PARENT-CHILD SEXUALITY EDUCATION IN FAMILIES WITH SONS OR DAUGHTERS WITH AUTISM OR DOWN SYNDROME: A PHENOMENOLOGICAL STUDY

A THESIS

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I am submitting herewith a thesis written by Margaret M. Reed entitled "Parent-Child Sexuality Education in Families with Sons or Daughters with Autism or Down Syndrome: A Phenomenological Study." I have examined this thesis for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Master of Sciences with a major in Family Therapy.

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DEDICATION

To my life partner, my husband, my one. Jonah, thank you for your unending support. I would not have wanted to do this without you.

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ABSTRACT

MARGARET M. REED

PARENT-CHILD SEXUALITY EDUCATION IN FAMILIES WITH SONS OR DAUGHTERS WITH AUTISM OR DOWN SYNDROME: A PHENOMENOLOGICAL STUDY

DECEMBER 2010

This phenomenological study's purpose was to explore parent-child sexuality education in families with sons or daughters with autism or Down syndrome. The focus was on the qualitative experience of the parents in these families, how and what they taught their son or daughter about sexuality, and what the parents thought family therapists need to know about their unique experience in sexuality education with children with these special needs.

Previous literature on this topic was focused in two main areas: the attitudes or concerns of parents or caregivers in regard to the sexuality or sexual behavior of the person with autism or Down syndrome, and the educational resources available to parents or caregivers on how to teach someone with autism or Down syndrome about sexuality. The literature review in this study also briefly addressed parent-child sexuality education as it occurs in families, as this was important to note for family therapy professionals who strive to understand the lived experiences of all types of families.

To explore the lived experience of the parents in this study, face-to-face interviews were conducted and audio recorded for the purpose of verbatim transcription. Recruitment letters, presentation of the proposed research, and snowball sampling yielded fourteen adoptive or biological parent participants of fifteen sons or daughters with autism or Down syndrome. After the interviews were transcribed verbatim, the transcripts were reviewed multiple times, divided by content, and then divided by thematic finding by research question.

Upon transcript reviews and analysis, it was determined that parents divided into two categories, tentative parents and assured parents. Tentative parents based the sexuality education they provided on concerns about embarrassment or safety of their son or daughter in public, found few or no resources available to help them teach, and seemed to have some difficulty with thinking of their son or daughter as a sexual being. Assured parents provided a more comprehensive sexuality education, one in which many different sexuality topics were covered, such as menstruation, masturbation, wet dreams, and homosexuality. Assured parents mentioned a variety of resources they found helpful in teaching their son or daughter about sexuality, and reported thinking of their son or daughter as a sexual person.

The parents' commonalities were religion and appropriateness; these topics arose in every interview. Also, both tentative and assured parents taught their son or daughter proper names for genitalia and that sexuality is primarily about relationships, not sexual intercourse. The groups of parents wanted family therapists to keep the family's cultural

and societal beliefs, and the son or daughter's intellectual abilities in mind, as well as the range of abilities that exist in the autism and Down syndrome population.

Finally, the results of this study were discussed in comparison to a review of previous literature. Conclusions were drawn and limitations were detailed. The implications for family therapists and recommendations for future research were conferred.

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CHAPTER I

INTRODUCTION

People with autism or Down syndrome experience emotions, feelings, desires, and needs as human beings. Although sometimes cognitively impaired, people with autism or Down syndrome experience typical bodily maturation at the same rate as the rest of the population (Ballan, 2001). The parallel physical developmental rate indicates that effective sexuality education is a need for people with autism or Down syndrome in the same manner that it is a need for everyone else. According to the Sexuality Information and Education Council of the United States (SIECUS) website (n.d.b), the deficiencies in sexuality education in the United States include the deceptive and erroneous messages the public receives about sexuality and the political polarization between comprehensive-education and abstinence-only sexuality messages.

In response to these flaws in communication on the topic of sexuality education, researchers, therapists, and education professionals have developed many resources for parents and educators of children with and without autism or Down syndrome, and even for the children themselves (see Couwenhoven, 2007; Maurer, 2009; Murphy, 1997; Planned Parenthood, 2004). Parents and their sons or daughters may have easy access to these resources via the internet or social programs, such as Planned Parenthood. With easy access to an abundance of resources, parents are undoubtedly teaching their sons or daughters some form of sexuality education. This sexuality education may reflect what

the parents glean from available resources, or parents may use their own lived experiences for the foundation of what they teach their children.

Whether the parents are teaching from a book, website, or their own familiarity, it is clear that parents with sons or daughters with autism or Down syndrome have strong opinions on the topic of sexuality. Many parents recognize that sexuality education is imperative for their sons or daughters with developmental disabilities (Grayson, 2004). Parents often express that their son's or daughter's happiness is of the utmost importance, and the parents understand that this includes romance and, in some cases, sexual expression or relationships (Camire, 2006). Parents of sons or daughters with autism or Down syndrome have specific concerns about the explicit display of sexual behavior in an inappropriate social setting (Camire, 2006; Moreno, 1996), and an increased likelihood that their sons or daughters may face issues of sexual abuse (Ruble & Dalrymple, 1993). Although these concerns may be universal to parents of all children, the parents of sons or daughters with autism or Down syndrome face these adversities uniquely because their children may not be able to comprehend the social repercussions of public masturbation, or to verbally express that he or she has been sexually abused.

Although sexuality education occurs in many forms, in peer groups, at school, or in group homes, for example, research has shown that sons, daughters, and parents want the parents to be the primary sexuality educators of the younger generation (Brock & Jennings, 1993, 2003; Byers, Sears, & Weaver, 2008; Swango-Wilson, 2008). Even if parents desired to be the first source of information about sexuality for their children, few parents viewed themselves as fully capable of providing sexuality education without the

support of professionals (Swango-Wilson, 2008). Parents of sons or daughters with autism or Down syndrome have the capacity to educate family therapists on how to better assist the parents in their family's experience of parent-child sexuality education. Family therapists could use the findings of this study to better serve this population of parents, in order for sexuality education to be a more affirmative occurrence in their families.

Despite the existence of helpful resources and a wealth of information on the attitudes of parents in regard to the sexuality and sexuality education of people with autism or Down syndrome, there is little academic research that explores what the parents of sons or daughters with autism or Down syndrome are actually teaching their children. This discrepancy in information is unfortunate because family therapists benefit from knowing the meaning of lived experiences of all types of families. In phenomenological research, it is assumed that most seek to comprehend their subjective world (Creswell, 2003). This study explored how the parents of sons or daughters with autism or Down syndrome made sense of their subjective experiences by examining how they did parent-child sexuality education in their families.

Statement of the Problem

Sexuality education is an important facet of successful social function (SIECUS, n.d.a). People with autism or Down syndrome experience sexual feelings and behavior, just as the rest of the general population. Parents have expressed in many studies that they want to be the primary sources to teach their children about sexuality and sexual matters, whether or not their sons or daughters have developmental disabilities (Brock & Jennings, 1993; 2003; Byers, Sears, & Weaver, 2008). There are many resources

available for parents in terms of what experts say they ought to be teaching, and specific information is even available for parents of children with autism or Down syndrome (see Couwenhoven, 2007; Maurer, 2009; Murphy, 1997). The resources tailored to parents of children with autism or Down syndrome prove to be particularly helpful because of the unique way these parents face different issues in the sexuality of their children, such as a higher rate of sexual abuse, socio-sexual stigmas, and unintended pregnancy, which may produce a child for which the parents could be ultimately responsible (Ballan, 2001). Despite the existence of numerous resources, there is little information about what the parents of children with autism or Down syndrome are actually teaching, and no information about what family therapists should know about the parents' experience in sexuality education with their sons or daughters with these developmental challenges. This study filled a gap in the academic information available to family therapists about the lived experiences of families with sons or daughters with autism or Down syndrome. Parent-child sexuality education in these families may benefit from the added support of family therapists' professional aid.

Statement of Purpose

This study's purpose was to explore parent-child sexuality education in families with sons or daughters with autism or Down syndrome. The focus was on the qualitative experience of the parents in these families, how and what they taught their son or daughter about sexuality, and what the parents thought family therapists need to know about their unique experience in sexuality education with children with these special needs.

Research Questions

To fulfill the purpose of this study, the following research questions were explored:

1. What are parents' experiences of teaching a son or a daughter with autism or Down syndrome about sexuality?
2. What do parents think family therapists need to know about their experience in teaching their sons or daughters with autism or Down syndrome about sexuality?

Definitions of Terms

The following definitions were used for the purpose of this study.

Sexuality is purposefully all-encompassing in this research. According to Creswell (2003), in phenomenological research, the participants of a study define the phenomenon being studied, in this case parent-child sexuality education. In this study, the participants came with an already self-defined notion of the experience of human sexuality. To be able to more fully explore the meanings of all the participants' individualized experiences, the researcher in this study approached the face-to-face interviews and the term *sexuality* from a phenomenological standpoint.

Down syndrome in this study refers to the diagnosis of a person with an extra copy of one of the 46 chromosomes with which a person typically develops. According the United States' Centers for Disease Control and Prevention (CDC) (2009), some persons with the extra chromosome matter may develop similar physical characteristics as others with Down syndrome, though there is wide variance in their cognitive abilities and functioning. The physical characteristics of Down syndrome may include "a flat face

with an upward slant to the eye, a short neck, small ears, and a large tongue,... small hands and feet,...[or] poor muscle tone or loose ligaments" (CDC, 2009, para. 3). The CDC (2009) approximates that 3,357 babies are born with Down syndrome per year, which means 13 out of 1000 births are babies with Down syndrome.

Autism is broadly defined by Johnson and Myers (2007) as a pervasive developmental disorder, in which persons demonstrate specific quantifiable symptoms. These symptoms include deficiencies in social aptitude; delayed or absent speech development; excessive repetition in behavior or interests; and an increased, noticeable sensitivity to certain sensory stimuli. The United States' Centers for Disease Control and Prevention (2007) reported that the prevalence of autism spectrum disorders (ASDs) increased in the previous ten years, and that over 500,000 people under the age of 21 may live with an ASD in the United States.

Son or *daughter* in this study refers to the person diagnosed with autism or Down syndrome whose parent participated in the face-to-face interview. The sons or daughters of the parents who participated in this study may have been of any age, as parent-child sexuality education may occur throughout a person's life, and may not be limited to the years of childhood and adolescence (SIECUS, n.d.a).

Parent refers to the participants in this study. They were the biological or adoptive mothers or fathers of a son or daughter of any age who was diagnosed with autism or Down syndrome.

Assumptions

The following assumptions were made in this study:

1. Parents were open and forthcoming in discussing sexuality education in their family.
2. Sexuality education is an important facet of family life, and parents were responsible for some form of sexuality education for their sons or daughters.
3. Parents already had defined the term "sexuality" for themselves, and had, either consciously or unconsciously, incorporated that meaning into their lives and into the messages about sexuality that they sent their sons or daughters.

Delimitations

The following delimitations were set for this study:

1. Participants had a biological or adopted son or daughter diagnosed with autism or Down syndrome.
2. Participants were at least 18 years old at time of interview.
3. Participants were volunteers willing to talk about the sexuality education that they provided to their sons or daughters.

Researcher as a Person

I am an active community volunteer and have worked with people with Autism and Down syndrome for fifteen years. When I was a young teenager, my initial contact with this population was for the non-profit organization Best Buddies International, whose mission is to "enhance the lives of people with intellectual disabilities by

providing opportunities for one-to-one friendships and integrated employment" (Best Buddies, 2009).

As an undergraduate student, I worked at a camp in Williamson County, Tennessee, for children and adolescents with developmental disabilities. In my work at this camp, specifically in my contact with parents of the campers, I soon recognized a unique parental experience in sexuality education in families in which there are sons or daughters with autism or Down syndrome.

I am a master's student in Family Therapy at Texas Woman's University, and a student member of the American Association of Sexuality Educators, Counselors, and Therapists (AASECT). I fully understand the delicate, sensitive nature for some people in discussing sexuality, both theirs and others'. It was my goal in this research to recognize and bracket my personal bias in interviewing the parents who agreed to participate in this study.

Summary

There is currently a dearth of information in academic, qualitative research on how and what parents of sons or daughters with autism or Down syndrome taught their children on the topic of sexuality education. This study was distinctive in that it bridged a gap in literature between what parents know and feel about sexuality education, what resources are available to them, and what they are actually teaching their sons or daughters. The focus of the research was on the qualitative experience of the parents in these families, to learn more about how and what they taught their son or daughter about sexuality, and what the parents thought family therapists need to know about their unique

experience in sexuality education with children with these special needs. The research questions, assumptions, and terminology used in this study were from a phenomenological perspective in order to gain a clearer picture of the lived experiences of the participants in the study. The researcher's past experience with parents of sons or daughters with autism or Down syndrome was briefly outlined, and delimitations were set for the study.

CHAPTER II

REVIEW OF THE LITERATURE

In this chapter, literature on three components of parent-child sexuality education in families in which there are sons or daughters with autism or Down syndrome is reviewed. First, the attitudes of parents of people with autism or Down syndrome on the topic of sexuality is discussed, including a further examination of the reported parental concerns about sons' or daughters' sexuality. Next, is a discussion of the resources available to parents as to what the parents should teach their sons or daughters about sexuality. Finally, there is a brief synopsis of reports on parent-child sexuality education in homes with and without children with autism or Down syndrome. The remainder of the chapter discusses the need for research on the topic of parent-child sexuality education in families in which there are sons or daughters with autism or Down syndrome.

Sexuality education is an integral part of personal edification. According to the Sexuality Information and Education Council of the United States (SIECUS, n.d.a), "all persons are sexual...and have a right to accurate information...and appropriate education about sexuality." Because sexuality, in an inclusive sense, is an intensely personal component of one's life, it is understandable that many people have strong opinions on the topic. SIECUS' position statement asserted that every person's sexuality is defined by some combination of ethics, spirituality, culture, and morality, regardless of physical or

mental disability. Parents with sons or daughters with autism or Down syndrome, like all parents, have the capacity to influence their son or daughter's view of his or her sexuality, and thus it is vital that parents have the professional, cultural, and emotional support that is needed to provide accurate, thorough, and appropriate sexuality education to their sons or daughters.

Parents' Perceptions

Throughout contemporary research, there is ample evidence of parental attitudes toward the sexuality of sons or daughters with autism or Down syndrome. It is understandable that this would be such a widely researched topic, as parents with sons or daughters with autism or Down syndrome face a parenting experience unlike that of other parents (Lalvani, 2008; Mullins, 1987). Many parents feel isolated and anxious in their experience of having a son or daughter with autism or Down syndrome, whereas others feel as though they were robbed of the way a parent's life traditionally should be (Mullins, 1987). In a qualitative study of nine mothers, Lalvani (2008) found that, while the mothers of fetuses or babies diagnosed with Down syndrome experience joy and hope at the prospect of having a child, they also have to redefine their beliefs about their impending parenthood and regulate how those beliefs will impact the sense of normalcy in their families. The mothers reported facing negative social interactions because of the diagnoses of their babies, but ultimately retained and shared with the researcher the more positive aspects of their family lives, such as having fun as a family, and living a fulfilling and contented life (Lalvani, 2008). Unfortunately, these rich accounts did not mention parent-child sexuality education. In the few studies that did include that

particular aspect of parenting, many parents expressed specific concerns about the sexuality of their son or daughter with autism or Down syndrome.

Throughout the academic literature that focuses on parental attitudes of sons or daughters with autism or Down syndrome, it is clear that parents often share similar concerns. Overall, parents of persons with intellectual and developmental disabilities reported having a greater amount of concern for sexuality education for their sons or daughters (Ballan, 2001). Ballan (2001) attributed the greater concern to the unique parenting experience of parents who have children with autism or Down syndrome, describing parents as "uncertain about the appropriate management of their children's sexual development" (p. 14). Parents of sons or daughters with autism or Down syndrome mentioned masturbation, sexual abuse, and safe sex as areas of paramount concern in parental attitude research reports.

In a qualitative study of ten Hispanic parents with sons or daughters with autism, Moreno (1996) noted that their son's or daughter's masturbation, both public and private, was found to be thematically upsetting to parents. To many parents in the study, discovering that their son masturbated was the parent's first inclination that their child was either approaching or already experiencing puberty. One mother said "it was terrible for me to learn to deal with his emerging sexual maturity" (Moreno, 1996, p. 169). Another mother stated that with her sons who were not diagnosed with autism, she never had to deal with the topic of masturbation, but her reaction to the self-pleasuring of her son with autism was "my God, it can't be that those kids do that too" (Moreno, 1996, p. 170). Although it is described as disconcerting by parents to face their child's sexuality in

this way, the parents expressed more concern that their sons or daughters will express their sexuality overtly, and therefore be more vulnerable to sexual abuse (Ballan, 2001).

Prevention of sexual abuse of their sons or daughters with autism or Down syndrome is of great concern to parents. Grayson (2004) found in a study of 43 mothers with adult sons or daughters with autism who lived at home that 55.3% of the respondents were concerned their child would demonstrate inappropriate sexual behavior, but almost 90% of respondents were concerned their child would be sexually abused. Grayson speculated that "these mothers have spent years advocating and caring for their children, but they realize that they cannot always be there to offer protection," a consideration that understandably would leave many parents anguished (p. 54). Researchers Ruble and Dalrymple (1993) reported that fathers were more concerned that their sons with developmental disabilities would be sexually abused by someone of the same sex; whereas mothers were concerned their daughters would be abused by someone of the other sex. Parents of sons or daughters with autism or Down syndrome may have found reassurance in teaching their sons or daughters about personal safety in the area of sexuality, though sexuality education does not by itself eradicate sexual abuse (DiGuilio, 2003).

In a qualitative examination of four mothers' and four siblings' attitudes toward the romantic relationships of their family members with Down syndrome (Camire, 2006), the mothers reported that among their foremost concerns was that their son or daughter were in a safe environment if he or she were to be sexually active. The parents in the

Camire study related the safety of an environment equally to the absence of sexual abuse as to the presence of the practice of safe sex.

In many cases, the parents of sons or daughters with intellectual disabilities viewed their children as eternally childlike and therefore in need of protection (Swango-Wilson, 2008). Protection, as the parents of sons or daughters with autism or Down syndrome defined it, was twofold. The greatest percentage of parents reported concern for their son or daughter in terms of sexual abuse, but the parents also widely shared their concern for the safe sex practices of their sons or daughters (Ballan, 2001). The parents of sons or daughters with autism or Down syndrome did not want to raise their children's offspring, and many parents saw the practice of safe sex as a top priority in sexuality education (Ballan, 2001; Camire, 2006; Moreno, 1996; Ruble & Dalrymple, 1993).

In a study of persons with autism in residential settings, Van Bourgondien, Reichle, and Palmer (1997) found that caregivers at the residential homes reported 34 out of 89 (38.2%) of the residents with autism had engaged in some form of interpersonal sexual behavior. If their son or daughter were of the third of the residential home population that engaged in sexual activity with another person, the parents who had not taught their sons or daughters about pregnancy prevention or sexually transmitted infections may have faced additional medical costs, emotional distress or embarrassment in addressing their child's behavior with the residential staff, or even the prospect of raising their son's or daughter's child. In her qualitative study of familial perspectives of sons or daughters with Down syndrome, Camire (2006) found that parents generally did not want their son or daughter with Down syndrome to have children, even if the parent

was supportive of their child having a romantic, and sometimes sexual, relationship. The parents in Camire's (2006) study were concerned mostly that, based on their son's or daughter's level of function, the son or daughter with Down syndrome would not be capable of physically, intellectually, or emotionally raising a child.

Resources Available to Parents

The second focus of the existing literature on the topic of parent-child sexuality education in families in which there are sons or daughters with autism or Down syndrome were the resources available in popular culture for those who want to teach or learn about sexuality. In a recent study, parents and caregivers reported feeling hesitant toward the sexuality of their sons or daughters with developmental disabilities (Swango-Wilson, 2008). Twelve of thirty-six parents surveyed by Grayson (2004) reportedly wished they had more resources to broach the topic of sexuality with their children. The immediate concern for therapists seeing parents with sons or daughters with autism or Down syndrome is that the "standard sexuality education curricula may not be appropriate because it does not match [the sons' or daughters'] learning styles or level of understanding" (DiGuilio, 2003, p. 63). Sexuality education in families with sons or daughters with autism or Down syndrome has to remain accurate and thorough, yet be tailored to the emotional needs and communication capabilities of the son or daughter. Parents and therapists have many existing resources from which to choose for assistance.

There are a multitude of print resources for parents of sons or daughters with autism or Down syndrome. Sexuality education professionals have written books, articles, and brochures to help parents to more easily broach the topic of sexuality with

their sons or daughters. In her book, Couwenhoven (2007) addressed parents with sons or daughters with Down syndrome directly:

> ...if you buy into the myth that people with disabilities are perpetual children or asexual, it prevents you from seeing your child as a maturing individual who needs information and skills that can help him progress from child-like behaviors to more age-appropriate ones. On the other hand, if someone who works with your child believes the myth that people with cognitive disabilities are 'oversexed' or 'uncontrollable' (meaning their sex drive is somehow more intense than the rest of the population), they may scrutinize or report every sexual behavior, even if they're developmentally appropriate. (p. 2)

Couwenhoven (2007) encouraged parents with children with Down syndrome to be their child's primary sexuality educator. She explicitly addressed the concerns parents have reported in past studies, such as privacy, masturbation, social skills, abuse and exploitation prevention, and parenthood (Couwenhoven, 2007).

Whereas Couwenhoven (2007) addressed *what* parents should teach, Maurer (2009) addressed *how* parents should teach their children with developmental disabilities about sexuality. The article listed guidelines that could apply to all parents about teaching sons or daughters about sexuality, such as the importance of identifying and validating a child's feelings about the topic, and repeating and introducing limited, but thorough, bits of information over the course of many conversations (Maurer, 2009). Other strategies may seem more specific to parents of children with developmental disabilities, such as "use pictures as often as you can," and "network with other parents" (Maurer, 2009, para.

3). These tips also applied to all parents, but parents with sons or daughters with autism or Down syndrome may have found them particularly useful because their children think primarily concretely (Maurer, 2009), and the parents struggled in feeling alone in their quest of parent-child sexuality education (Ballan, 2001).

To provide parents further opportunities to discuss sexuality with their sons or daughters with autism or Down syndrome, Planned Parenthood of Nebraska & Council Bluffs (PPNCB) provided additional resources. First, in 2004, PPNCB published a brochure written for persons with Down syndrome aimed at initiating sexuality-education conversations in families. The first pages of the brochure affirmed feelings persons with Down syndrome have toward potential sexual feelings and sexual partners, such as "touching ourselves can feel good," (p. 1) "sexual feelings are healthy and normal," (p. 1) and "sexual feelings are an important part of our lives" (p. 6). The final page of the brochure (PPNCB, 2004) was devoted to challenging parents and sexuality educators to provide quality sexuality education to a person with Down syndrome. For example, the brochure recommended that parents "avoid using analogies, [as] they may be confusing or misleading....If you say 'it takes a seed from a man and a woman,' [the person with Down syndrome] may picture a plant growing" (p. 7). Planned Parenthood provided other informative resources for all parents on the topic of sexuality education on their website (Planned Parenthood, 2008).

In 1994, several sexuality education professionals at Chedoke-McMaster Hospitals in Ontario, Canada, ran "Sexuality and Autism: A Parenting Skills Enhancement Group," as reported in the *Canadian Journal of Human Sexuality*. The

focus of the group was "on the promotion of positive sexual development in children with autism through parent training" (p. 283). Throughout the course of the group sessions, sexuality education professionals aimed to normalize masturbation by discussing it for an entire session, giving parents statistics about the prevalence and prevention of sexual abuse for their sons or daughters, and "alleviat[ing] any tension or anxiety...by role-playing first as a form of modeling" for the parents (p. 287). The professional sexuality educators sought to "empower parents and facilitate change in the area of sexuality education," by providing the parents an emotionally safe and supportive environment in which to express concerns or ask questions (p. 288). No information in academic or professional literature was found that explores what parents do with the sexuality education resources available to them.

Parent-Child Sexuality Education in Families

Parents of sons or daughters with autism or Down syndrome often think the amount of sexuality education their child requires is proportionate to the child's cognitive ability, but professional sexuality educators disagree with this stance (Ballan, 2001; Grayson, 2004; Moreno, 1996). Rather, sexuality educators advocate sex-positive comprehensive education through "repetitive learning and modeling" (Ballan, 2001, p. 17). Other research has reflected this view as well (Maurer, 2009; Meister, Honeyman, Norlock, & Pierce, 1994). Based on this philosophy, Birch and Rouse (1992) wrote a sexuality education curriculum for persons with developmental disabilities. Important components of the curriculum included "pictures, slides, and videotapes,...semantic mapping,...[and] role play" (Birch & Rouse, 1992, pp. 11-12). The curriculum was

designed to both address the potential social misunderstandings of persons with developmental disabilities and to help sexuality education professionals assess how persons with developmental disabilities incorporate the teachings into their own knowledge (Birch & Rouse, 1992). Their curriculum was designed for sexuality education in schools or other professional settings, however, and not necessarily for sexuality education as it occurs in families.

Parent-child sexuality education in families, and in particular in families in which there are sons or daughters with autism or Down syndrome, may require additional components. For many parents with sons or daughters with developmental disabilities, the ideal goal in providing sexuality education is to ensure that their children grow up to be sexually-conscientious adults (Ballan, 2001). However, many parents delay starting sexuality education with their children until puberty or later (Byers, Sears, & Weaver, 2008). In a study of 3,413 mothers and 426 fathers of children in kindergarten through eighth grade, Byers, and colleagues found that parents are hesitant to discuss sexuality age-appropriately with their sons or daughters. This is of concern to family therapists and sexuality educators because persons with autism or Down syndrome need early modeling and concrete discussion so that, when they reach puberty, they know what will happen to their bodies, they know how to better face the social issues of sexuality, and, for daughters in particular, they do not "mimic the seductive behaviors they see depicted on television and in films" inappropriately (Ballan, 2001, p. 17).

Many individuals, whether they are diagnosed with autism or Down syndrome or not, are, in increasing numbers, learning their behavior and sexuality information from

audio visual media (Ballan, 2001; SIECUS, 2001). Television and films do not always contain accurate information about sexuality, and research indicates that sons, daughters, and their parents want the parents to be the primary sexuality educators of the younger generation (Brock & Jennings, 1993, 2003; Swango-Wilson, 2008). In her study of 85 caregivers of persons with intellectual disabilities, Swango-Wilson (2008) noted that persons with disabilities were interested in the topic of sexuality and that they wanted parental involvement in learning about sexuality, and that the attitudes of caregivers of persons with disabilities were critical "to the development of positive sexuality for individuals" (p. 169). This sentiment echoed Brock and Jennings' findings in 1993 and 2003 about what daughters and sons wished their mothers and fathers, respectively, had taught them about sexuality.

In a qualitative phenomenological study of 30 women in their thirties, Brock and Jennings (1993) found that the women she interviewed longed to have received fuller discussions about sexuality from their mothers. Additionally, the women wanted for their mothers to have incorporated sexuality discussions into their everyday conversations, so as to indicate that no topic was off-limits. This was not the experience of most of the participants. Many of the women received very limited, nonverbal, negative messages about sexuality, something they remembered decades later during the study (Brock & Jennings, 1993).

Brock and Jennings (2003) interviewed 30 men in their thirties, who expressed that they had received similar messages from their father on the topic of sexuality. The messages were often incomplete and inaccurate, lacking discussion of both emotions and

facts that the men wished for in their thirties. Most of the men recalled with sorrow that their primary sexuality educators had been friends or media. The men in the study wanted to be able to talk to their fathers about anything, but many of them felt they could not approach their fathers about certain topics (Brock & Jennings, 2003).

The Brock and Jennings studies highlighted the importance of parents approaching sexuality education as positively as possible with their sons or daughters. Although neither study was with participants diagnosed with autism or Down syndrome, the two reports demonstrated the significant impact parent-child sexuality education had on a person.

Need for Research

This study fills an important gap in the existing literature on the experience of parents with sons or daughters with autism or Down syndrome in the role of parent-child sexuality educators. Until this point, research has focused on the parent attitudes towards the sexuality of their son or daughter with autism or Down syndrome or on the resources available for parents to teach about sexuality. While these are critical topics to study, and certainly serve as useful tools to parents in providing sexuality education, both skirt the issue: what are parents actually teaching? If family therapists knew what parents were teaching, they could better serve parents of sons or daughters with autism or Down syndrome by tailoring the family therapists' professional assistance to the particular needs of those families. Family therapists benefit from knowing the experiences of all types of families, and it would be to the benefit of family therapists to know about the

unique experience of parent-child sexuality education in families in which there are sons or daughters with autism or Down syndrome.

Not only does this research fill a gap in current literature, but it also highlights the need for future research. Family therapists could benefit in "abandoning the search for the discovery of a single universal truth in favor of allowing for multiple truths," as each family with which a family therapist works is its own expert in its function and needs (Allen, 2000, p. 8). Each exploratory qualitative study that discovers the lived experience of families benefits the field of family therapy in that it allows family scientists to paint a clearer picture of the intricacy of the human experience (Creswell, 2003).

Summary

This chapter explored the current literature available on parent-child sexuality education as it occurs in families in which there are sons or daughters with Autism or Down syndrome. First, research that outlined parental attitudes towards the sexuality of sons or daughters with Autism or Down syndrome was discussed. Secondly, available resources for parents on the topic of sexuality education with their sons or daughters with Autism or Down syndrome were further investigated. Next, academic literature on the topic of parent-child sexuality education was examined. Finally, a need for research was discussed, as there is currently a gap in the literature in what parents of sons or daughters with Autism or Down syndrome are teaching their children.

CHAPTER III

METHODOLOGY

This study's purpose was to explore parent-child sexuality education in families with sons or daughters with autism or Down syndrome. The focus was on the qualitative experience of the parents in these families, how and what they taught their son or daughter about sexuality, and what the parents thought family therapists need to know about their unique experience in sexuality education with sons or daughters with these special needs. In order to more fully understand the lived experiences of the participants in this study, a qualitative phenomenological approach was used (Creswell, 2003).

Data were collected during face-to-face interviews, and the interviews took place at the home of the participants in order for the participants to feel more at ease and for the researcher to more clearly perceive the lived experiences of the individuals in the study. The interviews were audio recorded for the purpose of transcription with the consent of the participants. Upon the completion of transcription, copies of the interview transcripts were read, and important quotations were highlighted. The highlighted quotations were analyzed and numerically ordered until no new information surfaced. Finally, the major quotations were analyzed for themes, and grouped accordingly.

This chapter will begin with a description of the theoretical frameworks of phenomenology and family systems theory, which were used as the foundations for this research. Next, the instrumentation of the study will be discussed, including the

researcher as a person. After instrumentation, a description of the participants and a discussion of the protection of human participants in research follow. This chapter concludes with a description of the procedure and data analysis used in the study.

Theoretical Frameworks

Phenomenology

This exploratory qualitative research was examined from a phenomenological viewpoint, so as to ascertain the "'essence' of human experiences concerning a phenomenon" (Creswell, 2003, p.15), which, in the case of this study, was parent-child sexuality education in families in which there are sons or daughters with autism or Down syndrome. Phenomenology is a strategy of inquiry in qualitative research that determines elements of the research such as the research questions, the interview protocol, the tape transcription procedures, and the use of personal experience bracketing by the researcher (Creswell, 2003; Morrissette, 1999). In bracketing, or defining, her own personal experience, this researcher was able to focus solely on the "lived meanings that events have for individuals, assuming these meanings guide actions and interactions" (Marshall & Rossman, 1999, p. 113). In completing this research with a phenomenological mind-frame, the researcher could "potentially enrich clinical practice" (Morrissette, 1999, p. 2) by highlighting the experiences of parents with sons or daughters with autism or Down syndrome in teaching their sons or daughters about sexuality.

Family Systems

In addition to phenomenology, this study was guided by principles of family systems. It was assumed in this research that families are part of relational patterns that fit

into a larger society. In conceptualizing families, the researcher believed that considering the context of the family was vital. Families fit into their communities, their social settings, and into society at large, and the influence of society on the family cannot be negated (Bronfenbrenner, 1977). Additionally, the researcher believed that families communicate in patterns, and that it is impossible for families to not communicate (Hanson, 1995; Watzlawick, 1967). It was assumed in this research that messages about sexuality were clear in the family, even if sexuality had never been verbally discussed amongst family members.

Instrumentation

In qualitative research, the researcher is considered the primary instrument (Marshall & Rossman, 1999). In conjunction with the interview questions, the researcher in this study created the interview process, an integral part of the instrumentation of qualitative research (Creswell, 2003). This research was guided by two fundamental research questions. First, what are parents' experiences of teaching a son or a daughter with autism or Down syndrome about sexuality? Second, what do parents think family therapists need to know about their experience in teaching their sons or daughters with autism or Down syndrome about sexuality?

The following interview questions, based on the research questions, were structured in order for the phenomenon of parent-child sexuality education to "unfold as the participant views it, not as the researcher views it" (Marshall & Rossman, p. 108).

Question 1: Tell me about your experience of teaching your son or daughter about sexuality.

Question 2: Are there any resources you've found particularly helpful in teaching your son or daughter about sexuality?

Question 3: What do you wish family therapists knew about your experience in teaching a son or daughter with autism or Down syndrome about sexuality?

An interview protocol containing the interview questions and additional prompts used for clarification were followed (Appendix A).

Researcher as a Person

I am an active community volunteer, and have worked with people with Autism and Down syndrome for fifteen years. When I was a young teenager, my initial contact with this population was for the non-profit organization Best Buddies International, whose mission is to "enhance the lives of people with intellectual disabilities by providing opportunities for one-to-one friendships and integrated employment" (Best Buddies, 2009).

As an undergraduate student, I worked at a camp in Williamson County, Tennessee, for children and adolescents with developmental disabilities. In my work at this camp, specifically in my contact with parents of the campers, I soon recognized a unique parental experience in sexuality education in families in which there are sons or daughters with autism or Down syndrome.

I am a master's student in Family Therapy at Texas Woman's University, and a student member of the American Association of Sexuality Educators, Counselors, and Therapists (AASECT). I fully understand the delicate, sensitive nature for some people in discussing sexuality, both theirs and others'. It was my goal in this research to recognize

and bracket my personal bias in interviewing the parents who agreed to participate in this study.

Participants

The participants in this study were the biological or adoptive parents of sons or daughters diagnosed with autism or Down syndrome. The parents were at least 18 years old at the time of the face-to-face interviews, and were volunteers willing to discuss how and what they taught their sons or daughters with autism or Down syndrome about sexuality. The target number of parents to participate in this study was 30. In qualitative research, however, the sample size is not as important as the depth, diversity, or quality of information gathered, and the researcher in this study ceased to gather data once she perceived saturation of the data had been reached, which occurred after fourteen interviews had been conducted (Kumar, 2005). Purposive sampling was the primary sampling method for this study. Recruitment letters (Appendix B) were sent to gatekeepers at organizations for families and persons with developmental disabilities, and placed as advertisements at local occupational therapy offices. The researcher also attended a seminar for parents seeking ways to teach their sons or daughters about sexuality, and potential participants gave the researcher their contact information to find out more about the study or to set an interview appointment. Additionally, snowball sampling was used to find participants. Snowball sampling (Marshall & Rossman, 1999) "identifies cases of interest from people who know people," (p. 78) which means that parents who agreed to participate in the study also knew of others who were interested in

participating. The parents who read the recruitment letter were encouraged to ask others who may qualify for the study to contact the researcher (Appendix B).

Protection of Human Participants

This study was submitted to the Texas Woman's University Institutional Review Board for approval. The researcher protected participants' confidentiality by numerically coding their interviews and using no identifying information other than the numerical codes on the interview tapes or transcriptions. The participants' names appeared on the consent forms, but the consent and demographic information forms were kept separate from the interview tapes and transcriptions. The audio tapes, transcriptions, consent forms, and demographic information forms were all kept in a locked filing cabinet in the researcher's home. All materials containing participant-identifying information will be destroyed within two years after the completion of the study.

Participants were given a list of professional referrals (Appendix C), in the instance that they may need to later discuss any discomfort they felt during the interview. The researcher informed participants during the recruitment, telephone information session, and before the interview that they may withdraw from the study at any time without penalty. Additionally, the participants were offered breaks periodically throughout the interview in order to prevent fatigue. The researcher was accessible to participants by phone before and after the interview, and in person at the interview site, if the participants had any questions about the study. Before the interview, the participants were given a consent form (Appendix D). The researcher brought two identical copies of the consent form for the participant. The consent form was reviewed by the researcher

with the participant and, if the participant was willing to voluntarily continue with the interview process, he or she signed both copies of the consent form. A copy of the consent form was given to the participant for his or her records. If the participant wanted a summary of the study's results, he or she included the address to which to send the results after the study was completed.

Procedure

To better understand the lived experiences and rich meanings of the lives of participants in this study, the face-to-face interview was a vital part of the research process (Marshall & Rossman, 1999). The researcher in this study purposefully recruited participants for the study by way of gatekeepers. A gatekeeper in this study was a person at an organization or business that comes in frequent contact with parents of sons or daughters with autism or Down syndrome (Creswell, 1998). The gatekeepers were persons professionally affiliated with organizations such as Arc of Texas, Best Buddies International, and the Down Syndrome Guild of Dallas. Snowball sampling was also used in this study to find additional participants who may not have had contact with a gatekeeper. The researcher encouraged parents who read the recruitment letter to pass the contact information or letter on to other parents who may have been interested in participating.

The recruitment letter contained a phone number where participants were able to reach the researcher or her research advisor with any questions about the study. When participants called the phone number on the recruitment letter, the researcher followed the Telephone Script to Set an Interview Appointment (Appendix E) in order to achieve

two goals. The researcher's first goal was to answer any questions potential participants may have had about being a part of the study and set appointments if they decided to participate. The researcher's second goal was to encourage the parents who called to pass the researcher's contact information to other parents who might have been interested in participating in the study.

The confidentiality of participants was protected by numerically coding the interview information of each parent. The participants were assigned a consecutive non-repeating number code, starting at 001. When the participant received his or her demographic sheet to fill out at the end of the interview, the numerical code was already written on the sheet so as to avoid any confusion of one's code. The Demographic Information Form (Appendix F) was the only identifying information of the participant. The Demographic Information Forms were kept separate from the Consent Forms and tape transcriptions at the researcher's home. After two years, all Demographic Information Forms (Appendix F), tape transcriptions, and tapes related to this study will be destroyed. The Consent Forms (Appendix D) were placed on file with a final report of the study at the office of Texas Woman's University's Institutional Review Board.

Interview Procedures

The interviews took place at the participants' homes located in the Dallas-Fort Worth area. The participants voluntarily were a part of a face-to-face interview that lasted no longer than ninety minutes. The researcher was on-site for the interview fifteen minutes before the interview began to test the audio taping equipment. The researcher

had pens and paper with which to take field notes. To put forth a professional and objective appearance, the researcher wore a dark suit.

When the participant arrived, the researcher greeted him or her and began to follow the Interview Protocol (Appendix A). During this time, the participants were reminded that they could take as many breaks as necessary throughout the interview, and they could withdraw from the study at any time without penalty.

The researcher presented the participant with two identical copies of the Consent Form (Appendix D). The participants were asked to read the form and ask any questions they might have. After all questions were answered, the participant was asked to sign both copies of the consent form and keep one for his or her records. After signing the consent form, the researcher reminded the participant to leave his or her address at the bottom of the second page of the consent form if he or she would like to receive a summary of the results of the study. There was no direct benefit to the participants for participating in this study.

Upon voluntarily signing the consent form, the participant was informed that the tape recorder would start recording. All interviews followed the Interview Protocol and did not exceed ninety minutes. The researcher did not ask a subsequent question until the participant had ceased his or her comments on the preceding question. During the participants' comments, the researcher may have used prompts (Appendix A) to encourage the participants and clarify their responses.

At the end of the interview, the participants received the Demographic Information Form (Appendix F). The form was presented to the participants to fill out at

the end of the interview so that the continuity of the interview process could remain the same for all participants. The participants also received the Referral List (Appendix C) of therapists they may contact in the event the participant needed to speak to someone about any emotionally distressing issues that arose during the interview.

Pilot Study

An important part of the procedure of this study was the pilot study. Due to the nature of phenomenological interviewing in which there is "an explicit focus on the researcher's personal experience combined with those of the interviewees," (Marshall & Rossman, 1999, p. 113), part of the effectiveness of the interview as a research instrument is that it is a clear and efficient way to gather data. The pilot study for this research consisted of the data from the first three participants (001-003). The researcher followed the Interview Protocol (Appendix A) as described, but also asked for participant feedback about the interview process at the end of the face-to-face interview. The researcher used the participants' feedback to determine whether modification was needed in the interview process. All three participants in the pilot study reported that the interview questions were clear, thus no changes were made.

Data Analysis

Following the interview, the researcher listened to the audio tapes as soon as feasible. Morrissette (1999) described listening to the tapes immediately after the interview as imperative in order to recall as many non-verbal messages as possible from that particular participant. After listening to each audio tape once, the researcher transcribed each tape verbatim. Of each tape transcript, two identical copies were made.

One copy remained unmarked, and one copy was used for note-taking for theme emergence. On the latter copy, the researcher highlighted major statements made by the participants, and numbered them consecutively until no new topics surfaced (Morrissette, 1999). The interview transcripts were then divided into the different research questions, which were put into different folders.

After the transcripts were sorted by research question, the research questions were examined by the researcher for similar numerical coding of information. The similar groups of numbers were read and compared for similarities in paraphrasing. The analogous significant statements were grouped so as to be able to determine the frequency of themes and to compare and contrast similarities and differences between the participants' individual lived experiences (Morrissette, 1999).

Summary

This chapter outlined the qualitative research process used in this study. The theoretical frameworks used to guide the study, phenomenology and family systems were described. Next, the interview process, including the researcher's interpretation of the data, was the primary instrumentation for this research, and the researcher as a person was described. The recruitment of participants through purposive and snowball sampling was discussed. The participants in this study were biological or adoptive parents who are at least eighteen years old and who have a son or daughter diagnosed with autism or Down syndrome. The participants voluntarily discussed the sexuality education they provided their son or daughter with autism or Down syndrome, and their protection was discussed in detail. The interview procedures, including the pilot study, were also

discussed. Finally, an explanation of the data analysis that occurred at the end of the face-to-face interviews was outlined.

CHAPTER IV

RESULTS

This chapter first describes the sample of fourteen parents who participated in face-to-face interviews as a part of the study. Next, the emergent themes are described, and the results of the audiotaped interviews are reported. This study's purpose was to explore parent-child sexuality education in families with sons or daughters with autism or Down syndrome. The focus was on the qualitative experience of the parents in these families, how and what they taught their son or daughter about sexuality, and what the parents thought family therapists need to know about their unique experience in sexuality education with children with these special needs.

Description of the Sample

The sample of this study consisted of fourteen biological or adoptive parents of persons with autism or Down syndrome. The parents interviewed were all mothers, as no fathers responded to recruitment flyers, presentations, or follow-up phone calls. All fourteen parents participated in the face-to-face interview process, and no participants requested to be withdrawn from the study.

The participants' demographic information, as seen in Tables 1, 2, and 3, follows: 85.7% of the parents identified as biological parents (n=12), and 14.3% identified as adoptive parents (n=2). The age range of the parents was 34 to 76, with a mean age of 51.2 years. 7.15% of the parents identified themselves as African American (n=1), 85.7%

identified themselves as Caucasian (n=12), and 7.15% identified themselves as Native American, of the Creek tribe (n=1). The education levels of the parents were High School (n=1), Some College (n=3), Bachelor's Degree (n=8), Master's Degree (n=1), and Doctoral Degree (n=1). The parents' marital statuses were Married (n=9), Divorced (n=1), Single (n=2), and two parents marked both Single and Divorced. The parents' socioeconomic levels were Under $25,000 (n=2), $25,001-$39,999 (n=2), $40,000-$54,999 (n=2), $55,000-$69,999 (n=2), $70,000-$99,999 (n=2), $100,000-$149,999 (n=3). One parent declined to answer socioeconomic level, and no parents marked the $150,000-$249,999 level.

Of the fourteen parent participants, thirteen had either one son or one daughter with autism or Down syndrome. One parent had both a son and a daughter with autism. Thus, the information from fourteen parents is about the parent-child sexuality education with twelve sons and three daughters. Of the sons or daughters, ten had received a diagnosis of autism and five had received a diagnosis of Down syndrome. Two parents wrote additional diagnoses of schizophrenia and fragile X syndrome on the Demographic Information Form (Appendix F). There were nine sons with autism, one daughter with autism, three sons with Down syndrome, and two daughters with Down syndrome. The age range of the sons or daughters with autism or Down syndrome was 9 to 38, with a mean age of 19.5 years. Ten parents noted that they had at least one other son or daughter in the family: 28.6% of participants had one other son or daughter (n=4), 35.7% of participants had two other sons or daughters (n=5), 7.1% of participants had ten other sons or daughters (n=1), and 28.6% of participants had no other children (n=4).

The majority of parents in the study were socially connected with organizations that pertained to their son's or daughter's developmental disability. Nearly 79% of parents (n=11) listed organizations to which they belong, which included ARC, Best Buddies, Down Syndrome Guild, Special Olympics, and the local Autism Society. Three parents reported that they did not belong to any social organization.

The reported history of mental health counseling or therapy was varied among the sample. Five parents in the study reported they had never been to therapy (35.7%), 42.9% of parents in the study reported they had received some type of mental health services (n=6), and 21.4% declined to answer whether or not they had ever been to therapy (n=3).

Table 1

Participants' Code, Age, Sex, Ethnicity, and Relationship Status

Code	Age	Sex	Ethnicity	Relationship Status
001	51	Female	Caucasian	Married
002	53	Female	Caucasian	Married
003	66	Female	Caucasian	Married
004	53	Female	Caucasian	Married
005	56	Female	Caucasian	Married
006	46	Female	Caucasian	Married
007	76	Female	Native American (Creek)	Divorced
008	55	Female	Caucasian	Married
009	53	Female	African American	Single, Divorced
010	40	Female	Caucasian	Single, Divorced
011	41	Female	Caucasian	Married
012	40	Female	Caucasian	Single
013	53	Female	Caucasian	Married
014	34	Female	Caucasian	Single

Table 2

Participants' Education Level, Socio-Economic Level, Organizations and Previous Mental Health Counseling

Code	Education Level	Socio-Economic Level	Organizations*	Previous Therapy
001	Bachelor's Degree	No Answer	ASCC, NAA-NT	None
002	Bachelor's Degree	$40,000-$54,999	ARC, Camp Summit	Psychiatrist, Family Therapist
003	Bachelor's Degree	$100,000-$149,000	ARC, DSGD, NDSC, Best Buddies	Premarital
004	Bachelor's Degree	$70,000-$99,999	ARC, Best Buddies	None
005	Some College	$55,000-$69,999	Apt. G (UMC)	None
006	Bachelor's Degree	$100,000-$149,999	ARC, NT Fragile X	None
007	Doctoral Degree	$25,001-$39,999	TALAC, DSGD	None
008	Bachelor's Degree	$70,000-$99,999	DSGD, Special Olympics	No Answer
009	Master's Degree	$40,000-$54,999	None	Counselor, Family Therapist
010	Bachelor's Degree	Under $25,000	None	No Answer
011	High School	$100,000-$149,999	ARC, Best Buddies, Autism Society of America	Psychiatrist, Counselor
012	Some College	$25,001-$39,999	TCDWC	Counselor
013	Some College	$55,000-$69,999	ARCNETC, NDSA	No Answer
014	Bachelor's Degree	Under $25,000	None	Psychiatrist Counselor Family Therapist

*Some of the organizations the parents listed were written in acronyms, and most were associated with autism or Down syndrome. Participant 012 wrote in a local chapter of a Democratic Society organization.

Table 3

Participants' Sons or Daughters with Autism or Down Syndrome, Diagnosis, and Age, Participants' Other Sons or Daughters and Age

Code	Son or Daughter	Diagnosis	Age	Other Sons or Daughters	Age
001	Son	Autism	23	Daughter	18
002	Son	Autism (and Schizophrenia)	23	None	
003	Son	Down Syndrome	32	Daughter, Son	37, 40
004	Daughter	Down Syndrome	20	None	
005	Son	Autism	14	Daughter	25
006	Son	Autism (and Fragile X)	16	Daughter, Daughter	16, 19
007	Daughter	Down Syndrome	38	(Only listed others' ages)	42, 46, 48, 50, 53, 55, 56, 58, 60, 60
008	Son	Down Syndrome	17	Daughter	19
009	Son	Autism	22	Daughter, Son	20, 28
010	Son	Autism	12	Daughter, Son	13, 15
011	Son, Daughter	Autism	18, 19	Son, Daughter	9, 15
012	Son	Autism	17	Son	19
013	Son	Down Syndrome	9	None	
014	Son	Autism	13	None	

Findings

To fulfill the purpose of this study, the following research questions were explored:

1. What are parents' experiences of teaching a son or a daughter with autism or Down syndrome about sexuality?
2. What do parents think family therapists need to know about their experience in teaching their sons or daughters with autism or Down syndrome about sexuality?

The following interview questions, based on the research questions, were structured in order for the phenomenon of parent-child sexuality education to "unfold as the participant views it, not as the researcher views it" (Marshall & Rossman, p. 108).

Question 1: Tell me about your experience of teaching your son or daughter about sexuality.

Question 2: Are there any resources you've found particularly helpful in teaching your son or daughter about sexuality?

Question 3: What do you wish family therapists knew about your experience in teaching a son or daughter with autism or Down syndrome about sexuality?

Based on the overall responses of the participants, it was determined that parents divided into two categories, tentative parents and assured parents. Tentative parents taught sexuality education messages based on their concerns, such as their son or daughter with autism or Down syndrome acting out in public, or the parents' belief that they were unequipped to teach their son or daughter effective sexuality education. As a group, tentative parents reported having access to or knowledge of fewer resources than the assured parents, and tentative parents were less likely to report thinking of their son or

daughter as a sexual person. Finally, tentative parents expressed some difficulty in seeing family therapists as helpful in the parents' teaching the sons or daughters about sexuality.

Assured parents taught a more comprehensive sexuality education to their sons or daughters with autism or Down syndrome. In addition to teaching about intercourse, assured parents taught a variety of sexuality education subjects, such as sexually transmitted infections, homosexuality, menstruation, and wet dreams. Assured parents were more likely to think of their son or daughter as a sexual person, capable of expressing sexuality or being sexual, either currently or in the future. Assured parents reported wanting family therapists to encourage parents to focus on sex-positive sexuality education messages if the family therapist were working with a family with a son or daughter with autism or Down syndrome.

The parents overall, despite the division of either being tentative or assured in their sexuality education messages, shared some commonalities. First, the topics of religion and appropriateness arose in all the interviews. Also, both tentative and assured parents taught their son or daughter proper names for genitalia and that sexuality is primarily about relationships, not sexual intercourse. Most parent participants in the interviews reported believing that sexuality education is important, even if, for example, a tentative parent reported not knowing how to teach her son or daughter about sexuality. Additionally, most parents reported that it is important to them that family therapists keep their family culture and their son or daughter's developmental abilities in mind while working with their families.

The first two interview questions were:

Question 1: Tell me about your experience of teaching your son or daughter about sexuality, and

Question 2: Are there any resources you've found particularly helpful in teaching your son or daughter about sexuality?

These questions were intended to answer the first research question:

1. What are parents' experiences of teaching a son or a daughter with autism or Down syndrome about sexuality?

The following section will report the parents' responses to the two interview questions from the tentative parents' perspective and from the assured parents' perspectives. Then, the commonalities between the two groups will be relayed.

Tell Me about Your Experience of Teaching Your Son or Daughter about Sexuality

Tentative parents. The responses to the first interview question demonstrated that many tentative parents based their sexuality education messages on their concerns about embarrassment in public or on how their son or daughter would use the information to keep themselves safe:

"I didn't even push body parts a lot because I didn't want him to say something inappropriate in public.... you know, we called them 'private parts' so we didn't want to get into too much detail." (001).

"[We've covered] certain aspects of sex education. Not involving condoms or the pill or anything like that, but abstinence, and, um, the Christian values of you wait until you get married, and, um, if somebody approaches you, and tries to touch you in an

inappropriate way, then you need to let somebody know right away.... Safety issues, stranger danger, that kind of thing. And, obviously, you know, keep your hands to yourself. You don't touch other people. You don't use those certain words." (004).

"I have to pull the information out of him, so it's more difficult for me. And what I did, what I've done so far is just try to keep him safe, you know? ...These are your private parts, and nobody can touch you here but me and dad when we're cleaning you up, you know, and if anybody touches you there, you know, you have to come tell me and dad, you have to tell someone, you know." (005).

"We've taught him, um, like if we're in public he tends to just have his hand there, and we just say "Pockets," and then he puts his hands in his pockets, and that way it's not quite so embarrassing." (006).

"Hm. [Long pause]. I guess just the touching. Telling him, you know, where it's appropriate to touch, and what to talk about outside the family.... Um, just no hugging. Handshakes [pause]." (008).

"When he was in the fifth grade, he had a problem where he would be touching himself in class and he'd have his hands down his pants, and the teachers had to, um, come talk with me to try to get him to stop.... [I explained] people in the world are not comfortable with that, and we have to, um, do things to make them feel comfortable, [laughs] including you can't go around touching yourself in public, like at school." (010).

"[Son] is nine, nine and a half, and, um. Our, you know, the only parts that we really talked about are, you know, he knows about, um, you know, that we all have private parts, and um, he knows, you know, that. [Sighs].... We've talked about who he

should kiss, what's appropriate, um, appropriate touch and not, and, so that's pretty much what, what we've talked about so far." (013).

Tentative parents also expressed during their responses to the first interview question that they were unsure how to provide quality sexuality education to their son or daughter with autism or Down syndrome, as shown in the following quotations:

"I would like somebody to tell me, because he's, my son is just, you know, he is very uncomfortable, he just is not, he's not. And I don't know. Do I force it on him? Is that the right thing to do? Or is it the wrong thing to do? What do I do? Do I wait, you know, until he gets a bit older?" (005).

"How do you talk about it? Use pictures, and all that, I guess. See? I mean, how do you use language that they understand? Pictures, yeah, that's what they do at school a lot." (008).

"I was trying to explain to him about wet dreams. That was a really difficult conversation that went bad, um, I was trying to explain to him that it's natural, and, um, then I went off into the, the explanation of how, uh, the blood will flow into the penis, and it'll get bigger for a little while, and that grossed him out. He got a really bad idea that it was gonna be something awful. Even though I know he's already had it, he didn't make the connection with what I was trying to explain to feelings that he's already had. I have to figure that one out, and start all over again." (010).

"[On discussing masturbation with her son:] You know, he doesn't say anything too much about it, and I just try to tell him that, you know, he needs to touch in private. And

that's pretty much all I've talked about. [Laughs]. Um, because I'm not really sure how. I'm not really sure what to say, so, um." (013).

In terms of when to start sexuality education, tentative parents often relayed the message that their son or daughter would have to ask questions before sexuality education occurred:

"We got my daughter when she was eight years old. She's adopted, and, I guess, we didn't start talking about it right away, when she was eight. She was, you know, really no reason to, but I think as things come up at school, and she has questions, then we'll just talk about it....If she has a question about a word, we explain it." (004).

"As far as the getting into deep details, this is how it happens, this is how it works, she hasn't asked those questions, and I haven't told her." (004).

"He's never really asked me, you know, anything." (005).

"If he starts to ask more questions or become more interested or agitated about it, then we'll have to sort that out as it comes." (006).

The final point that most of the tentative parents had in common was that they expressed difficulty in seeing their son or daughter as a sexual person:

"I don't see [Son] becoming a sexually active person, um, in a relationship with someone else." (001).

"She's been to camp...and that is a co-ed camp, but they have counselors, so I guess if she had wanted to, there might have been, you know, an opportunity, but as far as I know I don't think that she's had the desire." (004).

"Although he's going through puberty, I don't think that psychologically, he's really wanting to, to have a girlfriend or be interested in, you know, in girls. There's no. I haven't seen that at all, you know?" (005).

"The sad reality is the child with mental retardation and autism most likely is not going to get married....Um, there's not a lot of need to emphasize something that probably is not going to, shouldn't be a part of his future. He can't go around impregnating girls, or wouldn't have the motor skills to put on a condom anyway, so it's something that is, uh, that's just the fact and reality of it." (006).

"It's really kind of a non-issue, to be honest." (008).

One tentative parent did notice her son with autism show an interest in sexuality, as demonstrated in her story:

"I know he likes girls because last school year, in one of his assignments...he drew a copy of the Mona Lisa, and he gave her, um, cleavage, and that was a crack up, because we all know she's the plainest, most manly looking woman ever, and he made her look feminine, which means he notices these things." (010).

Assured parents. The group of assured parents reported doing a more comprehensive sexuality education with their sons or daughters with autism or Down syndrome, as demonstrated by the following quotations:

"We started out real basic and then, you know, as, now there are issues like, you know, about, um, relationships with women, and, how, you know, about babies and how they come about, things like that. So, you know, at first in his very young years it was

really basic information that he needed, and then now it's a lot more, um, more sophisticated." (002).

"Depending on his age, uh, we, well, and his ability level, what he was capable of understanding, we tried to give him as much information as we could." (003).

"I had to go into a longer conversation with her about what that means, other people's body parts. I got her a little book, a health book that showed her. We went through that one time, and then every evening instead of the regular story that we read, we started learning health and anatomy at that point, when she was thirteen." (007)

"I guess I believed from the very beginning, um, that it's important to teach children, um, as they, as they grow, and as they have questions, just to deal with each question as it comes up, but to start out by having a very open relationship." (009).

"I remember telling them, you know…it's not just the penetration. It's the sexual boundaries, and, and how to be appropriate, and that kind of stuff….I don't really remember having, like, a "Sit down. We're having the sex talk." I always, and the minute they asked questions, I was very straight-up about it." (012).

"I just said, 'Well, the man's penis ejaculates in the woman's vagina, and it meets,' …I didn't go on and on for five minutes, because that was probably, I want to say third or fourth grade…and I just told them straight up how it is, and they're kinda like, 'Gross.' And I also said, 'One of these days, you're going to be ejaculating sperm out of your penis before you even are with a girl.' And they're like, 'Really?' So I just kind of prompted them. Especially [Son], with the disabilities, because I don't want him to get freaked out when that happens, 'cause you know, more than likely, I'm not gonna be

there. It's gonna be him by his self, and, uh, probably accidentally in a wet dream or something like that." (012).

Assured parents interpreted sexuality education broadly, and reported teaching their sons or daughters with autism or Down syndrome about many different sexuality topics:

"He said, 'Well, what does this mean?' you know, 'What does gay mean?' And I said, just very matter-of-factly, that it's, um, some people love people who are the same sex that they are, you know. They want to be with them, um, and have a relationship with them, instead of being with the opposite sex, and I said there's people like that all over the world." (009).

"We finally got to our conversation about it, and this is when we got really down to the discreet facts of life, about what can happen, and that people's emotions, and that sometimes that boys or men get more emotional about sex than women do, and that, uh, she has to be aware of that, and never to lead anybody on." (007).

"I've always been really careful to, uh, let them know their bodies are normal and. We actually, with my daughter... when she started her period, we were all, like, congratulating her and telling her, you know, what a wonderful thing it was. Wow, now her body's producing eggs." (011).

"So I gave him a box of condoms for his room.... And to this day, he hasn't used them..... I said, 'It's important to try out. Put it on. See how it feels. Get to know it before you go with a girl, and then you're fumbling around trying to put this sucker on.'" (012).

"He started telling me about that he had a girlfriend, we discussed what that meant, and what boyfriends and girlfriends do together, and all that kind of stuff. And then we discussed, um, about sex, and that how you would know when you were ready for sex. And that was one of the things that I wanted to convey to him, was that if you weren't ready to care for a child, then you probably weren't ready to have sex, either." (014).

Assured parents also saw their son or daughter as capable of expressing sexuality:

"I think we're all guilty of underestimating them. They are very capable of a sexual relationship, um, at least, someone on his mental level. I can't say for people who have more limitations than he does. I really can't say. I haven't been there, so I'm not gonna judge that, but [Son] only has a fifty IQ, and his social IQ is a hundred, but his intelligent quotient, as has been measured in the past, is fifty. It's a very poor measurement of his capabilities." (003).

"She was feeling a little bit more confident about knowing what to do in a sexual situation, and about how she felt, and she said, 'Well, can I have a boyfriend now?' And I said, 'Well, I guess if you would really like to have a boyfriend, when you find somebody that you like…I'll be glad to take you all to the movie or out to dinner or whatever you'd like to do. Or you can cook here if you want to.'" (007).

"For [Son]'s twentieth birthday, um, [his uncle] asked [Son] if he wanted to go to a strip club. And [Son] said, "Yeah! Why not?" [Laughs]. And so I thought about it, and I'm like, OK, [clears throat]. If he were a typical twenty year old, it wouldn't be up to

me, you know. He probably would have gone already if he had the opportunity, so, I'm like. I didn't...say 'Don't do it.'" (009).

"At the time, I just was telling her you save it for later. You know, over the years you grow, you mature, you change. You know, now I have told her that it's OK, it's normal, there's, you know, nothing wrong with doing that, um, and, so. Actually, recently, I even gave her, um, a little, um, egg, vibrator thing for her, you know, uh, so, so we've had that discussion." (011).

"I want them to be good lovers. I want them to be good husbands."(012).

"We're at the point now that I know that he masturbates when he's in the shower, um, and I have to try to really hard to respect that." (014).

Are There Any Resources You've Found Particularly Helpful in Teaching Your Son or Daughter about Sexuality?

Tentative parents. The tentative parents reported almost exclusively that there were little to no resources that they found to be helpful in teaching their son or daughter with autism or Down syndrome about sexuality:

"No, um. That was why I went to the workshop" [where she met the researcher]. (004).

"Um, no. We went to, we did go to a, we did go to a seminar, ... [but we were] appalled." (006).

"[Long pause] No. Just my husband and I." (008).

"No. That class I went to where I met you first was the first, uh, help I've gotten at all." [This parent is referring to the presentation where the researcher recruited participants]. (010).

"No...No resources yet." (013).

One tentative parent (001) reported using Mayer/Johnson symbols to teach her son with autism about sexuality in a visual way, but no other tentative parents listed any resources they found to be helpful.

Assured parents. The assured parents listed several resources they used to teach their son or daughter about sexuality:

"We bought this amazing book that is called *Sexuality* or something like this, *and People with Down Syndrome*, or *and People with Disabilities*, and I can't remember which it is. He has it still, and I think he still refers to it. Um, it's written on a really good level for him. It has very good pictures in it of adults who have no clothes on, but they're very tasteful." (003).

"We had the book series...called Where Did I Come From? And then there was the What's Happening to Me?... Nielson? Leonard or something. Neilson, who did the, um, the original Way Back books that had the real photographs of babies inside the womb being developed... I bought them anatomically correct baby dolls...Oh, there was Dr. Ruth book. I almost forgot about the Dr. Ruth book. Dr. Ruth for kids. Or Dr. Ruth talks to kids. Something like that.... What Makes a Boy, What Makes a Girl." (009).

"Why Girls and Boys are Different by Carol Greene...Where Do Babies Come From? By Bruce Hummel...How You Are Changing by Jane Braver...Sex and the New You [by] Ridge Bimmler" (011).

"Sex, a Man's Guide. But I thought, and I really liked it, because it, family planning stuff. Better sex techniques from every, everything.... Female body. Sexual diseases. I mean, I love it. Come on. 'Cause it covers all the areas. Giving birth. STDs." (012).

Although many assured parents used books or other media resources, one assured parent did not use outside resources to teach her son about sexuality:

"No. Um, I, I can't say that I looked up any resources. Um, I went by what I learned in my classes, what was physically, developmentally normal for his age, for his, his chronological age, um, and then I just kind of went off instincts, um, you know, as to what felt right." (014).

Finally, one assured parent interpreted resources in a different, unanticipated way, stating:

"The resources that are important are space to do it in....Often times, parents will not, you know, they'll give the book, and they'll sit there and go through it with them, and then wait and want them to go through it again just to get the response and the reaction, but the best tool anybody ever had was space and privacy to absorb the learning." (007).

Parent commonalities in the first two interview questions. Despite the differences noted between the groups of tentative and assured parents in this study,

among the groups there was common ground. First, the topic of religion arose in almost every interview:

"And I know we're in the Bible belt, but [laughs], um, they should touch upon it at school. They do with health ed in, um, regular education kids, um, but they don't do anything for the special needs kids." (001).

"I did...begin imposing my own, uh, standards on him about husband and wife, that this was an act between a husband and wife, that it was reserved for them, and I feel very strongly that that is my privilege and right to do that, because he was raised in the church, the same church that we were, and with the same standards." (003).

"We're Christians, and, um, we take the route of 'If Jesus wouldn't want us to do it, then we shouldn't do it,' and that pretty well takes care of everything." (004).

"And the religious thing comes into it too. I mean, I don't really want him to have sex, you know, outside of, I don't, you know." (005).

"I've seen it happen numerous times in the south, it is a church-supported group, they don't allow them to have the normal relationships that should and could go on. And so when she started the hugging and kissing, and he was a willing recipient of that, once again, they stopped it. You can't do that here. You're just friends." (007).

"Some families are bound by religion, and...that will only allow them to say so much." (009).

"At the time, we were really, really, uh, very strong in our religion at that time, and so we were really, you know, just talking about how, um, you know, that God made, you know, that for marriage, and, you know, that it's a wonderful thing....It's this great,

beautiful thing, and. God made us all to do that, to enjoy that, and it's just, you know, like a treasure you keep for your husband one day." (011).

[In discussing resources she found:] "In fact, most of them were Christian-type books, which I'm a fan of, but not when it gets down to the nitty-gritty, 'cause it's all sugar-coated, and that ain't real life, especially in inner-city schools, you know. Maybe if you're at a private school, although, pshh, I remember those private school people had a good time." (012).

"When I was a child, it was a very religious household, and sex was to occur during marriage and...you weren't supposed to fornicate..., you weren't supposed to masturbate. [As you age], you come to realize that sexuality is normal. That different types of sexuality are acceptable aside from the religious viewpoints, and that masturbation is normal." (014).

Another common point the parents shared was appropriateness. In fact, all of the participants said the word *appropriate* at least one time during their interview. Among fourteen participants, the word appropriate, appropriately, inappropriate, or appropriateness was said a total of 91 times. Some examples follow:

"He was going through puberty, so he was getting a lot of hair in his private area, and, um, he would scratch it inappropriately, because he didn't understand, um, what is socially appropriate and what is not socially appropriate." (001).

"When he was in a preschool program, um, he was inclined to disrobing, and, um, he felt great about it. He liked it; it was freeing to him, but, of course, it's socially inappropriate, so we had to talk about." (002).

"We had to start teaching him right away what was appropriate and what wasn't, uh, because we knew a cute little five-year-old hugging everybody is one thing, but a twenty-year-old hugging everybody is something else." (003).

"If somebody approaches you, and tries to touch you in an inappropriate way, then you need to let somebody know right away." (004).

"He watches like, he has always been a night owl, and he watches, like, you know, cartoons, and when I, I try to have discussions with him, 'cause they're like, some of them, you know, the Adult Swim stuff is really inappropriate." (005).

"He doesn't ask any questions, and he's not, he's not saying anything inappropriate anymore." (006).

"When she was six, we had our first family conversation about sex, about human relations, about what is closeness, what is appropriate, and what's inappropriate." (007).

"I mean, he's shy. He doesn't talk much. So, it's not like he's going to go up and touch somebody inappropriately or something, you know what I mean?" (008).

"But they all know that phrase, 'Not appropriate.'" [Laughs] (008).

"I said, 'Just stay away from her,' you know, 'if you can't, if you can't, um, be appropriate,' I said, you know, 'she was nice enough to you. Now you need to be appropriate to her, and everybody else, too.'" (009).

"I don't know how to explain it to him. I don't think it's appropriate to, um, get out, like, nudie books, or anything like that. Kinda stumped on that." (010).

"We talked about, um, you know, appropriate touching, and where we don't touch, and he also knows it's his privates, and we've told him to be, you know, cover up when he comes out of the bathroom." (011).

"I just always have [taught him about sex]. I don't remember not, really. It was, um, you know, age-appropriate, of course." (012).

"I think that it would be, you know, a good idea to enlighten parents, you know. To talk about in, you know, what's appropriate." (013).

"The only constraints that I put on it then and still put on it now are that it needs to be in an appropriate area of the house. Um, it's not appropriate to sit in the living room and play with yourself when the other family members are watching T.V. It's not appropriate." (014).

Another commonality the parents shared across the tentative and assured groups was that the parents generally taught correct, proper names for body parts and that sexuality is mostly about relationships, and not solely physiology:

"When he was real little, um, we talked about the names of body parts....So, you know, to my chagrin in the store, he came up to a man and asked him if he had a penis [laughs]." (002).

"I didn't want him to just have, just to be given that information. I wanted it to be in conjunction with the information about the relationship, too, that's so important, is the relationship." (003).

"We do cover sex education at the school where I teach and she attends, and, um, it's the Catholic diocese, and they asked us to use correct words, and, so, we do use, you know, the physical ana[t]omically correct words." (004).

"Everything kids see on T.V., it's just no big deal, it's no big deal, says it's no big deal. That's the message they're getting bombarded with, and I don't believe that. I believe it is a big deal, and I believe that, it's, you're really, you know, that your soul and your body and, that's all, you can't separate all that stuff." (005).

"Like at two, [we used] the correct names for the different body parts. We never had any cute names about anything." (009).

"I tried to explain to him the biology of it all, tried to explain to him that he's gonna start growing hair." (010).

"I always taught my children the appropriate name, vagina and penis. Um, my mom taught me a really embarrassing name [laughs], and, uh, that I actually, you know, I think I said it to the doctor or something, and I look back and think how funny that must be." (011).

"From birth it was penis, you know, it wasn't a weenie or a tally-whacker. We might joke like that every now and then, but it was a penis and testicles and, then, of course,...it was breast, boobs, vagina, butt. We did say butt. We didn't call it the gluteus Maximus." (012).

"[Son] talked about one girl being very sexually active, and he was curious about her going down on him. He said, "I want to. I want her to be one of the people. What do you think about that, Mom? Do you think, because she's experienced that that'd be better

to go with her than somebody who's not?"...Ugh. He was sixteen. And then you have to put it in their lap and say, "You know, it's a personal choice. Do you really...want somebody who's at risky behavior like that?" (012).

"When he started telling me about that he had a girlfriend, we discussed what that meant, and what boyfriends and girlfriends do together, and all that kind of stuff." (014).

The final interview question asked of the participants was:

Question 3: What do you wish family therapists knew about your experience in teaching a son or daughter with autism or Down syndrome about sexuality?

This question was intended to answer the second research question:

2. What do parents think family therapists need to know about their experience in teaching their sons or daughters with autism or Down syndrome about sexuality?

The following section will report the parents' responses to the third interview question from the tentative parents' perspective and from the assured parents' perspectives. Then, the commonalities between the two groups will be relayed.

What Do You Wish Family Therapists Knew About Your Experience of Teaching Your Son or Daughter with Autism or Down Syndrome About Sexuality?

Tentative parents. Tentative parents showed some difficulty in considering family therapists as helpful when considering how to teach the sons or daughters with autism or Down syndrome about sexuality:

"Family therapist? Hm. [Long pause] I don't know, um. I don't know." (004).

"What I'm kind of afraid of is if, because this counselor's paid for by the school, they're gonna give me the same shitty advice that I got from the autism specialist who's also employed by the district." (005).

"[Family therapists] haven't had the [parents'] experience. So I don't think your research is going to help them." (008).

Also, one assured parent, who may have misunderstood the purpose of the study from a phenomenological perspective, answered in a similar way to these tentative parents:

"Nothing. A family therapist knowing about my experience with my daughter is not going to learn a thing. What they learn about, or learn through, the way a family therapist learns is through the work that you do, which is a conglomerate of experiences and out of that, you tease a pattern of behaviors that need to be dealt with." (007).

Assured parents. Assured parents exclusively mentioned sex-positive sexuality education messages as being of vital importance, and several assured parents stated they wished family therapists knew to help parents keep sexuality messages positive:

"I always believe in taking the best and leaving the rest, you know. So, the parts that I liked, I kept them, and continued those traditions, and the stuff that I didn't like, that made me uncomfortable, or that I didn't think was good enough, I tried to change it, you know, made a concerted effort to change it." (009).

"I think family therapists probably know this, but, uh, it's also really important to encourage parents not to shame their children about it." (011).

"[Family therapists should help] to try to take the, the negative thing around sex away, because there's so much guilt....There's so much guilt and shame associated with sex, masturbation, sex before marriage, and, as women, we're, we feel guilty enough about so much, you know, um. So hopefully, it's talk about the honesty, for sure, and to remove the guilt and shame from it, 'cause we are sexual beings, I mean, hello." (012).

"For people who are embarrassed to talk about it themselves. If they're embarrassed to talk about it, they're not gonna be very likely to go out and educate themselves about it, either. So, that would be what I would suggest." (014).

Parent commonalities in the final interview question. There were thematic answers that parents gave to the final interview question that also spanned the division between tentative and assured parents. Overall, the parents expressed the opinion that teaching sexuality education was important to them, and that they wished therapists would keep the family's individual cultural and societal beliefs in mind while working with families that are teaching sexuality education to their sons or daughters with autism or Down syndrome. Also, many parents discussed their son or daughter's intellectual abilities, and the range of abilities that exist in the autism and Down syndrome populations.

The following quotations demonstrate that parents believed that sexuality education is important and that family therapists should keep the family's culture in mind while working with families with sons or daughters with autism or Down syndrome:

"If I went to a family therapist because I was having marital relationships, I would probably go to one that was a Christian philosophy. If my daughter was going to a

family therapist, I don't know. I guess I would want them to counsel her with the philosophy that sex is not just something that you go out and do to have a good time. It's not, um, extracurricular activity." (004).

"[Sexuality education is important because] sex is the fifth strongest biological drive we have as human beings, and I underscore biological because it is a natural event." (007).

"There are a lot, there are as many patterns of living and behavior and approaches to sexuality as there are individuals on this green earth." (007).

"I would want a therapist not to try to influence a family one way or the other, um, and change, or try to change what they think should be told, based on their family culture. Even though I know some families have a culture that I would think was very weird, you know, that wouldn't be my culture, and it'd be hard for a therapist." (009).

"I wish that, um, boy, [sighs] I think that single, uh, parent families would be something that, uh, of particular interest for how important it is to support parents dealing with that. Uh, having to do, have that topic and that conversation, um." (011).

"Honesty is the best policy, I guess. I guess, I mean, just say it like it is. Um. That's what my parents did. I was raised by hippies. And, um, they taught me self-love, respecting and loving your body."

"I do believe it's extremely important to help our kids understand [sexuality]." (013).

"I think that the family therapists in, well, I think you have to look at [the] family of...the parents. As to what they were taught, and I think a whole lot of it is in relation to religion and or culture." (014).

The following quotations show that parents wish family therapists would keep cognitive abilities in mind while working with families teaching sexuality education:

"I know dozens of kids with autism and Down syndrome, ...and...they're so different from each other, you know. There are some of them that are in college, taking college-level classes, and there are some that are very low functioning and can't barely speak. Um, you know, my kid's kinda in the middle. There's a wide range." (001).

"He's developmentally, emotionally, psychologically, academically, he is years behind. Although he's fourteen, he sleeps with his kitty, his stuffed animal, every night, you know? He's more like a little boy, than...an average fourteen year old." (005).

"There is a difference. That even though they're physically, hormonally, whatever ready, mentally. What is their age mentally?...For ninety-nine point nine percent I think of the kids with these kind of severe developmental issues, it's inappropriate information, unless they are somehow being placed in an environment that would compromise them." (006).

"And we've had, [sighs] for [Son], even though he's thirteen, developmentally, he's about a year to two years behind where he is chronologically, and then academically, it varies, depending on the, um, subject, but academically, he's, um, up to three years behind. And so, for him, age-appropriate, when I say age-appropriate, I'm looking at, uh,

developmentally or academically. So, for instance, right now, you know, at thirteen, he could be anywhere between a ten and eleven-year-old age-level developmentally." (014).

Summary

This chapter describes the results of the fourteen face-to-face interviews with the parent participants of this study. First, a description of the sample was discussed. Next, the findings of the interviews were reported, delineating the differences between tentative and assured parents in the study. Each interview question was discussed in relation to the research question it was designed to answer. For each interview question, quotations were used to demonstrate first how tentative parents answered the question, then how assured parents answered the question, and finally what common answers were given.

CHAPTER V

DISCUSSION, CONCLUSIONS, LIMITATIONS, IMPLICATIONS, AND RECOMMENDATIONS

This study's purpose was to explore parent-child sexuality education in families with sons or daughters with autism or Down syndrome. The focus was on the qualitative experience of the parents in these families, how and what they taught their son or daughter about sexuality, and what the parents thought family therapists need to know about their unique experience in sexuality education with sons or daughters with these special needs. Two research questions guided this phenomenological study:

1. What are parents' experiences of teaching a son or a daughter with autism or Down syndrome about sexuality?
2. What do parents think family therapists need to know about their experience in teaching their sons or daughters with autism or Down syndrome about sexuality?

The following interview questions, based on the research questions, were structured in order for the phenomenon of parent-child sexuality education to "unfold as the participant views it, not as the researcher views it" (Marshall & Rossman, p. 108).

Question 1: Tell me about your experience of teaching your son or daughter about sexuality.

Question 2: Are there any resources you've found particularly helpful in teaching your son or daughter about sexuality?

Question 3: What do you wish family therapists knew about your experience in teaching a son or daughter with autism or Down syndrome about sexuality?

This chapter will give a summary of the study, a discussion of the results of the study as related to the research questions, and conclusions reached, based on what the researcher perceived to be the parent participants' main messages from the audio-taped face-to-face interviews. Next, limitations of the study will be discussed, implications for family therapists will be outlined, and recommendations for future research will be given.

Summary of the Study

This study consisted of fourteen participants who were adoptive or biological parents of a son or daughter of any age that had been diagnosed with autism or Down syndrome. The parents that consented to be interviewed were all female, as no fathers responded to recruitment flyers, presentations, or follow-up phone calls. The parents' age range was 34 to 76, with a mean age of 51.2 years.

The parents self-identified their race, education level, socioeconomic level, and marital status on a Demographic Information Form (Appendix F). One parent was African-American, 12 parents were Caucasian, and one parent was Native American, and additionally identified herself as being from the Creek tribe. One parent's education level was high school, three marked "Some College," eight marked "Bachelor's Degree," one marked "Master's Degree," and one marked "Doctoral Degree." The parents' socioeconomic levels were Under $25,000 (n=2), $25,001-$39,999 (n=2), $40,000-$54,999 (n=2), $55,000-$69,999 (n=2), $70,000-$99,999 (n=2), $100,000-$149,999 (n=3). One parent declined to answer socioeconomic level, and no parents marked the

$150,000-$249,999 level. Nine parents reported that they were married, one reported being divorced, two reported they were single, and two parents marked both divorced and single. Eleven parents reported belonging to a social networking organization pertaining to their son or daughter's developmental disability, and six parents reported having received some type of mental health services prior to the interview.

Although there were fourteen participants, one participant had both a son and a daughter who had been diagnosed with autism, thus the interviews were about the parent-child sexuality education with fifteen sons or daughters. Among the sons or daughters, ten had received a diagnosis of autism and five had received a diagnosis of Down syndrome. Two parents wrote additional diagnoses of schizophrenia and fragile X syndrome on the Demographic Information Form (Appendix F). There were nine sons with autism, one daughter with autism, three sons with Down syndrome, and two daughters with Down syndrome. The age range of the sons or daughters with autism or Down syndrome was 9 to 38, with a mean age of 19.5 years.

The parents were individually interviewed face-to-face. The interviews were recorded by the researcher for the purpose of verbatim transcription. The researcher listened to each tape before transcription, transcribed the tape, and then analyzed the content of the transcription and process of the reported sexuality education for themes among the sample. The first three participants were also asked to give feedback about the interview questions, in order to verify that the questions were clear. All three participants in the pilot study reported that the interview questions were clear, thus no changes were

made. The three participants' interview data were used as a part of the study due to their thematic accordance with the larger sample.

Discussion of Results

Three interview questions were used as a part of the face-to-face interview process:

Question 1: Tell me about your experience of teaching your son or daughter about sexuality.

Question 2: Are there any resources you've found particularly helpful in teaching your son or daughter about sexuality?

Question 3: What do you wish family therapists knew about your experience in teaching a son or daughter with autism or Down syndrome about sexuality?

The interview questions sought to fulfill the two guiding research questions of this study:

1. What are parents' experiences of teaching a son or a daughter with autism or Down syndrome about sexuality?
2. What do parents think family therapists need to know about their experience in teaching their sons or daughters with autism or Down syndrome about sexuality?

Findings Related to the Research Questions

What are parents' experiences of teaching a son or daughter with autism or Down syndrome about sexuality? The first two interview questions, *Tell me about your experience of teaching your son or daughter about sexuality* and *Are there any resources you've found particularly helpful in teaching your son or daughter about sexuality?* were

designed to answer the first research question, *What are parents' experiences of teaching a son or a daughter with autism or Down syndrome about sexuality?* As detailed in Chapter IV, it was determined that parents divided into two categories, tentative parents and assured parents. The two groups' similarities will be discussed after their unique responses to each research question.

Tentative parents. Tentative parents taught sexuality education based on their concerns, for example that their son or daughter with autism or Down syndrome might masturbate in public. Public masturbation has been shown to be distressing to parents in other previous qualitative research. In a study of ten Hispanic parents, Moreno (1996) also found that parents of sons or daughters with autism were sometimes in disbelief that their son or daughter masturbated at all.

The disbelief from the Moreno (1996) study was represented in the tentative parent group in this study, also. Tentative parents in this study seemed less likely to think of their son or daughter with autism or Down syndrome as a sexual person, calling their sexuality or sexuality education "a non-issue" (008), and "a sad reality" (006). This confirmed Swango-Wilson's (2008) study that parents and caregivers reported feeling hesitant toward the sexuality of their sons or daughters with developmental disabilities. It was indeterminable what precise element of sexuality or sexuality education of the sons or daughters these parents found non-existent or disheartening, but it could have been a part of the parents' feelings of adequacy as effective sexuality education providers in their family.

In this study, almost all tentative parents expressed that they did not know what and were unsure how to teach their son or daughter with autism or Down syndrome about sexuality. This finding substantiated Ballan's (2001) depiction that parents of persons with special needs were often "uncertain about the appropriate management of their children's sexual development" (Ballan, 2001, p. 14). It may have also referred to Lalvani's (2008) finding that parents of people with developmental disabilities redefined their beliefs about what being a parent meant to them once they became aware that they would have a son or daughter with Down syndrome. In this study, the parents may have been concurrently undergoing the aforementioned redefinition, and that may have been expressed as hesitancy in how to handle sexuality education with the son or daughter with autism or Down syndrome.

The tentative parents' hesitancy in teaching sexuality education to their son or daughter with autism or Down syndrome might have been compounded by their reportedly not having found any resources that would help them. Grayson (2004) found that one third of the parents surveyed wished they had more resources to broach the topic of sexuality with their children, and the tentative parents in this study could have been of the same opinion. Ballan (2001) asserted that parents struggled in feeling alone in their quest of parent-child sexuality education, and tentative parents in this study may have also felt alone if they were not aware of any resources they could use to teach their son or daughter with autism or Down syndrome about sexuality.

Assured parents. Assured parents taught a more comprehensive sexuality education to their sons or daughters with autism or Down syndrome. In addition to

teaching about intercourse, assured parents taught a variety of sexuality education subjects, such as sexually transmitted infections, homosexuality, menstruation, and wet dreams. Although no academic research was found prior to this study on what parents of sons or daughters with autism or Down syndrome actually taught their sons or daughters about sexuality, the assured parents in this study reported teaching what and how sexuality education professionals previously stated parents should teach (Ballan, 2001; Birch & Rouse, 1992; Couwenhoven, 2007; Maurer, 2009; Planned Parenthood, 2008). A multitude of variables could account for the difference in the assured parents' sexuality education style.

Assured parents were also more likely to think of their son or daughter as a sexual person, capable of expressing sexuality or being sexual, either currently or in the future. In line with previous studies, some assured parents of this study did mention the safety of their son or daughter as a consideration in teaching sexuality education, but their ideas about sexual safety did not prohibit the assured parents from teaching comprehensive information about sexuality to their sons or daughters (Camire, 2006; DiGuilio, 2003; Ruble & Dalrymple, 1993).

Assured parents listed several resources they used to teach their sons or daughters about sexuality. The resources were varied, as the parents listed books, websites, pamphlets, anatomically correct dolls, and seminars and workshops they attended. One tentative parent reported using Mayer/Johnson symbols to teach her son about sexuality, and one assured parents reported not having researched any resources, but the remainder of the parents either reported not finding any resources at all, as in the case of the

tentative parents, or reported finding a multitude of resources, as in the case of the assured parents.

Parent commonalities in the first research question. Religion, appropriateness, correct names for body parts, and the relationship aspect of sexuality were the four common elements between the tentative and assured parents in answering the first research question. In terms of religion and appropriateness, all the parents in this study demonstrated their lived reality of the mission statement of the Sexuality Information and Education Council of the United States (SIECUS, n.d.a), which asserted that every person's sexuality is defined by some combination of ethics, spirituality, culture, and morality, regardless of physical or mental disability. The parents in this study were influenced by external sources, such as spirituality, religion, and culture to define for themselves what was appropriate. Much in the way that the researcher assumed that the parents already had defined the term *sexuality* for themselves, and had, either consciously or unconsciously, incorporated that meaning into their lives and into the messages about sexuality that they sent their sons or daughters, the researcher, upon completing the study, inferred the same of *appropriateness*. The parents referred to their different forms of appropriate, as well. Some discussed age-appropriateness, some discussed appropriate touch or behavior, and some used appropriate and proper for body parts terms interchangeably.

The third commonality of the tentative and assured parents' responses to the first two interview questions and first research question was that most of the parents emphasized an importance in teaching their sons or daughters anatomically correct names

for sexual body parts. It was notable that, although parents and caregivers reported feeling hesitant toward the sexuality of their sons or daughters with developmental disabilities (Swango-Wilson, 2008), almost all the parents in this study used correct names for the body parts as a first building block to the process of sexuality education. This seemed a logical first step, except that the parents also almost all reported that the overall message they wanted their son or daughter with autism or Down syndrome to receive about sexuality was that it was primarily about the relationships, not the physiology, or "sex act" (003).

Almost every parent participant in the study conveyed that they wanted their son or daughter with autism or Down syndrome to understand that sexuality is about relationships. The assured parents taught this concept as a part of their comprehensive sexuality education, but the tentative parents seemed unsure how to relay the message that sexuality and relationships co-exist. There are plenty of examples for parents looking to teach this particular part of sexuality education to their sons or daughters with autism or Down syndrome. In their sexuality education curriculum, Birch and Rouse (1992) recommended "pictures, slides, and videotapes,...semantic mapping,...[and] role play" (pp. 11-12), but this curriculum was for teaching professionals, not necessarily for parents. For another parent's perspective, Couwenhoven (2007) could be an accountable, reliable resource, as she herself has a child with Down syndrome and is a professional member of the American Association of Sexuality Educators, Counselors, and Therapists (AASECT). Parents report feeling alone and anxious in their parenting a child with

special needs (Ballan, 2001), but with resources available such as the Couwenhoven (2007) book, parents may perceive an ally.

What do parents think family therapists need to know about their experience in teaching their sons or daughters with autism or Down syndrome about sexuality? The final interview question, *What do you wish family therapists knew about your experience in teaching a son or daughter with autism or Down syndrome about sexuality?* was designed to answer the second research question, *What do parents think family therapists need to know about their experience in teaching their sons or daughters with autism or Down syndrome about sexuality?*

Tentative parents. In response to the final interview question, tentative parents expressed some difficulty in seeing family therapists as helpful in the parents' objective of teaching the sons or daughters about sexuality. If parents feel particularly alone on their quest to provide sexuality education to their sons or daughters with autism or Down syndrome (Ballan, 2001), it is understandable that they would not know how helpful a family therapist could be.

Assured parents. Several assured parents responded to the final interview question by stating they wished family therapists would support the parents in keeping their sexuality education messages positive, and non-shaming. This demonstrated that the assured parents in this study believed that people with autism or Down syndrome experience feelings, needs, and desires, like any human being. Also, the assured parents of sons or daughters with autism or Down syndrome seemed to be cognizant of the magnitude of parent-child sexuality education in their families, and in other families like

theirs. Maurer (2009) recommended that parents "offer feedback and praise" while teaching their sons or daughters with developmental disabilities about sexuality, and the assured parents, as demonstrated by their responses to the final interview question, seemed to also think that positivity was a key component.

Parent commonalities in the second research question. When answering the final interview question, the participants of this study expressed that they understood the significance of sexuality education with a son or daughter with developmental disabilities. Also, the parents of this study wanted family therapists to keep in mind that families have different values, stemming from different cultural, societal, and religious beliefs. This finding of this study certainly supports Allen's (2000) assertion that family therapists could benefit in "abandoning the search for the discovery of a single universal truth in favor of allowing for multiple truths" (p. 8). These parents specifically asked for family therapists to do that.

Finally, many parents discussed their son or daughter's intellectual abilities, and the range of abilities that exist in the autism and Down syndrome populations as something they wished family therapists would consider. This expressed desire demonstrated what previous research found; that, although sexuality education professionals may not agree with this stance (Ballan, 2001; Grayson, 2004; Moreno, 1996), these parents of sons or daughters with autism or Down syndrome wanted family therapy professionals to support the parents' sexuality education proportionate to the son or daughter's cognitive ability. This is further discussed in the Implications section of this chapter.

Conclusions

The following conclusions were reached as a result of the data collected in this study and the review of academic literature on the topic of parent-child sexuality education in families in which there are sons or daughters with autism or Down syndrome:

1. The parents of people with autism or Down syndrome believe that sexuality education for their sons or daughters is important.
2. Parent-child sexuality education in families with a son or daughter with autism or Down syndrome is likely to include at least education about the correct name for body parts and the message that sexuality is primarily about relationships, not the physiology of sex.
3. Parents of sons or daughters with autism or Down syndrome believe that the sexuality education they provide to their son or daughter should be proportionate to the cognitive and emotional capabilities of the son or daughter, and not necessarily comprehensive.
4. There are differences among parents of sons or daughters with autism or Down syndrome in their comfort level of teaching their son or daughter about sexuality, and these differences account for both *what* the parents teach and *how* they teach.

Limitations

There were several important limitations to this study to consider. First, all participants were mothers, as no fathers responded to recruitment flyers, presentations, or

follow-up phone calls. Secondly, no participants were under the age of 34 or above the age of 76. Third, the sample was not evenly distributed between parents of people with autism and parents of people with Down syndrome. Nine parents had a son or daughter with autism and five had a son or daughter with Down syndrome, thus both groups were not equally represented in the study. The parents who participated in this study were highly-educated individuals, most of whom had at least one university degree (n=10). Also, the sample was primarily Caucasian (n=12), as only one African American and one Native American participant agreed to be a part of the study. Finally, this study took place with parents in the same geographical region of the southwestern United States.

Implications for Family Therapists

The following implications for family therapists were inferred from the information provided by the parent participants of this study:

1. Family therapists need to remain cognizant of the parents' different levels of comfort in discussing sexuality education with a son or daughter with autism or Down syndrome.
2. Family therapists could find ways to empower parents to increase their level of comfort in discussing sexuality education with their son or daughter with autism or Down syndrome, perhaps by encouraging parents to reach out to other, more topic-comfortable parents.
3. Parents want family therapists to be educated in autism and Down syndrome, including, but not limited to, the notion that a person with autism or Down syndrome is able to be a sexual being, and that there is a wide range of

cognitive, emotional, and behavioral abilities in persons diagnosed with autism or Down syndrome.

4. Family therapists could work to bridge the gap between what parents believe their son's or daughter's capabilities are and what experts recommend parents teach about sexuality education. Therapists could do this by continuing to advocate sex-positive comprehensive education, while still building therapeutic rapport with families, taking care to ensure the families' stories are heard.

Recommendations for Future Research

The purpose of this study was to explore parent-child sexuality education in families with sons or daughters with autism or Down syndrome. The focus was on the qualitative experience of the parents in these families, how and what they taught their son or daughter about sexuality, and what the parents thought family therapists need to know about their unique experience in sexuality education with children with these special needs. It is recommended that this study be replicated with a larger sample, and in different geographical locations. Furthermore, in future research, the study's sample should include parents of various ethnicities, marital statuses, and socioeconomic levels to create a clearer picture of the lived experience of all families.

Another recommendation for future research is to include quantitative measures to the study. Researchers could measure the parents' comfort levels on the topic of sexuality education, religiosity, or other beliefs or values. Adding quantitative measures would

enrich the emergent picture of the unique lived experiences of parents with sons or daughters with autism or Down syndrome.

The concept of tentative and assured parents could be further studied in order to explore what the parents could teach each other about sexuality education with a son or daughter with autism or Down syndrome. Both tentative and assured parents in this study reported being well-connected with social organizations for their son or daughter's developmental disability, and perhaps with future research and advocacy, family therapists could connect the two groups in a way that they could learn about sexuality education from one another.

Summary

This chapter first gave a summary of the study, and then discussed the results of the study as related to the research questions. Next, conclusions reached were outlined, based on what the researcher perceived to be the parent participants' main messages from the audio-taped face-to-face interviews. Next, limitations of the study were discussed, implications for family therapists were described, and recommendations for future research were given.

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APPENDIX A

Interview Protocol

Interview Protocol

Participant's Code:_____

Date of Interview:_____

"The purpose of this study will be to explore parent-child sexuality education in families in which there are sons or daughters with autism or Down syndrome. I want to learn more about your teaching your son or daughter about sexuality, and what you think family therapists need to know about your unique experience in sexuality education with a son or daughter with autism or Down syndrome."

"Thank you for agreeing to participate in this study. Do you have any questions?"

"Before we begin the interview, let's go over the consent form."

"Do you have any questions about the consent form? If you do not have any questions, please sign both copies, and keep one for your files. If you would like to receive a summary of the results of this study, please include your name and address on the space provided on the form."

"I will be taking notes during the interview. In order to protect your confidentiality, any names you mention will not be recorded on paper or transcribed. I'll just put the relationship. Do you have any questions before we begin?"

"I am going to turn on the tape recorder now."

1. "Tell me about your experience of teaching your son or daughter about sexuality."
2. "Are there any resources you've found particularly helpful in teaching your son or daughter about sexuality?

3. "What do you wish family therapists knew about your experience in teaching your son or daughter with autism or Down syndrome about sexuality?

The following is a list of prompts that will be used during the question and answer portion of the interview:

Nodding.

Smiling.

Silence.

What happened?

What else happened?

When you said _____, what did you mean?

In the last part, you said_____. Could you clarify what you meant for me?

Yes.

Would you like to take a break?

I see.

What else comes to mind?

Anything else?

What was that like?

Could you tell me more about that?

You mentioned _____. Tell me more about that.

"Here is a form with basic information about your family for you to complete. Do you have any questions about this form?"

[Summarizing statements of participants' comments].

APPENDIX B

Recruitment Letter

October 9, 2009

Dear Parents,

For my master's degree research, I am conducting interviews about parent-child sexuality education with parents of sons or daughters with autism or Down syndrome.

If you are a parent of a person with autism or Down syndrome, and are willing to share your experience of how you handled or are handling sexuality education with your son or daughter, I would be very interested to interview you as a part of this research. All interviews will be kept completely confidential, and will take place either at your home or at a professional family therapy practice office in downtown Dallas at a time convenient for you. If you are interested in participating in this research, or if you would like more information before you decide whether to participate or not, please contact me so that I can answer your questions and give you additional information.

I can be reached by phone at (469) 733-4343. If I do not answer my phone, please leave me a message, and I will return your call in a timely manner.

You may also contact my advisor, Linda Brock, PhD at (940) 898-2713 or lbrock@twu.edu with any questions about this study.

This is an important study, and I believe learning about the unique experience of parents with sons or daughters with autism or Down syndrome is essential. If you know of any other parents who may be able to participate in this research, please tell them about this study, and feel free to pass my contact information along.

I look forward to hearing from you soon.

Sincerely,

Margaret M. Reed

APPENDIX C

Referral List

Referral List

Texas Woman's University Counseling
and Family Therapy Clinic
P.O. Box 425769
Denton, TX 76204-5769
940-898-2600
cfdc@twu.edu

TherapistLocator.net
The American Association for Marriage and Family Therapy
Directory of Marriage and Family Therapists in the United States and Canada
112 South Alfred Street
Alexandria, VA 22341-3061
703-838-9808
www.therapistlocator.net

American Association of Sexuality Educators, Counselors, and Therapists
Member Directory
P.O.Box 1960
Ashland, VA 23005-1960
804-752-0026
http://aasect.org/directory.asp

Family Studies Center
6517 Hillcrest Rd., Suite 401
Dallas, TX 75205
(214)691-7223

Mary Ann Crosno, LMFT
718 N. Buckner Blvd., Suite 112
Dallas, TX 75218
214-321-1727
http://www.MaryAnnCrosno.com

Kim Dee Reynolds, LMFT
6611 Snider Plaza, Suite 107
Dallas, TX 75205
214-274-8524
http://www.familyparadigm.com

APPENDIX D

Consent Form

TEXAS WOMAN'S UNIVERSITY
CONSENT TO PARTICIPATE IN RESEARCH

Title: Parent-Child Sexuality Education in Families with Sons or Daughters with Autism or Down Syndrome: A Phenomenological Study

Researcher: Margaret M. Reed (469)733-4343, mreed2@twu.edu
Advisor: Linda J. Brock, PhD (940)898-2713, lbrock@twu.edu

Explanation and Purpose of the Research
You are invited to participate in this research study for Margaret Reed's thesis at Texas Woman's University. The purpose of this study is to explore parent-child sexuality education in families in which there are sons or daughters with autism or Down syndrome. It is anticipated the findings of this research will assist family therapists to gain greater insight into the meaningful lived experiences of the parents in this study.

Research Procedures
The researcher in this study will qualitatively analyze the responses given in face-to-face interviews with parents of sons or daughters who were diagnosed with autism or Down syndrome. The recruitment and interviewing process will last no longer than 120 minutes, and will be audiotaped. The purpose of audiotaping is to provide a transcription of the information discussed in the interview and to assure the accuracy of the reporting of that information.

Potential Risks
Potential risks related to your participation in the study include fatigue, embarrassment, and physical or emotional discomfort during your interview. To avoid fatigue, you may stop the interview at any time without penalty, or take as many breaks as needed during the interview. If you experience embarrassment, physical, or emotional discomfort regarding the interview questions, you may stop answering any of the questions at any time, or withdraw from the study without penalty. The investigator will provide you with a referral list of names and phone numbers that you may use if you feel as though you need to discuss this embarrassment, physical, or emotional discomfort with a professional.

Another possible risk to you as a result of participation in this study is release of confidential information. Confidentiality will be protected to the extent that it is allowed by law. The interview will take place in the participant's home or a professional office in Dallas, Texas. Your interview will be assigned a numerical code. Your name will appear only on this consent form. All data recorded will be kept in a locked filing cabinet at the home of the principal researcher. Demographic and consent forms will be kept separate from the interview audio tapes and transcriptions. Only the researcher or her research advisor will have access to the audio recording of the interview. The researcher has completed specific training in the protection of the confidentiality of research participants.

_____
Participant Initials

The audio tapes and transcriptions will be destroyed within two years of the completion of the study. It is anticipated that the results of this study will be published in the investigator's thesis as well as in other research publications. However, no names or other identifying information will be included in any publication.

Loss of time is another potential risk in this study. The face-to-face interview will last no longer than 90 minutes. The interviews will proceed in a timely manner, and you may stop the interview at any time without penalty.

The researcher will try to prevent any problem that could happen because of this research. You should let the researcher know at once if there is a problem and she will help you. However, Texas Woman's University does not provide medical services or financial assistance for injuries that might happen because you are taking part in this research.

Participation and Benefits

Your participation in this research study is completely voluntary, and you may discontinue your participation in the study at any time without penalty. There is no direct benefit for participating in this study.

Questions Regarding the Study

If you have any questions about the research study you may ask the researcher or her advisor; their phone numbers and email addresses are at the top of this form. If you have questions about your right as a participant in this research or the way this study has been conducted, you may contact the Texas Woman's University Office of Research and Sponsored Programs at 940-898-3378 or via email at IRB@twu.edu. You will be given a copy of this signed and dated consent form to keep.

_____ _____

Signature of Participant Date

If you would like to receive a summary of the results of this study, please provide an address to which this summary should be sent:

_____

_____

_____

APPENDIX E

Telephone Script to Set an Interview Appointment

Telephone Script to Set an Interview Appointment

"Thank you for calling. The purpose of this study will be to explore parent-child sexuality education in families in which there are sons or daughters with autism or Down syndrome. I want to learn about parents teaching their son or daughter about sexuality, and what family therapists need to know about the unique experience parents have in sexuality education with sons or daughters with autism or Down syndrome. I anticipate that family therapists who work with parents of sons or daughters with autism or Down syndrome might be able to better help families provide age-appropriate, cognitive-level-appropriate, comprehensive sexuality education to their sons or daughters, based on the information learned in this study."

"I'll be asking you these questions:

1. Tell me about your experience of teaching your son or daughter about sexuality.
2. Are there any resources you've found particularly helpful in teaching your son or daughter about sexuality?
3. And what do you wish family therapists knew about your experience in teaching a son or daughter with autism or Down syndrome about sexuality?"

"What questions you have about being in this study?"

"Let's find a time that would work for us to meet for an interview."

[Set up interview time and place.]

"If you know of any other parents who might be interested in participating, please give them my contact information and let them know they can call me with any questions about the study before they decide whether to participate."

"Thank you for agreeing to be interviewed."

[Confirm time, date, and place]

APPENDIX F

Demographic Information Form

Demographic Information Form

Date of Interview:_____ **Participant Code:**_____

Your Age:_____ **Your Sex:**_____

Your Race/Ethnicity (check as many as apply):

African American_____ Asian_____ Caucasian_____ Hispanic_____

Native American_____ Other_____

Your Relationship Status:

Married_____ Single_____ Widowed_____

Divorced_____ Cohabitating_____ Other_____

Your Education Level:

Elementary School_____ High School_____ Some College_____

Bachelor's Degree_____ Master's Degree_____ Doctoral Degree_____ Other_____

Socioeconomic Level:

Under $25,000_____ $25,001-$39,999_____ $40,000- $54,999_____

$55,000-$69,999_____ $70,000-$99,999_____ $100,000-$149,999_____

$150,000-$249,999_____ $250,000 or more_____

Sex of child with Autism or Down Syndrome? Circle one:

SON DAUGHTER

Which diagnosis did your son or daughter receive? Circle one:

AUTISM DOWN SYNDROME

What is the age of your son or daughter with Autism or Down Syndrome?_____

Do you have other children? What are their ages? (For example: Son, 15)

_____

Are you or your son or daughter a member of any organizations, such as The ARC of Texas, Circle of Friends, Best Buddies International, etc.? Yes_____ No_____

If yes, please list them_____

_____

_____

Have you or your son or daughter ever attended counseling or therapy?

Please circle any type of therapy you attended:

PSYCHIATRIST COUNSELOR FAMILY THERAPIST

APPENDIX G

IRB Approval Letter

TWU
TEXAS WOMAN'S UNIVERSITY
DENTON DALLAS HOUSTON

Institutional Review Board
Office of Research and Sponsored Programs
P.O. Box 425619, Denton, TX 76204-5619
940-898-3378 Fax 940-898-3416
e-mail: IRB@twu.edu

March 10, 2010

Ms. Margaret Macleod Reed
1118 Cascade Avenue
Dallas, TX 75224

Dear Ms. Reed:

Re: Parent-Child Sexuality Education in Families With Sons or Daughters With Autism or Down Syndrome: A Phenomenological Study

The above referenced study has been reviewed by the TWU Institutional Review Board (IRB) and appears to meet our requirements for the protection of individuals' rights.

If applicable, agency approval letters must be submitted to the IRB upon receipt PRIOR to any data collection at that agency. A copy of the approved consent form with the IRB approval stamp and a copy of the annual/final report are enclosed. Please use the consent form with the most recent approval date stamp when obtaining consent from your participants. The signed consent forms and final report must be filed with the Institutional Review Board at the completion of the study.

This approval is valid one year from October 2, 2009. According to regulations from the Department of Health and Human Services, another review by the IRB is required if your project changes in any way, and the IRB must be notified immediately regarding any adverse events. If you have any questions, feel free to call the TWU Institutional Review Board.

Sincerely,

Kathy DeOrnellas, PhD.

Dr. Kathy DeOrnellas, Chair
Institutional Review Board - Denton

enc.

cc. Dr. Larry LeFlore, Department of Family Sciences
Dr. Linda J. Brock, Department of Family Sciences
Graduate School

APPENDIX H

Research Questions, Interview Questions, and Findings

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Research Questions	Interview Questions	Findings
1. What are parents' experiences of teaching a son or a daughter with autism or Down syndrome about sexuality?	1. Tell me about your experience of teaching your son or daughter about sexuality.	**Tentative Parents:** Sexuality education messages based on concerns about embarrassment or safety. **Assured Parents:** Comprehensive sexuality education; many different topics covered. **Commonalities:** Religion, Appropriateness, Taught about body parts, Taught that sex is about relationships.
	2. Are there any resources you've found particularly helpful in teaching your son or daughter about sexuality?	**Tentative Parents:** Few or no resources found. **Assured Parents:** Multiple resources found.
2. What do parents think family therapists need to know about their experience in teaching their sons or daughters with autism or Down syndrome about sexuality?	3. What do you wish family therapists knew about your experience in teaching a son or daughter with autism or Down syndrome about sexuality?	**Tentative Parents:** Showed some difficulty in considering family therapists as helpful. **Assured Parents:** Sex-positive sexuality education messages are important. **Commonalities:** Sexuality education is important. Keep the family's cultural and societal beliefs in mind Keep the son or daughter's intellectual abilities in mind, as well as the range of abilities that exist in the autism and Down syndrome population.