or they are "oversexed" and must be constantly monitored in order to avoid predatory behavior (Block, 2000; Miligan & Neufeldt, 2001). While many parents may be able to recognize that their child falls more in the middle of that spectrum, these societal views may still have an impact on how they engage with their child.

Even if the adult does indicate a desire for a romantic relationship, many parents still expect that their adult with ID will never marry, live with a significant other, or have children. So, to them the relationships of individuals with ID will always be less "real" than the relationships of TD adults. Generally, parents view the desires of the TD adult as being the driving force in the experiences they will have. For example, parents feel as if their TD adult child will get married and have children if that is something they desire. However, for the adult with ID, parents feel that challenges such as cognitive level and the societal barriers they will face will have more of an impact on their experiences. Parents feel as if their adult with ID may be able to have these experiences, but many factors would need to be attended to in order for the relationship to occur successfully. These factors are specific to each person's needs. Parents also seemed to assume that their child's unique needs would cause more barriers in the area of sexuality and intimate relationships. The majority of adults with ID for whom parents reported on in these studies often had multiple diagnoses. The extra stress, time, and management of concerns related to these multiple diagnoses may be a contributing factor in why parents feel their adult child would not be able to have these experiences (Tonge, 2007). Most parents appear to have the mentality that adults with ID should be able to have these experiences, but they do not see the possibility for their own child. These differing expectations have a strong impact on how parents interact with their adult children around the topics of sexuality and intimate relationships. It could also be a component of why parents struggle with playing a larger role in the romantic lives of their adult with ID.

Parental Worry About Being Unprepared

For both sexuality expression and intimate relationships, parents indicated that they felt unprepared. Parents felt as if they did not have appropriate education and training on how to have these conversations with their adult child with ID, although they recognized that this responsibility falls solely on them. Parents also discussed how their conversations with their adult child with ID always looked different than conversations with their TD adult child, which further exacerbated their feelings of inexperience. When it comes to individuals with ID, learning needs to be repetitive and concrete in order to be most effective (MacFarland & Fisher, 2019). It also needs to be provided at their developmental level. This is a concern for parents of adults with ID when discussing sexuality and intimacy, since their child may be developmentally delayed cognitively but still have adult hormones and adult experiences (Gil-Llario et al., 2018). Parents constantly struggle with not wanting to provide their adult with knowledge that is beyond their current ability and understanding. This coupled with parents' feelings of unease around the topic of sexuality and intimate relationships (Holmes & Himle, 2014; Nichols & Blakeley-Smith, 2009), can unfortunately lead to avoidance of important issues.

Similarly, parents' unease around discussing these topics may also lead to avoidance until their adult with ID poses specific questions. Parents may assume that their adult child will ask questions directly, or that they will know the right time to approach certain topics. While parents may also wait for TD adult children to ask them questions, they do not feel the need to monitor them since they will often talk with peers or others if they do not ask parents (Barr et al., 2014). For the adult with ID, the parent is often the sole source of information. Unfortunately, parents may fail to recognize that their adult with ID may not feel comfortable asking questions, and their own discomfort with the topic may lead to avoidance of these issues. These dynamics inadvertently contribute to the lack of knowledge adults with ID have around sexuality and intimacy, which is a significant factor for later abuse and exploitation (Martinello, 2014).

Parents as Gatekeepers

A final common theme among the results of the two studies is that of parents as gatekeepers. Parents often determined what types of information to which their adult with ID has access (Swango-Wilson, 2010). Since parents are their main source of information, whatever information that is not shared by the parent will not get delivered to the individual with ID. Parents also determine what type of relationship experiences their child may have, because parents are often so closely involved in the lives of their adult with ID. For example, the individual with ID often relies on parents for transportation and finances, two main influencing factors in an adult's ability to engage in social or romantic activities (Foley, 2012). This is also impacted by issues of guardianship and independent living (English et al., 2018; Millar, 2007). If the adult does not have guardianship of themselves, or does not live independently, this may act as another layer of restriction the parent can place on intimate relationship experiences.

Much of parents' desire to act as gatekeepers stems from concerns around vulnerability and safety for their adult with ID (McDaniels & Fleming, 2016). Therefore, parents feel an increased need for involvement with the adult with ID and not their TD siblings. Parents want to ensure the sexuality knowledge their adult with ID gains centers around safe practices. This is why discussions of sexuality expression are often avoided and parents find it hard to manage sexual behaviors. Parents recognize that the easiest way to ensure safe practices within intimate relationships is to restrict experiences and opportunities (English et al., 2018). While this is a valid concern for parents, they struggle to balance this with a desire for their adult with ID to engage in adult relationships. Parents need more understanding about their gatekeeping role and how to protect their child while also allowing them to engage in romantic experiences.

Relationship to Theoretical Frameworks

Three theoretical frameworks guided these studies: the social model of disability (Oliver, 1983), the parental straddling theory (Johnson, 2000), and systems theory (Whitchurch & Constantine, 1993). Each theory helps provide a framework for understanding the integrated results of these studies.

The Social Model of Disability

The social model of disability posits that disability should be understood by examining societal labels of disability and the oppression and exclusion that results when one has a disability label, rather than a medical or deficit-based understanding (Anastasiou & Kauffman, 2013; Berghs et al., 2016; Hughes, 2010; Oliver, 1983). For example, social and environmental factors that impose limitations upon individuals with disabilities are examined rather than a focus on the physical or cognitive limitations of the individual (Hughes, 2010; Oliver, 1983; Oliver, 2013). The conceptual framework focuses on how individuals with disabilities can be supported for full inclusion in all aspects of life (Berghs et al., 2016; Kattari et al., 2017). In relation to sexuality and intimate relationships, the social model of disability specifically posits that for adults with ID, all social relationships and experiences are impacted by the individual's experience of their disability, and their identity within society. Regarding parents, due to their critical involvement in the social experiences of adults with ID, this theory posits that they have a significant impact as advocates and as the individual's connection to society.

The social model of disability helps explain some of the integrated results of these two studies. First, intimate relationships and sexuality are socially defined concepts and experiences, and further understanding of how an individual's disability identity impacts these experiences is needed. The way in which intimate relationships are defined socially for these individuals needs to change to better support full societal inclusion. Specifically, the social model of disability helps explain the societal and environmental barriers that adults with ID facing in these relationships. Helping parents understand these barriers and their role within these intimate relationships can help them act as advocates and lessen the social oppression adults with ID experience around sexuality and intimate relationships.

The Parental Straddling Theory

The parental straddling theory (Johnson, 2000) helps explain the common experience that parents of children with ID have “straddling” the world of “normality” and the world of “disability”. This occurs on three different levels: 1) parents straddle celebrating developmental milestones for their child while recognizing there is still significant work that needs to be done, 2) parents straddle helping the child live as “typically” as possible while also working to secure special services due to their disability, and 3) parents straddle dealing with their child’s anxiety while also attending to their own. This theory helps visualize the experiences of parents of adults with ID. As lifelong caregivers they often straddle recognizing their child’s status as an adult while also viewing them as someone who needs to be protected or strive to see their adult with ID as “normal” while also recognizing the label of “disability”. This all occurs as they deal with their own feelings and stresses of wanting to protect their child while simultaneously attending to the emotions, experiences, and desires of their adult with ID. This straddling places extra pressure on the parent.

The parental straddling theory provides a framework from which to understand the experiences of parents around the topic of sexuality and intimate relationships. Most parents of both adults with and without ID adults often struggle with recognizing their child’s sexuality and desire for relationships as they move into adulthood. This is also impacted by the fact that adult’s with ID may have delayed development of sexual interest and understanding. This may lead parents to avoid these issues or believe their adult will never have sexual interest, especially if comparisons are made to the sexuality development of TD adults. This chronological delay in development may also influence parental experiences of straddling two worlds. When adults with ID do develop sexual interest and expression, parents experience more moments where they must straddle due to the central role they play in the life of their adult with ID. Parents constantly straddle their increased involvement to support their adult child's romantic and sexual experiences, with their own desire to avoid being involved in their adult child's romantic and sexual life. This theory provides an understanding of why these experiences may be so stressful for parents.

Systems Theory

This theory provides an understanding of how different systems, or groupings of people, interact with one another and how these interactions affect each system (Whitchurch & Constantine, 1993). In relation to the family, this theory provides an understanding of how situations and experiences that families go through can impact each member of the family, and the family functioning as a whole (Taylor Sutphin et al., 2013; Whitchurch & Constantine, 1993). In the case of families who have family members with disabilities, the family system often shifts to accommodate the needs of that family member (Hill-Weld, 2011; Swango-Wilson, 2010; Whitchurch & Constantine, 1993). Family members, including parents and siblings, play larger support and care roles in the lives of adults with ID (Hill-Weld, 2011). This includes supporting their sexuality and intimate relationship experiences.

Systems theory can provide insight into the results of these studies. Parents play important roles in the sexuality expression and intimate relationships of adults with ID. Because of this increased role, the family system may shift to accommodate this need. By asking parents in these studies to specifically compare their experiences between their two adult children, parents were able to describe how this family shift occurs. They also described how information and experiences with their TD child impacted the view of their experiences with their child with ID, in essence discussing how interactions between members of the system impact their understanding of situations and experiences. This theory provides an understanding of how family systems and parental units need to adapt and change in order to help their adult with ID have fulfilling sexuality and intimate relationships experiences.

Study Limitations

One limitation of these studies is that both relied solely on parent report. No information was sought from either of the adult children discussed, other members of the family, or any staff that may work with these families and the individual with ID. Future research should explore the issues in these studies further by gathering input from the voices of adult with ID (Caldwell, 2014; English et al., 2018; Fulford & Cobigo, 2018; Whittle & Butler, 2018), as well as questioning clinicians and others who work with this population.

There are also limitations in the lack of diversity of the participants themselves. A large majority of participants were Caucasian, married, and had a family income of $40,000/year or above. Additionally, many indicated that their adult with ID lived in their home. Families with these demographics may have access to more resources and live in communities with more opportunities for adults with disabilities. Therefore, the results of these studies may not represent the experiences of families with more diverse backgrounds. The findings of these studies may not be generalizable to other cultures and experiences. As sexuality and romantic relationships are often culturally-driven experiences (Harding, 2017), future research would benefit from further examining the impact of diverse cultural background on these relationship experiences.

A final limitation across both studies is that the majority of participants for both the surveys and the interviews were also female (mothers). This limits the opinions and experiences of fathers. No specific gender-matching was done among participants and their adult children. This could have an impact on the study overall as discussions around the topics of sexuality and intimate relationship experiences between parents and their children can often be heavily influenced by gender (DiIorio et al., 2003). This may have impacted some of the experiences described by parents in these studies. Future research should explore the impact that gender and gender socialization have on the way in which parents navigate and manage areas of sexuality and romantic relationships for their adults with ID.

Implications for Practice

The findings of these two studies have important implications for families and adults with ID. Parents of adults with ID are significantly more involved in the lives of their adult children (Cheak-Zamora et al., 2015). This is especially true when it comes to supporting intimate relationships, sexuality education, and managing sexuality expression. Based on the importance of parents as sexuality educators, there is a strong need to include parents in sexuality education programs for adults with ID. This inclusion needs to go beyond simply being provided handouts of information to providing specific training on attending to issues of sexuality that are pertinent to adult experiences. This could include more detailed information on how their child’s delayed development impacts their sexuality so that parents can understand when to discuss topics, as well as sexuality expression concerns that occur most often in adulthood. Sexuality education for adults with ID and parents also needs to include discussions of healthy intimate relationships.

On top of being the main sexuality educator for their adult, parents also act as coaches and gatekeepers for their intimate relationship experiences. Yet despite the importance of these roles, parents often feel as if they are unprepared to perform them. Parents need more coaching and training in managing this area of sexuality and intimate relationships for their adult with ID. This could include being provided more detailed information on how healthy relationships function for adults with ID, and how these relationships will look different than they will for their TD adult children. This should include coaching for parents on how to talk about specific sexuality-related topics, and information on how these conversations will be different from those they experience with their TD adult child. The coaching for parents will be most effective if it is done in the context of their real, lived experiences. This could include coaching parents on how to advocate for their adult with ID to be able to engage in and experience romantic relationships. As their adult with ID's main source of support, parents need tools to help them tear down the barriers they face. This is especially evident surrounding the topic of marriage, as adults with ID are often discouraged from getting married due to the loss of funding they will experiences when they become a dual-earner household. These studies exemplify the need to help parents understand their role and the unique factors that make up sexuality and intimate relationships for adults with ID in order to best advocate for their adult child's rights.

A further implication of these studies is that specifically in the area of sexuality education, parents are still in need of training and coaching on how to manage sexual behaviors and the sexuality expression of their adults with ID. This has ramifications not only in the area of sexuality, but also in the area of intimate relationship as healthy sexual behaviors and expression of their sexuality can strongly influence intimate relationship experiences for the adult with ID and their parent who is guiding and coaching them. Parents often find themselves engaging in discussions and managing situations with their adult with ID that they never imagined they would have, and definitely that they never had to with their TD adult child. This can lead parents to feel extremely unprepared to deal with these discussions and situations. Further education and more person-centered coaching on managing these scenarios are needed for all individuals who work or live with adults with ID. This includes attending to these scenarios when they arise individually (e.g., managing inappropriate masturbation) as well as interpersonally (e.g., discussions with adult with ID and their partner around acceptable levels of public displays of affection). This type of training should be embedded within all programs for these adults, their staff, and their parents.

A final implication of these combined studies is that parents need an improved and innovative way to connect with one another. Despite describing similar experiences and perceptions, parents report struggling through these issues alone. Parents felt they would benefit from discussing these challenges with other parents going through similar experiences. Parents also expressed a desire for their adult with ID to be able to have these experiences. By connecting parents with one another, they could work to expand the social networks of their adults with ID and thereby provide more opportunities for these individuals to create social and romantic connections. Parents are often the driving force for creating social change for their children with ID. But they cannot do it by themselves, so in order to help them connect and share their stories and struggles with parents in similar situations and begin working towards this change, there needs to be intentional and accessible communities for these parents. The impact of relationships between parents is exemplified by the importance of the parent's relationship with the parents of their child's partner. The relationship between these two parents (i.e. the "other mothers") is vitally important to the success of the relationships between adults with ID. Their ability to work together can impact the ability of adult children to engage in a chosen relationship. These parental relationships deserve further exploration. There needs to be further education for parents on the importance of this relationship and how to navigate it. Clinicians working with these families need to be trained on the dynamics of this relationship and understand the important role of the "other mother" in order to best help these families facilitate these relationships and experiences.

Implications for Research

One of the main implications for research is the importance of including the voices of the adults with ID in future research (Caldwell, 2014; English et al., 2018; Fulford & Cobigo, 2018; Whittle & Butler, 2018). Throughout these studies, parents were asked to speculate and provide their own opinions regarding the sexual developmental and intimate relationship experiences of their adult children with ID. It would be important to also hear about these experiences from the adults with ID themselves and examine their opinions and perceptions of the role their parent plays in these experiences. While it is important to hear the viewpoints of everyone involved, future research should include adults with ID themselves to hear these viewpoints and to avoid further quieting the voices of these individuals within research and society.

Utilizing dyadic data collection methods with the adult with ID and their parent could potentially be a unique and innovative way to examine the interdependent nature of this relationship (Caldwell, 2014). This would allow for a deeper understanding of how this dynamic influences intimate relationship experiences for these individuals. By examining the relationship between the parent and their adult child, this could provide insight into what information or training is needed around this topic, as well as the most effective methods to deliver that information. In conjunction, there is a need to further study parent coaching and training programs around the topics of sexuality and intimate relationships, and to continue developing and evaluating these programs.

Conclusion

These two studies together provide important insight and information into how parents are navigating issues of sexuality and romantic relationships with their adult with ID. Parents constantly struggle with juggling the needs of their adult child related to sexuality and dating (e.g. more explicit sexuality education, transportation to dates) with their own (e.g. anxiety around discussing the topic, participating in their own hobbies). They also have differing expectations of the experiences their adult with ID will have compared to their TD adult, and this often impacts their own attitudes and perceptions. Parents feel unprepared to deal with these topics, especially since sexuality and romantic relationship experiences change significantly once an individual enters adulthood. Parents often must act as gatekeepers of these experiences and feel unprepared to do so. These studies exemplified a need for a clearer understanding of what intimate relationships can be expected to look like for adults with ID. It is well understood that these adults often need more support in daily living than their TD peers. However, parents and others who work with these individuals often do not extend this understanding to intimate relationships, instead comparing them to TD adult relationships. Parents may often feel uncomfortable with the relationship of their adult with ID looking similar to their TD adult's experiences, so to avoid this discomfort they prevent and restrict these experiences. These studies together showed that parents do not wish to restrict their adult with ID and would benefit from further understanding of what makes these relationships unique and their role within them. Coaching parents and connecting them with other parents who share similar experiences would be a huge benefit to both the parent and the adult with ID in better navigating these adult issues.

APPENDICES

APPENDIX A: Recruitment Flyer

Parental Roles and Attitudes Regarding Sexuality: Seeking Parents of Adults Diagnosed with an Intellectual Disability

Photo by Nathan Anderson on Unsplash

The Study

This research study is investigating parents and caregivers who have an adult child with an intellectual disability and an adult child without an intellectual disability, and their experiences regarding sexuality and intimate relationship experiences of both their adult children.

Participants

Parents and primary caregivers of an adult between the ages of 18-30 who has a diagnosis of an intellectual disability. Parents must also have another adult child between the ages of 18-30 who does not have a diagnosis of an intellectual disability.

What Will You Be Asked to Do?

Parents who participate in the study will be asked to fill out an online survey that will take approximately 30 minutes. After completing the survey, you will have the option to enter into a drawing for one of 4 - $50 gift cards. You will also have the option to participate in a phone or online interview that will take approximately 60 minutes. You will be given a $30 gift card for your participation in the interview.

If you are interested in participating in this study, please complete the survey using the following link:
[insert survey link]

For questions or further information, please contact:

Rebecca Kammes
rkammes@msu.edu
(630)884-8253

APPENDIX B: Original ASQ-ID

The ASQ-ID is comprised of 33 items. A 6-point Likert scale (anchored by strongly agree, and strongly disagree) was used for all items.

Attitudes to Sexuality

1. With the right support, adults with an intellectual disability can rear well-adjusted children.
2. Provided no unwanted children are born and no-one is harmed, consenting adults with an intellectual disability should be allowed to live in a heterosexual relationship.
3. Consenting adults with an intellectual disability should be allowed to live in a homosexual relationship if they so desire.
4. It is best to wait for the individual with an intellectual disability to raise questions about sexuality before discussing the topic with him/her. (R)
5. If adults with an intellectual disability marry, they should be forbidden by law to have children. (R)
6. Adults with an intellectual disability should be allowed to engage in non-sexual romantic relationships.
7. Sterilisation should be used as a means of inhibiting sexual desire in adults with an intellectual disability. (R)
8. Masturbation should be discouraged among adults with an intellectual disability. (R)
9. Discussions on sexual intercourse promote promiscuity in adults with an intellectual disability. (R)
10. Adults with an intellectual disability should only be permitted to marry if one has been sterilised. (R)
11. Masturbation in private for adults with an intellectual disability is an acceptable form of sexual expression.
12. Marriage between adults with an intellectual disability does not present society with too many problems.
13. Generally, adults with intellectual disabilities are able to make the distinction between sexual thoughts and sexual actions.
14. Sexuality education for adults with an intellectual disability has a valuable role in safeguarding them from sexual exploitation.
15. In general, sexual behaviour represents a major problem area in management and caring for adults with an intellectual disability. (R)
16. Sterilisation is an undesirable practice for men with intellectual disabilities.
17. Sexual intercourse should be permitted between consenting adults with an intellectual disability.
18. Group homes or hostels for adults with an intellectual disability should be either all male or all female, not mixed. (R)

19. Care staff and parents should discourage adults with an intellectual disability from having children. (R)
20. It is best not to discuss issues of sexuality with people with intellectual disabilities until they reach puberty. (R)
21. Adults with an intellectual disability have the right to marry.
22. It is a good idea to ensure privacy at home for adults with an intellectual disability who wish to masturbate.
23. Whenever possible, adults with an intellectual disability should be involved in the decision about his/her being sterilised.
24. Sexual intercourse should be discouraged amongst adults with an intellectual disability. (R)
25. Advice on contraception should be fully available to individuals with an intellectual disability whose level of development makes sexual activity likely.
26. Adults with an intellectual disability are not more easily stimulated sexually than people without an intellectual disability.
27. Masturbation is morally wrong. (R)
28. Adults with an intellectual disability typically have fewer sexual interests than people without an intellectual disability. (R)
29. Sterilisation is a desirable practice for women with intellectual disabilities. (R)
30. Sexuality education for adults with an intellectual disability should be compulsory.
31. Masturbation should be taught to adults with an intellectual disability as an acceptable form of sexual expression in sexuality education courses.
32. Marriage should not be encouraged as a future option for people with an intellectual disability. (R)
33. Adults with intellectual disabilities should be permitted to have children within marriage.

Items followed by (R) are reverse scored.

APPENDIX C: Theory, Research Questions, and Sample Data Collection Questions

Theory	Research Question(s)	Sample Survey Questions	Sample Interview Questions
The Social Model of Disability	How do parent attitudes towards sexuality education and expression differ in relation to their adult child with ID and without ID? What barriers do parents perceive for adults with ID in experiencing healthy sexuality education and expression?	With the right support, my child can rear well-adjusted children Sexuality education for my child has a valuable role in safeguarding them from sexual exploitation Marriage between adults with an intellectual disability does not present society with too many problems *all survey questions in this category will be asked as a rating comparison between adult child with ID and TD adult child	What barriers do adults with ID face in experiencing intimate relationships?
Parental Straddling Theory	How do parents perceive their role in creating and maintaining intimate relationships for individuals with ID compared to individuals without ID?	In general, sexual behavior represents a major problem area in management and caring for adults with an intellectual disability Care staff and parents should discourage adults with an intellectual disability from having children	How do you see your role in teaching [adult with ID] about real-life relationship experiences? For example, giving dating advice, discussing relationship rules and norms, and safety within a relationship How do you see your role in helping [adult with ID] maintain intimate relationships
Family Systems Theory	How does communication around sexuality differ for parents with adult	How often do you talk about sexuality and intimate relationships	What different expectations do you have regarding intimate relationship experiences

	children with ID and without ID, including type and amount of communication?	with [name of adult child]? How well do you feel you communicate about issues regarding sexuality and intimate relationships with [name of adult child]	for [adult child with ID] compared to [TD adult child] How do you communicate differently regarding intimate relationships and sexuality for [adult child with ID] vs. [TD adult child]

APPENDIX D:

Survey Materials

Survey Consent Form

Consent Form
Parental Roles and Attitudes Regarding Sexuality and Intimate Relationships: Comparing Adult Children with an Intellectual Disability to their Typically Developing Siblings

1. EXPLANATION OF THE RESEARCH and WHAT YOU WILL DO:

You are being asked to participate in a research study investigating parents and caregivers who have an adult child with an intellectual disability and an adult child without an intellectual disability and their experiences regarding sexuality and intimate relationship experiences of their adult children. As part of the study you will be asked to complete the following activities:

- An online written survey (approx. 30 minutes)
- An optional telephone interview (approx. 60 minutes)

To participate in this research project, you must be at least 18 years old and be the parent or primary caregiver of at least 1 adult child with an intellectual disability and at least 1 adult child without an intellectual disability.

2. YOUR RIGHTS TO PARTICIPATE, SAY NO, OR WITHDRAW:

Participation in this research project is completely voluntary. You have the right to say no. You may change your mind at any time and withdraw. You may choose not to answer specific questions or to stop participating at any time.

3. COSTS AND COMPENSATION FOR BEING IN THE STUDY:

As a participant in this research study you will be entered for a drawing for one of 4-$50 gift cards. Drawings will take place TBD.

4. CONTACT INFORMATION FOR QUESTIONS AND CONCERNS:

If you have concerns or questions about this study, such as scientific issues, how to do any part of it, or to report an injury, please contact the researchers:

Rebecca Kammes
Michigan State University
Human Development and Family Studies
406 Human Ecology Building
East Lansing MI, 48824
Phone: (630)884-8253
Email: rkammes@msu.edu

Dr. Sarah N. Douglas, Ph.D.
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In addition, if you have any questions or concerns about your role and rights as a research participant or would like to obtain information, offer input, or register a complaint about this study you may contact (anonymously if you wish) the Michigan State University Research Protection Program at (517)355-2180; FAX: (517)432-4503; email: irb@ora.msu.edu; or postal mail at 4000 Collins Rd., Suite 136, Lansing MI, 48910.

5. DOCUMENTATION OF INFORMED CONSENT

By clicking on the button below, you indicate your voluntary agreement to participate in this online survey.

Survey

Parental Roles and Attitudes Regarding Sexuality and Intimate Relationships: Comparing Adult Children with an Intellectual Disability to their Typically Developing Siblings Survey

[Insert survey consent form here]

Qualifying Questions

1. Are you the parent or primary caregiver of at least one adult child with an intellectual disability between the ages of 18-30 AND the parent or previous primary caregiver of at least one adult child without an intellectual disability between the ages of 18-30?

    If no, disqualify from study

2. Do you currently have an intellectual disability diagnosis?

    If yes, disqualify from study

3. Do you speak and understand English fluently?

    If no, disqualify from study

4. Do you currently reside within the United States?

    If no, disqualify from study

Part 1: Demographics

Please answer with the responses that best describe you, your adult child with ID, and your adult child without ID that you have chosen to use for this survey.

Parent/Caregiver Information:

1. What is your gender?
    Male
    Female
    Prefer not to disclose

2. What is your age?
    (fill in the blank)

3. What is your race/ethnicity?
    White
    Black, African-American
    Hispanic, Latino, or Spanish Origin

American Indian/Alaskan Native
Asian
Native Hawaiian/Pacific Islander
Prefer not to disclose

4. What is your highest education level?
   High school degree
   Some college
   Associate Degree
   Bachelor's Degree
   Graduate Degree

5. Please report the total number of children you have and the ages of each child
   (fill in the blank)

6. What is your relationship status?
   Married
   Divorced
   Separated
   Widowed
   Living together
   Single

7. What is your family's approximate annual income?
   Less than $20,000 per year
   $20,000-$50,000 per year
   $50,000-$80,000 per year
   $80,000-$100,000 per year
   More than $100,000 per year

<u>Demographics of your Adult Child with ID:</u>

1. What is this adult child's first name?
   [short answer→name will be inserted into all survey questions relating to this child]

2. What gender is [adult child with ID name]?
   Male
   Female
   Prefer not to disclose

3. What age is [adult child with ID name]?
   (fill in the blank)

4. What diagnosis does [adult child with ID name] have?
   Down syndrome

Autism Spectrum Disorder
General Intellectual Disability
Other
Additional detail about diagnosis: (fill in the blank)

5. What is [adult child with ID name]'s highest education level?
    - High school degree
    - Some college
    - Associate degree
    - Bachelor's degree
    - Graduate degree

6. What is [adult child with ID name]'s employment status?
    - Full-time employment
    - Part-time employment
    - Not currently employed
    - Full-time student

7. What is [adult child with ID name]'s current type of residence?
    - Living at home with parent/guardian
    - Living independently in the community
    - Living in the community with minimal support
    - Living in a group home or other supported community living
    - Rehabilitation facility/nursing home/hospital setting

8. Do you have guardianship of [adult child with ID name]?
    - Yes
    - No

9. Is [adult child with ID name] currently in a romantic relationship?
    - Yes
        - If yes, please describe: (fill in the blank)
    - No
    - Unsure

<u>Demographics of your Adult Child without ID:</u>

1. What is this adult child's first name?
    [short answer→name will be inserted into all survey questions relating to this child]

2. What gender is [adult child without ID name]?
    - Male
    - Female
    - Prefer not to disclose

3. What age is [adult child without ID name]?
    (fill in the blank)

4. What is [adult child without ID name]’s highest education level?
    High school degree
    Some college
    Associate degree
    Bachelor’s degree
    Graduate degree

5. What is [adult child without ID name]’s employment status?
    Full-time employment
    Part-time employment
    Not currently employed
    Full-time student

6. What is [adult child without ID name]’s current type of residence?
    At home
    Independently in community
    Group living situation (roommates)
    College living (dorms, other school-funded housing)

7. Is [adult child without ID name] currently in a romantic relationship?
    Yes
        If yes, please describe: (fill in the blank)
    No
    Unsure

Part 2: Survey Questionnaire

Section 1: Attitudes towards Sexuality—Adult Child Comparison

For the questions in section 1, you will rank your agreement with each statement using the following 1 (strongly disagree) to 6 (strongly agree) rating scale. You will first answer the questions as the relate to [adult child with ID name], and then following you will complete them for [adult child without ID name].

Please answer all of the following questions for [adult child with ID name]:

1. With the right support, my child can rear well-adjusted children

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

2. Provided no unwanted children are born and no one is harmed, my child and another consenting adult should be allowed to live in a heterosexual relationship

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

3. My child and another consenting adult should be allowed to live in a homosexual relationship if they so desire

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

4. It is best to wait for my child to raise questions about sexuality before discussing the topic with them

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

5. My child should be allowed to engage in non-sexual romantic relationships

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

6. Discussions on sexual intercourse promote promiscuity for my child

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

7. Masturbation in private is an acceptable form of sexual expression for my child

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

8. Generally, my child is able to make the distinction between sexual thoughts and sexual actions

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

9. Sexuality education for my child has a valuable role in safeguarding them from sexual exploitation

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

10. Sexual intercourse should be permitted between my child and another consenting adult

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

11. Group living situations (apartments, group homes, etc.) for my child should either be all female or all male, not mixed

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

12. It is best not to discuss issues of sexuality with my child until they reach puberty

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

13. My child has the right to marry

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

14. It is a good idea to ensure privacy at home for my child who wishes to masturbate

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

15. Sexual intercourse should be discouraged for my child

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

16. Advice on contraception should be fully available to my child

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

17. Masturbation for my child is morally wrong

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

18. Sexuality education for my child should be compulsory

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

19. Masturbation should be taught to my child as an acceptable form of sexual expression in sexuality education courses

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

20. Marriage should not be encouraged as a future option for my child

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

21. My child should be permitted to have children within marriage

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

<u>Please answer all of the following questions for [adult child without ID name]:</u>

1. With the right support, my child can rear well-adjusted children

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

2. Provided no unwanted children are born and no one is harmed, my child and another consenting adult should be allowed to live in a heterosexual relationship

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

3. My child and another consenting adult should be allowed to live in a homosexual relationship if they so desire

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

4. It is best to wait for my child to raise questions about sexuality before discussing the topic with them

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

5. My child should be allowed to engage in non-sexual romantic relationships

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

6. Discussions on sexual intercourse promote promiscuity for my child

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

7. Masturbation in private is an acceptable form of sexual expression for my child

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

8. Generally, my child is able to make the distinction between sexual thoughts and sexual actions

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

9. Sexuality education for my child has a valuable role in safeguarding them from sexual exploitation

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

10. Sexual intercourse should be permitted between my child and another consenting adult

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

11. Group living situations (apartments, group homes, etc.) for my child should either be all female or all male, not mixed

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

12. It is best not to discuss issues of sexuality with my child until they reach puberty

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

13. My child has the right to marry

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

14. It is a good idea to ensure privacy at home for my child who wishes to masturbate

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

15. Sexual intercourse should be discouraged for my child

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

16. Advice on contraception should be fully available to my child

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

17. Masturbation for my child is morally wrong

1	2	3	4	5	6

Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

18. Sexuality education for my child should be compulsory

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

19. Masturbation should be taught to my child as an acceptable form of sexual expression in sexuality education courses

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

20. Marriage should not be encouraged as a future option for my child

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

21. My child should be permitted to have children within marriage

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

Section 2: Parent Communication Around Sexuality and Intimate Relationships

In this section, we would like you to think about the ways you communicate with both of your adult children around the topics of sexuality and intimate relationships.

1. How often do you talk about sexuality and intimate relationships with [adult child with ID name]?

1	2	3	4	5
Never	Rarely	Sometimes	Often	Always

2. How often do you talk about sexuality and intimate relationships with [adult child without ID name]?

1	2	3	4	5
Never	Rarely	Sometimes	Often	Always

3. How well do you feel you communicate about issues regarding sexuality and intimate relationships with [adult child with ID name]?

1	2	3	4	5
Never	Rarely	Sometimes	Often	Always

4. How well do you feel you communicate about issues regarding sexuality and intimate relationships with [adult child without ID name]?

1	2	3	4	5
Never	Rarely	Sometimes	Often	Always

What types of social experiences do you expect your adult child to have? Check all that apply.

[adult child with ID name]
- ☐ Friendships
- ☐ Romantic/Dating
- ☐ Marriage
- ☐ Sexual/Physical Intimacy

[adult child without ID name]
- ☐ Friendships
- ☐ Romantic/Dating
- ☐ Marriage
- ☐ Sexual/Physical Intimacy

Section 3: Attitudes towards Sexuality—Adults with ID only

For the questions in section 3, you will rank your agreement with each statement using the following 1 (strongly agree) to 6 (strongly disagree) rating scale.

1. If adults with an intellectual disability marry, they should be forbidden by law to have children

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

2. Sterilization should be used as a means of inhibiting sexual desire in adults with an intellectual disability

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

3. Masturbation should be discouraged among adults with an intellectual disability

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

4. Adults with an intellectual disability should only be permitted to marry if one has been sterilized

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

5. Marriage between adults with an intellectual disability does not present society with too many problems

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

6. In general, sexual behavior represents a major problem area in management and caring for adults with an intellectual disability

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

7. Sterilization is an undesirable practice for men with intellectual disabilities

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

8. Care staff and parents should discourage adults with an intellectual disability from having children

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

9. Whenever possible, adults with an intellectual disability should be involved in the decision about his/her being sterilized

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

10. Adults with an intellectual disability are not more easily stimulated sexually than people without an intellectual disability

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

11. Adults with an intellectual disability typically have fewer sexual interests than people without an intellectual disability

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

12. Sterilization is a desirable practice for women with an intellectual disability

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

For the next set of question, think about how much you feel each factor listed is a current barrier to [adult child with ID name] having sexuality and intimate relationship experiences and rate using the scale provided.

1. [adult child with ID name]'s age

1	2	3	4
Not A Barrier	Minor Barrier	Moderate Barrier	Large Barrier

2. [adult child with ID name]'s gender

1	2	3	4
Not A Barrier	Minor Barrier	Moderate Barrier	Large Barrier

3. [adult child with ID name]'s adaptive functioning level

1	2	3	4
Not A Barrier	Minor Barrier	Moderate Barrier	Large Barrier

4. [adult child with ID name]'s cognitive level

1	2	3	4
Not A Barrier	Minor Barrier	Moderate Barrier	Large Barrier

5. Rules within [adult child with ID name]'s place of residence

1	2	3	4	5
Not A Barrier	Minor Barrier	Moderate Barrier	Large Barrier	N/A

6. Staff perceptions and opinions within [adult child with ID name]'s place of residence

1	2	3	4	5
Not A Barrier	Minor Barrier	Moderate Barrier	Large Barrier	N/A

7. Societal factors, such as availability of places for [adult child with ID name] to meet someone.

1	2	3	4
Not A Barrier	Minor Barrier	Moderate Barrier	Large Barrier

8. Other
   What other factors?:____

Part 3—Contact Information for Interview

As a follow-up to this survey, we are also asking for parents who are willing to be interviewed in a 45-60-minute phone interview. This interview will ask more in-depth questions regarding the topics previously discussed in this survey. Participants will receive $30 for their participation in the interview portion of the study.

You do not have to provide your contact information if you do not choose. If you are willing to be interviewed, please provide your contact information below. Your information you provide will not be linked to your answers and only the researcher will have access to the information in order to link your confidential interview to your survey answers for data analysis.

Are you willing to be contact for a follow-up interview?

- ☐ Yes →move to contact information questions
- ☐ No → move to thank you for your participation statement

What is your name?
[short answer]

What is your email address?
[short answer]

What is your phone number?
[short answer]

What is the best way to reach you?

☐ Email
☐ Phone

Thank you very much for your participation in this survey. There will be 4 $50 raffle drawings for participants of this survey on [enter drawing dates]. If you wish to be entered into the drawing, please follow the link below to a new survey. You will provide an email address to reach you at, but this will not be connected in any way to your survey.

[participants will have option to end survey or link to a new survey to enter their email for the drawing]

APPENDIX E: Interview Guide

Parental Roles and Attitudes Regarding Sexuality and Intimate Relationships: Comparing Adult Children with an Intellectual Disability to their Typically Developing Siblings

Parent/Caregiver Study Phone Interview Guide

Instructions before starting the questions:

Thank you for agreeing to participate in this research project and talk to me about your experiences regarding sexuality and intimate relationships with your adult child with an intellectual disability. Also, thanks for completing the questionnaire and rating scale I sent you. I appreciate your willingness to share your opinions and experiences. Before we start the interview, I want to review the procedures for today. First let me explain what we'll do.

Previously, you completed a survey asking you questions regarding intimate relationships and sexuality experiences of two of your adult children, one of whom has an intellectual disability diagnosis and one who does not. In this interview today, I am interested in learning more about your experiences with these two adult children, in particular the different roles you play in the lives of each when it comes to sexuality and romantic relationships. I will ask about your survey answers specifically, and also more general questions regarding other experiences you may have had. There are no right or wrong answers to these questions, I am only looking for honest opinions and views, and descriptions of your personal experiences. Your identity will not be tied to any of the answers that you provide. Please feel free to ask clarifying questions at any time during the interview. You do not have to answer any questions you do not want to, and you can stop the interview at any time. The interview will take approximately 60 min to complete. Also, for the purposes of this study, this interview will be audio recorded for later transcription, but any identifiable information you provide will be removed. As part of participating in this interview you will receive a $30 gift card. Are you still willing to be interviewed?

[Yes – continue interview, No – discontinue interview and thank them for their time.]

Do you have any questions before we begin?

[Answer any questions]

Intimate Relationships: Differences Between Adult Children

[interviewer note—all main questions are designated with a number. Potential follow-up questions are given as bullets following the question, not all follow-ups need to be used]

1. Before we begin, can you please provide me with the first names only of the two adult children you used in the survey? This will help me to tailor our questions to your adult children. You can provide pseudonyms for them if you would like.

2. What different expectations do you have regarding intimate relationship experiences for [adult with ID] compared to [TD adult]?
    a. What factors impact these different expectations? For example, their disability diagnosis, living situations, employment, societal expectations, etc.

3. How do you communicate differently regarding intimate relationships and sexuality for [adult with ID] vs. [TD adult]?
    a. How do the topics you discuss differ between [adult with ID] and [TD adult]?
    b. How often do you talk about sexuality with one compared to the other?
    c. Are there different situations for each child that would lead you to initiate a conversation around sexuality or intimate relationships?

4. What barriers does [adult with ID] face in experiencing intimate relationships?
    a. How are these different than barriers faced by [TD adult]?

5. We are now going to examine further some of the answers you gave on your survey [which questions specifically will be determined by individual survey answers that are going to be explored; the following are examples of potential prompts]
    a. For the question asking _____ you answered____ for [adult with ID] and _____ for [TD adult]. Can you explain further why you answered this way?
    b. Can you give me an example of…
    c. Tell me about a time when…
    d. What would say to…

Parent Role and Involvement in Intimate Relationships: Child with ID

Now we are going to move into talking specifically about your role in sexuality and intimate relationships for [name of adult child with ID].

1. How do you see your role in teaching sexuality education to [adult with ID]? For example, teaching them about biology, health, and safety?
    a. Do you feel your role is impacted by the sexuality education/lack of sexuality education they received in school?
    b. Who else plays a role? For example, siblings, staff, other family members?
    c. How is your role different than those you mentioned above?

2. How do you see your role in teaching [adult with ID] about real-life relationship experiences? For example, giving dating advice, discussing relationship rules and norms, and safety within a relationship?
    a. Do you feel your role is impacted by the sexuality education/lack of sexuality education they received in school?
    b. Who else plays a role? For example, siblings, staff, other family members?
    c. How is your role different than those you mentioned above?

3. How do you see your role in helping [adult with ID] find potential dating partners?
    a. What level of involvement do you feel you need to have?
    b. What factors make you feel like that is the appropriate or expected level of involvement as a parent?

4. How do you see your role in helping [adult with ID] maintain intimate relationships?

   a. What level of involvement do you feel you need to have?
   b. What factors make you feel like that is the appropriate or expected level of involvement as a parent?

Final Thoughts

We have gone through the list of interview questions. Is there anything regarding sexuality and intimate relationships, comparing experiences between [adult with ID] and [TD adult], and your role in helping [adult with ID] create and maintain relationships that I did not ask about that you would like to mention or discuss?

Thank you for taking the time to complete this interview, your participation is greatly appreciated.

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REFERENCES

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