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Autism spectrum disorders and romantic intimacy

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Autism spectrum disorders and romantic intimacy

by

Haley V. Wedmore

A thesis submitted to the graduate faculty
in partial fulfillment of the requirements for the degree of

MASTER OF SCIENCE

Major: Human Development and Family Studies

Program of Study Committee:
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I would like to thank the individuals who agreed to participate in this study. I have been moved and inspired by your words and I hope that I have portrayed your perceptions and experiences in a way that captures your reality and in a way that will be helpful for others who experience similar circumstances. I am grateful for your openness and honored by your willingness to share the intimate details regarding a very personal and valuable part of your experience as a human being. Thank you.

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ABSTRACT

Few would deny that romantic intimacy is an important part of the human experience. People with Autism Spectrum Disorders (ASD) may face impairments in communication, social understanding, and emotional responsiveness; however, the importance of romantic intimacy in their lives is no less significant than it is for typically developing people. In response to the dearth of voice in the literature from people with ASD as well a lack of previous research investigating the romantic perceptions and experiences of people with ASD, I set out to explore the lived experiences of individuals and couples with ASD in regard to romantic intimacy. The lived experience of eight participants including one couple, four individuals, and three guardians of participants with ASD were explored through a qualitative methodology using a Hermeneutic phenomenological approach via a critical disability lens. Three main themes emerged through the data analysis including: What Makes it Work?, What is Challenging?, and How is Intimacy Experienced? Themes that emerged indicated that overall aspects of romantic intimacy are similar for people with ASD and typically developing individuals, including the experience of attraction and various expressions of intimacy. Challenges regarding romantic intimacy are likely to be experienced that stem from characteristics of the disorder including sensory/processing issues and social/communication difficulties. Additional challenges may result from circumstances beyond the individual’s control such as his or her living situation and societal messages/pressures. Although such challenges may impede on one’s ability to be romantically intimate, a number of features have been identified that may transcend such barriers. Such features have been identified through the compatibility of partners, dedication and hard work on the part of both partners, and through helpful external supports. Implications for support services, interventions, and future areas for research are discussed.
CHAPTER ONE

Introduction

Romantic intimacy is an important part of the human experience, yet little attention or sensitivity has been dedicated to furthering an understanding of how adults with Autism Spectrum Disorders (ASD’s) experience romantic intimacy or in exploring and potentially lessening the barriers that people with ASD face in pursuing and developing such relationships. Most research efforts to date in these areas have focused primarily on children and adolescents with ASD and have narrowly focused on sexual behavior or social intimacy. Furthermore, it has been acknowledged that there is an absence of voice in the literature from people with disabilities and there is growing recognition that intervention oriented research could benefit from exploring the perspectives of individuals with disabilities (Muller, Schuler, & Yates, 2008).

Current understanding of how the general population experiences romantic intimacy is based on the perception and values of typically developing individuals; such understandings may not be relevant or meaningful to individuals with ASD because they may experience and value romantic intimacy differently. Individuals with ASD face certain challenges regarding intimacy and often have difficulty developing and maintaining relationships. Individuals with ASD experience impairments in communication, social understanding, and emotional responsiveness (Travis & Sigman, 1998). Little research has been done to explore interventions that people with ASD would find helpful in supporting them to initiate and maintain romantic relationships.

As an aspiring family therapist and based on ten years of experience working with individuals with ASD, I have developed interest in exploring how people with ASD experience and understand romantic intimacy in their lives. From my research my aim was to develop a multidimensional understanding of romantic intimacy through the perceptions of individuals
with ASD. I also aimed to learn more about the barriers that people with ASD face regarding romantic intimacy and to receive ideas and insight for interventions and supports that would be helpful for individuals with ASD to experience romantic intimacy in a way that is desirable and meaningful for them.
CHAPTER TWO

Review of the Literature

For purposes of this study, the experiences of individuals with ASD were explored. Autism is understood to be a disorder of neural development. The disorder is characterized by social withdrawal, repetitive behavior and deficits in communication (Currenti, 2010). There are five Autism Spectrum Disorders, also known as Pervasive Developmental Disorders (PDD) as classified in the DSM-IV-TR: Autism, Asperger’s, Rett’s Disorder, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS).

Characteristics of ASD include: “severe and pervasive impairment [in the development of] reciprocal social interaction skills, communication skills, or the presence of stereotyped behavior, interests and activities” (American Psychiatric Association, 2000, p. 69). The most commonly diagnosed ASD’s are Autistic Disorder, Asperger’s Disorder and PDD-NOS. Because these diagnoses are the most prevalent, the current study will explore how individuals diagnosed with these disorders experience romantic intimacy.

Diagnostic Criteria for Autistic Disorder, Asperger’s Disorder, and PDD-NOS

The diagnostic criteria for Autistic Disorder as taken directly from the DSM-IV-TR (2000, p. 75) include:

A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):

A.

(1) qualitative impairment in social interaction, as manifested by at least two of the following:
(a) marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction

(b) failure to develop peer relationships appropriate to developmental level

(c) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)

(d) lack of social or emotional reciprocity

(2) qualitative impairments in communication as manifested by at least one of the following:

(a) delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)

(b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others

(c) stereotyped and repetitive use of language or idiosyncratic language

(d) lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level

(3) restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:

(a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
(b) apparently inflexible adherence to specific, nonfunctional routines or rituals
(c) stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
(d) persistent preoccupation with parts or objects

B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.

C. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.

D. The disturbance is not better accounted for by Rett’s Disorder or Childhood Disintegrative Disorder.

The diagnostic criteria for Asperger’s Disorder as taken directly from the DSM-IV-TR (2000, p. 84) include:

A.

(1) qualitative impairment in social interaction, as manifested by at least two of the following:
(a) marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
(b) failure to develop peer relationships appropriate to developmental level
(c) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)

(d) lack of social or emotional reciprocity

B. Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:

(a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus

(b) apparently inflexible adherence to specific, nonfunctional routines or rituals

(c) stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)

(d) persistent preoccupation with parts or objects

C. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.

D. There is no clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years).

E. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than in social interaction), and curiosity about the environment in childhood.

F. Criteria are not met for another specific PDD or Schizophrenia.

The category of Pervasive Developmental Disorder Not Otherwise Specified (Including Atypical Autism) is used when the criteria are not met for a specific ASD/PDD, Schizophrenia,
Schizotypal Personality Disorder, or Avoidant Personality Disorder yet there is “severe and pervasive impairment in the development of social interaction associated with impairment in either verbal or nonverbal communication skills or with the presence of stereotyped behavior, interests, and activities” (American Psychiatric Association, 2000, p. 84).

The DSM-IV-TR (American Psychiatric Association, 2000) describes diagnostic features of adults with Autism and Asperger’s Disorder as potentially having an interest in friendship but lacking understanding of the conventions of social interaction with a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people. A lack of social or emotional reciprocity may be present.

The prevalence of ASD is debated; whereas 20 out of 10,000 people are diagnosed with ASD, some experts argue that up to 66 out of 10,000 are actually affected (Currenti, 2010). ASD occurs more commonly in males with a 4 to 1 male: female ratio. Currenti also reports an increase in prevalence among African Americans and a rise in prevalence in most countries.

There is ongoing controversy whether Asperger’s should be diagnosed separately from Autism. Asperger’s is commonly thought to be a mild form of Autism. Although they share many of the same diagnostic criteria, there are significant differences between the two disorders. In Asperger’s, the lack of social reciprocity is more typically manifested by an eccentric and one-sided social approach to others rather than the social and emotional indifference that is exhibited by individuals with Autism. Also in contrast to Autism, people with Asperger’s do not typically experience Mental Retardation or the early onset of cognitive or speech delays (American Psychiatric Association, 2000).

The term ASD can be used to refer to all five Autism Spectrum Disorders. In this paper, ASD will be used to refer to the diagnoses of the participants involved in the study who were
diagnosed with Autistic Disorder or Asperger’s Disorder. Based on the information found in the DSM-IV-TR that the severity of social and emotional deficit of Autistic Disorder and Asperger’s Disorder are closely matched, the term ASD will be used throughout this paper to refer to Autistic Disorder and or Asperger’s Disorder, except where there is specific need to distinguish between the two disorders. Because symptoms of Autism are commonly thought to be on a continuum from mild to severe (low-functioning to high-functioning) in which Asperger’s is considered to be the highest functioning form of Autism, the term ASD will be used to refer to varying levels of Autism unless determined otherwise necessary to specify.

A Definition of Intimacy

Intimacy is a social and personal construction. Particular discourses related to intimacy influence how we perceive our relationships as well as our expectations of them (Weingarten, 1991). Some believe that the quality of intimate relationships is directly attributable to the levels of self-identity of each partner (Barry, Madsen, Nelson, Carroll, & Badger, 2009) and that the self is further invented by the intimate partner (Weingarten, 1991).

Moss and Schwebel (1993, p. 33) offer a multidimensional definition of romantic intimacy that is based on analysis and integration of preceding definitions of intimacy found in the literature: “Intimacy in enduring romantic relationships is determined by the level of commitment and positive affective, cognitive, and physical closeness one experiences with a partner in a reciprocal (although not necessarily symmetrical) relationship.” Moss and Schwebel (1993) describe commitment as the desire to remain in an enduring relationship with a partner. Affective intimacy is described as awareness of a partner’s emotional world and exchanges of emotions such as compassion. Cognitive intimacy is described as awareness of a partner’s cognitive world and exchanges of shared cognitions such as values. Physical intimacy involves
shared physical encounters ranging from physical proximity to sexual intercourse. The components in this definition are seen as interrelated. Moss and Schwebel (1993) suggest that the levels of these components will be high in romantically intimate relationships in which the partners rate high levels of relationship satisfaction.

Moss and Schwebel’s (1993) definition of intimacy will be used to inspire the interview process and as a source of comparison to how the participants in this study perceive and experience romantic intimacy. Despite the parsimonious nature of this definition, it may not be necessarily relevant or meaningful for individuals with ASD. Intimacy may have different meanings for individuals with ASD and may be experienced in different ways than what is covered in the definition offered by Moss and Schwebel (1993). Individuals/couples with ASD may not display high levels in all of the intimacy components that Moss and Schwebel (1993) have delineated and may emphasize the importance of different intimacy components all together. Moss and Schwebel (1993, p. 33) also point out the assumption that in order for partners to experience “genuine intimacy” they must be able to “accurately process information about their partner’s cognitive, affective, and physical level.” Such an assumption may not represent people with ASD because of their difficulty in understanding the emotional and cognitive worlds of others. Such an assumption may also indirectly and falsely assume that people with ASD are not capable of experiencing “genuine intimacy.” Further, individuals with ASD may have different expectations for romantic intimacy and these expectations may play a role in shaping how romantic intimacy is practiced and understood.

Social Barriers

Individuals with ASD face many internal barriers regarding intimacy and often have difficulty developing and maintaining relationships. Individuals with ASD experience
impairments in communication, social understanding, and emotional responsiveness (Travis & Sigman, 1998). Internal barriers such as a difficulty with “theory of mind” (TOM) have been found to contribute to the challenges that people with Autism face in attributing thoughts and beliefs to other persons. “Theory of mind” describes the ability of a person to attribute mental states to the self and to others and to predict the behavior of others based on their mental states (Spek, Sholte, & Van Berckelaer-Onnes, 2010). It can be speculated that the egocentric tendency that stems from a lack of TOM ability makes it difficult for people with Autism to relate intimately with social partners.

TOM does not affect all people with Autism to the same degree. Belmonte (2009) provides an intriguing discussion of the limitations of TOM, arguing that it is not universal and offers a “narrative practice hypothesis” instead. This hypothesis shifts the focus from theory of mind to the practice of mind through the argument that the challenge for individuals with ASD is not an issue with theorizing about mind states as much as it is an issue with making the necessary connections so they can be in sync with others. Belmonte (2009, p. 128) suggests that people with Autism be guided through social narratives at the “pace and focus that is consistent with autistic cognition.” In other words, people with ASD are not necessarily oblivious to the social workings of the world around them or to the mind states of others, but rather, they often experience a delay and some degree of confusion in processing social information.

My interpretation of what Belmonte suggests above is that this delay and confusion in processing social information should be taken into consideration when teaching people with ASD how to navigate the social world. A common tool that is used to help individuals with ASD cope with new or uncomfortable situations is through use of a scripted story. Often, a support person will write up a story or a “script” that informs or prepares the individual on what to
expect and that offers instruction on how to behave in a socially appropriate manner. Because individuals with ASD do not process social information as automatically or as intuitively as neurotypical persons, it is helpful to have this script as a source of external guidance.

Belmonte (2009) does not offer specific interventions; however, the findings of Muller, Schuler, and Yates (2008) provide insight into effective social supports as recommended directly by people with Asperger’s. In this study, 18 individuals diagnosed formally or informally with Asperger’s, high-functioning Autism, or PDD - NOS were interviewed in a semi-structured style in order to explore their social experiences and their recommendations for effective social interventions. Among these recommendations, participants revealed that joint focus and shared interest activities, such as membership in a chess club, or watching a movie with another person provided opportunity for them to be with others without having to do much talking beyond the exchange of information related to their specific interests. Structured social activities, such as church services, were also recommended as being optimal environments for them to interact with others without having to improvise since these activities are highly predictable and provide a “high level of social scripting” (Muller et al., 2008, p. 182). Participants also mentioned the benefit of having their social interactions facilitated by another person since they reported difficulty knowing when or how to organize or initiate social activity. Participants shared the importance of having alternate modes of communication that could alleviate the anxiety and frustration of face to face interaction such as e-mail, chat groups, or writing notes. Explicit communication and instruction in use of social cues were also emphasized as critical social supports in which literal explanations and direct instruction on social skills are most helpful. Overall, participants revealed that being with others was necessary for their overall well-being.
and that certain accommodations and supports can help them to be successful in achieving a level of social interaction that is satisfying and meaningful for them (Muller et al., 2008).

The Desire for Intimacy

Participants in Muller’s (2008) study with ASD commonly reported experiencing feelings of isolation, difficulty initiating social interaction, longing for greater intimacy, the desire to contribute to one’s community, and the effort to develop greater social and self-awareness. These findings challenge the assumptions that individuals with ASD are not interested in pursuing intimate relationships or that they are oblivious to the social workings of the world around them. On the contrary, individuals with ASD may be distressed by the lack of intimacy in their lives and may desire to improve their level of social understanding and their interpersonal skills.

In a quantitative study by Bauminger, Schulman, and Agam (2004), a group of 16 preadolescent or adolescent participants with high functioning Autism were matched to a group of 16 typically developing preadolescent or adolescent participants and assessed for perception of friendship, friendship qualities, lack of social relationships, and self. Consistent with the findings of Muller et al. (2008) that people with ASD long for connection with others, this study found that although children with high-functioning Autism perceive close friendship differently, they consider it to be a valuable type of relationship that can contribute to their general self-worth. Qualitative differences were noted between the groups in which typically developing children tended to ascribe affective characteristics to friendship whereas children with Autism tended to attribute shared activities and close proximity to friendship. Children with ASD who reported having a close friendship experienced less loneliness and reported a higher sense of general self-worth (Bauminger et al., 2004).
Studies up to the present suggest that a significant number of individuals with ASD are interested in being involved in romantic relationships. In a 20-year, longitudinal study of outcomes for adults with Autism by Farley et al. (2009), parents of 41 individuals with Autism were asked a series of questions related to the outcomes of their adult child including romantic outcomes. Of the sample whose children were not in romantic relationships, 44% believed that their son or daughter would like to be in a romantic relationship.

Another study by Siebelink (2006) revealed that romantic relationships are important to adults with intellectual disabilities, and sexual needs and interest in sexuality are evident. Seventy-six individuals with intellectual disabilities participated in structured interviews to assess their knowledge, attitudes, experiences, and needs regarding sexual and romantic relationships. Some respondents revealed that they were interested in pursuing a committed relationship without immediate need for a sexual relationship while others revealed the desire to have a sexual relationship without the need for a steady relationship.

**ASD and Sexuality**

Often, individuals with ASD are viewed by society as being asexual. Although it is true that some individuals with ASD do express disinterest in having a romantically intimate or a sexual relationship with others, studies reveal that a significant number of individuals with ASD are indeed interested in pursuing such relationships (Farley et al., 2009; Siebelink, 2006). Some caregivers are not supportive of the desire of people with ASD to date or to experiment sexually with other people. Out of protection, caregivers may avoid the topic of sex or expressively set rules against it. It could also be questioned here if perhaps people with Autism are less likely to be interested in being in a romantic or sexual relationship when they are raised in families that view them as incapable of this level of intimacy or as being asexual. Perhaps the “longing” for
intimacy is not entirely innate and is to some degree learned. Perhaps individuals with ASD who do not seem interested do experience the same feelings or desires, but have not learned how to identify or understand such feelings.

Individuals with ASD who do experience sexual desire may express themselves in dangerous or socially unacceptable ways. They may be at an increased risk of sexually perpetrating, being sexually perpetrated against, or practicing unsafe sex. Siebelink (2006) found that many participants with intellectual disabilities lacked basic sexual knowledge and that even those who were sexually active did not necessarily know more than those who were not active.

According to a study done by Kalyva (2009), children with lower functioning Autism were reported to exhibit less appropriate and more dangerous sexual behavior than their peers with higher functioning Autism or Asperger’s syndrome. Only 12.5 percent of teachers reported that they would feel confident providing sex education to children with Autism (Kalyva, 2009). This finding suggests that although children and adults with lower functioning Autism have a great need for sex education, those in a position to educate are not equipped with the necessary skills/confidence to provide such education thus leaving individuals with lower functioning Autism at a greater risk of expressing their sexuality in dangerous or socially inappropriate ways.

The findings from Kalyva’s (2009) study could also suggest that ignoring the sexual curiosity that many individuals with Autism experience and the lack of skills/confidence that those in care providing positions express only serves to exacerbate issues of sexual deviance and sexual harm among and between individuals with Autism and individuals without Autism. It would benefit society as a whole to affirm the sexual nature of children and adults with varying degrees of Autism and to provide education on how to express their sexuality in healthy and socially appropriate ways.
The counterfeit deviance model has been presented as a hypothesis that people with intellectual disabilities act in sexually deviant ways based on a lack of sexual knowledge, poor social skills, limited opportunity to express sexuality, and sexual naivety (Michie, Lindsay, Martin, & Grieve, 2006). Overall, studies of the counterfeit model have not supported the hypothesis that people with intellectual disabilities are more likely to express their sexuality in inappropriate or harmful ways when educated about sex and therefore such findings are not in sync with the recommendation that people with intellectual disabilities should be educated about sex. However, most studies related to the counterfeit model have been limited to males, males in highly structured settings and males who have previously offended. The findings of such studies are not necessarily representative of males and females with ASD since few of these studies have incorporated females into their sample or have focused exclusively on individuals with ASD. Such studies may also be narrowly focused on researching the level of sexual knowledge rather than looking at all aspects of the counterfeit deviance model and thus, may simplify the experience of sexuality for persons with intellectual disabilities/Autism by failing to acknowledge the complexity of the disorder itself and the complex nature of human sexuality in general. Caution should be used when interpreting such findings so that results are not used as evidence that people with ASD should not be educated on sexuality as such negligence has not yielded any more positive results. Rather, such findings should be further explored to offer direction on how sex education should be structured and delivered to persons with ASD.

Siebelink et al. (2006) suggests an integrated approach that takes into account the individual attitudes, experiences, and needs of the person in regard to romantic and sexual relationships.

Gougeon (2009, p. 277) argues that the current sexuality education curriculum or rather, the “ignored curriculum of sexuality,” promotes sexual incompetence and leads to exclusion,
legal issues and denial of full citizenship/inclusion for people with disabilities. The ignored curriculum is described as the lived experience of sexuality – the component that typically developing teens learn about by interacting with peers. The implication is that people with intellectual disabilities are left out of this process of sexual socialization because their sexuality is denied or infantilized by society. Gougeon (2009) asserts that every citizen of any community should have the right to membership, the option to participate, access to knowledge and be able to make informed decisions. People with intellectual disabilities are easily excluded in many regards because there lacks clarity around who is included in the term “citizen” (Gougeon, 2009). Gougeon (2009) recommends that a comprehensive sexuality education curriculum should teach sexuality in a contextual and practical fashion. It is suggested that this curriculum include information about STD’s, relationship skills and intimacy, physiological aspects, puberty and masturbation (Gougeon, 2009).

The aim of the current study is to explore not only the sexual aspect of romantic intimacy for individuals with ASD, but to explore the complexities of romantic intimacy and to present how individuals with ASD perceive and experience it in their lives and relationships.

Research Question

My main research question of exploration was: How do people with Autism experience and perceive romantic intimacy? In relation to this question, I was interested in exploring how romantic intimacy is understood by people with ASD and what dominant discourses have influenced this understanding. What influences in particular have led to the understandings, experiences, and expectations that people with ASD have come to develop in relation to romantic intimacy? I imagined that many people with ASD have learned about romantic intimacy in a similar fashion to neurotypical individuals—through the observation of others in
romantically involved relationships, through media portrayal of romantic intimacy, and through their own thoughts and feelings about being romantically involved with another person. I hypothesized that these observations, thoughts, and feelings were further impacted by the messages that are received from caregivers\(^1\). I was curious to learn about how the messages from caregivers influence the way individuals with ASD perceive romantic intimacy and the choices they have made to pursue romantic and sexual interests. Through this research I also expected to gain supplemental information regarding the perceptions and experiences of participants with ASD through guardians. Additionally, I hoped to learn about their experiences and perceptions regarding their support of the participant with ASD. Moreover, I was interested in developing a multidimensional understanding of intimacy for people with ASD and to discover themes within this understanding related to their lived experiences and perceptions. I wanted to learn more about what is challenging and what is helpful for people with ASD in regard to romantic intimacy. I hoped that learning more about challenges and strengths would shed insight for particular supports and or interventions that may be helpful in supporting people with ASD to achieve the level of romantic intimacy that they desire in their lives.

\(^1\) In relation to this study, the term “caregiver” refers to an unpaid relative, friend, or guardian who assumes responsibility in assisting the individual with ASD to make important decisions pertaining to his or her life.
CHAPTER THREE

Method

Theoretical Orientation: Qualitative Methodology

The study is qualitative. The nature of qualitative research is an inductive and emergent process. In quantitative research, theory guides the data whereas in qualitative research the data guides theory. Throughout the process, the researcher makes new discoveries that aid and may alter the way the researcher goes about collecting and analyzing his or her data. In this way the research process is constantly evolving. The primary paradigm stance that is taken in qualitative research is constructivism and assumes that reality is socially constructed (Bloomberg & Volpe, 2008).

In qualitative research, the researcher is viewed as the main instrument as compared to surveys or questionnaires in quantitative research; therefore, it is openly acknowledged that the results of the study are interpretive or subjective. The assumption is that there are multiple realities and that these realities are socially constructed through society and one’s personal experiences. There is no absolute truth and no absolute way of knowing or coming to know.

Phenomenological Methodology

A phenomenological methodology was adopted in the data collection process and the data analysis. Phenomenological research is a tradition within the qualitative paradigm that investigates the meaning of the lived experience of people around a particular phenomenon (Bloomberg & Volpe, 2008). Literally interpreted, phenomenology is the study of phenomena. In this case, the meaning of romantic intimacy is being explored according to how it is experienced by individuals with ASD. Therefore, participants with ASD and their caregivers were asked
through open ended questions to discuss with the researcher their experiences and perceptions regarding romantic intimacy.

Finlay (2009) explains that there is some confusion and a lack of consensus regarding how “sound” phenomenological research should be done. As a novice researcher, this explanation resonates with me and reassures me since I have experienced some confusion and difficulty in deciding which branch of phenomenology was the best fit for my study. Researchers agree that the main focus of phenomenological research should be to focus on experiential meaning – the lived experiences of how certain individuals experience a particular phenomenon.

There are two main phenomenological approaches, and in order to provide consistency, it is necessary for the researcher to pick between a descriptive or interpretive approach to the data collection and data analysis process (Finlay, 2009). Descriptive interpretation stems from Husserl’s philosophy that human subjectivity plays an important role in the human ability to perceive reality; therefore, Husserl believed that a scientific approach is necessary in order to reveal the essence of experience for any group of people (Flood, 2010). Bracketing is a strategy recommended for the researcher to employ so that he or she is not overwhelmed by personal biases and in order to ensure rigor.

Heideggarian (Hermeneutics) phenomenology is interpretive in nature and involves focus on the lived experience versus what one knows (Flood, 2010). In this approach, the individual is viewed as inextricably linked to his or her relational and cultural context. It is explained that the Hermeneutic phenomenologist will focus on the lived experience of the participants and how their choices are influenced rather than being purely descriptive (Flood, 2010).

Based on my personal views as a researcher, I would argue that Heideggarian phenomenology is more consistent with the emergent and constructivist nature of qualitative
research. In addition, this branch of phenomenology does not attempt to “quantify” the researcher by attempting to make him or her objective. I appreciate the Heideggarian philosophy that our subjectivity cannot be teased apart from our humanity regardless of what role we adopt. Contrary to the assumption of Husserl phenomenology that there is one correct interpretation of experiences, Hermeneutics acknowledges that there are multiple ways of interpreting experiences (Flood, 2010). The assumption that there are multiple ways of interpreting also seems most consistent with the social constructivist assumptions of qualitative research.

Part of the confusion when attempting to determine which approach is most suitable for research lies in the fact that phenomenological research is both descriptive and interpretive to some extent. Finlay (2009) asserts that a more descriptive approach is usually taken initially followed by a more interpretive approach later in the research as the researcher inevitably must read between the lines in order to provide a meaningful presentation of findings (Finlay, 2009).

A component of the phenomenological methodological approach is to prescribe phenomenological reduction. In phenomenological research, reductionism is the standard for rigor. In Husserl phenomenology, one such technique for reductionism lies within the researcher’s effort to “bracket.” The process of bracketing involves putting aside the assumptions of the researcher and allowing the lived experiences of others to be viewed from an unadulterated perspective (Ashworth, 1999). In Hermeneutics the researcher is not encouraged to bracket since the concept of bracketing is counterintuitive to the interpretive approach to phenomenology (Finlay, 2009).

Heidegger would argue that the researcher cannot be separated from his or her context or biases and that interpretation is not something that we do additionally, but is rather the natural outcome of being in the world (Finlay, 2009). In other words, we cannot help but interpret; it is a
part of our nature. In addition, “we experience a thing as something that has already been interpreted” (Finlay, 2009, p. 11). There is no separating interpretation in any human experience. Overall, Heidegger would argue that the meaning in phenomenological methodology arises through interpretation (Finlay, 2009). Heidegger also reasons that researchers are drawn to topics that they are already drawn to and that it is impossible to rid the mind of the pre-existing meanings and understandings of that topic during the data collection and analysis.

In Hermeneutic phenomenology the researcher can only approach the data collection and analysis process with an open mind (Finlay, 2009). It was not difficult for me to approach each interview and the coding process with an open mind based on my constructionist worldview and open personality to new or different ideas. At the same time, as a human being it was not possible for me to forget all of my previous knowledge or emotion about the topic of romantic intimacy and ASD and these factors were present in every step of the process. I embrace that my findings are subjective and that a different researcher may well have organized my findings in a different way or pulled different meanings than what I have. I view the qualitative process as art; therefore, it makes sense that a different artist could use the very same art utensils and mediums as I have, yet create a somewhat different looking piece of art.

Rather than try to bracket my prior knowledge and experiences towards my topic, I simply maintained awareness of them. I often reflected on my experience with romantic intimacy, what I already knew about typically developing individual’s experiences with romantic intimacy, my personal or conventional values about what romantic intimacy means or entails and what I have previously observed, heard or learned about other individuals with ASD and their experiences with romantic intimacy. I wrote about some these areas in my Interview Summaries/Analytic Memos.
Critical Theory and Critical Disability Theory

A critical paradigm may be taken when there is a need for the researcher to take a position of advocacy as in the case of participants who are disenfranchised or marginalized. In the case of this research, a critical disability paradigm is assumed because the participants of the study are members of a marginalized group. Research embedded in critical theory aims to increase awareness of “the contradictory conditions of action which are distorted or hidden by everyday understandings” (Comstock, 1982, p.378). The method of investigation and validation according this theory stems from dialogue with participants. The overall goal is to emancipate those who experience marginalization.

People with disabilities are a minority group with a history of oppression, unequal treatment/rights, and discrimination based on societal assumptions that they are not capable of contributing to society or gaining from it in a meaningful way. Critical disability theory proposes that issues of disability are actually issues of social values (Pothier & Devlin, 2006). The theory raises questions of power and how it is determined who gets power and who gets marginalized. Productivity is strongly valued in our society and it is a commonly held assumption that in order to be productive, one must be able-bodied and able-minded. The theory challenges such assumptions that stem from typically developing people and advocates for individuals with disabilities to have more full and active participation in society (Pothier & Devlin, 2006). It is asserted that to ignore disability is to perpetuate exclusion. My overall purpose in conducting this research was to contribute meaningful information to the literature based on the voices of individuals with ASD that portray how romantic intimacy is perceived and experienced. Additionally, I hoped that my findings would offer insight as to what supports
or interventions would be helpful in improving or lessening the barriers that people with ASD may face in building and maintaining romantically intimate relationships.

Participants

Participants were selected through purposive sampling and were asked to participate based on an existing diagnosis of ASD: Autism, Asperger’s, or PDD-NOS and through self-report of being involved in a romantic relationship currently or at some point in his or her life. The data gathering technique used in this study was interviewing; therefore, I sought participants that had sufficient verbal ability to respond beyond “yes/no” answers and who were to discuss their experiences openly with me and in some detail.

Due to the communication barriers that many people with ASD face, I expected that I might not obtain substantial information through these interviews alone. Therefore, I was also able to conduct separate interviews with three of the participant’s caregivers.

Most of the participants with ASD received some level of supported community living services and were offered the choice to have a direct support professional\(^2\) present during their interview. No participants chose to have anyone present during their interviews. Three types of participants were involved in the study: 1) participants with ASD, 2) couples and 3) caregivers/guardians of participants with ASD.

Description of Participants

I conducted a total of eight interviews during the data collection process of this study. Included in this number of interviews, I interviewed one couple, four individuals diagnosed with ASD and three guardians of participants diagnosed with ASD. A total of nine individuals chose to participate in the study including five participants diagnosed with ASD, one partner of a

\(^2\) A direct support professional is a paid employee who supports individuals with disabilities in their homes and in the community.
participant with ASD who was not herself diagnosed with ASD, and three guardians.

Demographic information regarding participants is summarized in Table 1.

**Table 1**
**Description of Participants**

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age</th>
<th>Gender</th>
<th>Race</th>
<th>Diagnosis</th>
<th>Relationship Status/length</th>
<th>Religion</th>
<th>Occupation</th>
<th>Education</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brad</td>
<td>34</td>
<td>M</td>
<td>C</td>
<td>Autistic Disorder, ADHD, CP</td>
<td>Married/12 years</td>
<td>Christian</td>
<td>Crossing Guard</td>
<td>High School</td>
</tr>
<tr>
<td>Kathy</td>
<td>33</td>
<td>F</td>
<td>C</td>
<td>Autistic Disorder</td>
<td></td>
<td>Christian</td>
<td>Crossing Guard</td>
<td>High School</td>
</tr>
<tr>
<td>Richard</td>
<td>39</td>
<td>M</td>
<td>C</td>
<td>Autistic disorder</td>
<td>Currently single, previous 10 years relationship</td>
<td>Christian</td>
<td>Unemployed</td>
<td>High School</td>
</tr>
<tr>
<td>Charity</td>
<td>29</td>
<td>F</td>
<td>C</td>
<td>Asperger’s disorder</td>
<td>Dating/2 years</td>
<td>Catholic</td>
<td>Unemployed</td>
<td>High School</td>
</tr>
<tr>
<td>Penny</td>
<td>--</td>
<td>F</td>
<td>C</td>
<td>N/A</td>
<td>Married</td>
<td>Catholic</td>
<td>CEO</td>
<td>--</td>
</tr>
<tr>
<td>Vicki</td>
<td></td>
<td>F</td>
<td>C</td>
<td>Asperger’s disorder</td>
<td>Dating/Under 1 year</td>
<td>Catholic</td>
<td>Hardware Clerk</td>
<td>High School</td>
</tr>
<tr>
<td>Sharon</td>
<td>64</td>
<td>F</td>
<td>C</td>
<td>N/A</td>
<td>Married</td>
<td>Christian</td>
<td>Direct Support Staff</td>
<td>High School</td>
</tr>
<tr>
<td>Sally</td>
<td>50</td>
<td>F</td>
<td>C</td>
<td>N/A</td>
<td>Unmarried</td>
<td>Catholic</td>
<td>Religious Education Teacher</td>
<td>Graduate degree</td>
</tr>
<tr>
<td>Vivian</td>
<td>29</td>
<td>F</td>
<td>C</td>
<td>Autistic disorder</td>
<td>Dating/5 ½ years</td>
<td>--</td>
<td>Unemployed</td>
<td>BA degree</td>
</tr>
</tbody>
</table>

Each participant was offered the choice to select his or her own pseudonym. One participant, Vivian, chose her pseudonym and I chose the remaining pseudonyms for participants. All of the guardians who participated in the study were the parents and guardians of individuals diagnosed with ASD who also participated in this study. For purposes of maintaining confidentiality, however, I do not indicate or directly make the connection between the guardian’s involved in this study and the participants diagnosed with ASD who are their children.
The first participants that I interviewed were Brad and Kathy, a married couple. Brad and Kathy shared that they have been married for 12 years and have been together for about 13 years. Brad is diagnosed with Autistic disorder although he speculates that he may actually be more accurately diagnosed with Asperger’s disorder. He is 34 years old, has graduated from high school and has received a two-year degree in Office Technology. He does volunteer work for the high school and the library. He is particularly interested in weather and enjoys reading railroad maps. Kathy is 33 years old and is diagnosed with Attention Deficit Hyperactive Disorder (ADHD) and Cerebral Palsy. Brad also speculates that Kathy may be on the autism spectrum although she is not diagnosed. Kathy graduated from high school and enjoys knitting in her spare time. Neither of them receives any supported community living services at this time and report that it has been about two years since they had a staff person coming into their house to help them. Kathy shares that she receives some day services that assist her to take classes and do fun activities. Both identify as Caucasian and work as crossing guards. They regularly attend church together. They live together in their own apartment. They have two cats in their household and no children.

The second participant that I interviewed was Richard, a 39 year old, Caucasian male who is not currently involved in a relationship, but has dated in the past. The longest relationship he was involved in lasted approximately 10 years. He is diagnosed with Autistic disorder. He reports graduating from high school and being currently unemployed. He has a particular interest in collecting model cars. He regularly attends church with his family.

The third participant that I interviewed was Charity, a 29 year old female who is diagnosed with Asperger’s disorder. She takes medication to manage her symptoms of depression. She identifies as heterosexual and Caucasian. She currently lives with two other
female roommates; she receives supported community living services in which she has staff supervision in her home 24 hours a day. She occasionally sees a therapist. She enjoys reading, superhero movies and playing an online role-playing video game called World of Warcraft®. She and her boyfriend Steve, have been dating for approximately two years. Steve is diagnosed with Bi-polar disorder and is currently homeless.

Penny, a guardian and parent of a participant with ASD, was the fourth participant to be interviewed. She is married and is of the Catholic faith. She works as a CEO for a company that provides supported community living services to people with intellectual disabilities. This is the extent of the personal information that she was comfortable revealing.

Vicki, was the fifth participant interviewed. Vicki is a 34 year old, heterosexual Caucasian female. She is diagnosed with Asperger’s disorder. She graduated from high school and is not interested in pursuing any college education. She identifies as Catholic and reports that she does not go to church. She works for a hardware store stocking shelves and taking care of plants. She enjoys scrapbooking and doing beadwork in her spare time. She sells her beadwork for profit. Vicki has been dating her current boyfriend less than one year. Her boyfriend is also diagnosed with ASD although she did not disclose his specific diagnosis.

The sixth participant to be interviewed was Sharon, a female guardian and parent of a participant with ASD. She is 64 years old. She is divorced and is remarried. She works as a direct support staff and oversees services for her child. She is Caucasian and has a high school diploma in addition to much continuing education in real estate, mortgage banking and autism.

Sally, a female guardian was the seventh participant to participate in the study. Sally is 50 years old, Caucasian, and unmarried. She is of the Catholic faith and works as a religious
education teacher. She has obtained her Bachelor’s degree in Theology and her Master’s degree in Journalism and Mass Communication.

Vivian, a female participant, is 29 years old and is Caucasian. She is diagnosed with Autistic disorder. She received her Bachelor’s degree in Music Technology with a minor in Photography. Vivian reports that she is currently looking for work and would like to do work related to the disability field. She and her boyfriend do advocacy work and public speaking related to Autism. She identifies as heterosexual although she has been bi-curious from time to time but has only dated men. She has not received services since she received early intervention services as a child. She and her boyfriend Dave have been dating for about five and a half years and have been living together for about four years. Dave is also diagnosed with Autistic disorder.

Trustworthiness

In qualitative research, the researcher is viewed as the main instrument. It is openly acknowledged that the results of the study are interpretive or subjective. Trustworthiness is pursued by the researcher in order to explore this subjectivity and to produce quality results. In qualitative research, the researcher attempts to make findings transferable to similar settings and contexts. The standards used to identify quality research are achieved through efforts on the researcher’s behalf to ensure that the descriptions and analysis are accurate and representative of the reality of the participants (Bloomberg & Volpe, 2008). The researcher also takes steps to make findings apply to other settings. This is achieved through measures of credibility and dependability.

Credibility

Credibility in qualitative research mirrors the internal validity and validity of measures used in quantitative research. Credibility is the criterion used to identify whether the researcher
has understood and portrayed an account of the participant’s reality that is congruent with the perceptions of the participants (Bloomberg & Volpe, 2008). The steps I took to ensure credibility according to the standards for credibility as posited by Bloomberg and Volpe (2008) include the clarification of researcher bias, collection of data via different sources, and use of member checks.

Clarification of researcher bias is described by Glesne (2006) as one way of contributing to the trustworthiness of a qualitative study. This process involves reflecting upon one’s subjectivity and how it may impact one’s research. My subjectivity is apparent as a researcher of this topic based on my previous work and personal experience with people with ASD. I approached each participant aware of my biases as a typically developing person and as an advocate for people with disabilities. The awareness of these biases has enabled me to be reflexive and to analyze and challenge my biases throughout my data collection and data analyses.

My biased assumptions may have impacted the way in which I interpreted my findings, perhaps in a way that is consistent with my previous experiences and knowledge of people with ASD. For example, my personal belief that adults with disabilities are deserving and capable of pursuing and maintaining romantic and sexual relationships is what fuels my interest in conducting this research to begin with; therefore, I am not neutral to the outcomes of this study and I had indeed hoped to support this belief through my findings. I have taken efforts to explore my subjectivity throughout the research process to minimize its influence on my interpretation as captured in my Analytic Memos and via inner reflection in the attempt to be transparent about the process.
Triangulation is the process of using a variety of sources for gathering data (Glesne, 2006). This method increases trustworthiness in qualitative research as it enables the researcher to cross examine the findings across multiple data sources. Triangulation serves to combine different types of data and most importantly, increases validity through comparing and contrasting findings (Bloomberg & Volpe, 2008). I was able to triangulate my research findings by collecting data from multiple sources. In three situations, I was able to interview individuals with ASD as well as their guardians. Interviewing guardians as well as individuals with ASD enabled me to connect the data and to supplement the information I received from each participant in order to ensure a more accurate interpretation and portrayal on my part as the researcher.

I was able to complete member checks with five participants. As a typically developing person I am not able to completely enter the shoes of a person with ASD and therefore, I cannot fully or purely understand his or her experience without subjecting it to the process of my personal and subjective interpretation. In an effort to portray the perceptions and experiences of my participants as accurately as possible, I shared my preliminary findings with participants via email or via the telephone. Via email, I included instructions for participants to respond to the member check in addition to 3 attachments. The attachments included the preliminary findings that were customized for the specific participant with their pseudonym initial highlighted and with other participant information deleted if necessary to protect the participants’ identity, an outline for the categories, themes and subthemes, as well as a member check feedback form (See Appendix A: Member Check Forms).

**Dependability**
Dependability in qualitative research mirrors the reliability process in quantitative work (Bloomberg & Volpe, 2008). Dependability describes making the processes and procedures used for data collection and data analysis available for tracking purposes. In an effort to provide an audit trail, I have completed and saved the following documents: full transcriptions of all participant interviews, completed interview summary forms and analytic memos for each participant, coding documents, transcriptions with coding and themes hand-written in the margins, category/themes/sub-themes outlines, and results. Documents are either hand-written or saved as word documents. All documents capture the evolving and emergent process from initial stages to later stages in the analysis process. Some of these documents can be found in the Appendices as referred to under Data Analysis.

Transferability

In quantitative research, the purpose is to generalize findings. In qualitative studies, however, the focus is less on the representativeness of the sample and more on the transferability of the findings. Transferability is the likelihood that findings can be applied to other settings and or similar contexts (Bloomberg & Volpe, 2008). Transferability is up to the reader’s discretion and is considered in terms of how well the findings would apply to other settings. The researcher attempts to produce transferability by using thick, rich description by communicating a holistic picture and by providing detailed information about the context.

In the participant description section, I provided a detailed picture of participants, their situations and their backgrounds from what I was able to get to know of them through the interview process as well as through their demographic information. In the results section, I included the actual words of participants through quotes and I did my best to describe the context of their statements based on my observation and interpretation.
In addition, I sought to increase the transferability of my findings by selecting participants from different agencies. Although my contact with particular agencies was fruitless in my quest to locate participants, the participants in my sample were from diverse living situations, and two participants (one participant with ASD and one guardian participant) resided in different states from the researcher and other participants in this study. Two participants lived independently with their partner and received no supported community living services. Two participants received approximately 24 hours of services daily from supported community living staff. One participant received supported community living services during the day only. One participant shared a home with two other roommates. The majority of participants lived in a midwestern state, however three participants lived outside of the state. By seeking participants from diverse living situations, my goal was to increase the transferability in terms of the ranges of contexts that participants may experience as well as the transferability of my findings to other individuals with ASD living in this area who experience similar circumstances.

Data Collection

After receiving approval from Iowa State University’s Institutional Review Board (see Appendix B: IRB Letter), I contacted three agencies in a Midwestern city to see if any agency would be interested in participating in the study or would be willing to solicit interest from any eligible clients that they served (See Appendix C: Email to Agency). One agency responded immediately that they did not have any clients who would meet the eligibility requirements for my study. The other two agencies granted me permission to approach their staff and clients about participating in my study. I received letters of agreement from both agencies (See Appendix D: Letters of Agreement). I supplied the agencies with flyers to advertise for my study (See
Appendix E: Flyer). No clients within these agencies expressed interest in my study, however, and I was not able to interview any clients from either agency.

I was able to locate participants via friends, colleagues, and professors. In addition, I found two participants through snowball sampling as a result of asking initial participants if they knew of any other prospective participants whom they thought would match my eligibility criteria and potentially be interested in my study.

In order to develop and guide the interview process, it is also necessary for the researcher to maintain some assumptions in order to facilitate the interview with purpose. The critical assumption for the researcher to maintain is that all information received from our participants is important as their knowledge and lived experiences are meaningful (Ashworth, 1999). The questions that I asked were developed in order to gain as holistic a picture of the participants’ perspectives and experiences as possible. Questions were also framed in an open-ended way to enable a naturally flowing conversation in which the participant could lead the direction of the interview if he or she desired as long as the conversation was related perceptions and experiences regarding romantic intimacy. The interview process was not identical in each interview; not all of the same questions were asked for each interview and questions were not necessarily asked in the same order.

Because of the qualitative and emergent nature of this research, the questions listed below provided the framework for the interview process and were revised or expanded upon throughout the interviewing process and as the research process evolved. Questions were designed to answer the main research question and to gain any information that could lead to an enriched understanding of how people with ASD perceive and experience romantic intimacy.
First, I asked questions to gain demographic information about the participants related to their age, ethnicity, relationship status, disability, DSM-IV diagnosis, sexual orientation, age of diagnosis, number of hours and number of years of supported community living services received, level of education, occupation, and religious affiliation.

In the following paragraphs, I will describe how I conducted each interview and the types of interview questions that I asked participants depending on if they were an individual participant with ASD, a couple with ASD or a guardian of a participant with ASD. I followed a script of questions when interviewing all participants that listed my main questions in bolded font and included follow-up or probing questions in normal font. Follow-up or probing were asked if it was necessary to further clarify my main question or to facilitate more discussion. Questions were phrased or worded differently depending on what type of participant I was interviewing as well as their current relationship status. (See Appendix F: Interview Script)

I attempted to ask all bolded questions during each interview although time did not always permit me to ask each question. Otherwise, I allowed the participant to guide the interview to a large extent and only asked probing questions if they were necessary in order to facilitate more conversation. When necessary, I used modified words or synonyms to help convey the meaning of my questions when participants did not seem to understand. For example, while interviewing one participant with ASD, I asked her, “What does romantic intimacy mean to you?” She responded that she didn’t know what that word meant. I rephrased my question by asking her “What does it mean for you to have a boyfriend?”

I started each interview with participants with ASD by asking a “grand tour” question. Such questions are described by Glesne (2006, p.84) as a “request for the respondent to verbally take the interviewer through a place [or] a time period.” Grand tour questions are effective in
breaking the ice and in generating detail. The particular grand tour question I asked was, “How did you meet your partner?” I found that this question was effective in setting the stage for further questions and made it possible to quickly establish rapport. Additional questions that I asked participants with ASD were to tell me what their relationship was like with their partner, what they valued about their relationship, how they showed one another that they cared and how they experienced sexual intimacy.

I started each interview with guardians by asking them what they thought romantic intimacy meant for their child with ASD. I used follow up and probing questions with guardians in a similar way that I used them with participants with ASD. Additional questions that I asked guardians were to tell me about their thoughts and feelings about their child being in a romantic relationship as well as what advice they would give other guardians.

Data Analysis

Phase one: All interviews were recorded by audio tape and transcribed. Interview summary sheets and analytic memos were combined into one document and were started within 24 hours after completing each interview to capture my immediate observations and impressions. Interview summary sheets and analytic memos were completed within one week after I was able to partially or fully transcribe the interviews so that I could answer more specific questions about potential codes and themes (See Appendix G: Interview Summary Form/Analytic Memo).

Phase two: After transcribing all interviews in full, I began the second phase of the analysis process by reading through all transcriptions. I then re-read the transcriptions and underlined anything that stood out. While doing this I generated a list of potential codes by hand for each interview based on concepts and words that seemed to emerge within a particular interview or across the eight interviews. During this process I developed 292 “codes,” many of
which were descriptive in nature (See Appendix H: Initial Descriptive Information). I transferred these codes into a computer document then revisited my transcriptions and began writing down the codes in the margins (See Appendix I: Coding Annotations). During this process I modified existing codes from my code list to be more interpretive or comprehensive, deleted codes and created new codes. I was also able to arrange some codes according to a hierarchy and many of these hierarchical code sets were eventually developed into themes and sub-themes further into the analysis process. For example, I identified the code, “Communication/Social Difficulties” at the top of a hierarchy and then listed subsequent codes underneath that were related to this code including, “Difficulty verbally expressing, Difficulty making friends, Difficulty dealing with conflict, and Difficulty coping with overwhelming emotions or social interactions.”

**Phase three:** During the third phase of coding, whenever I coded passages that seemed similar to previously coded passages based on my recollection, I would compare the passages before selecting the code. This is referred to as the constant comparison method, which involves making comparisons between codes and categories during each stage of the analysis (Charmaz, 2006). I used this method in an attempt to provide the most appropriate code and to ensure consistency in coding. Throughout this process I would often find that certain codes were not as suitable for some of the passages as others. This process also guided me to further modify or delete codes, rearrange codes into hierarchies and to develop more appropriate or all-encompassing codes that would better describe the phenomenon.

After narrowing down the codes and categories and during the preliminary stages of recognizing themes, I recorded salient categories and themes into a computer document and began cutting and pasting corresponding quotes and passages from the transcripts that were coded accordingly. During the process of cutting and pasting quotes to fit under certain codes
and themes into a computer document, I began conceptualizing what the layout would look like for my categories, themes and sub-themes and wrote notes to myself with different ideas. Once I had copied and pasted all quotes and passages that I had coded and that stood out, I began writing in a notebook what my categories would be based on what the main ideas were overall. I asked myself, “What were my participants trying to tell me overall? What were they saying directly or indirectly?” After establishing some tentative ideas for categories, I began laying out the themes and fitting them under the three categories I had developed. Then I went on to include all of the sub-themes under the most fitting themes (See Appendix J: Initial Outline of Categories/Themes/Sub-themes).

Afterwards, I read through the outline to make sure all quotes and passages seemed connected under each category at face value. Then I went backwards, looking at my sub-themes first to make sure that they fit well under the themes and that the names of the themes were most appropriate. Then I went on to include all of the sub-themes in the most appropriate category and that the category name was most appropriate.

After completing a tentative outline of categories, themes and sub-themes, I moved passages around significantly in order to fit with the organization of my outline but while remaining true to the meaning within the passage. In other words, I did not “force” anything to fit. I was able to see different meanings in the passages or different ways that the passages would connect with my organized categories, themes and sub-themes. This part of the process was much like having a box full of 3 different puzzle pieces in which each puzzle had some of the same or similar pictures with similar shapes and colors. It was my job to sort through and re-sort until I was able to make it all fit into 3 distinct puzzles. This analogy may imply that there was a “right” way to put the puzzles together, when in reality, a different person could have been
presented with all of the same pieces yet put together 3 puzzles that looked somewhat different than the puzzles I was able to construct.

Certain quotes seemed like they could fit into several different themes; the process of deciding which quote belonged more fully under which theme was admittedly challenging. Often when one passage contained elements from other themes, I would write “could also fit under other theme or sub-theme” in order to remind myself later in the process as I finalized themes. For example:

**Category 2: What is Challenging?**

Theme: Categories of ASD

*Sub-theme: Physical Contact*

P: But it had gotten to a point where what would have happened when Rachel was dating this fellow is he would sit very close to her and he might hold her hand or ya know, and you know when you’re holding someone’s hand you might rub somebody’s thigh and then he might start petting, like literally petting her thigh or her back or her arm. I mean it was literally petting her. But what it did was it helped her to get used to touch. It really helped; I mean it was very interesting to see how it kind of, umm transpired because at first she was very uncomfortable but she trusted, you could see there was a trust there and I think – (there is also mention of trust in the last sentence here).

At this stage I was able to recognize that this passage cut across two different sub-themes, “Physical contact” and “Trust.”

**Phase four:** During the fourth phase of the data analysis, I attempted to contact all participants for a member check and was able to complete member checks with five willing participants. I emailed four participants with preliminary findings and directions for feedback. Of
the four participants I emailed, only one participant responded via email with feedback. I implemented all relevant feedback into my findings and discussion. The feedback that this participant provided was the most detailed and clarified some incomplete and or inaccurate information that I had in my findings. The feedback also provided elaboration regarding some areas as well. Some of the feedback indicated a disagreement in how the participant’s statements were interpreted and this enriched or changed my understanding of the statement and enabled me to incorporate it under a theme that more accurately portrayed the participant’s meaning. I was able to complete four member checks with participants by phone during which time I explained the connecting themes regarding their quotes and read their responses aloud. I asked them if I captured what they were saying accurately and if there was anything else that they would like to add. Through these member checks, participants corrected some details that were inaccurately captured and otherwise expressed agreement with my interpretation of their responses and did not elaborate beyond what they originally said. I also incorporated these clarifications into my findings. Ultimately, I was able to complete member checks with all five participants diagnosed with ASD although I was not able to complete any member checks with guardians since they did not respond with any feedback through email or via the phone.

Phase five: In the fifth phase of data analysis and after conceptualizing my three categories and copying and pasting quotes according to where they seemed to best fit, I began to write my results section. It was during this process that I began to tell the story of my findings and was able to become even more intimately involved with the passages. During this stage I found that I could not justify the need for several of my sub-themes to stand alone and I combined them further or eliminated a few all together (See Appendix K: Sample of Results Draft). I continued making notes to myself regarding what themes and or sub-themes might
incorporate certain passages more appropriately. During this process, I found again that many passages could still fit under different themes or sub-themes depending on what aspect of the passage was attended to. In some cases, I eliminated the theme and fit the passage under a different sub-theme of a different theme of a different category all together. To illustrate, in the example above, the passage was listed under sub-theme: Physical Contact within the theme of ASD Characteristics within the category of What is Challenging? During this stage of the analysis/results writing, I found that the element of trust seemed more salient within this passage and therefore, I moved it under sub-theme: Trust within the theme of Compatibility within the category of What Makes it Work? In order to decide where certain passages would best fit, I attended to what seemed most salient from the passage or perhaps split the passage up so that it could be incorporated into two different themes or sub-themes. For example: “And I think sometimes just being able to have the words to communicate how she’s feeling I think sometimes that foreign feelings are scary for her… I don’t know if this is OK or not, I’ve not had this before… I’m just thinking and I’m just speculating her, but I’m just wondering if she starts to have some sort umm, of arousal feeling like that, is that foreign ya know? I’m not used to this.” From this passage, I cut the first sentence out and included it under sub-theme: Social/Communication Issues and included the rest under sub-theme: Sensory/Processing Issues.

Ethical Considerations

The topic of this research is a sensitive one that involves a vulnerable population. I ensured that participants were informed of the sensitive nature of the questions and their right to decline answering any question or to leave the study at any time. I informed the participants of the sensitive nature of the questions and informed them prior to our interview that I would ask questions about their sexuality as a part of the interview and that they could decline answering
any question at any time. I also reminded them of this while reviewing the consent form immediately preceding the interview I obtained written approval through the IRB. Because I had not included telephone interviews a means for collecting data in my original IRB request, I submitted a modification and was granted approval (See Appendix L: IRB Modification). I also obtained written consent from each participant prior to conducting any interviews (See Appendix M: Consent Forms).

Because participants in this study are from a vulnerable population, I also needed to obtain consent from a legal guardian of each participant with ASD unless the participant with ASD was his or her own legal guardian and was able to consent for him or herself. I received at least a verbal consent from all guardians of participants with ASD prior to interviewing the participant with ASD and eventual written consent from each guardian. Although I am not expected to act as a mandatory reporter in my role as researcher, I did feel that I would be ethically accountable for reporting any reasonable suspicion of abuse and or neglect if such information was disclosed during the interview. I included this limitation on confidentiality in my consent form.

**Confidentiality**

In the consent form, I clearly explained how any information they revealed could be used and that any information disclosed in my results will be anonymous. I also explained that all information disclosed by participants with ASD would not be shared with their caregivers unless they chose to disclose this information themselves.

In order to ensure confidentiality, I removed passages that contained any identifying information so that other participants would not be able to recognize other participant’s statements. I offered all participants the opportunity to select their own pseudonym; only one
participant chose her own pseudonym. I assigned all pseudonyms to all remaining participants.
For guardian passages, I assigned their children with pseudonyms different from the actual
participant’s pseudonym. For example, in the guardian’s passages, I would refer to her son as
“Charlie” when the actual pseudonym for her son was “Bill.” These are not pseudonyms used in
my actual study.
CHAPTER FOUR

Results

No two qualitative research studies could have identical studies/findings because different researchers are conducting them and each researcher will understand and interpret his or her findings somewhat differently based on her or his own knowledge and biases. In addition, the researcher is interested in how the world is perceived through the experiences of others and these experiences may not be generalizable as they are transferable in qualitative research. The idea is that information revealed in one study can help to inform another study or be useful in other settings but it does not claim findings as factual information that can be generalized to an entire population.

Throughout the process, the researcher makes new discoveries that aid and may alter the way the researcher goes about collecting and analyzing his or her data. The researcher is constantly making comparisons between data, codes and categories to advance conceptual understanding. In this way the research process is constantly emerging and evolving. Because the researcher is the main instrument, results of the study are interpretive. The qualitative researcher does not deny his or her biases in the research process and instead works to be more transparent and to discuss openly how these biases could impact his or her lens for gathering and analyzing data. From a phenomenological perspective, all of the information I received from my participants is meaningful and important; however, what I ultimately attend to is a reflection of my own lens and ability to interact with and interpret the data.

Overall, the voices of people with intellectual disabilities have been largely missing from the literature, especially in terms of their experiences with and perceptions of romantic intimacy. The purpose of this study was to provide the opportunity for people with autism spectrum
disorders to share their personal experiences and perceptions regarding romantic intimacy. My role as the researcher was to listen to their voices, to explore the underlying meaning of their words and to draw connections between the ideas and situations of different participants. Themes discovered during my analysis ranged from collective themes in which statements from all or nearly all participants were included or individual themes in which statements from only one or very few participants were included.

Through this process, I was able to organize what my participants told me into 3 overall categories that consist of various themes and additional sub-themes (See Appendix N: Final Outline of Categories/Themes/Sub-themes). A visual representation of this information is found in Figure 1. The three overall categories address the following areas: 1) What Makes it Work?, 2) What is Challenging?, and 3) How is Intimacy Experienced?.

Within the first category, What Makes it Work?, three themes were developed. These themes include: 1) Compatibility, 2) Dedication/Hard Work, and 3) External Supports. Four sub-themes were developed within the first theme including 1) Commonality, 2) Good Match, 3) Love and Spirituality, and 4) Trust. Two sub-themes were developed within the second theme including: 1) Accommodating, and 2) Communication. Two sub-themes were developed from the third and final theme within this category and included, 1) Parental Involvement, and 2) Helpful Professional Support/Treatment/Attitudes.

Within the second category, What is Challenging?, three themes emerged. These themes included: 1) Autism Characteristics, 2) Living Situation, and 3) External Pressures. Two sub-themes were developed within the first theme including: 1) Sensory/Processing Issues, and 2) Social/Communication Difficulties. Two sub-themes were developed under the second theme
including: 1) Roommates, and 2) Protective Housing. Two sub-themes were developed within the third theme including: 1) Family and Religion, and 2) Societal messages/Pressures.

The third category, How is Intimacy Experienced?, included four themes: 1) Attraction, 2) Expressions of Intimacy, 3) Affection, and 4) Companionship. One sub-theme was developed under the first theme: 1) Admiration/Appreciation/Liked Qualities or Characteristics. The second theme included six sub-themes including, 1) Physical, 2) Sexual, 3) Emotional, 4) Intellectual, and 5) Spiritual, and 6) Non-Physical/Non-Sexual. The third theme of this category included
three sub-themes consisting of: 1) Terms of endearment, 2) Teasing, and 3) Caring Acts. The fourth and final theme included two sub-themes: 1) Togetherness, and 2) Knowing Partner.

Guardians play an influential role in the lives of people with intellectual disabilities as they are responsible for helping them to make decisions regarding their well-being. The guardian participants in this study are also parents and have been involved in the lives of their children from the day their children were born. My initial purpose in interviewing guardians was to gain supplemental information regarding how the participant with ASD perceives and experiences romantic intimacy. Additionally, I was able to learn more about the experiences of guardians as they have supported their children throughout the years. I included statements from guardians as they were relevant to the perceptions and experiences of participants with ASD. At times the personal perspective or experiences of guardians are shared in order to portray their reality. Guardians play an influential role in the lives of people with ASD and it is hoped that their experiences can be relatable, informative and helpful for other guardians or caregivers.

In the rest of this chapter, I will share direct quotes from the participants having ASD as well as guardians of participants with ASD who openly--and at times, bravely--shared their experiences and perceptions regarding romantic intimacy. The responses from the participants are the findings of this study. I have included verbatim responses as much as possible with minor editing in the effort to make the document more readable. Additionally, I share my observations and interpretations of their responses as I share their experiences and perceptions of romantic intimacy with you.

**Category 1: What Makes it Work?**

**Theme 1: Compatibility**

*Sub-theme: Commonality*
A characteristic of ASD is an encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus (American Psychiatric Association, 2000). All participants mentioned having common interests with their partners. Many participants expressed that having common interests was very important. Sally, a guardian of a participant with ASD emphasized the importance of her daughter finding someone with similar interests or someone who would at least tolerate or be supportive of her interests in the following passage:

“…Umm, she really needed someone who liked her same interests or who tolerated her same interests. She loves animals; he’s very good with animals. Now I don’t think he’s crazy about animals like she is, but he’s very good with animals. He’s very kind and gentle. And he has feeling for animals, ya know, empathy for animals and that would have to be [the case] because of her Asperger’s. That would have to be something that was compatible for them…”

Another guardian, Penny also expressed the same understanding of her daughter’s need to be involved with someone who shared her same interests. She stated:

“She actually likes a lot of sports. She likes NASCAR and football so she wants somebody who is going to be interested in sports and watch sports with her. She also likes to play cards but it’s [based on] her schedule. So, if she wants someone to be there to play cards, she doesn’t want that person to do their own thing. If it fits for her she wants them to be available for her.”

Often, common interests revolved around an obsessive interest of the participant. Sally also shared that some of her daughter’s obsessive interests were non-negotiable; that is, her partner must also share the interest in order for the relationship to work. She said:

“Well and you know, [people with] Asperger’s are almost obsessive. It has to be something that they don’t find annoying or [are] obsessed with…They both like action movies, they both like superhero type stuff. If he didn’t like superhero stuff, I don’t think it could work…I mean, that sounds really dumb, but that’s the truth.”

In the following passage, Sharon, a guardian, discusses her attempt to find a good match for her son:
“See I was thinking this other this one girl [from karaoke group], I was thinking, man that would be a perfect match, and this was just real recently and then they got together and she and her girlfriend came together and they both drive and they brought real beer. I thought Thomas would have a heart attack. I mean, I drink NA [non-alcoholic] beer [impersonating Thomas].”

When it is discovered that the prospective partner shares different interests than her son by drinking alcoholic beer rather than the non-alcoholic beer that her son prefers, she becomes aware that a romantic relationship is unlikely to work out between the two.

Participants also mentioned discovering common interests when they first met their partners:

“And then I initiated conversation and then we found out that we both liked Harry Potter and a lot of the same stuff… [such as] World of Warcraft® (online role-playing video game)…we both like to read, which is funny cause we met at a bookstore.”

Vicki shares how she and her current boyfriend met at a coffee shop and began talking about their shared interests:

“We got into [talking] with sports, the first thing was actually up here playing cards with a group then he started talking about sports and I got into it with him.”

The fact that each participant mentioned the interests they have in common with their partner suggests that common interests are something of value. It is further suggested that the discovery that a prospective partner shares common interests increases interest in pursuing a romantic relationship with the person.

Brad expresses a keen interest in weather, particularly in storm development. His wife, Kathy did not outwardly agree or disagree with sharing this interest with him during our conversation. After Brad discussed their enjoyment of watching the news together, she simply stated, “He’s the weather nut.” Based on the perception that Brad shares in the following statement, it could be reasonably assumed that Kathy is at least tolerant of Brad’s obsessive interest and shows support by joining him in activities revolving around his interest. He said:
“We both like to keep up with what’s going on in the news and that’s very important to us. In particular, the weather segment of the news…that is the most important segment to us.”

Vivian discussed the important role that having common interests plays in enabling two people to connect:

“I also believe that shared interests would be great, is very important [in order] for two people to be able to connect. So I think there are some things that Patrick and I do share interest in, because if we had no shared interests at all, I know we wouldn’t work. Part of that is combining interests into an activity we both enjoy, however I think we still have some shared interests. For one thing, autism. I mean we’re very interested in autism and I think that connects us. Our interests in giving talks, and presentations and workshops and connecting with people in the autism community, that’s a huge one [common interest] I think.”

Common experiences were also expressed by participants to provide them with the opportunity to experience greater emotional connection and the ability to empathize with one another and to feel more understood. In the passage below, Vivian describes how her common experiences and ability to relate with her partner have contributed to their hard work and achievement as a couple:

“I think one aspect of why it’s been a positive relationship is that we both have, even though we don’t really have an understanding of how our particular sensory issues play out or why it’s such a big deal to have particular issues, we [do] understand the underlying reason of it. Yeah, so it’s that [ability to relate] and I guess because we both have autism and we both have similar stories as far as when we started speaking, when we started mainstream schooling, that [has enabled us] to work very hard and achieve what we’ve been able to achieve.”

In the reverse, Sally describes how her daughter’s relationship with a young man was not successful due to her daughter’s inability to relate to the man and therefore was unable to feel compassion for his situation:

“Umm, well, when she was dating this one guy who was in love with Dungeons and Dragons® [an interest that Emily also shares] and he was almost obsessed with it, but he was very umm, she thought he was arrogant. And I don’t know that he was arrogant. He was a little bit maladjusted. And super, super bright and very gifted and talented. So he didn’t understand what it was like to struggle with stuff. Now, when he went to college
he sort of skated through everything and did very well and went to college and it actually
required more studying for him than he was capable because he had no study skills. And
he failed…in school so then he was dropped out when he met Emily and he was
regrouping. Now he was going to have to learn for the first time in his life to discipline
himself to overcome some barriers. And she really had trouble with that because her
whole life she had learning disabilities and had to like accept C’s as a victory... And I felt
like she could not feel much compassion in his…she felt like he was a big baby…I think
that’s [difficulty with compassion] very typical of the Asperger’s.”

Although common interests seem to play a crucial role in a person’s decision to enter a
relationship with another person and in the future success of the relationship, it does not
necessarily guarantee the success of the relationship. Although Charity was very interested in
Dungeons and Dragons®️, her inability to relate or empathize with her boyfriend’s situation led to
the demise of the relationship. This could suggest that having common interests alone is not
enough to determine the success of a relationship.

From participants with ASD and guardians alike, the overall consensus seemed to be the
perception that commonality was a paramount feature in order for the relationship to succeed. A
lack of common interests or experiences was perceived to lead to failure of the relationship. The
lasting impression is that it is essential for the person with ASD to be paired with someone that
shares at least some of their same interests, especially in regard to obsessive interests.

Sub-theme: Good match

This theme primarily captures the voices of two guardians whose experiences led them to
believe in the importance of their child finding the “right match.” Sally reflected on the many
challenging experiences that her daughter had with different boyfriends and suitors during her
years of young adulthood as a result of difficulty in finding a good match:

“She always had those tendencies [to second guess herself or have “meltdowns”] when
she got invited to the prom or she invited a boy to the prom and then she started second
guessing herself if she really liked him because he smoked…That’s what she told me was
because he smoked. Well, it turns out he was a lot wilder than she was. He was going to
go on a wild, but she told me, that’s the only thing she could say about him.”

In the next passage, Sally describes her daughter’s need for authenticity and ability to “click”
with a partner in order to be able to appreciate the relationship and enjoy dating:

“But, they didn’t click, and he was crazy about her and he wanted to spend a lot of money
on her, but she wanted something [different], and even though he’d lost a job, he was
really going through a rough patch but he had saved up money and he was still spending
money on her. And she couldn’t appreciate it. She just didn’t like him and couldn’t
appreciate the way he was liking her…She couldn’t play the game. She couldn’t just
enjoy the date for the date…There was a part of her that was uncompromising, had to be
authentic.”

In the passage below, Sally explains that finding the right person enabled her daughter to have a
successful relationship:

“Well I think she was interested in it [romantic intimacy], very much so. I think it had to
be the right person. She was not willing to cross certain thresholds with certain
boyfriends that were not right for her. Boys were attracted to her and approached her and
it just did not work…But when she found someone that fit with her it worked out very
well and she seems to be happy and content with him.”

Sally goes on to describe how her daughter’s ability to find a boyfriend that she “clicks” with has
proven to serve a resilient role in the face of other relationship challenges:

“So, the guy that she’s dating now has actually gone through a period of homelessness,
where he had no money and she has stuck it through with him and been able to manage
this as complicated and difficult [as it is]…he didn’t always have a telephone because he
had pre-paid phone minutes and she could be true to him and stick it out with him…And
ya know, she could handle those barriers that were very difficult that would probably
break up a relationship…But, she liked him and because she could resonated with him
and because they clicked… She’s with someone now who’s mainstream, he has a job. He
is bi-polar, which is another thing that could break up a relationship and she seems to ride
out his bi-polarity just fine…So, this [her daughter] is a person who couldn’t even stand
in the parking lot at [grocery store] and talk to her prom date when he carried the
groceries out… when it was someone she didn’t like and she didn’t feel attracted to and
safe with, she couldn’t even do the most fundamental social things.”

Sharon discusses the importance of getting matched up with a person who not only wants
similar things out of the relationship in terms of sexual activity, but also a person who has
complementary characteristics. Below she talks about a previous girlfriend who was well-matched for her son because she was able to take the initiative in contacting him and arranging dates, something that her son had difficulty doing. She also talks about another girlfriend who was not well-matched due to differences in desire for a sexual relationship:

“It’s important that you get matched up with the right person. …So see, that was a good match in that way [because the girlfriend would take initiative]… and they totally enjoyed being boyfriend girlfriend. No matter what that meant to them, they were special to each other. She’s autistic also and has the same sensory issues…And this other one [different girlfriend] was an example of one that was not a good match for him in that way…he wasn’t attentive enough and he’s never been one to take the bull by the horns and neither was she. She was used to the guy [taking initiative] and she had typical relationships, I’m quite certain. What I think truly happened one day is she just called him and told him that she had another boyfriend. And I think she was on a different plane…based on some of the things that her mom said. I got the impression that there were issues with her being vulnerable to the typical population or whatever and they were always trying to control this so I think she was sexually experienced and that that’s more of a relationship that she was looking for but Thomas couldn’t give her that.”

During our conversation, Sharon expressed the overall hope for her son to find “an equal relationship where they really are a match.” A good match for her son would be a girlfriend who would be able to take the initiative and not need to have a sexual relationship.

*Sub-theme: Love and Spirituality*

Participants revealed a feeling of connection towards their partner and the sense that something greater or some inexplicable force was at work in bringing them together. Vivian describes having a feeling about her partner when she first met him, although she could not quite articulate it at the time:

“Yeah, but I felt something, I felt there was something about this guy, I thought that even as I dropped him off at the airport…I thought there is something about this guy but I can’t quite put my finger on it, but I know we’re gonna somehow be in touch and somehow something, I don’t know. But I had gotten that weird feeling from the beginning.”
Brad and his wife Kathy reported that they regularly attend church and are actively involved in the life of the church. They shared a belief that God brought them together and that their love for one another plays a powerful role in their relationship:

B: “I would definitely say that the love that we have for each other and, uh, the man upstairs too. I don’t know where we’d be without [those things].”

K: He decided to put us together…We know he brought us together because look how long we’ve been together. Because we balance each other out. He’s got the spelling and math skills which I don’t have very well and I’ve got the social skills [gently smacks his head]. But he keeps getting better all the time.”

As Vivian talked with me about her perceptions that companionship and compromise can be difficult for couples with ASD, she also shares her belief that love is a natural experience for people with ASD, “It’s odd, so I guess the particular feeling of love is not fake, that’s natural, but the idea of sharing the same roof, sharing a life together, combining things, combining our schedules, that is challenging.” She further discusses their challenges with compromise and then reveals that love has proven a resiliency factor in their relationship:

“Yeah so, I’m not going to lie, that [compromise] has also been an issue, that’s challenged us too at times. I think though, because we love each other so much, we’ve been able to work through it and I feel very blessed about that.”

Penny describes the resiliency that her spirituality has offered in her own personal experience as the parent of a child with ASD. She advises that parents of children with ASD find support through a loving God:

“Well, take care of yourself, get a God. Believe in a higher power that loves your child, [and] just thinks your child is the greatest thing in the world. Get a God that really thinks your child is wonderful…And then sees your child the way you do and not the way society does…not as marginalized but as absolutely wonderful. I would say get a God or something that is bigger than you that is loving and steadfast that will care and sustain you.”

*Sub-theme: Trust*
Brad and Kathy both expressed the feeling that Kathy’s mom had played an important role in their lives and in their relationship. Brad expressed that, “…my mother-in-law I think especially liked the idea that we were together because she knew from what she could see of me that I was the type of individual that would never hurt her daughter.”

As Brad was sharing this, I sensed that he really appreciated and valued the trust that his mother-in-law had in him. He seemed to feel motivated by this trust he had gained and proud of the fact that his wife’s mother believed he was good for her daughter.

Charity and Vicki both live in protective housing and receive supervision from staff workers throughout the day. Vicki lives in her own home without any roommates and does not receive supported community living services overnight. Charity lives with other roommates and receives 24 hours of supported community living services daily. For both of these women, trust seems to play a significant role in the level of freedom that they experience in terms of when and how often they are allowed to see their partners. Charity says:

“Well my mom really likes Steve, she’s always liked him from like the beginning. My staff pretty much are [supportive] like cause I’ve never like gotten in trouble with him. So they’re like, oh if Steve wants to take her someplace, they’re like OK with that. And also, one of the rules my mom and me made if I ever go with Steve I don’t have [a] time restriction. I can be gone as long as I want.”

Vicki also shares the role trust plays in her ability to spend time with her boyfriend:

“Depends on the way that they think it’s going with things and how stuff is…Like right now it’s one night a week that I can have after my staff leave the house that he can stay till like 10. The other ones, I couldn’t really have the guys over that much. My mom didn’t really know them as much and didn’t think it would be good to have that…She knew them and she kind of didn’t trust them as much cause this one I’m dating now is a [member of the same agency from which she receives services].”

Vivian receives no services and lives in her own house with her boyfriend. She expresses how her parents have surprised her with their level of support. She speculates that her parents’ supportive attitude is partly the result of them getting a good feeling about him:
“I didn’t know what they [her parents] would think about that [she and her boyfriend living together] before we were married. Surprisingly both of them were supportive and it was very humbling… Perhaps they had met Patrick and they felt very good about him and so it surprisingly went very well.”

Guardians also perceived that trust contributed to their child’s ability to open up and feel safe with a partner. Below, Sally describes the history of her daughter’s relationship with her father and her resulting tendency to be self-protective. In the following statement, Sally touches on the mediating effect that trust has played in her daughter’s current romantic relationship:

“Well, she’s very self-protective because she didn’t have a father…or she had a father who was emotionally, who lied to her and would say stuff to her, he just neglected her and he was the worst kind of dad that would say, I’m going to come see you in a week and then he wouldn’t see her for three years…She’s gonna be more guarded, ya know. But she trusts this guy.”

Penny describes the role that trust played in helping her daughter to become accustomed to physical touch with a romantic partner:

“But it had gotten to a point where when Rachel was dating this fellow he would sit very close to her and he might hold her hand or rub [her] thigh and then he might start petting, like literally petting her thigh or her back or her arm. I mean it was literally petting her. But it helped her to get used to touch. It really helped; I mean it was very interesting to see how it transpired because at first she was very uncomfortable but she trusted [him]. You could see there was a trust there.”

Theme 2: Dedication/Hard Work

There is the perception that people with ASD may need to work even harder at achieving romantic intimacy in their lives than typically developing people based on the social difficulties they commonly face. There is also faith that if two people are willing to put in this hard work, the relationship can be successful. Brad expresses such faith in the following passage:

“And another thing I’d like to say is if they’re willing to work at it, now I’m not saying that a relationship is easy, no relationship is, but if they’re willing to work at it, good things can and will happen. I’m not saying a relationship whether it be just boyfriend and girlfriend or a marriage like what Kathy and I have is easy. It takes work and you gotta have a lot of support. But if the couple is willing to work at it, there is no reason why a relationship cannot succeed.”
Vivian asserts that it takes two people making strong efforts to work together in order to make a relationship work:

“You have to be willing to put in the time, put in the effort of ya know, sometimes it’s not always going to go your way. Before you can successfully date or pursue, it has to go both ways. If you are doing the work yourself and you find someone and you want to pursue that person and if person doesn’t have [relationship] etiquette…then it’s not going to work. You both have to work towards it; it’s not a one way street.”

Sub-theme: Accommodating

A need for independence and personal space was expressed. Two participants expressed that they and their partner spent a great deal of time doing things apart. Although she agrees that common interests are very important for her and her boyfriend Patrick, who is also on the autism spectrum, Vivian shares that she and Patrick do have plenty of separate interests and actually enjoy doing many things separately. In the following passage, Vivian shares that she and Patrick have worked together to accommodate and respect one another’s need for separateness in terms of interests, activities, and space:

“It’s funny because there’s lots of things that based on our special interests and obsessions and routines that we kind of do separately and on our own. So, some of the stuff that you would think typical couples do together, we don’t mind doing on our own…We shop separately for our own groceries. I don’t dare take him out with me to go shopping or anything, to the mall or grocery shopping because it takes me awhile to sort of process a lot of the things down the aisles and [make decisions] and for Patrick it’s more like, OK, can I just grab it and go. So, yeah, we do that stuff separately. We sometimes will travel separately, like if he wants to go back to his family for the weekend which is a couple hours from here and then I’ll sometimes visit my family separately.”

Despite the societal messages that he feels can pressure couples into feeling that they should spend all of their time together, Brad also expresses the need for him and his partner to have time apart. He says, “There’s not very many things that we do together that I’m aware of.”

In the following passage, Brad shares that he and Kathy have had to disregard society’s
expectations and create their own definition of marriage to accommodate their separate needs as individuals:

“Well, that’s where [the media] I tend to get a lot of mixed messages and it’s very confusing. That’s why I think that Kathy and I have basically just had to define marriage to suit what it means to us personally. The thing is, I don’t see marriage as having to be around our significant others 24/7. I mean, we both have separate interests, we both have our separate activities that we like to be involved in and we’re very happy with that. Just so long as at the end of the day we can talk to each other and basically have time to ourselves – couple time. Basically like I just said we have to ignore what society’s ideas about relationships are because they just are not compatible with ours.”

Vivian also shares how she and Patrick have been accommodating of one another’s separate interests in their home:

“we both have very different decorating tastes, interests. He’s very into retro… I’m very much into contemporary, Asian kinds of things, so we’re both so into our own styles that it’s great where we could have [our own] bedrooms and we can just basically set it up the way we want it. And with the common areas, it’s like we’ve found a way to blend it and make it seem OK, it still looks OK. So it’s like we’ve had to communicate to try to accommodate and compromise on those things.”

Additionally, Vivian and Patrick have found a creative way in which to accommodate both of their separate interests. In the following passage, Vivian shares an example of how they have been able to combine their interests into a single shared activity they could both enjoy:

“Well, I guess one thing that I’ve sort of discovered even though we have separate interests and they really differ is finding a way to combine our interests. One year when he was living in Mississippi, I visited him and I had a real interest in photography and I had a special interest in photographing storm damage and he has some interest in observing storm damage cause that’s part of his job. So we took a road trip down to the Mississippi gulf coast in New Orleans and it was about a year after hurricane Katrina hit. I was photographing storm damage and Patrick was driving us to different places to observe things and it was something we both really enjoyed doing and I think it had a lot to do with the fact that we were able to combine both of our special interests.”

It is common for people on the autism spectrum to require their own space when feeling emotionally, physically, or socially overwhelmed. In the next passage, Vivian shares that she and Patrick have been able to honor one another’s need for personal space and privacy:
“There have definitely been some challenging periods or challenging times because of those separate interests or separate needs. If we are in a situation where we are kind of enclosed in a place or not having enough space that can be challenging as well…I think the biggest thing…is that we have our own bedrooms…We [people with ASD] just have to isolate [sometimes]. And it’s no different with Patrick and I in that sense. So, that’s really another big reason why when we first were living in an apartment together, we had our own rooms. It allowed us to have our own designated personal space if we did need [it].

Through her written member check feedback, Vivian added that, “Not having enough space can aggravate sensory issues and make the accommodating process more difficult to honor.”

Vivian expresses that although compromise can be very challenging at times, it is often crucial in order for her and Patrick to inquire about other’s comfort level, especially regarding their specific and sometimes conflicting sensory issues:

“I’m humbled by his willingness to compromise or accommodate. For instance, we have different temperature preferences…we have to practice compromises where we have to be openly communicative and ask each other how we’re feeling, ask [one another] are you feeling comfortable? Do we have to set it a certain way where you feel comfortable? That is something we always will work on.”

Sub-theme: Communication

The communication skills necessary for a successful relationship were described as the same skills necessary to pursue and maintain friendships. Vivian emphasized the importance of building overall communication and social skills in order to pursue and maintain a successful relationship:

“I think one of the most important things about learning how to successfully pursue somebody or to date [is that] you need to learn and practice the art of social skills before you are able to successfully practice dating and relationship skills. If you don’t have that component of social skills building then relationships aren’t going to work. So you have to learn friendship building and social skill building and learning how to get along with people and how to communicate with people, friends, acquaintances, so forth… That stuff [inaudible] gave us the tools in learning how we could have effective relationships as well because when it comes to dating etiquette and relationship communication, it’s really quite similar to how you would communicate with like a friend. In nurturing a friendship, in nurturing a relationship when it comes to the communication aspect at least, it’s really quite similar, the same.”
Vivian also added through her written member check feedback that consulting with others is also found helpful, “What I have also found beneficial is networking and talking with other adults on the spectrum who have had their fair share of relationship and/or marriage experiences.”

The need for open communication and collaboration between guardians and or parents was described by Sharon as an important element in order for her to be able to support her son in a romantic relationship. In the passage below, Sharon describes a situation where she was not able to collaborate with the parents of her son’s girlfriend in order to support their relationship:

“Now the second girl was sweet as can be, I never knew her diagnosis. She’s in a group home across town. Her parents were kind of secretive; I think it possibly was mental illness. Her parents never wanted to get together, they were lovely people, I mean not low lives or somebody who doesn’t care, but we never could get together with them to say, how can we support them in their relationship? That’s what I wanted to be able to do.”

“So, what went wrong with that relationship, we really couldn’t discuss it with her [her son’s girlfriend], I would not try to bring things up with her. I really wanted to talk with her parents.”

Communication and collaboration between the guardian and support staff were also seen to play an important role in Penny’s ability to be supportive of her daughter in times of relationship distress:

“Ya know, I think when things were kinda ramping up with [Rachel’s previous boyfriend] it was good because the agency notified me and so I was able to keep my antennas up and talk with her so I think there was some great teamwork there. If that communication wasn’t there I could have been oblivious to it. Because I started spending more time with her just make myself a visible presence by being available if she wanted to talk.”

**Theme 3: External Supports**

*Sub-theme: Parental involvement*

Positive parental support was described in terms of help advocating on the behalf of the person with ASD. Parents seem to play an important role by educating their child about romantic
intimacy by offering advice and by encouraging them to pursue and maintain romantic relationships. In some cases, the participant with ASD required assistance from the guardian in order to advocate on his or her behalf. Penny’s assistance in soliciting her daughter’s concerns was required in the following example as well as her assistance in order to advocate on her behalf. Penny discusses her daughter’s experience with unwanted physical touch and her difficulty advocating for herself:

“And so we knew something was going wrong, we just couldn’t quite figure out what it was. And then once we started putting the pieces together I asked her, is this something you want? And she said no, and I said well then why are you saying it’s OK? I think it was one of those things where she just felt – it’s kind of like the petting, the longer he did it the more accepted it was and I think he just, he wore her down. But I asked her if that’s something she wanted to do and she said no and I asked her how do you want to handle it? She asked me if I would talk to him and I said no. I’ll help you talk to him if you want me to help you but it has to be your words. And that was very hard for her. She ended up wanting to come home. She stayed home for like 3 or 4 days, she didn’t want to go back. It was just a very hard situation. But it seems like once the relationship gets to a point, she doesn’t want that aspect of it.”

Penny provides an additional example of needing to solicit her daughter’s concerns in the following passage:

“he [previous boyfriend] was the one that wanted to do, or tried calling her and wanting the [phone sex]… that was bizarre. She got a few phone calls and she didn’t know how to handle them and again, the seizures started and I’m like Rachel, something is going on, what is it? And, ya know, just learning how to ask the right questions of her. And she just doesn’t seem to know the right words to express how she is feeling and I don’t want to put words in her head but…”

Penny goes on to explain her unique position as a guardian and a parent:

“I think, there’s some fine lines though in being her guardian. I have some responsibilities in helping her to make the best informed decision. I don’t feel like I have the right to make the choice for her but I can help her to make the best informed decision. In a similar vein, Sally describes a situation in which her daughter also experienced difficulty advocating on her own behalf when she was involved in an undesired romantic relationship. Sally talks about how her daughter required assistance from her:
“And there was a time when he came over to our house at night and she started having anxiety attacks. She couldn’t be with him, she wanted him to go home…Emily would have to drive him home and she felt like she was having a panic attack and couldn’t drive him home…So, she left him in the living room and came and got me out of bed and I had to go tell him that he had to go home and that he had to find a way home…She did that more than once with boyfriends where she would just have a meltdown and just freeze and stop and I would have to go tell the boyfriend.”

The reader may have also taken note that both of the guardian’s daughters in the examples above experienced physical symptoms including seizures and anxiety attacks in which their mothers were able to attend to as signals of emotional or psychological distress.

Another guardian, Sharon explained the difficulty that her son had initiating and maintaining contact with his girlfriend when she wasn’t assertive in contacting him. In the passage below, she reveals playing an active role in seeking out his desires in terms of dating. She also shares her attempts to improve his ability to initiate and maintain contact with his girlfriend through use of creative interventions often utilized for people with ASD including schedules and social stories. She describes her supportive efforts in the following passages:

“And I would say to him, Thomas is Meg really your girlfriend? ‘Well yeah.’ [Impersonating Thomas]. And I’d say do you want her to be a girlfriend? And he’d say, ‘yeah.’ And I’d say, well men lose their girlfriends if they don’t treat them just right. And the way you treat a girlfriend is different than the way you treat a friend that you just call up once in a while for what are you doing, let’s go out for a movie or something, ya know? We did some social stories on it, to call her and invite her to come to eat…Nothing would happen without a Bridget to do the whip thing [Referring to how previous girlfriend took charge of organizing dates]. And she wasn’t doing that and so we had him invite her, ask him if he’d like to invite her over for dinner and he could cook…but it was all being reminded and kind of prodded by us. I mean Bridget arranged everything. I think they just had the formality of she was the drill sergeant, I’m your girlfriend, you’re my boyfriend, we’re going to do this, this and this…Anyway, so [with Meg] we were really working with him on having a schedule that you need to remember to call her. He wasn’t calling her and he wasn’t making any plans with her at all. They’re just boyfriend girlfriend.”

During my discussion with Charity, she mentioned, “I’ve had crushes in the past, like I know I’ve had them in high school and stuff but I never really initiated them because I’m like,
they’re crushes.” When I asked Charity if she felt like she knew how to initiate she explained that her mom had talked to her about how to approach boys if she was attracted to them. She said:

“To a certain extent I did know because my mom did talk to me about it and stuff. Like, how you see cute guys and you gotta talk to them and like let them know that you are interested in them and go ask if they want to go to like movies or something. Ya know, stuff like that.”

Vicki disclosed that she had been molested in the past and she also shared that, “there’s been a guy that kinda wanted to try and do that stuff [sexual touching] in my past dating.” When I asked Vicki how she was able to handle that situation, she expressed, “I didn’t. I had to go to my mom.” I asked Vicki if she felt like she could talk to her mom about stuff like that and she responded, “Yeah, cause I’m just not one of those people.”

Brad and Kathy shared the impression that their family supported their relationship. When asked how their family felt about their relationship, Kathy responded, “They felt fine with it otherwise they would have said something.” Brad agreed with her logic and followed up by saying, “No, nothing was ever really said outright. I tend to think of that as no news is good news, I would say.” They spent several minutes talking about the impact that Kathy’s mom had on them and that they found her to be supportive. Here is a passage including some of the conversation they had about Kathy’s mom:

B: “My mother-in-law, like I said earlier, I always felt I could go to for advice. She’s one of those people that is a real go-getter. Like I said earlier, she always used the saying, “Nothing ventured, nothing gained.”
K: “I can say, what’s that saying? And he reminds me of it.”
B: “Truth is, I don’t know where I’d be without all that she did all those years ago. I don’t think I would have tried half of what I did without [her support], all I had to do was remind myself of it [the phrase].”
Sharon demonstrates a supportive attitude in the passage below and a desire for her son to experience some level of normalcy in his life by having a close, intimate relationship. In this passage it is also apparent that she attempted to expose him to romantic intimacy by taking him to weddings:

“So, nothing would make us happier than for him to have the appropriate, loving relationship...So, we would love it, we would really love it and we take him to weddings for all our nieces and nephews and cousins and friends, our friends kids and all that. And I know that he doesn’t look sad about it or anything but I’m sure he wishes that he could have some of that, though he’s got a wonderful life.”

Sub-theme: Helpful Professional Support/Treatment/Attitudes

Participants revealed that assistance from professionals who are familiar with ASD would be helpful at times. Other participants revealed areas that they would like to see changes in their services or regarding limitations set upon them by guardians. Other participants revealed statements that a greater level of societal understanding in general about Autism would be helpful to them.

When I asked Sharon what would be helpful for her in terms of supporting her son to be romantically intimate, she suggested individual counseling without her son present and couples therapy to guide her and her husband how to work together to support their son. She expressed that it would need to be an expert in ASD:

“Really, it would be some kind of counseling for me, separate from him from an expert with ASD, definitely, it would have to be...Counseling for [husband] and me together on how to support him [son], how to approach it [romantic and sexual intimacy]. We can’t show him, but I know they still have appropriate training tools for people with MR or maybe even autism, specifically or the combination.”

During this part of the interview, Sharon began taking notes regarding the steps that she would like to take in seeking information from experts about how to best support her son:

“I left one thing out, [his psychologist] would be involved. She is his psychologist and she is amazing. OK? She’s been his psychologist forever...she only sees her autistic kids
through adulthood...I need to write this down. I’m going to write this down...So, I’m going to [ask] the doctor at physical my questions, 123. [His psychologist] will know the right steps...Yeah, she will counsel us regarding him but she will not do my counseling. I wanted her to do that for me, but she says I’m a pediatric psychologist and I can’t do that. And I said, well you’re really the only one here that really knows, you know autism, you know us as parents...She knows what we go through as parents and how to fix, well 75% of husbands and wives are divorced of parents of children with Autism...Counseling and advice for me.”

Sharon expressed some curiosity about her son’s ability to be sexually intimate and also mentioned that she wanted to seek some guidance from his regular physician:

“His physical comes up in August and he is very comfortable with this doctor, he is wonderful...But I think I’m on the right track with it. But I need some education on it. I don’t want to open a can of worms with him.”

Vivian shared that couples therapy would be helpful for her and her boyfriend at times. She also expressed the desire for the counselor to be knowledgeable about ASD and relationships:

“I think it would be beneficial once in a while if there was a relationship counselor kind of that we knew about that had an understanding of the spectrum and relationships. Every once in a while, even healthy relationships need that.”

From an early age and despite not knowing that her child had Asperger’s, Sally actively sought treatment for her daughter in order to improve some of the delays she was experiencing. Below Sally describes how her daughter benefited from individual therapy and play therapy:

“I didn’t know she was Asperger’s so for years I had her in therapy as a child. And so she learned how to process feelings and how to recognize feelings both on an intellectual and then on an emotional level...And, she knows all this because she was in day treatment and she understands the dynamics of healthy relationships. [She knows] what a healthy relationship looks like clinically and what an unhealthy relationship looks like, what healthy behavior looks like because she’s had a lot of years of therapy. She was in play therapy and we worked on her socialization skills not even knowing she was Asperger’s, I just thought it was because of her learning disabilities so we worked on play therapy where she would be in small groups of 3 to 5 kids with 1 or 2 adults and they would learn how to do cooperative type play and she did that for a couple years...we didn’t get the diagnosis until she was a teenager for Asperger’s.”

Sally goes on to describe the involvement that her daughter had with a 12 step program:
“The other thing is she went to Al-ateen…And a lot of those kids have experienced a lot of hurtful things in their lives and it’s a safe place where they can go and they learn to use the 12 step program to deal with what it is in their life that is troubling them like if it’s an alcoholic relative…And they would share about how they really felt, what was really going on and they knew and they would identify what they had power over and what they didn’t have power over and they also identified that it takes a power greater than themselves like God, if they wanted to call it God. You didn’t have to call it God if they didn’t want to, but it would take something bigger and more powerful than yourselves to make things right…So, she followed that model and did very well and I think that that really gave her a resource for coping with life. And to this day she’s very clear on what she can manage and control and what is out of her control and [is able to let] go of things that are not hers to be obsessed with or controlling of…especially with his [her boyfriend’s] bipolarity. She just really works off the model like when he gets sick or gets depressed, it’s not something that she can control and that she has to take care of herself and it’s a one day thing at a time.”

Sally wraps up her discussion of the treatment her daughter experienced by sharing that her daughter gained emotional and spiritual strength from attending the 12 step program:

“I just wanted to say, the other thing you learn in a 12 step program is how to ask for help. You rely on a sponsor, you make outreach calls and Emily knows that. She knows that there is no shame, in fact it takes more strength to ask for help than it does to isolate and try to manage something that is overwhelming on your own. So, I would say that’s a huge thing. And she was in a lot of therapy and as a result she has an emotional and she actually has a spirituality that helps her now.”

On a personal level and as the parent of a person with an intellectual disability, Sally talks about the resources that she draws on to give her greater strength:

“I have to have my own support system. I had my own friends, I have called girlfriends freaked out because my daughter was taking the next step [having sex]. I myself didn’t have a partner, her father was gone, I was a single mother and so I needed support to let go. I needed support to just trust in God, in a higher power, that something big was taking care of her and watching over her.”

Brad and Kathy offered an idea regarding how their services could be improved in terms of staff support. When I asked what would be helpful to them, Kathy responded, “One staff works with us, not two or three otherwise it’s sometimes them throwing too much information.”

To clarify what she meant, I asked, “You mean one staff person at a time?” In response, Brad
said, “Yeah, because often times when there’s two or three there, sometimes there is just too much going on…”

Vivian talks about the services and skills that her and her boyfriend received growing up and how these have benefited them in regards to their current relationship. She also mentions a particular resource that her and her boyfriend were both able to draw upon later in life to help them socially and as an added benefit, their current relationship with one another:

“There’s lots of different materials and resources out there. I think one thing that helped both of us ironically was Carnegie’s books, especially Dale Carnegie’s book, “How to Influence People.” It’s a really simple lesson, but it has some valuable tools in learning how to approach friends and all that. We’ve had to work really hard at learning how to do that.”

Vivian considers how the unique experience of being profiled in the media enabled her and Patrick to grow closer and also resulted in learning and activating additional support from others regarding their experiences with ASD as well as their romantic relationship:

“I think because of that [being interviewed] it helped us really understand how we work. And so I think in a way that was kind of like pre-relationship therapy because it really helped us, going through that process of interviews and being in the article and just the support we’ve gotten from people and our friends and families, I think that has really just strengthened us, because we were forced how to learn or to explain and dig deep down into how we work.”

Vivian and Brad both provide statements of how a more knowledgeable and accepting society could benefit them both personally and relationally. Below, Vivian describes how a more general understanding of ASD could benefit her:

“But I think what more concerns me is wishing there was more of an understanding from society or people I encounter, or just more general understanding just of our autism, more than just the relationship aspect of it. For instance at my last job, it [having autism] was something I didn’t want to disclose at first and eventually I did, but I always felt weird because people know my oddities when they work with me. I always felt like they didn’t quite understand me and I was always being misunderstood. So I guess in that sense I wish there was more of a general understanding of why Patrick and I have our particular mannerisms and social issues. So, yeah, it’s not really as much of a concern in the relationship aspect as it is more of our everyday lives as we live with autism.”
Below, Brad articulates that he would appreciate if society would accept him and Kathy as a unique couple and not pressure them to be a certain way:

“They can just be more understanding of who we are as a couple; that we are not going to fit anyone’s preconceived notions of what a marriage is supposed to be like. Because as I’ve said earlier in this conversation, Kathy and I have had to reinvent the wheel in practically every aspect of our marriage. I would just appreciate, I just want people to be more understanding of us as a couple because [the] preconceived notions they have, the ideas that most people have of a marriage would not work for us…I’ve never liked being told that our marriage should be this way or that. I don’t like it, because to me, that’s like being slapped in the face like being told that our marriage isn’t quote on quote perfect just because we have intellectual challenges. I’ve never agreed with that.”

I also get the impression that Brad would find it helpful for his relationship to be recognized and validated by society and not to be compared according to typical standards.

Although Penny does not directly state the need for professionals to be more knowledgeable and open toward the uniqueness and range of needs and desires that people with ASD experience, I would presume that her following statement is hinting in this direction,

“I think understanding how different people with ASD process information is helpful. Cause I think that when you first called me, there is the perception, actually Rachel’s psychologist has told us that people on the spectrum are asexual. Well, are they or aren’t they? I don’t know. I mean to me, it makes me uncomfortable when we categorize people into one ya know, there’s always exceptions to every rule.”

**Category 2: What is Challenging?**

**Theme 1: Autism Characteristics**

*Sub-theme: Sensory/Processing Issues*

An aspect of autism that differs from typically development lies in the way people on the spectrum may process information. It is common for people with ASD to experience delays, confusion, or to feel overwhelmed when processing information. Emotional or social information seems most likely to prove difficult to process. Processing may also prove difficult when experiencing too many sources of stimulation at once.
During our discussion, Brad and Kathy presented the idea that it would be helpful to have only one support staff present in their home at once because otherwise it is too overwhelming. Brad added to the conversation by disclosing his difficulty in attending to multiple things occurring at once. He expressed, “…and my mind, while I have a good memory, my mind does not process information all that fast and whatever they’re saying could get lost, it’s gonna to get lost in the shuffle.” I offered the analogy of too many staff coming into their house being like a tornado tearing through their house and Brad responded, “Exactly! That’s it! Exactly it! That’s exactly how it feels!” Brad shared his need to withdraw from the over stimulating environment as a result of feeling overwhelmed by too much external stimuli:

“Sometimes when I get too stressed out, when I get overwhelmed when there is just too much going on, I have to physically remove myself from the situation otherwise I’ll get mad, very mad. And I’ll admit there are times when I feel myself getting mad enough that I could use physical force, I have to step away. I’ve developed that coping mechanism because I could never live with myself if I used physical force on Kathy. So, whenever I feel like I’m getting mad enough that I could do that, I have to step away for a few moments. I believe it is wrong for a man, for anybody in a relationship to use physical force.”

Vivian disclosed some lingering psychological effects from her previous struggle with anorexia, specifically symptoms that are attached to or exacerbated by her autism including self-control, obsessive, and ritualistic tendencies. She explains that she cannot go out to eat spontaneously and that she often eats by herself as a result of the rigid routines that have been established around food. Below she clarifies that she is able to go out to eat when she has ample time to psychologically prepare for the event:

“I can do it [eat out] but I just need to have a little heads up at least a few days in advance, maybe a week in advance and then I’m fine, I’m totally fine…OK, how am I going to be comfortable going out to eat or doing this and that while we travel? I’ve [gotten]to the point where I’m able to prepare for that OK. But I need to have a little head’s up before.”
Sharon reveals that her son experiences greater difficulty processing social or emotional information at certain times than others. For example, she states, “Thomas is pretty hyper around his birthday and that’s when all the psychotic breaks happen.” Sharon expressed that Thomas had experienced a recent psychotic break as the result of being informed by a case worker that his services were potentially in jeopardy and that he may end up having to find a roommate. She elaborated, “He’s at the lowest functioning and the most severe without those things. So we’re dealing with two different Thomas’s too.”

Penny alludes to the delay in her daughter’s ability to process new information as a potential obstacle in her romantic and or sexual development.

“I’m just trying to get her to not use that as her reason to not [be sexually active], but I think that’s just a comfort thing to say that right now. The thing I worry about with her is that what I may be able to talk about with my other kids, adult kids, and it may take them a year or two to process, it may take Rachel 5 to 10 years [to process].”

Sharon guesses being sexually intimate may be far too physically and emotionally intense for many people with ASD to process:

“So, many of them [people with ASD] I believe are not able to participate with that much emotion or whatever would be going on during the act [sexual activity], ya know?...Well it’s overwhelming…A climax or whatever.”

Penny contributes somewhat to Sharon’s statement by speculating that perhaps certain unfamiliar feelings or sensations are frightening to her daughter:

“I think sometimes that foreign feelings are scary for her… I don’t know if this is OK or not, I’ve not had this before [speaking as if she was her daughter]…I’m just thinking and I’m just speculating here, but I’m just wondering if she starts to have some sort of arousal feeling like that, is [it]foreign? I’m not used to this [speaking as if she was her daughter].”

Sensory stimuli may be overwhelming in some cases and may result in the person experiencing sensory issues associated with certain stimuli. Vivian shares how her boyfriend’s sensory issues impact their ability to eat together or to go out to eat at times:
“Usually I need to eat by myself, I can’t be bothered. I don’t like being watched. I learned that Patrick is actually kind of similar in that sense, sometimes he has to eat alone or with a lot of noise or with background noise because he has a lot of sensory issues with a lot of loud chewing sounds.”

In the following passage, Vivian describes how sensory issues can impact a relationship when one or more persons with ASD are involved, particularly in terms of sexual intimacy. She also discloses how sensory issues may impact her and her boyfriend’s ability to be physically intimate:

“…I’m just saying that some people [with ASD] that I’ve talked to [have said that] the physical, sexual intimacy aspect has had to be altered or it’s very different. I guess the only thing that might be kind of different [for us] and I think that this applies to a lot of people on the spectrum, is our sensory issues and our sensory input. Because of that there’s going to be some areas of sensory where there’s going to be hypersensitivity, certain areas that might be overstimulated or that might get touched too much it can get too painful or too, I don’t know. With hyposensitive issues, some areas are kind of numb, so if an area is touched or massaged or caressed, it doesn’t really produce a reaction at all. I think that we all sort of have that, especially as far as people on the spectrum, and it varies with each person as far as where those hypersensitive areas and hyposensitive areas are. [However] as far as it is between us, there’s nothing highly unusual about our physical intimacy I don’t think… So if our sensory issues are not being met or if we’re having sensory violation areas, physical intimacy is tough [laughs].”

Sharon reflects on Thomas’ history of difficulty regarding physical touch. She talks about working with Thomas in order to help him become accustomed to loving family touch:

“Well I think he understands - with the Autism and the emotional side of that, there was a time where Thomas couldn’t even hug. He stood stiff as a board for a hug, pulling back. So, we’ve worked with him all these years to sensitize him to touch…so he could enjoy normal loving touch from family, appropriate to family, but then knowing for the future how difficult it could be. Thomas still is hyper-sensitive to touch [and] sounds, not as hyper as it was… so he’s got all of the sensory issues, I can’t even imagine what they’re all like.”

From reading this passage, one can walk away with the impression that people on the autism spectrum who experience sensory issues may be able to grow more tolerant of touch through consistent efforts; however, it would not suggest that sensory issues are possible to
overcome entirely. It’s as if the person with ASD, as with Thomas in this case, has a threshold for touch that is likely to be much lower than a typically developing person.

Sub-theme: Social/Communication Difficulties

Difficulty processing information may also be connected to the person with ASD’s ability to interpret and or interact with external or internal processes such as social information, verbal information, or internal thoughts and emotions. People with ASD are often task oriented and may have difficulty attending to multiple stimuli at once.

In the following passage, Brad expresses that he sometimes experiences difficulty reading his partner’s cues. He also touches on how his tendency to be task oriented can sometimes interfere with his ability to attend to his partner’s needs.

“And not knowing what she, sometimes I’m good at knowing when she needs a shoulder to lean on and sometimes I can be virtually blind to that fact…Yeah. And that’s real frustrating. That’s real frustrating to me. Sometimes I can be so focused on one thing that I, and that’s part of autism is that I can be single-mindedly focused on one thing and totally shut everything else out including her and I don’t like doing that but it’s just so hard for me to transition from one thing to another.”

Vivian hypothesizes that the social skills they learned growing up in order to make friends have helped her and Patrick to become better at communicating with one another and knowing how to be in a relationship. In the passage below, she also indicates that their communication is impacted by a delayed ability to transform their internal feelings and thoughts into verbal, communicative form with one another.

“So, I think that’s why we are able to, maybe we’re not always able to articulate verbally all the time and maybe it takes a little while sometimes to get our messages across, but we do get it out and we do try to remain open about how we feel.”

When I asked Charity if there was anything about being in a relationship that was difficult as a person with Asperger’s, she reflected on her dating history and talked about not being interested in dating until she was in her early twenties, which she perceived to be later than
most typically developing individuals. She shares her belief that the social barrier of shyness impeded her dating experiences initially.

“I didn’t start dating until I was 22 so that’s a big thing. You’re very developmentally delayed, like I just wasn’t interested in boys. I’ve always had guys that like had crushes on me, but it’s like I wanted to more be their friends in school than actually date them…I think shyness is a big one [difficulty with dating associated with having Asperger’s. And also just talking about stuff that is uncomfortable.”

Sally presented an example of a boyfriend in her daughter’s past having difficulty with what Sally perceived to be communication aspects of her daughter having Asperger’s:

“Some of the things that were wrong with the relationship were [due to] her Asperger’s, like he felt that she was too immature She’s pervasive delayed development and he felt like they didn’t talk things through well enough and he broke up with her and the next day came over and didn’t remember what he had done. And she held him to it and they stayed broken up…She felt like he couldn’t respect the way her brain worked.”

Penny shares an example of how communication between her daughter and her daughter’s boyfriend looks different than communication between two typically developing people:

“Well, one thing I’ve noticed, especially with the boyfriend that she is dating right now, is that they’re both, ASD. So the two of them can be having a completely parallel conversation but not interacting with one another. Like if there is a provider there or I’m there - a third person, the two of them are both talking to me, but they’re not really talking to each other. So it’s that [lack of] ability to connect with another person.”

In this example, it would appear to the onlooker that direct communication is not occurring between this couple and that they are either uninterested or unknowledgeable of how to attend to one another in a two-way, mutual conversation.

When asked what sorts of challenges she perceived her son to face in regard to his ability to be romantically involved, Sharon asserts:

“I think he’s got physical and I don’t want to say mental, but communication. Autism is a communication disorder, but it affects you mentally, I mean your abilities, you know.”
Sharon also expressed that her son has difficulty dealing with conflict and talks about how this may interfere with his ability to communicate openly within an intimate relationship. She says:

“So like intimate relationships, if they had a fight, I mean Thomas falls apart if there is yelling. We cannot yell, [or] even [use] stern voices. So, that’s a barrier to the relationship in the communication areas like that or the typical types of behaviors that people have.”

Theme 2: Living Situation

Individuals with ASD may receive supported community living services characterized by support staff working with them in their homes to support them with daily living tasks and to provide supervision to ensure their health and safety. These services can range from just a few hours a day to 24 hours of staff supervision. Such living situations often require the individual to live with additional roommates. The presence of staff and or roommates can limit the ability to have time alone or privacy when with a romantic partner.

Sub-theme: Roommates

In some cases, roommate restrictions or house rules interfered with the participants’ ability to have alone time or to have privacy. Sharon informs us of what dating can be like for a person who has roommates and the limiting impact that having roommates can have on a person’s ability to spend time alone with a partner.

“Her staff brought [her] over [to Thomas’ house] and they [staff and roommates] stayed with her the first time and they must get clearance from mom to report back to her that we’re not low lives that she’d be safe there. Cause then, they brought her and left her. Cause the three [roommates] have to do everything together, that’s when you start piling in roommates, ya all gotta go together, you all got to go do this [Impersonating staff talking]. And so they [staff] took them [roommates] somewhere else. She never invited him [over for dinner], she’s got three roommates involved, ya know?”

Charity expressed the opinion that sexual activity would be inappropriate in her home due to the presence of roommates. The participant felt that it would not be respectful of others
living in the house to engage in sexual activity and also did not feel that her living situation would allow sufficient privacy:

“No, I have 24 hours [of supervision/staff present] and also I don’t think it would be appropriate because I have roommates that have disabilities as well and like and I (inaudible) could be by myself. Somebody’s usually home.”

After Charity shared that she didn’t think having sex in her home was appropriate, I sensed that part of her discomfort could be due to a lack of privacy. I asked her if she felt that she had enough privacy if she did want to engage in sexual intimacy with her boyfriend in her home. She responded:

“Well one of the house rules because one of the other girls had some issues, is we’re not supposed to have the door shut with the boyfriends in the room…That’s the only restriction that’s their restriction that’s my restriction too. And I kind of agree with it because like, ya know, I live with other people and yes this is their house too and people are home a lot and I don’t want them to feel uncomfortable in their own house.”

There is a movement in the human services field to try to provide the least restrictive environment for adults with intellectual disabilities living in group homes or supported community living arrangements. Rights review committees such as Independence in Action annually review the rights restrictions of clients living in these environments to ensure that they are fair and that they are clearly connected to a health or safety concern. Sometimes, however, these rights restrictions are informal and may not be written up in a team approved plan, yet are requested by guardians and carried out by staff persons. In my past experience working with adults with intellectual disabilities as a support staff, I often witnessed situations in which team approved or ambiguous restrictions of one client would become rights restrictions for other clients living in the same house by default. For example, I worked with two young men who lived together as roommates. One could only eat out once every two weeks (per guardian’s request) and the other could eat out an unlimited amount. Because the other roommate could not
go out to eat and they both required 24 hours of supervision, the roommate who did not have a team approved restriction was also restricted as a result of his roommate’s restrictions.

Charity’s situation illustrates how the restrictions of another roommate can infringe on the rights of others living in the same house. In this example, Charity’s roommate had issues with having a boyfriend in her room. It was not Charity who had the issue, yet it has impacted her adult rights to have a sexual relationship with her boyfriend in her home. Charity expresses that she agrees with the restriction to an extent yet at the same time she also expresses her desire to have more alone time with her boyfriend and more opportunity to be sexually active with him. At other points during our conversation she remarks, “I like it [seeing Steve]. I don’t like not being around him, I get like Steve deprivation… I wish we could spend more time together and have more alone time. Charity is fortunate that her guardian is supportive of her having a sexual relationship and that her situation is likely to only be temporary until her boyfriend finds a different living arrangement and she can begin spending the night at his house again. Other adults living in similar circumstances may not have guardians or staff who are supportive of them having a sexual relationship; they may face certain restrictions that prevent them from having a physical or sexually intimate relationship and they may not have any recourse or refuge.

*Sub-theme: Protective housing/Supervision*

As a result of living in protective housing with staff supervision, Vicki and Charity were both limited in their ability to spend time alone with their boyfriends. In the next passage, Charity reveals her desire to spend more alone time with her boyfriend:

"He’s where he is and I’m where I am right now so we don’t get to do a whole lot of the fun stuff… like fooling around stuff… It’s kind of hard though when you aren’t able to spend a lot of time with each other. It’s hard to get in the mood and especially if you don’t have your own place so you can have that kind of relationship. But I know it’s coming."
Vicki expressed the desire to have more alone time with her boyfriend without staff present:

“Well, [at] some point in time, I don’t know [what] my mom would say [about] it, but us going on a one-on-one date, or even if it’s a date that I don’t have a staff sitting at my table. Us sitting at our own tables, even, say they’re sitting on the opposite side like over where he’s sitting [points to man across room] then we sat in our own area like this even if it’s across the area or something. We’d hopefully get to do stuff one-on-one kind of thing, even if it’s like going to a ball park so we don’t have to sit next to workers [support staff], sit a couple seats over…I don’t know if they would do that [allow one-on-one dates].

In the next passage, Sally expresses her decision making power regarding the amount of time her daughter is able to spend time with her boyfriend. She also shares her reasoning for setting limits in regard to how much time her daughter spends with her boyfriend.

“Because she lives in protective housing and I gave them permission, she lives in transitional housing and I am the guardian so if I say she could see [her boyfriend] three times a week, she could see [her boyfriend] three times a week and I said that she could spend the night with [her boyfriend] one night a week…And they seem to be happy with that…They don’t question it…Well I think it’s a good balance and I didn’t want them getting into that overly immature, where you [inaudible] boyfriend which a lot of normal kids in their 20’s go through in the early stages of romance where your practically living with the guy and you never go home and sleep in your own bed.”

**Theme 3: External Pressures**

**Sub-theme: Family & Religion**

In some cases participants expressed religious pressures that stemmed from their upbringing or family background. Below, Charity discloses the pressures that she felt from family and her Catholic faith not to have premarital sex:

“Growing up I was born Catholic and ya know, [inaudible] don’t give it away, gotta wait til you’re married. I had this one boyfriend it was stupid, but I lost my virginity. But, I like don’t regret it, ya know.”

She goes on to reveal the pressures she feels from family and the underlying concern she has that certain family members will not approve of her boyfriend because he does not share the same religious faith:
“He’s not Catholic so I know my Grandpa’s going to freak out. But (whispers) he doesn’t know that yet. He did, he did grow up -his mom was Lutheran so I don’t see what the big frickin deal is. And he never went to church and currently I’m not going to church [whispers] but Grandpa doesn’t know that. What he doesn’t know won’t kill him.”

Vivian’s experience mirrors the concerns that Charity faced regarding family/religious disapproval of premarital sex. In addition, she expressed feeling hesitant to talk to her parents about her relationships:

“In the past, dating experiences I’ve had, I was not open very much at all to talking about my past relationships with my family. I really didn’t want to share that part of my life with my parents or my relatives. And part of that was because I was raised in such a strict religious upbringing. We were at least with the religion we were practicing at the time. Things like dating before you’re 16 was frowned upon, and premarital sex is a huge sin according to the religion and just a lot of different things that were kind of forbidden or not talked about very much and so it was kind of a real pressure in that sense. So that was a big reason why I didn’t want to talk about it with them.”

In one participant’s experience, her partner’s mother encouraged sexual activity and this may have led her to feel somewhat pressured into engaging in physical or sexual behaviors with her partner.

“The fellow that she’s dating now he’s also on the autism spectrum. She made that very clear up front, ya know, I’m not interested in a physical relationship [speaking for daughter]. And she told that to [her previous boyfriend] too before they started dating. And umm [previous boyfriend]’s mom said to her, oh you’ll want to do that and umm, that’s just natural…”

Sub-theme: Societal Messages/Pressures

Charity asserts that society is responsible for creating discomfort around the issue of sexuality:

“Like the whole sex thing -I know talking with my friends who have it, they get all uncomfortable it’s like, it’s not a big deal! Ya know, we’re human beings, really? See, I’m not as uncomfortable as some of my friends…What’s so funny is that’s the way American society has raised us to be though -o be uncomfortable about sex and so part of it is then also the influence of society.”
Vivian acknowledges that not everyone will be accepting of people with ASD being romantically intimate and that people will continue to have their own judgments and biases:

“There’s always going to be people that don’t approve, there’s always going to be people who think that people who are autistic dating and having a sexual relationship is taboo and you’re going to face those kinds of critics, regardless…”

Brad expresses awareness of his and Kathy’s differences as a couple:

“I know we’ve always been different from other people…I just know that we don’t think in the same way as the average couple. We don’t think the same way…I know other couples have different ideas about sexual intimacy and society does too, but like I said, we’ve had to reinvent the wheel for it to suit us.”

In the passage below, Brad converses about the societal pressures he feels to be a perfect husband:

“Perfect husband. Basically that I’d be, well I guess it’s just a preconceived notion of what I’ve seen on TV shows and that sort of thing (sigh). Basically that they’re around for their spouses whenever they’re needed, that they provide anything they can for their spouses. But now I can see that that’s an ideal that is basically impossible to achieve. I said basically impossible, I didn’t say it was impossible, but I was saying that would be very difficult for someone like me to achieve. Basically because I have to do the best that I can for my wife within my abilities. I have to do the best I can for her with the abilities that I have.”

**Category 3: How is Intimacy Experienced?**

**Theme 1: Attraction**

*Sub-theme: Admiration/Appreciation/Liked Qualities or Characteristics*

When I asked participants what they liked about their partners, they responded by telling me about personal qualities that they liked about their partners, interests that they appreciated about their partners, or about their appreciation towards how their partner treated them. During my conversation with Richard, I asked him what he liked about his previous girlfriend, he replied, “Umm, she was nice.” After asking him if there was anything else that he liked about her, he responded, “She wears car shirts all the time. Like her Volkswagen shirt that somebody
made for her (unintelligible) Ghost Busters Volkswagen.” Richard clarified during a member check that he liked that she wore a t-shirt that had the Ghost Busters Volkswagen on it because he is a fan of that movie and because he likes cars.

As Charity was telling me about how she met her boyfriend, she mentioned his interest in Latin and she seemed to admire this interest of his and to be intrigued by it:

“He was talking about his Latin dictionary and I thought that was really cool.”

“Ya know and he also has a, How the Grinch Stole Christmas in Latin…But that’s, I just thought that was cool. That’s a book to have – How the Grinch Stole Christmas in Latin.”

When I asked Charity directly what attracted her to Steve, she mentioned finding him physically attractive:

“He was cute. And he kind of had long hair and I kind of like guys with long hair.” Later in the interview, while talking about Steve’s values, she indirectly mentioned another quality about him that she found attractive, “He’s a hard worker and I already like that about him and I don’t think that will change.”

When I asked Vicki what she liked about her relationship with her current boyfriend, she mentioned liking a personal characteristic and an admiration for some of his abilities:

“He has good humor and times and he likes sports. He knows almost every single player in football, what their position is. He also knows what causes, sometimes I don’t know what causes the crash on a race and he can tell me that. When we have the radio on I ask him who sings the song and he knows every single song in the book and also can say the year that it came out…Yeah, cause he knows about every single song on [the] radio…It’s quite the talent. And he can drive a car…”

As Vicki was talking about a previous boyfriend, I noted that they had a common interest and directly asked her if this interest is what attracted her to him.

V: “He liked cars, classic cars like I do.”
I: “So you had that common interest. Is that what attracted you to him?”
V: “That was, yes cause he owns a classic car.”
I: “So he actually drives one?”
V: “Right, owns one and drives it.”
In this experience, Vicki’s attraction was materialistic and tied to a common interest. Below, Brad directly expresses feeling attracted to Kathy based on the support she shows him:

“It’s just, I mean I think that’s another reason why I was attracted to her because Kathy has always been very supportive in her own way, just like I have been supportive of her in my own way. She’s been supportive in her own way. Like I said, we’re not the typical couple”

When talking about what attracted Brad and Kathy to one another, Brad shared an example of how he first became attracted to Kathy and expresses that he is still attracted to the same quality that first attracted him to her:

“I’ve got a story that I like to bring up. I’ve been doing volunteer work for the high school for almost 20 years now. She ran track in high school. She ran the, you’re going to have to correct me here if I’m wrong, Kathy. She ran the 100 and the 200 and I always thought that she had a lot of guts running varsity track. I always thought it took a lot of courage, a lot of guts. She always ran at her own heat, there was nobody competing against her, but still, I always thought she had a lot of guts running varsity track…like I said this was when I was still in high school but that’s the thing that has always stood out for me, is that, and she’s one of the most persistent women I’ve known… I also like how she doesn’t let anything get in the way of what she wants to do. I like that. She doesn’t let anything get in the way of what she wants to do, she will find a way around it…believe me, if there’s any obstacles get in her way, she’ll find her way around them.”

Vivian reveals that part of what has attracted her to Patrick was based on the way he treated her with a level of respect she had never experienced before:

“I think one of the main reasons why I’ve really just connected or gotten to fall in love with him was just because of the way he treats me… I’ve just never been with anyone in my life who treated me with such respect and such admiration.”

Vivian also shares her insight and perception that attraction is a natural experience for people with ASD:

 “…whether you are asexual; it doesn’t mean that you can’t develop an emotional attraction to someone or an emotional love for somebody. That is natural to us on the spectrum -falling for somebody, whether it be in a physical [or] emotional aspect and developing love and interest in pursuing somebody, but it’s the umm, concept of companionship that is uh, a concept that has to sort of be learned and cultivated.”

Theme 2: Expressions of Intimacy
While listening to participants discuss their experiences with romantic intimacy, I was cognizant of the fact that I was hearing a diverse array of ways in which romantic intimacy is expressed and shared across participants. A majority of the expressions of intimacy were unique to each individual or couple and did not fit tidily into one area. In addition, responses from participants did not seem to concentrate in any particular area of romantic intimacy and were rather, spread out across the different sub-themes.

Descriptions of romantic intimacy did not always fit specifically into one specific area. Descriptions often indicated the perception that romantic intimacy is something beyond sex and that it traverses different expressions of intimacy.

Vivian wisely recognizes that one definition of romantic intimacy cannot account for the diverse levels of intimacy that people experience:

“Well, every person will define it differently. I think that romantic intimacy comes in several forms. I think there is a physical aspect, there is a psychological aspect. I think there’s an emotional aspect. So, romantic intimacy is not just necessarily only reserved for like physical touching, sex, [or] whatever. But people [also] connect through conversation, or people connect through the heart or even if it’s non-verbal connection or non-touching, that can be romantic intimacy as well…I think we’ve experienced it in all the forms that I mentioned to you. We’ve definitely had an exchange of the physical aspect, the psychological aspect and the emotional aspect. [The different forms interchange with each other or combine.

When Charity was asked to define romantic intimacy and to talk about what it means to her, she responded that she had never really thought about it before. Within a minute or so, she responded:

“I guess just a lot of it is probably spending time with each other. Maybe kissing and hugging. Cuddling, maybe a little bit of, not really sex because sex is something different where being together I think is more romantic. ya know.”
Charity’s definition also traverses different areas of romantic intimacy and also directly suggests that it is something beyond sexual intimacy and that in some way sexual intimacy is distinct from other forms of romantic intimacy.

Sharon also divulged the perception that sexual intimacy is something different than other types of intimacy:

“So, and when you’re in a real relationship there is other intimacy besides sexual intimacy and that intimacy is friendship and being together and enjoying each other’s company and watching a movie at home together.”

Brad does not directly state that sexual intimacy is something different, however he does emphasize that he and his wife have had to develop their own design for intimacy that is beyond the general model for romantic intimacy.

“Generally I like to think, I try to support her in whatever ways I can. I mean, when it comes to the general idea of romantic relationships, I disregard whatever has been said because as far as I’m concerned we’ve had to develop our own way of doing things when it comes to having a relationship like we do. I mean the way I see it, I’ll just support Kathy in any way I can.”

Sub-theme: Physical

When asked how she and her boyfriend show each other that they care, Charity responded:

“Oh, we hug a lot. We’re not into PDA, public displays of affection. We do a lot of the making out and stuff like that behind like closed doors, but we hug a lot and we like, he likes to sit by me if we’re on the couch and stuff. So, people do know we’re a couple but it’s not like we’re like blatantly like oh my god like making out [where] it’s like, oh my god, really, can you please get a room?”

Vivian also shared some level of discomfort with PDA although it seems to have lessened over time. In the next passage, she also describes ways in which she and Patrick express intimacy in a physical way.

“I was never really into PDA, umm, and I, at first when I started dating Patrick, I noticed right away that he was much more affectionate than I was used to being and affectionate,
not in an intimidating way but in a very romantic way. He was far more [into] holding hands kind of deal, arm around each other when you are walking to places, or touching my face or pushing my hair, looking at me, just the little innocent kinds of affection. And it was so weird at first, but I did grow into it. So, he’s definitely far more affectionate in that sense and I’m more than willing to do it back, but he definitely initiates a lot… we certainly love to cuddle, we do it a lot. We love hugging, we do it a lot. We kiss a lot.”

As a part of her written member check feedback, Vivian added that she and Patrick “also love to give each other massages.”

Sub-theme: Sexual

When asked how she and her boyfriend experience sexual intimacy, Charity responded, “Well, we’ve obviously done it. The big it (laughs).” Vivian also shares that she and her boyfriend are sexually intimate. She says, “…It probably wasn’t a year into the relationship that we actually started becoming officially sexually active, so umm, we also are sexually active.”

Brad and Kathy talked about reinventing the wheel in many areas of their relationship. When I asked them how sexual intimacy was experienced between them or what it meant to them, they responded that physical closeness or cuddling was equivalent to sexual intimacy for them.

B: “Sexual intimacy. Sexual intimacy. Yeah I just think personally that is another area we have had to like reinvent the wheel so to speak.”
K: “There’s a lot of those [areas].”
B: “Yeah, we’ve just had to reinvent the wheel when it comes to sexual intimacy. I like to think that just being physically close is enough to be sexually intimate for us… basically as long as we are physically close, that to me is sexual intimacy, that to me is being intimate.”
K: “Especially when I know you’re in bed, cause then I just reach over and rub ya.”
I: “So do you guys sleep in the same bed?”
B: “Yes.”
I: “Do you cuddle?”
B: “Yes, we try to, yes. That’s our biggest idea of sexual intimacy.”

Sub-theme: Emotional
Brad describes that when he first met Kathy she was in need of emotional support in which he was happy and able to provide for her:

“…I just remember when I met her that she was going through a very difficult time in her life because there were several people in her life that she was very close to that had passed away so I provided the listening ear. I provided the listening ear for her and I would also say that I, I provided a shoulder to lean on.”

Sally highlights the role of emotional support in her daughter’s relationship:

“And I think for her, it’s more like that he is there emotionally for her. I don’t think it’s nearly as physical as it might be for other people. That’s what I’ve observed.”

Sub-theme: Intellectual

It could be reasonably deduced that common interests are a form of intellectual intimacy for couples on the autism spectrum. I chose to include common interests under the category: What makes it work, theme: Compatibility, sub-theme: Commonality based on the powerful message I was hearing from participants that common interests played a significant role in determining the compatibility of the partners as well as the success of the relationship. Nonetheless, I do feel that common interests deserve mention here since there does appear to be a connection.

During my interview with Richard, I asked what kinds of things he and his partner talked about. He responded, “Umm, like Amy did you get all kinds of Volkswagens lately? And she said, yeah.” When asked what made his relationship with a girlfriend romantic, Richard responded, “Her car collection, Volkswagen collection. Mmm-hmm.” This is a fairly blatant example of how the value of intimacy was directly related to common interests for this man.

Sally speculates that her daughter intellectualized sex at least in the early stages of her relationship:

“Well I think sex was more of an intellectual thing for her…She did like reading romantic novels and stuff like that, but it was something like an intellectual thing. And I
think when it gets to actual physical contact, she’s not a hugger. She’s not kissy with him when they say good-bye and stuff like that…Well, I think in the beginning, her interest was [intellectual], and when she crossed that threshold. I don’t know where she is at right now; she would have to tell you…”

One of Brad’s main interests is the weather and he shares that, “Often times she’ll [Kathy] ask me questions based on the weather forecast. She asked me for some advice this morning.”

Those on the autism spectrum report enjoy talking about their specific interests with others. Brad’s statement above also reveals that his wife actively seeks out his knowledge on the subject of weather and allows him the opportunity to discuss his interests. It could also be speculated that discussing his interests with his wife could be a way of connecting intellectually and experiencing an intellectual level of intimacy.

Sub-theme: Spiritual

The passages under this sub-theme can also be found under the sub-theme, Love and Spirituality. I found both sub-themes to be necessary since spirituality seems to play a powerful role in the success of a relationship as well as being an important expression in which romantic intimacy is experienced.

In the passage below, Vivian reveals a feeling of connection with her boyfriend when she first met him and before they officially started dating:

“Yeah, but I felt something, I felt there was something about this guy, I don’t know I thought that even as I dropped him off at the airport in Nashville but I thought there is something about this guy but I can’t quite put my finger on it, but I know we’re gonna somehow be in touch and somehow something, I don’t know. But I had gotten that weird feeling from the beginning.”

Brad and Kathy reflect on the mutual feeling that God brought them together:

“He decided to put us together…We know he brought us together because look how long we’ve been together. Like, because we, we balance each other out. He’s got the spelling
and math skills which I don’t have very well and I’ve got the social skills [gently smacks his head]. But he keeps getting better all the time.”

Sub-theme: Non-Physical/Non-Sexual

There were several descriptions of how romantic intimacy is not experienced specifically related to physical or sexual intimacy. Vicki shares that a previous boyfriend had tried to engage in a physical/sexual relationship with her and that she was not interested:

“Well, that and there’s been a guy that kinda wanted to try and do that stuff in my past dating... Yeah, cause I’m just not one of those people... Just like I was saying I wouldn’t want it to be that kind of a relationship that would want to do sex or any of that stuff... This one [referring to current boyfriend] I haven’t had any of that [referring to sexual intimacy]... The one that I was telling you, that one boyfriend kept [trying to do sexual things], so I didn’t really want to do that kind of thing though... Well, the thing was he would try to like touch me in areas I wouldn’t want to be touched... Would try to stuff I didn’t want to do and [be] touchy feely and all that.”

Penny describes how her daughter will arrange situations in order to avoid physical contact:

“But even like with the boyfriend that she has now, they typically don’t even sit on the couch together. He’ll sit in her lazy boy chair and she’ll sit on the couch... Yeah, and I think it’s because she doesn’t want the alternative, she doesn’t want to sit next to him.”

Penny shares additional information that her daughter and current boyfriend are not involved in a sexual relationship, “And this fellow she’s dating now, he’s told her he is fine with not having a sexual relationship.” She also explains the history behind her daughter’s disinterest and speculates that perhaps she uses this experience as justification not to be sexually intimate:

“I think that Rachel has one distinct memory in her mind of when she was molested when she was 15 and she actually doesn’t remember the exact age, I think she’ll tell you 13, but the point is... she uses that as a barrier to, ya know, I’m not going to do it because I was molested [speaking for daughter]. So, whatever that could be, [she will not do] anything more than kissing.”

Sharon guesses that her son may not be sexually interested based on his lack of self-masturbatory history and wonders if he may be physically incapable:
“I’ve never had a staff say they’ve interrupted Thomas masturbating, I don’t think he’s ever done that, I don’t think he has. I think he has a low hormonal level…So, he could have a problem with that.”

Theme 3: Affection

Affection can also be a way of expressing romantic intimacy. Affection can be expressed or experienced in physical, verbal, or emotional ways. Descriptions of affection included verbal expressions of love, pet names, talking fondly of one another, teasing, and flirting. Levels of comfort with affection ranged between partners; however, this is an area that partners expressed the ability to grow more comfortable with over time.

Sub-theme: Terms of Endearment

Charity shares that she and her boyfriend speak fondly of each other and expresses some surprise about being assigned a pet name by her boyfriend:

“Oh, like I say I love you and stuff, but I don’t know. We don’t like really say I love you, but we talk fondly of each other. But, I don’t know, we’re not like big into I love you. But, he’s like, hey honey, like on World of Warcraft®. I’m like, how did I become honey?

According to the statement below, Vivian and her boyfriend exchange verbal expressions of love:

“Especially like before we go to bed at night, we give each other a long hug and say we love each other.”

Vivian also expresses a feeling gratitude and feeling flattered as a result of the respectful and fond way in which her boyfriend talks about her.

“…at least the way that he treats me like the way he comforts me and the way he talks about me in front of other people. Even to this day, I’m blown away. I’ve just never been with anyone in my life who treated me with such respect and such admiration.”

Even to this day, I’m blown away.”

Sub-theme: Teasing
Several examples of good natured teasing were shared by participants in response to asking them about how they show affection towards one another. Charity shared the following:

“We giggle a lot...He teases me a little and I tease him back...I poke him. I like to poke him. I don’t know why I’ve started this, like I got in the habit of poking people. I’ve always been a poker. It got in my head to be flirty, you poke.”

Vivian shares a general example of how she and her boyfriend have fun together and tease one another:

“Sometimes, nothing really specific, but we just really enjoy laughing together, sometimes teasing each other, that connects us as well...it’s over silly things sometimes.”

Vicki and her boyfriend enjoy watching racing and differ in their driver preferences. Vicki shares how her boyfriend teases her about this difference:

“Yeah, but he likes to tease me about, like I like Gordon, he likes 48, which is who beat Gordon the other day and he likes Junior more,”

Kathy expressed not liking to be apart from Brad at night. Playing off of this, Brad will tease her in the following way:

“Well, I’m just going to use this as an example. You know I would never do this [talking to Kathy]. There are times I say I’m going to sleep on the floor or I’ll sleep outside by the railroad tracks and have the cats out with me, like I said I would never do that, I would never do that. It’s more like when I’m in a joking mood, but she knows darn well I’ll never do that.”

Sub-theme: Caring Acts

Participants revealed many ways in which they show their partner that they care and vice versa. Below, Richard briefly tells me about a couple of ways in which he and his previous girlfriend would show one another that they cared through helping behaviors.

I: “How did you show her that you cared?”
R: “She helped me with puzzles and stuff.”
I: “Show did you show her that you cared? What kinds of things did you do for her?”
R: “Umm, helped her.”
I: “Like with what?”
R: “The dishes.”
Vivian also expressed that her boyfriend shows her that he cares by assisting her with daily tasks or by carrying out favors for her:

“So, also when I ask him to do favors he is very willing to help me with favors and assist me with things if I need assistance… If I bring home a lot of things, he’ll ask me, ya know do you want me to help you get into your car? And, if I ask him, he might be willing to walk with me in the dark somewhere where I don’t feel comfortable walking alone. So a lot of unprompted favors and prompted favors he does are a very good indication that he cares.”

Charity also mentioned ways in which her boyfriend helps her with things. When I asked Charity what she liked about her relationship, she stated, “Well, I like having someone there to talk to and help me with stuff.” I asked her what sorts of things he helped her with and she responded, “Like with guy stuff, like I need you to help me open a bottle or like put something together, you know. That’s nice so like I don’t have to do it by myself.”

During our conversation, Vicki shared that she has a special affinity for candy. When I asked her how she and her partner show one another that they care, she responded:

“We get candy for each other…Like tonight he’s coming over to my house and he’s going to stop at Target and get those, have you had those coconut M&M’s?...”

When Vivian was telling me about different temperature preferences that she and her boyfriend have, she revealed another caring behavior when Patrick notices her discomfort and demonstrates consideration for her:

“I get very cold easily and he gets very hot easily. And when he notices I get very cold, he’ll like bring over a blanket or he’ll like set up a personal heater in my room without me even asking.”

Below, Vivian shares an additional way that she and Patrick have been able to demonstrate consideration towards one another in their daily lives:

“I tend to get startled very easily especially if someone enters the room and I’m kind of lost in my world. So, I get startled if someone just suddenly walks in. Having learned that between us, we’ve developed a little system where if he’s about to enter a room or enter into the apartment or house, he’ll do a little [makes a “psst” sound] and umm, he’ll wait
for me to do a [“psst”] sound back. We just exchange these little [“psst”] kind of sounds, so that turned into a very long lasting kinds of endearment, per se, because I’ll even do it myself even though Patrick isn’t one to get startled.”

Kathy revealed an appreciation for Brad’s consideration towards her well-being. She says, “Cause like if I need my wheelchair, he’s like, OK, go ahead, take it…He said, you have to bring your chair so you can get around today.” After Kathy said this, Brad followed up by saying, “I wasn’t taking any chances on it being slick because one wrong move by her in these conditions and…” Brad’s statement reflects his desire to protect his wife’s physical being. Additionally, Brad expresses that he makes an effort to be there for Kathy emotionally and overall he wishes that he could be more helpful towards her regarding household tasks:

“Well, for one, I provide her with a listening ear as much as I can. Two, I try to help her with the household chores, but frankly, I could be a lot better about that…I would like to be more helpful to her. That’s where I feel inadequate. There are times where I feel that I don’t do enough for her…That I don’t help her around the house when something needs to be done. That’s where I feel like I lack.”

Theme 4: Companionship

Sub-theme: Togetherness

Although many people with ASD require time to be alone, or separate from others, several participants in this study revealed a need or desire to spend time with their partners. Sharon believed that her son enjoyed spending time with his girlfriend. In her response below, she also indicates that he valued being in a committed relationship:

“Ah, holding hands, going and doing things together. All those things really interested them. He likes to say, ah, we’re boyfriend and girlfriend and Bridget’s the only one. Ah, and that was for several years.”

When asked what romantic intimacy means to her daughter, Sally reveals that her daughter is comforted by the level of closeness that she experiences in her current relationship and the fact that she has a partner:
“Well, she did not have a father and I think just having the closeness with a man is very valuable to her. Someone that she trusts, someone that she feels safe with because she did not have that growing up with a father…I think it’s very important to her because she feels that she has somebody and she does have somebody. I think it’s very important to her.”

Brad talked about his need to have individual time spent apart from his partner. At the same time, he also expressed valuing their time together as a couple:

“…Just so long as at the end of the day we can talk to each other and basically have time to ourselves - couple time….most of the time it can be very quiet for us. And some of the time it’s discussing the next day’s plans or, basically discussing how our respective days went, that sort of thing…We usually sit near each other.”

When Kathy talked about the early days of their relationship, she mentioned that they desired to spend a lot of time together:

“…and hung out at each other’s apartments. It’s like we kept going back and forth! Which, which one are we gonna be at today?!…We just enjoyed spending time together.”

Brad also brought up a special tradition that he and Kathy do together in connection to their church:

“And we’ve got, while we’re thinking about that, Kathy and I have a special tradition here at our church. We have soup suppers every Wednesday night while school is in session and on the Wednesday closest to our wedding anniversary we will make soup for soup supper. It is a tradition that started shortly after we were married and has continued ever since. We do that twice a year, once for our anniversary in October and also for my birthday in April.”

When I asked Vicki what it meant to her to be in a relationship, she responded, “Umm, to me [having a boyfriend] it’s like you’ll have other friends to hang out with other than not having anyone to hang out around.” Her statement could reveal that she values having someone to spend time with and that having a boyfriend prevents her from feeling lonely.

Vivian asserted that while people with ASD may need to isolate when feeling overwhelmed, overall, people with ASD want to be around others and do not want to feel lonely:
“…we don’t like to be lonely. Yeah, it’s kind of odd about people on the spectrum because I think [for] the vast majority on the spectrum we really like to have times where we are alone, where we need to isolate but we don’t like to be lonely. So in other words, the vast majority of us want to have friends. We want to feel like we’re loved and cared for by other people.”

On the other hand, there is the sense that companionship does not come naturally to people with ASD although other aspects of it such as not feeling lonely, mutual caring, and experiencing shared interests are highly desired by many. Vivian expresses the view that companionship is an art that people with ASD must become adept to in order to experience closeness.

“So, it’s that concept of companionship I think that is the challenge…But that is something that you have to learn and you have to keep cultivating and keep learning and keep growing in companionship and the idea of sharing a life together. That is kind of unnatural for us on the spectrum, cause we’re so independent in our ways and our thinking [and] all that. The concept of joining together in unison and all that, some aspects of that is still strange. So, it’s funny because we talk about someday maybe getting married, but we worry (laughs).”

Sub-theme: Knowing partner

While listening to participants speak about their partners, I was struck by how much was known about their partner’s habits, interests, backgrounds, or daily lives. Charity spoke to me extensively about her boyfriend’s history of homelessness and mental health and was even able to recall details about events going on in his life, “But now his hair is short but that’s cause he had a job interview and he needed to make it nice cause it was bleached blonde. So then he didn’t want to have roots [showing].”

I began to wonder how much she knew about her partner’s cognitive and emotional world. In response to my asking her what she thought Steve’s values were, she responded, “A lot of his is probably the same way [as her values]. His values growing up was very opposite of his mom] His mom was like a hippie and wasn’t the best mother but that’s not how he wants to raise
his kids. He wants to raise his kids like to be nice to people and treating people with respect…And being a good dad for them and stuff like that, which is pretty much the same way I feel if we were to like have kids.”

During my conversation with Richard, he freely shared knowledge of his previous girlfriend’s interests and habits. He mentioned, “She likes to play Uno Spin.” Later, as he was talking about her showing him her car collection, he mentioned, “She doesn’t collect movies though, because she sleeps through them.”

When asked how their relationships differed from other friendships, two participants explained that their level of understanding towards and knowledge of their partners was greater. Vivian says, “I guess we both, obviously you do have the sense that you both know each other very well when you and a partner are together and dating.” In the passage below, Brad echoes this opinion:

“I’ve had all this time to get to know her and know what her strengths and weaknesses are, I’ve had all this time to be as supportive to her as I have, though I realize I haven’t always been the quote, unquote, perfect husband. I really feel like I’ve had a lot of time to get to know my wife inside and out, although I have to admit, I’m certain there are still some things that I don’t totally know about her.”

I also observed Brad’s inside knowledge of Kathy’s family when Kathy was talking about her knitting hobby and Brad added, “That is a tradition on her dad’s side of the family. Her paternal grandmother used to do that but is no longer physically able to so the tradition was handed down to Kathy.”

When I asked Charity what was different about her current relationship with Steve as compared to previous relationships, she replied:

“I think Steve understands me more because like my other boyfriends had the idea in their head like to get me drunk to have sex with me. I’m like do you really, like they wanted to see me drunk [in disbelief] I’m like, really a person with Asperger’s drunk? I don’t think so.”
It is evident from Charity’s statement above that she had not felt as understood by previous boyfriends. She feels that her current boyfriend has a better understanding of her and of her experience with Asperger’s.
CHAPTER FIVE

Discussion

General understanding of romantic intimacy is based largely on the experiences and dominant discourses of typically developing individuals. The voices of individuals and couples with ASD have not been adequately represented in the literature in regard to their perceptions and experiences with romantic intimacy. Through this research, I sought to capture the voices of individuals with ASD. In addition, I set out to identify and draw connections between the voices of individuals with ASD regarding their experiences with romantic intimacy.

Through the data analysis process, I was able to identify three over-arching categories to capture the experiences and perceptions of individuals with ASD regarding romantic intimacy. In discussing my findings, categories and themes are explored in relation to previous research findings that are relevant to the findings of this research study. Implications as well as potential contributions of the findings will also be discussed in terms of how they could impact the literature in this area. Finally, limitations of the study as well as future research directions will also be discussed.

Characteristics of ASD include: “severe and pervasive impairment [in the development of] reciprocal social interaction skills, communication skills, or the presence of stereotyped behavior, interests and activities” (American Psychiatric Association, 2000, p. 69). Other characteristics of Autistic Disorder as listed by the DSM-IV include a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people. It is also possible that a person with ASD will have an encompassing preoccupation with one or more stereotyped and restricted pattern of interest that is abnormal either in intensity or focus.
In review of the *Commonality* sub-theme of my findings, the reader could find that many of the participants demonstrated characteristics of ASD regarding the presence of stereotyped or restricted patterns of interest that is abnormal in intensity or focus. Participants revealed unusual and potentially obsessive interests including cars, sports, super heroes and weather. However, not a single participant in this sample exhibited a disinterest in seeking to share their interests or activities with others. It was found that participants wanted to share their interests with others, especially with those who held their same interests. They sought and valued partners who also shared their interests or at least tolerated them.

Participants in this study were found to participate in joint focus and shared interest activities, such as going to movies, watching sports, playing video games, or going to car shows. Findings by Muller, Schuler, and Yates (2008) suggested that activities that revolve around shared interests or are structured are desirable for people with ASD since there is little need for improvisation and there is little talking beyond the exchange of information related to their specific interests. The findings within the sub-themes, *Commonality* and *Togetherness* seem consistent with the findings of findings of Muller, Schuler, and Yates (2008). Findings of this study may contribute to these findings by adding that people with ASD not only prefer these types of social settings with friends and acquaintances, but also with romantic partners and that they may seek romantic partners who will enjoy doing the same things that they enjoy.

As mentioned in the literature review section of this paper, individuals with ASD experience impairments in communication, social understanding, and emotional responsiveness (Travis & Sigman, 1998). These findings are reflected in the experiences and perceptions of participants in this study, however, participants also expressed attitudes of faith and feelings of hope and determination towards making romantic intimacy work in spite of such challenges.
Under the theme of **Dedication/Hard Work**, participants expressed determination in terms of **Accommodating** one another’s needs for space, separate interests and sensory issues. Building **Communication** which also included consulting with and collaborating with others were also expressed as necessary efforts on the parts of participants with ASD and guardian participants.

Participants in the study conducted by Muller et al. (2008) mentioned the benefit of having their social interactions facilitated by another person since they reported difficulty knowing when or how to organize or initiate social activity. This finding was also reflected in the experiences of one participant who had difficulty initiating contact with a romantic partner. In his case, he benefited from being paired up with a partner who was assertive in this regard. Otherwise, his mother played a monumental role in supporting him to carry out this integral step in pursuing and maintaining romantic relationships.

**Parental Involvement** in this study was found to play an important role in the participant with ASD’s romantic development. As a result of communication barriers and difficulties labeling and expressing emotions, some participants with ASD in this study had difficulty advocating on their own behalf and required assistance from guardians. Parent guardians in this study expressed the desire to see their child experience some level of normalcy in their lives in regard to romantic intimacy, specifically. Parent’s wanted their children to be involved in loving and caring relationships with a **Good Match**. Overall, parents wanted their children to experience the fulfillment of a romantic relationship and were willing to make special efforts in supporting their children to achieve romantic intimacy in their lives. **Parental involvement** in this study included parents taking on special roles as educators, encouragers and advocacy workers.

“Theory of mind” (TOM) describes the ability of a person to attribute mental states to the self and to others and to predict the behavior of others based on their mental states (Spek et
al., 2010). As described in the literature review section of this paper, individuals with ASD may have difficulty with “theory of mind” as a result of their difficulty interpreting social information.

In some ways the results of this study may support that difficulty with TOM may impact one’s ability to participate in a romantically fulfilling relationship. At the same time, findings may better support Belmonte’s (2009) argument that TOM is not universal and that the challenge for individuals with ASD is not an issue with theorizing about mind states as much as it is an issue with making the necessary connections so they can be in sync with others. The Autism Characteristics theme reveals the difficulties that some participants experience in processing social cues such as when a partner is in need of emotional comfort or in having give-and-take conversation. The findings within the sub-theme, Sensory/Processing Issues could also indicate that difficulty or delay in reading social cues is related to making connections at a different or slower rate than how typically developing individuals may process such information. Therefore, the social and communication difficulties experienced by people with ASD could be more indicative of delays or differences in processing such information versus the overall lack of ability to process such information as TOM suggests.

Moss and Schwebel’s (1993) multidimensional definition of romantic intimacy consists of commitment, affective, cognitive and physical closeness. Based on the assumption that people with ASD struggle with theory of mind or with making the necessary connections in sync with others as Belmonte (2009) describes, it could be speculated that people with ASD would have particular difficulty with affective and cognitive intimacy. However, findings from this study would suggest that individuals with ASD are in fact capable of entering the emotional and cognitive worlds of others as evidenced in the category, How Romantic Intimacy is Experienced.
and subsequent themes including *Emotional Intimacy* and *Knowing Partner*. Within these sub-themes, participants demonstrated emotional compassion towards one another and revealed knowledge of their partner’s feelings and values. Additionally, within the *Caring Acts* sub-theme, participants were found to show consideration and helpful attitudes towards one another. It could also be speculated that individuals with ASD are more likely to feel empathy towards others who they can identify with more literally through common experiences as identified in the *commonality* sub-theme of the category, What Makes it Work.

In further exploration of Moss and Schwebel’s (1993) definition of romantic intimacy, participants in this study demonstrated commitment either through marriage or prolonged dating. Participants demonstrated physical closeness in sub-themes, *Togetherness* and *Physical Intimacy*. Within these themes, participants expressed a desire to spend time with their partners, to engage in activities with them and to be physically or sexually intimate through various forms of physical touch or sexual activity.

A study by Siebelink (2006) revealed mixed results regarding participant’s interest in being involved in a committed relationship or in a sexual relationship. Findings related to sexual intimacy were also mixed in this study in which participants revealed a diverse range of experiences or non-experiences regarding sexual intimacy. Those who did not practice sexual intimacy revealed a disinterest in sexual activity, or experienced sexual intimacy in unique ways such as cuddling. Those who did practice sexual intimacy valued the place of sexual intimacy in their relationship.

Findings in this study were consistent with previous findings in a study by (Muller et al., 2008), in which participants with ASD revealed that being with others was necessary for their overall well-being and added that certain accommodations and supports can help them to be
successful in achieving a level of social interaction that is satisfying and meaningful for them. Participants in this study reflected the need for togetherness as well as separateness. Participants expressed a need and desire to be with their partners in the sub-theme, Togetherness and also revealed a need to isolate when experiencing Sensory/Processing Issues. Couples that were able to accommodate one another’s needs for Togetherness and separateness (via Accommodating) reported being more successful.

Participants with ASD in Muller’s (2008) study reported experiencing feelings of isolation, difficulty initiating social interaction, longing for greater intimacy, the desire to contribute to one’s community, and the effort to develop greater social and self-awareness. Participants in this study reported needing to isolate or withdraw socially when feeling overwhelmed, yet also disclosed not wanting to feel isolated from others. Participants also revealed a desire to have more alone time with their partners or to experience greater levels of sexual intimacy. Participants in this study also demonstrated great efforts in attaining self-growth and greater social and communication skills by seeking treatment, consulting with others or accessing additional resources. One participant also expressed the desire to learn how to be more helpful towards his partner and to become better skilled at reading social cues and responding to her emotional needs.

Previous research findings combined with the findings of this study challenge misguided assumptions that individuals with ASD are not interested or capable of being romantically involved. The experiences of participants in this study demonstrates that many individuals with ASD are likely to be interested in being romantically involved although they may need to work harder at acquiring the necessary social and communication skills to be romantically involved.
They may also require additional support, education or accommodations in order to make romantic intimacy a reality in their lives.

Through this study, I had also hoped to learn more about the influences that have shaped the understandings, experiences and expectations of romantic intimacy that people with ASD have come to develop. From the voices of participants in this study included in the sub-theme, *Societal Messages/Pressures* it can be surmised that the media and the larger society are partly responsible for reinforcing and delivering dominant discourses around romantic intimacy. Individuals and couples with ASD are not immune to feeling pressured by such messages and may feel potentially alienated as a result of not feeling that the messages are meaningful or relevant to their own unique situation or relationship.

It would stand to reason that parents of participants with ASD are also influenced by similar discourses around romantic intimacy and that these messages could influence their own attitudes and expectations for their child in regard to romantic intimacy. It was also revealed that people with ASD may be influenced or pressured by the expectations and messages that *Family and Religion* bring into their lives. Overall, *Parental Involvement* in the lives of the participants in this study was supportive and encouraging of their child being romantically involved. Majority of the participants in this study were currently involved in or had experienced successful, committed relationships. This finding could suggest that the positive attitudes of the caregivers have played a role in how the participants with ASD view their potential to be in a romantic relationship.

*Implications*

Several participants mentioned that seeking services from professionals who are specialized in ASD would be most helpful. This was posed as an intervention that would be
helpful in terms of individual, couples or family counseling. Participants emphasized the importance of the professional being knowledgeable about autism in order to be able to understand their situation and to be most effective in helping them.

Within our society, people with ASD are sometimes viewed as asexual. This perception can be reinforced or perpetuated by misinformed professionals in the helping fields and can lead to misguided professional guidance. According to one guardian, her daughter’s psychologist asserted that people with ASD are asexual. The guardian in this situation was skeptical of the psychologist’s words although her daughter does express disinterest in sexual intimacy. Upon reading this passage during a member check review, a different participant who is diagnosed with Autistic Disorder and is sexually active articulated the importance of finding professionals who are qualified in working with ASD. She commented through written feedback, “What needs to be made clear is that this psychologist that she saw is very likely not a qualified professional in the autism field. For a psychologist to say that people on the spectrum are asexual is an ignorant comment. It’s important to be clear that although there are some with ASD (and without ASD) who identify as asexual, there are plenty of people with ASD who are extremely sexual.”

Based on these findings, it is important for clinicians and other professionals in the helping fields to become knowledgeable about autism and stay informed of current research findings and controversies regarding autism. It is not the individual or the family’s responsibility to educate the clinician. Individuals with ASD and their partners and families are likely to feel understood and valued by clinicians who demonstrate sensitivity and take an active effort and interest in their autism and are more likely to view the clinician as competent and capable of helping them with their presenting issues.
One participant mentioned the benefit of consulting with or spending time with others who can relate to her personal experiences. A guardian participant emphasized the need to collaborate with the parents of her son’s partners in order to be most supportive of her son’s relationships. Another participant was mentioned to benefit socially and personally from attending a 12 step program. Organized support groups could provide participants with ASD and parent guardians the opportunity to come together with others that they can relate to and learn from. In addition, the structured environment and familiarity that would develop over time may provide safety and security for individuals with ASD.

As reflected in the findings of this study, many individuals with ASD experience social and communication difficulties. Regardless of these inherent difficulties as a result of the disorder, it is possible for the individual to develop their communication skills and to learn to better read and respond to the social cues of others. Participants in this study benefited from communication and social skills training through structured activities such as play therapy or through informational resources such as books. This finding suggests that early interventions as well as later interventions can help facilitate the social and communication development of the individual. Perhaps group workshops that would provide structured skills training as well as the opportunity for individuals to practice social skills would be most effective. Such a setting could have the added bonus of enabling individuals to meet prospective dating partners.

Individuals with ASD may experience difficulty initiating or maintaining social contact with their romantic partners. This lack of initiation may be misinterpreted as disinterest in being socially or romantically involved when it is often a result of the processing or communication/social difficulties that people with ASD may face. It has been found that structured activities around shared interests are appreciated by people with ASD and help to
facilitate the social involvement in which they crave. Therefore, it is recommended that support persons help the individual or the couple with ASD to arrange or participate in structured social activities that revolve around their common interests or in activities that do not require a lot of verbal interaction yet allow the individual with ASD to experience a sense of togetherness and or close physical proximity.

*Future Research*

Previous studies have found that a significant number of people with ASD desire to be romantically involved in some capacity. There was much variance across participants so that one participant may have mentioned experiencing physical and emotional aspects of romantic intimacy, denied any sexual intimacy and not have mentioned any other expression or sharing of intimacy whereas another participant may have only mentioned physical aspects of their relationship. This speaks to the unique and personal experience of romantic intimacy within this sample.

There appeared to be a lack of consistency or universality across participants regarding their overall understanding of romantic intimacy and how it is expressed or shared. Intimacy is a fairly elusive construct to explore overall and the findings of this research study would attest to that notion based on the researcher’s identification of several different *sub-themes* regarding the ways in which romantic intimacy is expressed or shared and the overall lack of universal experiences among participants. In addition, participants with ASD reflected on how their unique experiences with *Processing or Sensory Issues* can impact the way in which romantic intimacy is shared or expressed. This raises questions of whether romantic intimacy is perhaps experienced in even more diverse ways among individuals and couples with ASD than individuals or couples of typical populations.
Additional research could focus more directly on the ways in which romantic intimacy is perceived and experienced among individuals and couples with ASD in comparison to typically developing individuals and couples. Learning more about what is similar and what is different between these groups could contribute to greater overall understanding and validation of the romantic experiences of people with ASD as well as offer further insight into possible interventions and or accommodations that may prove to be more helpful for individuals and couples with ASD. In addition, such studies could provide information that could potentially confirm or dispel myths that people with ASD are less capable or interested in participating in romantic intimacy or that there is a greater incidence of asexual relationships than compared to members of the typically developing population.

It is difficult to conduct qualitative research with participants who have lower verbal or cognitive ability, yet at the same time, it is this group of individuals who likely face the most marginalization in our society and who could stand to gain the most from having their voices heard in the literature. Future research could implement creative means of reaching out to individuals who are less cognitively and verbally able in order to represent their voices in some capacity. Although their voices are missing from the literature and are difficult to collect, their experiences and needs are equally valuable and important to higher functioning individuals. Greater inclusion of the experiences and needs from this population could lead to improved supports and interventions that may help them to achieve a level of romantic intimacy in their lives that would be desirable and meaningful to them.

There were several statements that indicated a lack of perceived support from society as well as a host of responses from guardians and participants alike that indicated a desire for normalcy in terms of romantic intimacy and greater societal awareness and acceptance. Future
studies from a feminist, critical disability perspective could focus more in depth on the marginalization, societal messages, and pressures that are perceived and experienced for people with ASD and how they are individually and relationally affected by dominant discourses around romantic intimacy. Additionally, participants in this study expressed a desire for society to be more understanding and accepting of them as individuals and as couples. Therefore, it could be explored how greater social justice and support could be achieved for people with ASD and their romantic lives.

There was also indication of the physical manifestation of emotional distress among two of the participants in this study. Another participant experienced exacerbated mental health symptoms as a result of emotional distress. Future studies could investigate the relationship between the difficulties that people with ASD commonly experience in the processing and expression of difficult emotions and the appearance of physical or mental health concerns. The implications of such studies could guide and help improve supports and clinical interventions.

**Limitations**

The sample size for this study was small as is often the case in qualitative studies and therefore the results of this study are not generalizable; however, the aim of most qualitative research is to be transferable rather than generalizable (Bloomberg & Volpe, 2008). I have attempted to produce transferability by providing thick, rich description of the participants and by providing many of the participant’s actual words. The majority of participants were from a mid-western city and surrounding areas. Two participants were interviewed by phone and lived out of state. It was not possible for me to describe as much about the context regarding these interviews.
It is also worth exploring that in my work experience prior to organizing this study, I had encountered several parents and guardians of clients with ASD and other intellectual disabilities who avoided the topic of their child’s sexuality or established rights restrictions that would prevent their child from engaging in sexual intimacy. I commonly witnessed rights restrictions such as not allowing the client to have members of the opposite gender in their bedrooms. In another situation, a guardian of a client wanted to have him vasectomized lest he ever became sexually active in addition to other restrictions in place that restricted him from ever being unsupervised with his girlfriend.

Overall, parents in this study were supportive and encouraging of their children’s romantic and sexual involvement. In one situation in which the participant was sexually active and received 24 hours of supervision, her guardian had established protective limits around the amount of contact she could have with her boyfriend which impacted their ability to have a sexual relationship, but there was no direct account of a guardian restricting any participant with ASD’s rights to practice sexual intimacy all together.

The guardian participants in this study were highly supportive of their children being involved in romantic relationships and may not be representative of parent guardians at large. Additionally, all of the participants with ASD in this study were 29 years or older and it is possible that ages of participants could influence how open parent guardians are towards their child with ASD being romantically intimate. Parents of younger children may not have demonstrated such openness.

Because I interviewed three different types of participants (one couple with an ASD partner, four individuals with ASD and three parent guardians) and due to the small sample size, it is unlikely that I reached as much saturation in this study as I may have achieved had I been
able to interview more participants. At the same time, the topic of romantic intimacy is a highly personal experience for typically developing and non-typically developing people alike and this could account for much of the diversity of experiences and perceptions within this study. Additionally, a majority of the participants between guardians and participants with ASD in this study were female which is disproportionate to the actual ratio of individuals diagnosed with ASD since the rate of ASD is much higher in males. Participants in this study were all Caucasian and therefore the findings may not be culturally representative.

The eligibility requirements of this study called for participants who were capable of responding to open ended questions and who had been involved in a romantic relationship at some point in their lives. These requirements enabled me to gain rich information from participants and to learn about their lived experiences and perceptions regarding romantic intimacy. At the same time, these eligibility requirements discriminated against participants with less verbal ability or those who may be interested in pursuing romantic intimacy but had not yet experienced a romantic relationship. Therefore the voices in this study reflect the voices of higher functioning individuals with ASD overall while the voices of individuals with lower cognitive and verbal skills are not well represented.

**Conclusion**

Romantic intimacy may be challenging for people with ASD as a result of the social, communication and reciprocal difficulties that are commonly experienced by individuals with ASD. These characteristics may serve as barriers to experiencing a desired level of romantic intimacy with another. Other circumstances related to their living situation, societal or family pressures may also impede one’s ability or confidence to be involved in a fulfilling romantic relationship.
Despite such challenges that a person with ASD may face as a result of his or her disorder and due to circumstances beyond his or her control, the findings of this study indicate that if a person with ASD is interested in having a romantic relationship, such barriers are surmountable. Several features of a successful relationship have been identified via the stories and words of the participants in this study. These features have been identified through the compatibility of partners, dedication and hard work on the part of both partners, and through helpful external supports. The relationship of themes and sub-themes is illustrated in Figure 2.

**Figure 2**
**Connection of Themes**

The expressions of romantic intimacy are similar for people with ASD and for typically developing people. Participants described a range of ways in which romantic intimacy is experienced, expressed and shared including attraction, other expressions of intimacy such as
physical or emotional intimacy, affection and companionship. There was great diversity between the experiences of participants regarding how romantic intimacy is experienced across the expressions of intimacy that emerged from this study, yet all participants revealed that romantic intimacy was of significance in their lives in some way.

To summarize the words of one participant, Vivian, the experiences of attraction and love are natural for people with ASD. The findings of this study would support her assertion as well as add to it by declaring that people with ASD are in fact capable and deserving of experiencing romantic intimacy in their lives. It is necessary for caregivers, support staff and society at large to recognize and validate the reality of romantic intimacy as it is experienced and valued by people with ASD. It is the responsibility of those who are in influential positions to advocate on the behalf of individuals with ASD, to empower them, and to entrust a place for romantic intimacy in their lives.
REFERENCES


APPENDIX A

Member Checks

Instructions for Reviewer

Attached you will find my Preliminary Findings and Outline of Themes for your review as well as a Feedback Form. The Outline of Themes document is offered as a quick reference for how I conceptualized and organized my findings. The Preliminary Findings document includes all of the responses that I believed fit under these categories, themes and sub-themes and some preliminary explanations. The Member Check Feedback Form is a two-page document for any feedback you would like to offer.

Within the Preliminary Findings document, I have highlighted the initial for your pseudonym, Vivian = VN to enable you to quickly reference all of your personal responses. I would greatly appreciate if you would review your personal responses in particular and let me know if you feel that I have captured your words and meaning. I would also like to know if you feel that my interpretation of your responses make sense. Additionally, I would like to know if the way I have organized your responses according to the particular Category, Theme or Sub-theme resonates with you. An important aspect of the qualitative research process is the interpretation of findings – the ability of the researcher to read between the lines, so to speak. It is very important to me that I have captured and represented your responses in a meaningful way that resonates with you.

In an effort to make my findings more credible and trustworthy, I have used exact quotes without any editing. This means that your statements will have grammatical errors because that is the natural way that we speak. Please keep this in mind as you review your responses and do not be concerned about editing your responses in any way. My purpose in checking in with you is to make sure that I have appropriately captured what you have said and that I have interpreted your statements in a way that makes sense to you, or that resonates with you.

In the Preliminary Findings document, you will also find responses from other participants. Please feel free to review these as well and let me know if you think that the way I have interpreted them or the themes that I have applied to them make sense to you. If you can think of other interpretations or themes that you think would be more appropriate or fitting, please feel free to share your ideas.

In addition, I have included all other participant’s responses for your review. The sample for this study included 8 participants that consisted of 4 individuals diagnosed with ASD, 1 couple in which the male is diagnosed with ASD and 3 guardians of participants with ASD. If you are interested and willing, I would also greatly appreciate your feedback regarding how I have interpreted and organized my findings overall. Please refer to the second page of the Feedback Form to offer feedback in terms of my overall findings.

I should also mention that the documents I am sending you have not been through the editing process in terms of my own writing. This is essentially a “rough draft” of findings and my
current goal is to get these findings to you as quickly as possible to give you time to review them. Please do not feel that you have to give feedback in terms of my writing, unless you really feel compelled! 😊

Overall, I am interested in any additional input or perspective that you would like to offer at this time regarding your own personal responses or my overall findings. I will consult with your feedback as I continue to explore, reflect upon and refine my findings.

Timeline

My defense date is quickly approaching and I have to submit my thesis on June 15th! Therefore, I am asking to receive all feedback by Saturday, June 11th by 12pm or sooner. That is one week from today.

I would like to thank you for your willingness to review my findings and to participate in this study overall. Your voice has been very important in this process and I look forward to hearing more from you!

If you would only like to provide feedback regarding your own responses, simply complete the first page of the Member Check Feedback Form for “Personal Responses.” If you would like to give additional feedback regarding my findings overall, please complete the second page of form as well “Reflection of Overall Findings.”

Feedback Form

Please indicate below if you are a Participant with ASD, Couple with ASD or a Guardian of a Participant with ASD:

- [ ] Participant with ASD
- [ ] Couple with ASD
- [ ] Guardian of Participant with ASD

Please write your Pseudonym and/or Initial below:

_____Vivian_____ Pseudonym/Initial

Personal Responses

(My responses are in red)

1. How did I capture what you said? – Were there any interpretations in which I hit the nail on the head? Were there any interpretations in which I missed the mark? Were there any interpretations that left you wondering?

It is difficult to tell at this stage in your Preliminary Documents. The categories, themes and sub-themes are outlined as well as direct quotes from all the participants. But it is difficult for me to capture what you are trying to interpret or how the final version of these documents will be presented. Perhaps when it all starts coming together, the interpretations you are trying to express will be more clear to me.
2. **What made sense to you?** – What stood out for you? What resonated with you?
My quotes you highlighted on companionship resonated. I also think you captured the topic of sensory issues well.

3. **What differing perspectives did you have?** – What didn’t make sense to you? What do you feel like I could have said, interpreted or conceptualized differently? What different ideas did you have?

**Category: What makes it work?**

**Sub-theme: Love**
VN: “I’m not going to lie, that has also been an issue, that’s challenged us too many times.”
I can not recall what in particular we were talking about at that moment. But I don’t believe I was referring to “that” as love. Part of the quote was left out here somehow. I have added the rest of the quote. VN: “...so I guess the particular feeling of love is not fake...”
We are born with the capability to love, and to feel love. **Incorporated into results**

**Sub-theme: Trust**
VN: “I didn’t know what [my parents] would think about [us moving in together] before we got married...”
Trust was one component, but the larger concern I had was to do with religious upbringing and previous religious practices. Trust might fit in there, though. I moved this into the **Sub-theme: Family and Religion**

**Sub-theme: Accommodating – honoring separateness, sensory issues**
VN: “...we’re both into our own styles that it’s great where we could have a bedroom...”
Clarification: “our own bedrooms” added [our own]
VN: “...if we are in a situation where we are kind of enclosed in a place or not having enough space, that can be challenging as well.”
Clarification: Not having enough space can aggravate sensory issues and make the accommodating process more difficult to honor. **Incorporated into results**

**Sub-Theme: Building communication/social skills**
VN: “sometimes it’s not always going to go your way, kind of deal, before you can successfully date or pursue and it has to go both ways.”
Clarification: Both partners have to put in the effort. I have previously clarified this in my own words

**Sub-theme: Professional support/treatment**
VN: “I think it would be beneficial once in a while if there was a relationship counselor kind of that we knew about that maybe umm, had an understanding of the spectrum and relationships. Ya know, every once in a while, even healthy relationships need that.”
What I have also found beneficial is networking and talking with other adults on the spectrum who have had their fair share of relationship and/or marriage experiences. **Added this**

**Category: What is challenging?**

**Sub-theme: Communication/social difficulties**
VN: “...each person has their own particular sensory inventory issues.”
Clarification: “each person has his or her own particular sensory sensitivities.” **Am not using this quote in final draft**
Sub-theme: Sensory issues
VN: “I guess the only thing that might be kind of different and I think that this applies to a lot of people on the spectrum…”
Clarification: “One factor that makes us different (and I think this applies to a lot of people on the spectrum)…”
VN: “So, yeah, in that sense, as far as it is between us, there’s nothing highly unusual about our physical intimacy I don’t think…”
Clarification: “However, as far as it is between us, there’s nothing highly unusual about our physical intimacy…” Clarified in brackets

Sub-theme: Physical
VN: “We certainly love to cuddle We love hugging, we love kissing…”
We also love to give each other massages. Added

4. What additional input or reflection might you have? - Did I miss anything? Is there more that you are thinking about now?
Were you only going by the particular quote snippets that were on the Preliminary Documents, or were there additional quotes / info you were going to add to the final version? If you were only going to use the quote snippets, I would suggest providing at least a little background about the participants so the reader can follow their stories better. (Background information that would not reveal the participants’ identities, of course). I am going to edit the quotes by deleting “umms” and false start-ups, and by tidying up fragmented speech. Thank you for bringing this to my attention.

5. Any other comments you would like to share?
As far as our quotes – I know you had mentioned that we don’t worry about editing them for grammatical errors. Will they be edited in your final version of your findings? My assumption is that you had planned on doing that but just wanted to make sure. Some of my quotes definitely don’t sound clear with the grammatical tidbits of my speaking voice.

Reflection of Overall Findings
1. How did I capture what the participants said? – Were there any interpretations in which I hit the nail on the head? Were there any interpretations in which I missed the mark? Were there any interpretations that left you wondering?
   As mentioned earlier, it is difficult for me to tell at this point, as they are just direct quotes from the participants.

2. What made sense to you? – What stood out for you? What resonated with you?
   I have to admit it was difficult for me to tell at this stage. However, I found myself very interested in the personal perspectives that each participant had to share. The stories they contributed are valuable to the topic of relationships. I like how we each are coming from a different place because that just validates the fact that every individual on the spectrum has their own unique perspective to share. There’s no “one-size-fits-all” strategy to one’s personal skill building towards achieving successful friendships and relationships. I’m going to incorporate your reflection on this in my Discussion section, I think. Thanks!
3. What differing perspectives did you have? – What didn’t make sense to you? What do you feel like I could have said, interpreted or conceptualized differently? What different ideas did you have?

I wish there was a slightly better explanation on the participants’ background or history. It was hard at times to follow along with their quotes and to connect them all because they were scattered and did not have a background for me as the reader to fall back on. There will be! ☺

One quote from “P” really stuck out...

P: “I think understanding how different people with ASD process information is helpful. Cause I think that when you first called me, there is the perception, actually Rachel’s psychologist has told us that people on the spectrum are asexual. Well, are they or aren’t they? I don’t know. I mean to me, it makes me uncomfortable when we categorize people into one ya know, there’s always exceptions to every rule.”

What needs to be made clear is that this psychologist that she saw is very likely not a qualified professional in the autism field. For a psychologist to say that people on the spectrum are asexual is an ignorant comment. It’s important to be clear that although there are some with ASD (and without ASD) who identify as asexual, there are plenty of people with ASD who are extremely sexual. Would also love to incorporate this in my discussion if it works!

4. What additional input or reflection might you have? – Did I miss anything? Is there more that you are thinking about now?

5. Any other comments you would like to share?

I’m really looking forward to reading the final version of your research findings! I will email you with them once I have passed my defense!

THANK YOU!!!!!
APPENDIX B:

IRB Letter of Approval

IOWA STATE UNIVERSITY
OF SCIENCE AND TECHNOLOGY

Date: 10/4/2010
To: Haley Wedmore
4323 Ovid Ave
Des Moines, IA 50310

From: Office for Responsible Research

Title: Autism Spectrum Disorder and Romantic Intimacy
IRB Num: 10-383

Approval Date: 9/28/2010
Continuing Review Date: 9/27/2011
Submission Type: New
Review Type: Full Committee

The project referenced above has received approval from the Institutional Review Board (IRB) at Iowa State University. Please refer to the IRB ID number shown above in all correspondence regarding this study.

Your study has been approved according to the dates shown above with the contingency that approval is obtained from Homestead prior to commencing research there, and a copy of the approval letter is sent to our office. To ensure compliance with federal regulations (45 CFR 46 & 21 CFR 50), please be sure to:

- Use only the approved study materials in your research, including the recruitment materials and informed consent documents that have the IRB approval stamp.
- Obtain IRB approval prior to implementing any changes to the study by submitting the "Continuing Review and/or Modification" form.
- Immediately inform the IRB of (1) all serious and/or unexpected adverse experiences involving risks to subjects or others; and (2) any other unanticipated problems involving risks to subjects or others.
- Stop all research activity if IRB approval lapses, unless continuation is necessary to prevent harm to research participants. Research activity can resume once IRB approval is reestablished.
- Complete a new continuing review form at least three to four weeks prior to the date for continuing review as noted above to provide sufficient time for the IRB to review and approve continuation of the study. We will send a courtesy reminder at this date approach.

Research investigators are expected to comply with the principles of the Belmont Report, and state and federal regulations regarding the involvement of humans in research. These documents are located on the Office for Responsible Research website http://www.compliance.iastate.edu/ehforms/ or available by calling (515) 294-4566.

Upon completion of the project, please submit a Project Closure Form to the Office for Responsible Research, 1138 Pearson Hall, to officially close the project.
APPENDIX C

Email to Agency

Hello,

Thank you very much for returning my call and I apologize that I wasn’t able to get back to you sooner! I am a master’s student in the Couple and Family Therapy program at ISU. I am conducting a qualitative study for my thesis research and I am exploring how people with Autism Spectrum Disorders (ASD’s) experience and perceive romantic intimacy in their lives.

I’ve become interested in this area based on my years of experience working with individuals with disabilities and I have observed that despite the barriers that people with ASD face in developing and maintaining intimate relationships due to impairments in communication, social understanding and emotional responsiveness as well as society’s overall misconception that people with cognitive disabilities are asexual or incapable of having intimate relationships, many disclose the desire to be in romantic relationships. Previous research has suggested that although people with ASD may face challenges in developing intimate relationships and may perceive intimacy differently (e.g. they may value affective characteristics of intimacy less), they report greater overall well-being and less loneliness when involved in intimate relationships.

Although romantic intimacy is a very important part of the human experience, little research attention has focused on adults with ASD and there is an overall lack of voice from people with disabilities in the literature. Through my research, I hope to develop/proposal a multidimensional definition of what romantic intimacy is for people with ASD and to provide family members, service providers and clinicians with information and possible interventions that would be helpful in supporting people with ASD to pursue and maintain romantic relationships in a way that is meaningful for them.

I am looking for 6-12 participants who are diagnosed with Autistic Disorder, Asperger’s Disorder or PDD-NOS to be interviewed about their romantic relationship experiences and their feelings and thoughts about romantic intimacy. I will ask for information regarding their romantic experiences overall, and because sex is an aspect of romantic intimacy, I will ask for information regarding their sexual experiences as well (basically whether or not they have had them or would want them and any other information they would feel comfortable to disclose), what barriers they may perceive towards accomplishing romantic intimacy in their lives and what would be helpful to them in regard to interventions/external supports. It would be great to find couples, although that is not a requirement. If and when possible, I would like to interview a close relative/guardian/caregiver to help supplement the information I gain. I’m looking for more capable (higher functioning) individuals who have sufficient verbal ability and cognitive ability to respond beyond “yes/no” questions and who could speak in a meaningful way about their experiences and beliefs. Of course, I will have to get signed consent from participants and their guardians if they are not their own guardian.

After giving you a little more information about what my research entails, I would like to ask 1) for permission to distribute flyers around campus inviting residents to participate, 2) to contact
residents to ask them to participate in my study, and 3) to ask staff to invite residents to participate in my study. Because I am using human participants, I will need to have my research approved through the IRB. They need a letter saying that I have contacted you about my proposed research project involving adults with ASD. If granted permission, would you be able to send me a letter outlining the 3 permissions written above and written on official letterhead and signed by the appropriate person to grant such permission? This letter will be reviewed, along with all other materials for this study by the Institutional Review Board who will grant me permission to begin my study after finding it to be ethical and to pose minimal risk to participants.

I would also like to mention that although I am not a mandatory reporter in my role as researcher, I will use my own discretion if presented with information of suspected dependent adult abuse and I may report such findings to DHS.
APPENDIX D

Letters of Agreement

I omitted identifying information using the erase option in Microsoft Word Paint.

July 7, 2010

To whom it may concern,

This letter will serve as verification that Haley Wedmore has contacted me about her proposed research project involving adults with ASD. I have granted the following permissions:

- To have Haley Wedmore contact residents at Candeo to ask them to participate in her study
- To place flyers around Candeo inviting residents to participate
- To ask staff to invite residents to participate in her study.

Please contact me at (should you have any questions) regarding this arrangement.

Best regards,

Chief Executive Officer
APPENDIX E

Flyer

**Volunteers needed to participate in a study to learn more about how adults with Autism Spectrum Disorders perceive and experience romantic intimacy**

Are you over 18 years of age and have you ever been in a romantic relationship? Do you have a diagnosis of Autistic Disorder, Asperger’s Disorder or PDD NOS?

Are you able and willing to speak openly about your experiences, thoughts and feelings about romantic intimacy? Do you want to share ideas for how family members, service providers and clinicians can help you to be involved in a romantic relationship in a way that is meaningful to you?

If you answered YES to these questions, you may be eligible to participate in a study about Autism Spectrum Disorder’s and romantic intimacy.

This study is being conducted by Haley Wedmore, a graduate student at Iowa State University.

Please contact Haley for more information about this study or to schedule an interview.

Phone: [Redacted]

Email: [Redacted]
APPENDIX F

Interview Script

Interview questions for individual participants with ASD (main participants):

Questions for Couples with ASD:

How did you meet?

What is your relationship like with your partner?

What types of things do you like to do together? What is romantic intimacy to you? How do you experience it as a couple? What do you like/value about your relationship? How would you like it to be different? How are your ideas about romantic intimacy similar or different? How would you rate your relationship satisfaction overall? How is it different from your relationships with other people?

How is your family or your caregivers supportive of your relationship? What led you to decide you wanted to be in this relationship? What can you say about other people’s romantic relationships? (friends, family, famous couples)

How do you show your partner that you care? How do you express affection with your partner? (Hold hands, sit close, kiss, have sex?)

How have you experienced sexual intimacy in your relationship? What is sexual intimacy to you? If you haven’t experienced sexual intimacy, is it something you want? Are you satisfied with the physical/sexual intimacy you have in your relationship?

If there are things that make it difficult to be in a romantic relationship, what are those things? What would make your relationship better? What are your dreams as a couple?

What would be helpful for you? How can others support you in your relationship?

What advice would you give to other people with ASD who want to be in a romantic relationship? What advice would you give to their family/caregivers?

Questions for Individuals with ASD in a current or recent relationship:

How did you meet?

What was/is your relationship like with your partner?
What types of things do you like to do together? What is romantic intimacy to you? How do you experience it as a couple? What do you like/value about your relationship? How would you like it to be different? How are your ideas about romantic intimacy similar or different? How would you rate your relationship satisfaction overall? How is it different from your relationships with other people?

**How is your family or your caregivers supportive of your relationship?** What led you to decide you wanted to be in this relationship? What can you say about other people’s romantic relationships? (friends, family, famous couples)

**How do you show your partner that you care?** How do you express affection with your partner? (Hold hands, sit close, kiss, have sex?)

**How have you experienced sexual intimacy in your relationship?** What is sexual intimacy to you? If you haven’t experienced sexual intimacy, is it something you want? Are you satisfied with the physical/sexual intimacy you have in your relationship?

**If there are things that make it difficult to be in a romantic relationship, what are those things?** What would make your relationship better? What are your dreams as a couple?

**What would be helpful for you?** How can others support you in your relationship or to be in a relationship?

**What advice would you give to other people with ASD who want to be in a romantic relationship?** What advice would you give to their family/caregivers?

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**Questions for Individuals with ASD not in a current or recent relationship:**

**How did you meet your old partner?**

**What was your relationship like with your partner?**
What types of things do you like to do together? What is romantic intimacy to you? How did you experience it as a couple? What do you like/value about your relationship? How would have wanted it to be different? How were your ideas about romantic intimacy similar or different? How would you rate your relationship satisfaction overall? How is it different from your relationships with other people?

**How was your family or your caregivers supportive of your relationship?** What led you to decide you wanted to be in that relationship? What can you say about other people’s romantic relationships? (friends, family, famous couples)
How do you show your partner that you care? How did you express affection with your partner? (Hold hands, sit close, kiss, have sex?)

How have you experienced sexual intimacy? What is sexual intimacy to you? If you haven’t experienced sexual intimacy, is it something you want? Were you satisfied with the physical/sexual intimacy you had in that relationship?

If there were things that made it difficult to be in a romantic relationship, what were those things? What would have made the relationship better? What were your dreams as a couple?

What would be helpful for you? How could others have better supported you in your relationship? How could others support you to be in a relationship now?

What advice would you give to other people with ASD who want to be in a romantic relationship? What advice would you give to their family/caregivers?

Questions for Caregivers:
What are your observations and perceptions of how the participant with ASD experiences, understands and values romantic intimacy? What does it mean for him or her to be romantically intimate with another person? What do you suppose he or she values about romantic intimacy? What does it mean for him or her to be sexually intimate with another person? How important to him or her is it to be in a romantic relationship or to experience sexual intimacy?

What internal or external barriers do you believe may interfere with the participant with ASD’s ability to be romantically intimate? Other challenges?

What strengths do you believe he or she has that may contribute to him or her having a successful romantic relationship? What personal qualities might he or she have that are helpful?

What are your thoughts or feelings about the person being involved in a romantic relationship or a sexually intimate relationship?

In what ways have you been able to be supportive or not supportive of him or her being in a romantic relationship? What challenges do you face? What fears or concerns might you have?

What would be helpful for you as a caregiver in supporting the participant with ASD to be in a romantic relationship?
What advice would you give other caregivers?
APPENDIX G

Interview Summary Forms/Analytic Memos

ASD Interview Summary Sheet/Quick Transcription Notes/Analytic Memo

**Date of interview:** November 24\textsuperscript{th}, 2010 (Audio recorded initial observations and thoughts immediately following the interview).

**Today’s date:** November 27\textsuperscript{th}, 2010

**Location:** Collegiate Methodist Church in Ames, IA

**Code for Interview:** Couple1Interview11-24-10

**Interviewer:** Haley Wedmore

**Demographic Information:**

Relationship History: Couple has been married for 12 years, dated for about 1 year prior to getting married. Have two cats and no children.

Husband: Caucasian male; 34 years old; 2 year degree in Office Technology; Autistic Disorder but suspects that he has Asperger’s; employed as a school crossing guard about 10 hours a week, volunteers at the library and for a basketball team.

Wife: Caucasian; 33 years old; ADHD and CP; High School; employed as a school crossing guard about 10 hours a week; sells and donates some of her knitting; husband suspects that she has ASD but could not articulate why he suspects this.

Services: Wife receives some residential and day services. Both received some SCL services up until about 2 years ago. Husband receives no services currently.

**Observations:**

Husband shook my hand, spoke in a low soothing voice, seemed rather intelligent, spoke more than his wife and seemed a little annoyed with her a few times when he thought she was misinterpreting my questions, made very little eye contact and appeared to have his eyes closed during most of the interview. He also repeated what his wife said when I could not understand her words. They did talk over each other several times throughout the interview. The husband would be talking and the wife would interrupt and he would either seem somewhat annoyed and stop talking or would keep on talking.

Wife arrived approximately 15 minutes late using a wheelchair, spoke in a louder, more energetic voice, knitted through most of the interview, made direct eye contact when she spoke.
Interaction of the Couple: They seemed to know a lot about what goes on in each other’s lives (what they do at work, where family traditions come from, when they are going through difficult times – death of family members). He rubbed her back once during the interview. She smacked his head at the beginning of the interview in a joking manner and again lightly when commenting that she was more socially competent. Overall, their interaction seemed endearing and they each were able to point out strengths in one another. She appreciates how he is supportive of her (helps her with his wheelchair). He is impressed with her “guts” and “persistence.” They seemed appreciative towards one another when talking about ways that they help one another. She helps him to remember to look for his visual signs when he doesn’t know where things go or where to find things. He appreciates how she helps him with household tasks.

What are the main perceptions, ideas and values expressed about romantic intimacy?

What is your relationship like? Husband: “I try to support her in whatever ways I can. When it comes to the general idea of romantic relationships, I disregard whatever has been said because as far as I’m concerned we’ve had to develop our own way of doing things when it comes to having a relationship. We’re obviously not an average couple, we just happen to have intellectual disabilities, but I don’t see that as imperative to our relationship, at all. We may have those challenges, but we go around them.”

What do you value about it? “I have someone to talk to…to be generally supportive of me…supportive of each other in our own ways.

What are the main explanations for how intimacy is expressed?

How do you show that you care about each other? “I provide her with a listening ear. I try to help her with the household chores, but frankly, I could be a lot better about that.”

How do you show each other affection? Sometimes when she’s feeling down I will hug her, sometimes I’ll even get the cats involved” (While rubbing her back) says he also does this to show that he cares.

How have you guys experienced sexual intimacy in your relationship? Husband: “Sexual intimacy, sexual intimacy…I just think that personally, that is another area we have just had to like reinvent the wheel so to speak. Wife: There’s a lot of those [areas]. Husband: I like to think that just being physically close is enough to be sexually intimate with each other. Wife: “especially when I know you’re in bed, cause then I just reach over and rub ya.”Husband: “I know other couples have different ideas about sexual intimacy and society does too, but like I said, we’ve had to reinvent the wheel for it to suit us.”

So what does it mean to your relationship to be sexually intimate? Husband: “Basically as long as we are physically close, that to me is sexual intimacy, that is intimacy. Wife: And we try to
stay that way because if we get too far apart, then I go crazy. Husband: If we’re too far apart, she doesn’t like that.

**How was family/staff support described?**

They agreed that their family has been supportive of their marriage. They miss the wife’s mother as they have not been in contact for a couple of years. They describe her and the wife’s grandmother as being people they can go to for advice and encouragement.

**How is your family supportive of your marriage?** Wife: “Very.” Husband: “I feel that we’ve always had supportive in-laws, especially my mother in law, I can’t say enough about her…I still think of her as very special…we just haven’t seen her for quite some time…I always felt I could go to her for advice and I know [my wife] felt the same way.”

**Was your family encouraging of your relationship in the beginning, how did they feel about it?** Her: “They felt fine with it, otherwise they would have said something.” He says, “Nothing’s ever really been said outright. I tend to think of that as no news is good news. My mother in law especially liked the idea of us together b/c she knew I was the type of individual that would never hurt her daughter. She liked to say “Nothing ventured, nothing gained.” I don’t think I would have done half of what I did without her.

**What significant influences have played a role in their perception and expression of intimacy?**

Husband expressed that they have had to reinvent the wheel in many ways and the wife agreed with this statement. He commented that their ideas about romantic and sexual intimacy may be different from other couples of from society’s preconceived notions. These views were expressed in response to other questions as well.

Husband: “Basically, we have to ignore what society’s ideas about relationships are because they just don’t…are not compatible with ours.”

**What are the main challenges that were expressed?**

Challenges in daily living were expressed in terms of his ability to assist with household tasks. The husband disclosed that he sometimes feels inadequate because he is not always able to do his share around the house. He also revealed some frustration/sadness about not being able to be as emotionally supportive to his wife when he is focused on something else or is oblivious to her needs.

**Are there ways that you feel like having autism impacts your relationship?** Husband: “Sometimes I’ll be able to figure out when…sometimes trying to balance out the relationship is a difficult act…trying to figure out when I should be spending time with her instead of, ya know…sometimes trying to balance out the friendships and this relationship…it’s a balancing
act. Sometimes I’m good at knowing when she needs a shoulder to lean on and sometimes I can be virtually blind to that. And that’s real frustrating. Sometimes I can be so focused on one thing that I can be shutting everything else out, including her and I don’t like doing that but it’s just so hard for me to transition from one thing to another.”

He mentions something about not being the perfect husband which prompts my next question: What is the perfect husband? Husband: “I guess it’s just a preconceived notion of what I’ve seen on TV shows and that type of thing…basically that they provide anything they can for their spouses, but now I can see that that is an ideal that is basically impossible to achieve. I didn’t say it’s impossible, but that’s why I said basically impossible but that would be very difficult for someone like me to achieve. I have to do the best that I can for my wife within my abilities.”

What are the main ideas about support/interventions; what would be most helpful?

They mentioned that if they were receiving SCL services, it would be helpful to only have one staff member present at a time. They seemed ambivalent about services; as if on some levels it would be helpful to have staff assisting them to find strategies that work for getting things done around the house, but that having staff can also bring added stress. I have not yet transcribed this part, but the wife talked about staff being all over the place in their home and they both agreed whole heartedly when I asked them if it was like having a tornado running through their house.

What would be helpful to you guys? Wife: Figuring out some ways to get things done. We just need to find a concrete method, figure out a way to make it visual b/c we’re both visual. Husband: They can just be more understanding of who we are as a couple, that we are not going to fit anyone’s preconceived notions for what a marriage is supposed to be like. We have had to reinvent the wheel in practically every aspect of our marriage. I just want people to be more understanding of us as a couple because the ideas that most people have of a marriage would not work for us.

Wife: and if there is staff, no more than one staff working with us at a time. Husband: Sometimes I get overwhelmed when there is just too much going on…I’ll get mad, very mad…Sometimes I have to step away. Sometimes there is just too much going on and my mind does not process information all that fast and whatever they’re saying could get lost in the shuffle.

How is this information different or similar from prior information I have gained? What personal biases am I aware of?

In a way, I was surprised and noticed a tinge of disappointment when they reported not having sexual interaction and being satisfied with their level of physical intimacy.

How will I modify the interview process for future interviews based on experiences from this interview? How will I do things differently? What questions will I ask or not ask?
I noticed that the husband had difficulty providing specific examples, but offered profound general statements. How I can help my participants to provide more specific examples to supplement such statements?

I also made a conscious effort to verbalize any non-verbal interaction I saw so that I would not have to rely on memory when transcribing (rubbing each other’s back, Wife using a wheelchair, etc.)

Analytic Memo

**Relationship with Participants** Over the phone, I sensed that the husband was potentially annoyed with me for calling multiple times. Once I met him in person, he did not seem annoyed. I engaged in quite a bit of small talk with them about the weather, their cats, Thanksgiving plans and her knitting hobby. I was very comfortable talking with them and it seemed that they were also comfortable with me. They agreed to do a member check and offered to meet with me again if I desired. They also mentioned that they may know other couples who would be interested in participating in my study so I gave them a few flyers.

**Emergent Codes** Caring for, Feelings of inadequacy, Us against them (society) mentality, We-ness/togetherness, frustration, sadness, feeling different, commitment, feeling ambivalent about services, hope, appreciation, endearment.

**Emergent themes, patterns and possible connections** Society’s preconceived notions about romantic intimacy do not fit for them, Not having the right amount of support from SCL services,

**Reflect on any problems encountered or considerations for future interviews or follow up questions:**

I found myself wanting to slip into the therapist role a few times and had to disregard some intriguing questions I had in order to stay on task. Overall, I was able to ask my main questions, but did not have time to ask my planned probing or follow up questions because the interview did take its own course. We also took about a half hour total to actually work up to the interview as the wife was about 15 minutes late and we had some small chat before getting to the consent form. The consent form also took a bit longer than I was expecting and could have taken even longer had my participants asked more questions. Overall, I was glad that I had allocated an hour and a half for this interview and that the participants were able to meet with me for this amount of time. I will try to plan all interviews for an hour and a half.

I found that the husband (the participant with ASD) was able to articulate very intelligent and general responses, but had difficulty providing examples to support his ideas. He seemed uncomfortable when I would ask clarifying questions and would begin sighing and taking long pauses before responding. Ex: **Is there more that you can tell me about how you have had to**
**define your own marriage?** Basically, we have to ignore what society’s ideas about relationships are because they just don’t…are not compatible with ours. **Can you think of specific ways that they don’t fit?** Well, hmm, that’s a tough one. I’ve never really been asked that question. I wonder how I can help my participants to provide more specific examples.

**Guardian Interview Summary Sheet/Quick Transcription Notes/Analytic Memo**

**Date of interview:** 5/2/2011  
**Today’s date:** 5/3/2011  
**Location:** Participant’s home  
**Code for Interview:** Guardian_Participant_1_Interview_5/2/2011  
**Interviewer:** Haley Wedmore

**Demographic Information:**

General: Participant is female, 64 years old, Caucasian, works as a direct support staff, has completed high school and has taken continuing education courses in real estate, mortgage banking and autism. Is the mother and guardian of participant with ASD, Richard. Divorced from biological father of participant with ASD and is remarried.

**Observations:**

The participant was friendly and welcoming towards me and offered me a drink although I declined. She asked me if I minded dogs and I responded by petting her dog and showing that I was also a dog lover. She seemed to be quite the dog lover and initially talked quite a bit about the dog’s history and their experiences together. The dog had her own basket full of toys in the living room. She asked me how I was doing and could not remember my face from working with her son in the past. She talked with me about several topics for the first 45 minutes of my visit unrelated to her son’s experiences with romantic intimacy including personal concerns and services for her son. She expressed a lot of worry over the day that she and her husband would no longer be around to see to her son’s well-being. She asked me if I minded her smoking while I was there and smoked several cigarettes during my visit. Her husband came home right before we started the actual interview and she introduced us briefly before he left again. During the interview, the participant shared some information about another guardian and her son that she did not seem very comfortable disclosing and therefore, I will not include this information in my transcription or in my findings. Towards the end of the session, she was brainstorming of different ideas for what she should do at this point to support her son and began making a list. Overall, I got the impression that she would really like to be supportive of her son in the area of romantic relationships but that she is not certain of how interested he is in being in another
romantic relationship again in the future or if he would be capable of having a sexual relationship based on physical and or sensory reasons.

**What are your observations and perceptions of how the participant with ASD experiences, understands and values romantic intimacy?** What does it mean for him or her to be romantically intimate with another person? What do you suppose he or she values about romantic intimacy? What does it mean for him or her to be sexually intimate with another person? How important to him or her is it to be in a romantic relationship or to experience sexual intimacy?

We think probably, I see it, ah, holding hands, going and doing things together. All those things really interested them. He likes to say, ah, we’re boyfriend and girlfriend and Bridget’s the only one. Ah, and that was for several years.

I think they just had the formality of she was the drill sergeant, I’m your girlfriend, you’re my boyfriend, we’re going to do this, this and this. Save your money, ah and I don’t think they had an intimate physical relationship and I don’t think they had that nice intimate relationship that I’m talking about, snuggle up, watching TV and stuff. None of that.

What I think truly happened one day is I think she just called him and told him that she had another boyfriend. And I think she was on a different plane and I know she was, based on some of the things that her mom said, I got the impression that there were issues with her being vulnerable to the typical population or whatever and they were always trying to control this so I think she was sexually experienced and that that’s more of a relationship that she was looking for but Richard couldn’t give her that.

**What internal or external barriers do you believe may interfere with the participant with ASD’s ability to be romantically intimate?** Other challenges?

With the Autism and the emotional side of that, there was a time where Richard couldn’t even hug. He stood stiff as a board, for a hug, pulling back.

So, we’ve worked with him all these years to sensitize him to touch and for that reason, ya know knowing, first of all so he could enjoy normal loving touch from family, appropriate to family, but then knowing for the future how difficult it could be.

And personally I believe that match [Richard and Bridget] was a good match for them and they totally enjoyed being boyfriend girlfriend. No matter what that meant to them, they were special to each other. Umm, she’s autistic also and has the same sensory issues.

So, many of them I believe are not able to participate with that much emotion or whatever would be going on during the act, ya know?
And she was from work, Meg, and ah, I kept coaching him. I mean Bridget arranged everything. The first one was so, ah, she was everything and she had a much bigger budget, money wise than Richard. He couldn’t do all that stuff and she was always on him. And we can’t afford, even when we could afford [omitted irrelevant side talk]..we can’t be giving him a hundred dollars or fifty dollars a week to go on dates with Bridget. Ah, then it would stop or it’s not right, we want him to live within his means and still learn how to stretch his dollar and have fun.

I think he’s got physical and umm, I don’t want to say mental, but communication. Umm, autism is a communication disorder, ah, but it affects you mentally, I mean your abilities, you know. Umm, so he’s got all of the sensory issues, I can’t even imagine what they’re all like.

He’s at the lowest functioning and the most severe without those things. So we’re dealing with 2 different Richards too. So like intimate relationships, if they had a fight, I mean Richard falls apart if there is yelling. We cannot yell, even stern voices. So, that’s a barrier to the relationship in the communication areas like that or the typical types of behaviors that people have.

So see, that was a good match in that way. And this other one was an example of one that was not a good match for him in that way but it was [inaudible], but he wasn’t attentive enough and he’s never been one to take the bull by the horns and neither was she, she was used to the guy and she had typical relationships I’m quite certain.

**What strengths do you believe he or she has that may contribute to him or her having a successful romantic relationship?** What personal qualities might he or she have that are helpful?

But, there’s a lot of women that just want to have a good man like him, ya know.

See when he’s, relationships, it’s going to be the same thing that it would be for a relationship in that he is a good person and he tries to be considerate. If he’s not, it’s because he’s not in gear, ya know? Umm, he likes to do fun things. He likes to be with someone and he likes to have a girlfriend and someone to do things with. But I think he, we love Richard so much and we see, he can be inconsiderate sometimes and think that like it’s all about me but he’s, it’s always been only him. But, so those are the areas that we want staff really working on him with in relationships that there is going to be a girlfriend is that staff needs to go along in the beginning.

I think Richard has a lot to offer and being such a nice person and he would never do anything on purpose to hurt anyone else. He wouldn’t yell or scream at anyone. Those things that he doesn’t like, he knows that other people wouldn’t like.

**What are your thoughts or feelings about the person being involved in a romantic relationship or a sexually intimate relationship?**
Umm, nothing would make us happier than for him to have a wonderful, loving relationship. If there’s a way that, ya know, we could look into that, not if he was having a psychotic break every 2 years, but he’s doing so well with his good services now that are consistently good, that that’s something we really could, could put on our agenda and talk to him about. He would never bring that up. Cause he doesn’t know what he’s missing. He’s not shy about talking to me about stuff. And maybe he’s told you he had intercourse and maybe I’m way wrong. Ya know, I don’t know. So, ah, ah, but nothing would make us happier than for him to have the appropriate, loving relationship.

So, we would love it, we would really love it and we take him to weddings for all our nieces and nephews and cousins and friends, our friends kids and all that. And I know that he, he doesn’t look sad about it or anything but I’m sure he wishes that he could have some of that, though he’s got a wonderful life.

I think he felt the relationship with Bridget was ideal. I really do. He’s not, uh, assertive. He can be if you’re pushing him the wrong way, he can say I don’t want that. But, I think he liked her arranging everything and he liked all the things they were doing together.

I: Absolutely. Umm, it kinda sounds like part of what you’re saying maybe is that you would really like for Richard to have a like kind of an equal relationship with somebody else.
S: An equal relationship where they really are a match.
I: Yeah, yeah.
S: Where they have a real match.

I’ve never had a staff say they’ve interrupted Richard masturbating, I don’t think he’s ever done that, I don’t think he has. I think he has a low hormonal level.

We’re going to be dead someday. There is no doubt about that, no doubt about it. And I just think about right now, his real, his main relationships are staff. And at least it’s good staff and it’s stable staff. And if the whole world fell apart and Richard couldn’t have any staff, there would be nobody getting paid, they would still keep in touch with him.

He loves going to church and is still going every Saturday night. I would love for him to meet somebody at church.

In what ways have you been able to be supportive or not supportive of him or her being in a romantic relationship? What challenges do you face? What fears or concerns might you have?

And umm, so, we also tried to do something with Planned Parenthood that had a special program with ARC years ago, video training and there was some reason that that never got taken off. It was for kids 11 and above and we went down to ARC and I don’t know why it didn’t ever come to fruition, I don’t understand that.
Yes, and it’s not even like a typical family, you don’t always have a choice, but –

And so I really think that she, umm, but we never could get together with them to say, how can we support them in their relationship? That’s what I wanted to be able to do. And in the relationship with Bridget, it was always, how can I protect Richard from Bridget?

I know, but we’re not naïve parents and we certainly would love his life to be as normal as possible, especially in that area. [omitted irrelevant conversation]. So, what went wrong with that relationship, and we kept, the staff and I kept working with him on it, on social stories and journaling. Umm, we really couldn’t discuss it with her, I would not try to bring things up with her. I really wanted to talk with her parents. Cause I did not know her. If you don’t even know the diagnosis – so what we were encouraging is that he invite her over for dinner. And he can cook now, I mean he’s doing all of his own cooking.

Anyway, so we were really working with him on having a schedule that you need to remember to call her, girlfriend’s, he wasn’t calling her and he wasn’t making any plans with her at all. Their just boyfriend girlfriend. Nothing would happen without a Bridget to do the whip thing. And she wasn’t doing that and so we had him invite her, ask him if he’d like to invite her over for dinner and he could cook.

And I would say to him, Richard is Meg really your girlfriend? Well yeah. And I’d say do you want her to be a girlfriend? And he’d say, yeah. And I’d say, well men lose their girlfriends if they don’t treat them just right. And the way you treat a girlfriend is different than the way you treat a friend that you just call up once in awhile for what are you doing, let’s go out for a movie or something, ya know. So I said, I think if these are some things you’ll consider, we did some social stories on it, to call her and invite her to come to eat.

What would be helpful for you as a caregiver in supporting the participant with ASD to be in a romantic relationship?

Really, it would be some kind of counseling for me, separate from him from an expert. With ASD, definitely, it would have to be.

Counseling for [husband] and me together on how to support him, how to approach it, where, ya know, we can’t show him, but I know they still have appropriate training tools for people with MR or maybe even autism, specifically or the combination. You don’t want to turn him into a sex monster where he’s chasing all the girls and scaring them ya know, he’s gotta be able to understand the responsibilities that go with, ya know. And, and before we even did that, they would be the ones that would be able to tell me how to find out, ya know, if it works or not.

So, his physical comes up in August and he is very comfortable with this doctor, he is wonderful. [omitted irrelevant details]. But I think I’m on the right track with it. But I need some education on it. I don’t want to open a can of worms with him.
I left one thing out, [psychologist] would be involved. She is his psychologist and she is amazing. OK? She’s been his psychologist forever. She was a school psychologist over at Ruby Van Meter, that’s how we met her at age 19, uh 18. She just moved to Des Moines Pastoral Counseling. But she’s a pediatric psychologist, she only sees her autistic kids through adulthood. I need to write this down. I’m going to write this down.

Yeah, she [psychologist] will counsel us regarding him but she will not do my counseling. I wanted her to do that for me, but she says I’m a pediatric psychologist and I can’t do that. And I said, well you’re really the only one here that really knows, you know autism, you know us as parents. She knows what we go through as parents and how to fix, well 75% of husbands and wives are divorced of parents of children with Autism.

Counseling and advice for me.

What advice would you give other caregivers?

Well, you have to be proactive. And we do the social stories and the journaling. Ah, it’s pretty much what we talked about on there, I don’t want, I mean obviously it’s most likely going to be somebody else with a disability. And, it’s important that we know the family, that the families know each other and that we support them together and have similar morals, values, I mean, ya know. They should have the same concerns. Our kids could be taken advantage of horribly, god knows, in ways that we wouldn’t even imagine sometimes, ya know.

So, umm, but it, it would be the stuff we’re talking about right here. Ya know, talk to the doctor [omitted irrelevant information]. So, but I was saying when I went through this, I mean, be involved with the schools when they’re teaching these things and Planned Parenthood is an important thing and I might write that down again cause they’ve had to come a long ways since ah, back then. Umm, on having appropriate things.

How is this information different or similar from prior information I have gained? What personal biases am I aware of?

I was somewhat surprised at how much this guardian wanted to support her son to be in a romantic relationship. She didn’t want to push him into one, but she expressed how happy it would make her and her husband if her son could be in a well-matched relationship. She talked about being concerned about who would be there for her son when she dies and I inferred that she would be comforted by knowing her son had a meaningful and well matched relationship with romantic partner. She expressed curiosity of her son’s physical ability to have sexual intercourse and wondered if he would have sensory issues regarding sexual intimacy.

I would say that my main surprise in all of this is just how supportive the guardians I have interviewed in this study have been towards their children in terms of them being
romantically involved. The participants with ASD that were involved in this study were all in their late 20’s or older and I speculate that their parents may have been less approving or desiring of this had their children been younger.

**How will I modify the interview process for future interviews based on experiences from this interview? How will I do things differently? What questions will I ask or not ask?**

I can’t really think of anything I would do differently. This was a great interview!

**Analytic Memo**

**Relationship with Participants** I had previously worked with the participant’s son approximately 10 years prior when I worked as a direct support staff for an agency that specialized in serving adults with Autism. I worked with her son a few times, but was never a regularly scheduled staff with him. I had met her on a few occasions; however she could not place my face, although she claimed to remember me otherwise. She seemed very eager to talk with me and answered my questions openly with rich description. She also expressed concern that I might think that she and her husband were naive or overprotective and I assured her I thought they seemed involved and supportive. I enjoyed meeting with this participant and we discussed getting our dogs together for a play date in the future.

**Emergent Codes:** Parental concerns of child being left alone in the world once they are gone and the comfort of knowing the child has a partner, parental desire to be supportive of child but not always knowing how, need for outside guidance and support.

**Emergent themes, patterns and possible connections:** Importance of shared interest for participant with ASD in romantic intimacy, parental need to protect child with ASD, parental desire for child to experience some normalcy.

**Reflect on any problems encountered or considerations for future interviews or follow up questions:** I asked my initial question much more concisely in this interview and the participant seemed to respond with ease to my question.
APPENDIX H

Initial Descriptive Information

1. Emotional
2. Physical
3. Mental/psychological
4. Common interests
5. Shared activities
6. Appreciation or admiration of partner’s qualities
7. Lack of privacy, others around
8. Desire for relationship to be better
9. Partner dissatisfaction with appearance
10. Sharing
11. Trust
12. Helping behaviors
13. Lack of physical intimacy
14. Future
15. Talked to her to show he cared
16. Annoyance with certain qualities about partner or certain interests of partner
17. How they met
18. Started dating, became boyfriend – girlfriend
19. Relationships are boring
20. Relationships are hard
21. Expresses lack of desire to be in a relationship
22. Impact of ASD
23. Different interests
   a. Personal interests

24. Attraction
   a. Physical
   b. Psychological
   c. Emotional

25. Knowing what is going on with partner
26. Admiration of partner’s interests
27. Living situation – impact on relationship
28. Frequency of contact
29. Duration of contact
30. Method of contact
   a. Physical visiting
   b. Talking over phone
   c. Online, playing video games
31. Rituals/Routines/Traditions
   a. Personal
   b. Relationship
32. Decision making
33. Guardian involvement
34. Allowance of alone time
35. Fooling around
36. Roommates
37. Considering others
38. Desiring more sexual intimacy
39. Acceptance of situation
40. Patience
41. Wanting more time together
42. Sexual experience
43. Virginity
44. Religious influences
45. Previous relationships
46. Feeling understood by partner
47. Relationship satisfaction
48. Commitment
49. Marriage and kids
50. Family likes partner
51. Family trusts partner
52. Family/staff trusts participant
53. Responsibility
54. Satisfaction with family/staff support
55. Doesn’t feel restricted
56. Incentive
57. Discomfort with PDA
58. Perception that others are aware they are a couple
59. Never considered interviewer’s question
60. Meaning of sex
61. Uncertainty
62. Expression of affection
   a. Verbal
      i. Flirting
      ii. Teasing
   b. Physical
      i. Flirting
      ii.
63. Satisfaction with sex
   a. Frequency
64. Impact of roommates restrictions
65. Cooperation with rules/limitations
66. External things that would make relationship better
67. Internal things that would make relationship better
68. Future plans
69. Role of animals in relationship (like family or children)
70. Family influence
71. Knowing partner’s values
72. Common values and dreams
73. Delayed dating
74. Lack of interest in opposite gender through adolescence
75. Preference for friendship over dating relationship
76. Downplay of crushes
77. Shyness
78. Parent taught about how to pursue relationships – talking through script/scenario
79. Social/Romantic scripts
80. Encouragement
81. Dating is fun
82. Discomfort
83. Societal impact
   a. Sex attitudes
84. Social circle – common friends
85. Admiration of what partner knows or can do
86. Learning from partner
87. Convenience/perks of relationship
   a. Partner having transportation
   b.
88. Friendship
89. Uncertainty about getting married
90. Sexual abuse may contribute to lack of desire for a mutual sexual relationship
91. Sexual identity
   a. Identifies as not being a sexual person “not one of those people.”
92. Focus on interests extends to other views also
93. Doing things for each other – caring acts
94. Relationship not perceived as different from a friendship
95. Feeling that parent is too involved
96. Not desiring of a sexual relationship
97. Self-conscious discussing sex
98. Experienced unwanted physical sexual touch in past relationship
99. Needed assistance from guardian to advocate for self in relationship
100. Reasons for breaking up
101. Importance for partner to have a job and income
102. Ideal relationship
103. Desire to have same interests
104. Desire to have one on one dates without staff present
105. Hesitancy to ask for support
106. Restricted time together
107. Both partners have ASD
108. Both connected to Autism society
Both speak at conferences, panels, etc.

Common interest in Autism and dating

**111. Experienced lack of interest in dating due to bad dating history and previous negative experiences.**

Decision to give dating another chance

Convenience of long distance relationship

Sensing something about partner

Obsessions

Combining interests

Impact of anorexia
  a. Lingering psychological aspects
  b. Exacerbated autism symptoms for self-control, ritual and routine.
  c. Perception that this is one of the biggest challenges in their relationship

Difficulty with compromise

Summary of Relationship Struggles
  a. Anorexia
  b. Separate interests
  c. Compromise

Need for additional processing time

Connection and intimacy beyond verbal and physical: non-verbal connection, non-touching.

Interrelatedness of 3 forms of intimacy

Difficulty making friends

**124. Common experiences/upbringing**

Gratefulness for healthy communication

Shared resources for social skill building

Takes dedication, hard work, investment

Ability to work hard comes from the hard work they have both done in building social skills

Relationship skills and friendship skills are similar in communication aspects

Sometimes experience difficulty articulating needs or feelings verbally

Each experiences different sensory issues

Ability to relate to one another’s sensory issues since both have ASD, however may not fully understand them

Sensory issues may interfere with sexual intimacy at times

Perception that interviews about their relationship has made them more aware of how they work and has strengthened them as a couple.

Desire to do more things that typical couples do

Both experience some issues around eating that are related to ASD – for him sensory issues around chewing sounds.

Need for separate space

Don’t like to be lonely

**139. Need to isolate when overwhelmed in a negative or a positive way**

Need for friends, to be loved and cared about

Accommodating
  a. sensory issues
b. decorating styles
c. separate interests

142. Humbled and surprised by family’s level of supportiveness towards them living together before marriage and of their relationship overall.
143. Get along with each other’s families
144. Surprise towards acceptance generated as a result of public profiling
145. Desire to have a relationship counselor who specializes in ASD at times
146. Views parents as being protective
147. Feels misunderstood by others at times
148. Desires more general understanding towards autism
149. Values the way partner shows respect
150. Acts of consideration
151. Prompted and unprompted favors
152. Experience of innocent affection
153. Differing levels of comfort with affection
154. Unique terms of endearment/affection
155. Words of affirmation
156. Difficulty with “Concept of companionship” – sharing a life together is not viewed as a natural concept
157. Belief that it is natural for people with ASD to become attracted to another person
158. Belief that not all are capable of being in a successful romantic relationship
159. Independence and self-reliance are highly valued for people with ASD.
160. Being vulnerable and co-dependent are foreign and counterintuitive concepts for people with ASD.
161. Necessary ingredients for relationship to work
162. Necessity for both to want to work at it and to be attracted to one another
163. Emphasizes importance of learning and practicing social skills
164. Love is a resilience factor
165. Role of spirituality in relationship, belief that God brought them together
166. Desire to support partner physically and emotionally “provide a listening ear”
167. Suspicion that partner also has ASD although not diagnosed.
168. Suspicion that diagnosis of Asperger’s would be more appropriate for self.
169. Disregarding general ideas of romantic intimacy
170. Developing own way of doing things “reinvent the wheel”
171. Go around obstacles
172. Implement creative accommodations and or modifications
173. View relationship as unconventional, non-typical, not average
174. Resistant to being influenced by societal expectations or pressures for what they should be like as a couple or as husband and wife.
175. Difficulty contributing to household chores
176. Receiving mixed messages from society
177. Talking about day to day things
178. Spend quiet time together
179. Perception that they think differently than an average couple
180. Influential relative to them both
181. Finding support talking to one another and to other family members about missing their mother in law  
182. Creative interventions are found to be useful  
183. Receive financial assistance from family when needed  
184. Regrets  
185. Appreciation of differing personal strengths  
186. Perception that their differences are complimentary  
187. Involvement in organized social activities  
188. Awareness of other couple’s differences  
189. Appreciation of partner’s help  
190. Protective ness towards partner  
191. Partner with ASD needing to be reminded to focus on and spend time with partner.  
192. Expresses difficulty knowing when to spend time with partner or friends “balancing act”  
193. Difficulty always knowing when partner needs emotional support  
194. Tendency to become focused on one thing may lead to shutting partner out  
195. Sense of knowing partner well  
196. Resists preconceived notions of “perfect husband”  
197. Doing one’s best within personal abilities  
198. Feeling inadequate at times  
199. Hope that other couples can also be successful in relationships  
200. Overwhelming to have more than one staff supporting at a time  

201. Uses past sex abuse as barrier to additional sexual experiences  
202. Personal gain  
203. Manipulation of partner  
204. Parental desire for child to experience normalcy  
205. Becoming used to physical touch, sensitized to touch  
206. Concern that child was receiving confusing messages about engaging in sexual behavior for personal gain.  
207. Discomfort talking about sex  
208. Physical manifestation/expression of internal conflict  
209. Grooming  
210. Avoiding physical touch  
211. Disclosure of not being interested in physical intimacy  
212. Limits/sexual boundaries when having engaged in sexual intimacy  
213. Difficulty verbally expressing feelings  
214. Parental caution not to instigate or manipulate child into doing things that they desire them to do  
215. Parallel conversations  
216. Difficulty connecting with partner  
217. Parent-child communication – learning how to approach and support child  
218. Fear of or discomfort with foreign feelings such as arousal  
219. Parental encouragement of romantic relationships/sexual relationships
Child’s strengths

Task oriented

Parental treasuring of intimate conversations

Fear of child becoming addicted or obsessive towards sex if ever becomes interested

Influential messages from other professionals
Child is exposed to multiple outside influences through SCL services
Parental limitations in finding good opportunities to talk to child
Important role of teamwork
Parental values and wishes for child

Parental comfort knowing child will talk to her

Parental experience of “fine lines” as parent and guardian and increased responsibilities – informed decisions
Parent would find it helpful to know child is in a mutual, respectful and growing relationship.

Influence of generational differences

Societal messages
Impact of growth, maturity
Supporting child’s need for reassurance

Need for sex education
Significance of boyfriend-girlfriend label for child
Believing that partners are special to each other
Parental desire for child to be in a loving, well-matched relationship
Belief that child would not bring up wanting to be in a relationship
Lack of initiation
Impact of resources

Intimacy beyond sexual intimacy
Pursuing romantic intimacy
Need for communication and collaboration between parents
Parental encouragement to initiate spending time with partner

Utilizing ASD supports
   i. Social stories
   ii. Scripts

Soliciting and responding to child’s cues

Parent role as educator

Not well-matched in terms of sexual interests
Parental efforts to expose child to romantic intimacy through various experiences

Communication difficulties as a result of ASD
Difficulty dealing with upset in a relationship, can exacerbate MH symptoms
Lack of interest in masturbation
Lack of sexual desire

Positive regard for child
Uncertainty how to go about making this a reality for child

Safety protocols
259. Fear of not being there for child in the future and child not having meaningful relationships
260. Would treat others as he would like to be treated
261. Social influence of Church
262. Desire individual/couple counseling with an expert on ASD
263. Fear of losing services
264. Involvement with professionals
   a. Psychologist
   b. physician
265. Being proactive/involved
266. Importance of child being educated on what is not normal in order to prevent abuse

267. Importance of a good match – the “right person”
268. Sexual pressures from partners
269. Non-autistic partner’s difficulty with ASD qualities
270. Similar experiences to typically developing relationships
271. Feeling safe
272. Sex is private
273. Moderation of sexual activity
274. Guardian determines frequency and duration of visiting with partner
275. Self-protection
276. Impact of family relationships
277. Has somebody
278. Sex is intellectual
279. Parental respect for privacy
280. Lack of sexual knowledge led to frustration
281. Lack of financial independence will lead to partner’s willingness to provide
282. Right partner eliminates many social challenges
283. Difficulty showing compassion towards others when unable to relate
284. Could not appreciate partner’s kindness if did not have genuine interest/feelings for them
285. Feeling overwhelmed by the interest of the opposite sex or with having to advocate for self in a relationship
286. Need for authenticity
287. Authenticity leads to resiliency of relationship
288. Social and relationship benefits of early interventions
289. Previous parental concern not only of child’s potential to be harmed, but by potential for child to hurt others
290. Parental relief
291. Necessity of support system
292. Necessity of finding a higher power who will love and accept your child
APPENDIX I

Coding Annotations

Excerpts from four coded transcriptions have been included in this Appendix.

B: Yeah, that’s true. As I said before, I have other friends, but as far as I’m concerned I only have one bride.
I: Are there ways that you feel like having autism impacts your relationship?
B: Yeah. Sometimes I’ll be able to figure out when —
K: On Friday, you’ll be cleaning.
B: Oh, mom, don’t remind me. That wasn’t what I was gonna say, Kathy. Sometimes trying to balance out the relationship is a difficult act, trying to figure out when I should be spending time with her instead of being with, ya know. What am I thinking here? Darn, this is hard to explain. Basically it’s trying to balance out the friendships and this relationship… It’s a difficult juggling act. And not knowing what she, sometimes I’m good at knowing when she needs a shoulder to lean on and sometimes I can be virtually blind to that fact.
I: Do you attribute that to having autism?
B: Yeah. And that’s real frustrating. That’s real frustrating to me. I just, sometimes I can be so focused on one thing that I, and that’s part of autism is that I can be single mindedly focused on one thing and totally shut everything else out, including her and I don’t like doing that but it’s just so hard for me to transition from one thing to another.
I: Mmm-hmm. What’s different about your relationship with Kathy from your other friendships?
B: Different. Well, I think what’s different is that I’ve had all this time to umm, get to know her and know what her strengths and weaknesses are. I’ve had all this time to be as supportive to her as I have, though I realize I haven’t always been the quote, unquote, perfect husband. I really feel like I’ve had a lot of time to get to know my wife inside and out although I have to admit, I’m certain there are still some things that I don’t totally know about her.
I: What is the perfect husband?
B: Perfect husband. Basically that I’d be, well I guess it’s just a preconceived notion of what I’ve seen on TV shows and that sort of thing [sigh]. Basically that they’re around for their spouses whenever they’re needed, that they provide anything they can for their spouses. But now I can see that that’s an ideal that is basically impossible to achieve. I said basically impossible. I didn’t say it was impossible, but I was saying that would be very difficult for someone like me to achieve. Basically because I have to do the best that I can for my wife within my abilities. I have to do the best I can for her with the abilities that I have.
I: What would be helpful for you guys?
B: I’m sure Kathy has some ideas.
K: Figuring out some ways to get things done.
I: Mmm-hmm. Like around the house and stuff? Like does anything come to mind in particular?
B: We’ve tried so much.
K: We just need to find a concrete method, figure out a way to make it visual because we’re both visual.
B: I have to have visual aids. [her phone begins to ring] Oh, not now.
I: Mmm-hmm. Would that help your relationship?
K: Oh yeah. [she answers phone]
B: Kathy, take that elsewhere. Now what were you saying?
I: How can other people like your family be in staff or just in general, how can other people be supportive to you?
B: They can just be more understanding of who we are as a couple, that we are not going to fit anyone’s preconceived notions of what a marriage is supposed to be like. Because as I’ve said earlier in this conversation, Kathy and I have had to reinvent the wheel in practically every
also some mutual stuff going on in her, ya know, we found out later and like he would buy a lot of things for her and I just, I really was concerned about what kind of message she was getting in all of this. I didn’t want her to get confused in that you do things so that somebody will pay for something. That really was a big concern in all of the relationship.

I: Right.
P: Umm, it got to a point though that, umm, he— was living in a 2 bedroom duplex and I would stay in the second bedroom when I was here and one night I came home and I went to bed and I don’t know why but the neighbors upstairs, their music woke me up and I could see that the lights were on and I thought, why are you up? Well come to find out had come back and snuck in and umm—

I: Unbeknownst to

P: No, I think she knew at that point, but I don’t think she knew. I think it was one of those things that, when he would sneak back I don’t know, I think what was happening at that point, at least what I understand was happening is that he was wanting to take showers with her. And I’d say, oh, what were you doing in the shower. And he would rub her all over and he wanted her to do the same and she was just very uncomfortable about talking about it.

I: Did you think that is because you were mom or just in general?
P: Umm, I don’t know if it was because I was mom or if it was because at the same time we were also finding that she was also getting money out of his wallet. Whether he was giving it to her or whether she was taking it I’m not quite sure. I never got to the bottom of that but I do know that she started having a lot of seizures and what we’ve found with is that when she has a lot of internal conflict she has seizures.

I: Mmm-hmm, yeah.
P: And so we knew something was going wrong, we just couldn’t quite figure out what it was. And then once we started putting the pieces together, umm, ya know I asked her, I said is this something you want? And she said no, and I said well then why are you saying it’s OK? And ya know, I think it was one of those things where she just felt it’s kind of like the petting, ya know the longer he did it the more accepted it was and I think he just, he wore her down. But I asked her if that’s something she wanted to do and she said no and I asked her how do you want to handle it? She asked me if I would talk to him and I said no. I’ll help you talk to him if you want me to help you but it has to be your words. And that was very hard for her. She ended up wanting to come home. She stayed home for like 3 or 4 days, she didn’t want to go back. Umm, it was just a very hard situation. But it seems like once the relationship gets to a point, she doesn’t want that aspect of it.

I: So, in that situation it’s like it went a little bit too far for her, beyond her comfort levels?
P: Mmm-hmm.

I: I guess, is there any other experience that you can think of how she has experienced sexual intimacy in a mutual relationship or is that really the only one?
P: Just kissing, yeah, just kissing and holding hands. But even like with the boyfriend that she has now, they typically don’t even sit on the couch together. He’ll sit in her lazy boy chair and she’ll sit on the couch.

I: And she’ll allow that?
P: Yeah, and I think it’s because she doesn’t want the alternative, she doesn’t want to sit next to him.

I: Oh, OK.
H: I think one aspect of, of why it is probably the way it is, or why it’s been a positive relationship is that we both have, even though we both don’t really have an understanding of how our particular sensory issues play out or why, ya know, why it’s such a big deal to have particular issues, we understand the underlying reason of it, if that makes sense.

I: Right. Like you can relate to that.

H: Yeah, so it’s that relations and I guess because we both have autism and we both have similar stories as far as when we started speaking, when we started mainstream schooling, umm, that we were able to, ya know, work very hard and achieve what we’ve been able to achieve. It’s umm, I think it was, it’s that too, although he’s the first man I’ve dated who has autism as well. And I wasn’t actively seeking anyone on the spectrum.

I: Right.

H: But I wasn’t actively seeking a date, so it’s not that that was a requirement. So, yeah, I guess it’s those kinds of things that have really connected and I also think, umm, although ya know the first couple years was really strong in itself because of what I mentioned to you, those aspects, I think umm, the opportunity of umm, being able to — when Glamour approached us and gave us the opportunity to be profiled in the article, umm, ya know the journal asked us [inaudible] a lot of very detailed questions and it really forced us to really think and analyze how we were really able to make our relationship work.

I: Yeah.

H: And I think because of that it helped us really understand how we work. And so I think in a way that was kind of like pre-relationship therapy in a way because it really helped us, ya know, going through that process of interviews and being in the article and just the support we’ve gotten from people and our friends and families, I think that has really just strengthened us, because we were forced to learn or to explain and dig deep down into how we work.

I: Right. I think that makes so much sense, you might not have had that opportunity otherwise and that opportunity allowed you to reflect on your relationship. And so, umm, are there any ways that you would like for your relationship to be different, do you think?

H: Umm, well I think just based on the challenges that I mentioned to you, umm, I do really wish on my part that I was able to get over that particular issue that I have with my meal rituals and stuff, like eating issues. I wish that that was eliminated completely, cause I think that would make things a lot easier for us.

I: Yeah.

H: Both being able to do a typical thing that couples do, like go out to eat more often or, ya know, eating together. Yeah, that’s just something we, I just, ya know I will do it with people, but again I have to have a head’s up and ya know, all that. Usually it’s like I need to eat by myself, I can’t be bothered, I don’t like being watched. And James, I learned that James is actually kind of similar in that sense, sometimes he has to eat alone or with a lot of noise or with background noise because he has a lot of sensory issues with a lot of loud chewing sounds.

I: Ah, yeah.

H: So, sometimes eating with people is umm, ya know especially if there’s no background noise, he can’t do it because of sensory issues and auditory issues on his part.

I: I see, so that’s sort of one of those things that you guys do separately. Are there other things that you guys do separately more than you would do together?

H: Sometimes we will watch the same TV shows or movies, uh, we also have our particular like shows we like and movies we like so we kind of do that part separately too, but other times we’ll watch things together as well that we’re both interested in. Umm, but I think uh, well we shop
very kind and gentle. And um, he has feeling for animals, ya know, empathy for animals and that would have to be because of her Asperger’s. That would have to be something that was compatible for them.

I: Mmm-hmm. I’ve been hearing a lot, pretty much with all of my interviews that shared interests are very important.

S: Yeah, and it’s shared, well and you know, like Asperger’s are almost obsessive. It has to be something that they don’t find annoying or obsessed with.

I: Yeah, like even with each other? Like the other person’s interests? It can’t be something that they are annoyed by? Is that what you mean?

S: Right. They both like action movies, they both like superhero type stuff. Umm, and, ya know, if he didn’t like superhero stuff, I don’t think it could work.

I: Mmm, mmm-hmm, that would be an issue, yeah.

S: I mean, that sounds really dumb, but that’s the truth.

I: Yeah, that’s the reality. What, ah, do you think there are any social challenges or anything like that that you think might impact the relationship?

S: Well, once she was with the right boyfriend, the social challenges kind of melted away.

I: Ah.

S: But yeah, I really worry about that. But she’s with the right guy and they seem to function very well as a couple in society.

I: Mmm-hmm. And I’m just curious as you say that about how he’s the right guy, they have similar interests and—

S: I mean ya know, like I would have said, it would be a very different interview if she wasn’t happy with her boyfriend.

I: Right—

S: And I don’t know if he’s the one, but with him, things that were a problem are not a problem.

I: Mmm-hmm.

S: Or things that were predicted to be a problem are not a problem.

I: Hmm, umm, yeah, are there any specific ways that you can think of off hand, other ways that make him compatible.

S: Umm, well, when she was dating this one guy who was in love with Dungeons and Dragons and he was almost obsessed with it, but he was very umm, she thought he was arrogant. And I don’t know that he was arrogant. He was a little bit maladjusted. And super, super bright and very gifted and talented. So he didn’t understand what it was like to struggle with stuff. Now, when he went to college he sort of skirted through everything and did very well and went to college and it actually required more studying for him than he was capable because he had no study skills. And he failed.

I: Right.

S: In school so then he was dropped out when he met— and he was regrouping. Now he was going to have to learn for the first time in his life to discipline himself to overcome some barriers. And she really had trouble with that because her whole life she had learning disabilities and had to like accept c’s as a victory. And umm, do things the hard way in order to get what was going on. And I felt like she could not feel much compassion in his, ya know and I felt like this guy has been a hero his whole life and now he’s a 0 and he’s trying to figure out who he is and she felt like he was a big baby.

I: So, it was kind of hard for her, to umm—
APPENDIX J

Initial Outline of Categories/Themes/Sub-themes

Category: What makes it work?

Theme 1: Compatibility

Sub-theme: Common interests

Sub-theme: Good match

Sub-theme: Common Experiences: Ability to relate

Sub-theme: Connection: Love, Spirituality, Trust

Theme 2: Dedication/Hard work

Sub-theme: Accommodating – honoring separateness, sensory issues

Sub-theme: Building communication/social skills

Sub-theme: Collaboration

Sub-theme: Creativity – interventions, combining interest, unconventional attitudes

Theme 3: External Supports

Sub-theme: Parental involvement

Sub-theme: Professional support/treatment

Category: What is challenging?

Theme 1: Autism Characteristics

Sub-theme: Need for additional processing time

Sub-theme: Communication/Social difficulties

Sub-theme: Sensory Issues

Sub-theme: Foreign Feelings/Overwhelming feelings

Sub-theme: Difficulty advocating for self or initiating
Theme 2: Living Situation

Sub-theme: Protective housing / not having alone time / lack of privacy
Sub-theme: Roommates

Theme 4: External Pressures

Sub-theme: Family/Religion
Sub-theme: Societal Messages/Pressures/lack of understanding
Sub-theme: Desire for Normalcy

Theme 3: Discouraging Situations

Category: How is intimacy experienced?

Theme 1: Attraction

Sub-theme: Admiration/liked qualities

Theme 2: Expression/sharing/of intimacy

Sub-theme: Physical
Sub-theme: Sexual
Sub-theme: Emotional
Sub-theme: Intellectual
Sub-theme: Spiritual

Theme 3: Affection

Sub-theme: Terms of endearment – speaking fondly, pet names, verbal expressions of love
Sub-theme: Teasing
Sub-theme: Caring Acts

Theme 4: Companionship
Sub-theme: Togetherness
Sub-theme: Friendship
Sub-theme: Shared activities
Including my results section in entirety would be cumbersome; therefore I have included a sample of the results draft that illustrates my process of organizing and combining passages and themes.

**Theme 4: Companionship**

**Sub-theme: Togetherness**

S: “…ah, holding hands, going and doing things together. All those things really interested them. He likes to say, ah, we’re boyfriend and girlfriend and Bridget’s the only one. Ah, and that was for several years.

SA: Well, she did not have a father and I know that she does a lot of, I think just having the closeness with a man is very valuable to her. Someone that she trusts, someone that she feels safe with because she did not have that growing up with a father…I think it’s very important to her because she feels that she has somebody and she does have somebody. I think it’s umm, very important to her.

…and hung out at each other’s apartments. It’s like we kept going back and forth! Which, which one are we gonna be at today?!...We just enjoyed spending time together.

Brady also brought up a special tradition that he and Kathy do together in connection to their church,

“And we’ve got, while we’re thinking about that, Kathy and I have a special tradition here at our church. We have soup suppers every Wednesday night while Iowa State is in session and on the Wednesday closest to our wedding anniversary we will make soup for soup supper. It is a tradition that started shortly after we were married and has continued ever since. We do that twice a year, once for our anniversary in October and also for my birthday in April.”

When I asked Vicki what it meant to her to be in a relationship, she responded, “Umm, to me it’s [having a boyfriend] like you’ll have other friends to hang out with other than not having anyone to hang out around.” Her statement could reveal that she values having someone to spend time with and that having a boyfriend prevents her from feeling lonely.

MOVED TO LIVING SITUATION

*DELETED THIS SUB-THEME AND COMBINED SOME PASSAGES WITH “TOGETHERNESS” OR “SHARED INTERESTS”*

On the other hand, there is the sense that companionship does not come naturally to people with ASD although other aspects of it such as not feeling lonely, mutual caring, and experiencing
shared interests are highly desired by many. Vivian expresses the view that companionship is an art that people with ASD must become adept to in order to experience closeness.

“So, it’s that concept of companionship I think that is the challenge…But that is something that you have to learn and you have to keep cultivating and keep learning and keep growing in companionship and the idea of sharing a life together. That is kind of unnatural for us on the spectrum, cause we’re so independent in our ways and our thinking, all that, the concept of joining together in unison and all that, it’s some aspects of that is still strange. So, it’s funny because we talk about someday, ya know, maybe getting married, but we worry [inaudible] but it’s cause it’s this interdependent sort of thinking. [laughs].”

(I’m beginning to think I should combine Shared Activities and Shared Interests since there is a lot of cross-over between the two)
APPENDIX L

IRB Modification

IOWA STATE UNIVERSITY
OF SCIENCE AND TECHNOLOGY

Institutional Review Board
Office for Responsible Research
Vice President for Research
1138 Pearson Hall
Ames, Iowa 50011-2017
515-294-4566
FAX 515-294-4487

Date: 4/29/2011
To: Haley Wedmore
CC: Dr. Megan Murphy

4380 Palmer Bldg

From: Office for Responsible Research
Title: Autism Spectrum Disorder and Romantic Intimacy
IRB Num: 10-383

Approval Date: 4/22/2011
Continuing Review Date: 9/27/2011
Submission Type: Modification
Review Type: Expedited

The project referenced above has received approval from the Institutional Review Board (IRB) at Iowa State University. Please refer to the IRB ID number shown above in all correspondence regarding this study.

Your study has been approved according to the dates shown above. To ensure compliance with federal regulations (45 CFR 46 & 21 CFR 56), please be sure to:

- Use only the approved study materials in your research, including the recruitment materials and informed consent documents that have the IRB approval stamp.

- Obtain IRB approval prior to implementing any changes to the study by submitting the “Continuing Review and/or Modification” form.

- Immediately inform the IRB of (1) all serious and/or unexpected adverse experiences involving risks to subjects or others; and (2) any other unanticipated problems involving risks to subjects or others.

- Stop all research activity if IRB approval lapses, unless continuation is necessary to prevent harm to research participants. Research activity can resume once IRB approval is reestablished.

- Complete a new continuing review form at least three to four weeks prior to the date for continuing review as noted above to provide sufficient time for the IRB to review and approve continuation of the study. We will send a courtesy reminder as this date approaches.

Research investigators are expected to comply with the principles of the Belmont Report, and state and federal regulations regarding the involvement of humans in research. These documents are located on the Office for Responsible Research website http://www.compliance.iastate.edu/irb/forms/ or available by calling (515) 294-4685.

Upon completion of the project, please submit a Project Closure Form to the Office for Responsible Research, 1138 Pearson Hall, to officially close the project.
APPENDIX M

Consent Forms

I developed three consent forms with different wording to address participants with ASD, Couples with ASD or Guardians of participants with ASD. All content is the same otherwise. I have included the Informed Consent designed for participants with ASD as an example.

INFORMED CONSENT DOCUMENT for Participants with ASD

Title of Study: Autism Spectrum Disorders and Romantic Intimacy

Investigators: Haley Wedmore

This is a research study. Please take your time in deciding if you would like to participate. Please feel free to ask questions at any time.

INTRODUCTION

The purpose of this study is to explore how adults with Autism Spectrum Disorders (ASD’s) experience and perceive romantic intimacy in their lives. Specifically, I would like to learn more about what people with ASD value about romantic intimacy, how their perceptions about romantic intimacy and experiences are shaped by systemic factors, what barriers are faced and what interventions would be helpful for them to achieve a desired level of romantic intimacy in their lives. You are being invited to participate in this study because you have identified yourself as having a diagnosis of Autistic Disorder, Asperger’s Disorder or PDD-NOS, have been or are currently in a romantic relationship, are 18 years of age or older, are able to respond to the interview questions beyond “yes/no” responses and you are able to give consent to participate or to gain your guardian’s consent.

DESCRIPTION OF PROCEDURES

If you agree to participate, you will be asked to participate in one face to face or telephone, semi-structured interview, lasting approximately 1 hour. Face to face interviews will be audiotaped using a cassette recorder and telephone interviews will be recorded using a computer software program.

You will be asked about your perceptions and experiences related to romantic intimacy, how your ideas about romantic intimacy were learned, what you value about romantic intimacy, what challenges you may face in achieving and or maintaining romantic intimacy in your life and what interventions would be helpful in supporting you to achieve and maintain a level of romantic intimacy in your life.
intimacy that is meaningful for you. Because sex is an aspect of romantic intimacy, I will ask for information regarding your physically intimate or sexual experiences as well (basically whether or not you have had any physically intimate or sexual experiences or would want them and any other information you would feel comfortable to disclose).

**RISKS**

While participating in this study you may experience the following risks: You will be asked to openly share your perceptions and personal experiences regarding romantic intimacy. You may experience emotional or psychological discomfort discussing private matters and you are free to refrain from answering any question at any time.

**BENEFITS**

If you decide to participate in this study there may be no direct benefit to you. (A benefit is defined as a “desired outcome or advantage.”) It is hoped that the information gained in this study will benefit society by giving people with ASD the opportunity to be heard and to provide valuable information and ideas for interventions that may guide family members, service providers and clinicians to be more effective in supporting people with ASD to achieve romantic intimacy in ways that is meaningful for them.

**COSTS AND COMPENSATION**

You will not have any costs from participating in this study. You will not be compensated for participating in this study.

**PARTICIPANT RIGHTS**

Your participation in this study is completely voluntary and you may refuse to participate or leave the study at any time. If you decide to not participate in the study or leave the study early, it will not result in any penalty or loss of benefits to which you are otherwise entitled. During the interview you can skip any questions that you do not wish to answer.

**CONFIDENTIALITY**

Records identifying participants will be kept confidential to the extent permitted by applicable laws and regulations and will not be made publicly available. However, federal government regulatory agencies, auditing departments of Iowa State University, and the Institutional Review Board (a committee that reviews and approves human subject research studies) may inspect and/or copy your records for quality assurance and data analysis. These records may contain private information.
To ensure confidentiality to the extent permitted by law, the following measures will be taken: The subjects will be assigned a code name which will be used on forms and in writing instead of their names. Any other identifying details obtained in the course of an interview or observation will be altered to protect confidentiality. All data gathered will be kept in a password coded computer file that only the principal investigator will have access to. Data will be destroyed 2 years after the interview. If the results are published, your identity will remain confidential.

If reports of abuse are mentioned during the interview involving the dependent participant with ASD, the investigator will report the allegation to the agency that provides services to the participant with ASD and follow their instruction which may involve reporting the allegation to the Department of Human Services (DHS). If the participant does not receive services through an agency, the investigator will report the allegation to DHS. Once the allegation is reported to the agency and or DHS and the investigator follows through with agency and or DHS instruction, the investigator will have no further obligation in the matter.

QUESTIONS OR PROBLEMS

You are encouraged to ask questions at any time during this study.

- For further information about the study contact: Haley Wedmore or my major professor, Megan J. Murphy, Ph.D (deleted phone numbers in thesis document).
- If you have any questions about the rights of research subjects or research-related injury, please contact the IRB Administrator, (515) 294-4566, IRB@iastate.edu, or Director, (515) 294-3115, Office for Responsible Research, Iowa State University, Ames, Iowa 50011.

PARTICIPANT SIGNATURE

Your signature indicates that you voluntarily agree to participate in this study, that the study has been explained to you, that you have been given the time to read the document, and that your questions have been satisfactorily answered. You will receive a copy of the written informed consent prior to your participation in the study.

Participant’s Name (printed) __________________________________________
If you are not your own guardian, you will need to sign your assent above as the participant and obtain your guardian’s signature below to indicate his or her consent for you to participate in the study.

(Participant’s Signature)     (Date)

(Signature of Parent/Guardian or Legally Authorized Representative) (Date)
APPENDIX N

Final Outline of Categories/Themes/Sub-themes

Category: What makes it work?

Theme 1: Compatibility

Sub-theme: Commonality

Sub-theme: Good Match

Sub-theme: Love and Spirituality

Sub-theme: Trust

Theme 2: Dedication/Hard work

Sub-theme: Accommodating

Sub-theme: Communication

Theme 3: External Supports

Sub-theme: Parental Involvement

Sub-theme: Helpful Professional Support/Treatment/Attitudes

Category: What is challenging?

Theme 1: Autism Characteristics

Sub-theme: Sensory/Processing Issues

Sub-theme: Social/Communication Difficulties

Theme 2: Living Situation

Sub-theme: Roommates

Sub-theme: Protective Housing
Theme 4: External Pressures

Sub-theme: Family and Religion

Sub-theme: Societal Messages/Pressures

Category: How is intimacy experienced?

Theme 1: Attraction

Sub-theme: Admiration/Appreciation/Liked Qualities or Characteristics

Theme 2: Expressions of Intimacy

Sub-theme: Interconnected Intimacy/Beyond the Sexual

Sub-theme: Physical

Sub-theme: Sexual

Sub-theme: Emotional

Sub-theme: Intellectual

Sub-theme: Spiritual

Sub-theme: Non-Physical/Non-Sexual

Theme 3: Affection

Sub-theme: Terms of endearment

Sub-theme: Teasing

Sub-theme: Caring Acts

Theme 4: Companionship

Sub-theme: Togetherness

Sub-theme: Knowing Partner