HOW COUPLES RAISING CHILDREN ON THE AUTISM SPECTRUM

NEGOTIATE INTIMACY: A GROUNDED THEORY STUDY

Jake Johnson

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Fred Piercy, Chair

Joyce Arditti

Megan Dolbin-MacNab

Adriana Ginanjar

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How Couples Raising Children on the Autism Spectrum Negotiate Intimacy:

A Grounded Theory Study

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ABSTRACT

This study has explored how couples raising children on the autism spectrum negotiate intimacy in their marriages/committed partnerships as well as what contextual factors influence these process and how they change over time. Twelve couples currently raising children on the autism spectrum were interviewed conjointly regarding their experiences of intimacy negotiation. A methodological approached based on constructivist grounded theory was used to analyze the data collected from these couples. The results of this study indicate that intimacy negotiation for couples raising children on the autism spectrum is an interactive process in which both partners must work together to make several key cognitive and relational shifts. Couples were either aided or hindered in making these shifts by the degree to which contextual and environmental factors were experienced as resources or roadblocks. The result of the degree to which couples raising children with ASDs navigate the necessary cognitive and relational shifts, also taking into account the influence of any contextual factors on these processes, was found to be a couple's experience of intimacy. However, this study also found that intimacy was not a fixed point at which a couple one day arrived, but was instead an iterative process taking place over time and requiring work to develop and maintain.

Dedication

To Christina, Bjorn, Nicolas, and Baby #3. I love you all so very, very much. Tears come to my eyes as I consider all you have given to and sacrificed for me as I worked toward the completion of this project. Thank you.

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CHAPTER 1: INTRODUCTION

According to recent research conducted by the Centers for Disease Control and Prevention (CDC), autism spectrum disorders (ASDs) affect one out of every 68 children in the United States, over double the figure of one out of every 150 children reported by the CDC just a decade ago (CDC, 2012a). Research also demonstrates that ASDs affect not only the children who have been diagnosed with a disorder on the autism spectrum but also those who have been charged with caring for them. In particular, studies have found that having a child on the autism spectrum in the family can negatively impact the physical and mental wellbeing of mothers (Allik, Larsson, & Smedje, 2006; Barker et al., 2011; Hastings, 2003; Wolf, Nol, Fisman, & Speechley, 1989), fathers (Hastings, 2003; Mugno, Ruta, D'Arrigo, & Mazzone, 2007), and other primary caregivers (Higgins, Bailey, & Pearce, 2005).

Additionally, research focused on how couples as dyadic units experience and are affected by raising children on the autism spectrum suggests that couples raising children with ASDs are susceptible to more negative relationship outcomes, including less closeness with and commitment toward one another, than couples raising typically-abled children (Fisman, Wolf, & Noh, 1989; Gau et al., 2012; Hartley et al., 2010; Myers, Mackintosh, & Goin-Kochel, 2009). For couples raising children on the autism spectrum, these outcomes have been found to relate to the unique strains on their marriages/ committed partnerships that accompany caring for children with ASDs (e.g., ambiguous loss, behavioral issues, financial concerns, lack of couple time; Gray, 2002; Higgins et al., 2005; O'Brien, 2007), which other couples do not experience. However, other studies have indicated no significant difference in experiences of commitment and closeness

among these couples (as compared to couples raising typically-abled children; Freedman, Kalb, Zablotsky, & Stuart, 2012) and that these couples may, in fact, experience an increased sense of closeness and commitment toward one another despite the aforementioned stressors related to raising children with ASDs (Bayat, 2007; Cowan, 2010; Hock, Timm, & Ramisch, 2012; Myers et al., 2009). Given these differing results, it becomes important to explore why it is that some couples caring for children with ASDs experience more commitment and closeness (part of what this present study will later define as "intimacy") in their relationships than others. Also important in shedding light on these divergent outcomes would be to investigate the processes by which couples raising children on the autism spectrum experience more or less intimacy in their relationships, including what, if any, outside factors may come to bear on these processes and how they might change over time.

Definition of Intimacy

Before further discussing the importance of the aforementioned areas for exploration related to intimacy among couples raising children on the autism spectrum, a definition of what is meant by "intimacy" will first be provided.

Intimacy may be conceptualized in myriad ways within various types of relationships. To this point, many scholars have noted the disagreement in the literature over what intimacy is and how it may be best defined (Lippert & Prager, 2001; Moss & Schwebel, 1993; Shaefer & Olson, 1981). Despite these conceptual disagreements, what a number of scholars do agree upon is that intimacy is best understood as a dyadic process in which one individual reveals something personal or private to another with the other responding in a way that feels positive and affirming to the first (Acitelli & Duck,

1987; Prager, 1995; Reis & Shaver, 1988). As such, in this study, intimacy will be viewed as an interactional phenomenon between two parties involving two parts: 1) an act of self-revelation and 2) a response that promotes positive affect between the individuals involved in the interaction (Lippert & Prager, 2001).

In addition to viewing intimacy as a process, it is also necessary to have a conceptual definition of what comprises intimacy and what, for the purposes of this study, falls outside the bounds of such a definition. Therefore, I have made use of Moss and Schwebel's (1993) formal definition of intimacy in romantic relationships that was formulated in response to their content analysis of 34 general, 10 multidimensional, and 20 operational definitions of intimacy. Based on their findings, Moss and Schwebel (1993) defined intimacy in romantic relationships as "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" (p. 33). Stated more simply, this definition of intimacy includes five specific components: commitment, affective closeness, cognitive closeness, physical closeness, and mutuality. *Commitment* deals with one's desire to permanently remain with one's partner; *affective closeness* has to do with emotional exchanges between partners (e.g., expressing feelings of care and concern for the other); *cognitive closeness* involves the level of awareness partners have of one another's inner thoughts, values, and goals; *physical closeness* refers to the degree to which partners engage in bodily encounters with one another (ranging from a pat on the back to sexual intercourse); *mutuality* addresses the level of give-and-take in one's relationship, including the energy each partner invests in maintaining intimacy in their relationship as well as the level of importance each places on fostering

intimacy in the relationship (Moss & Schwebel, 1993). Lastly, in Moss and Schwebel's (1993) definition of intimacy, the word "positive" connotes thoughts, feelings, and physical interactions that attract individuals to their partners.

Taken together, this conceptual definition of intimacy, combined with the notion of intimacy as an interactional process, allows me to view intimacy as relational, dynamic, and negotiable in relation to issues of commitment, closeness, and reciprocity in one's marriage or committed partnership.

Relevance of Intimacy to the Study of Couples Raising Children with ASDs

A variety of studies on intimacy have revealed that the presence of intimacy and intimate interactions (including self-revelation and partner responsiveness) in one's close relationships is associated with positive individual and dyadic characteristics, while a lack of intimacy may lead to more negative individual and couple outcomes (Lippert & Prager, 2001; Moss & Schwebel, 1993; Prager and Buhrmester, 1998; Prager, 2000; Sanderson & Cantor, 2001). In particular, individuals who engage in intimate couple interactions have better overall mental health and well-being (Moss & Schwebel, 1993; Prager, 2000). As Prager and Buhrmester (1998) maintain, these positive outcomes relate to the fact that intimacy in romantic relationships has been demonstrated to fulfill one's needs for self-esteem, belonging, validation, and acceptance. In addition, the presence of intimacy (or even simply having intimacy-related goals) in marriages and committed partnerships helps to maintain relationship satisfaction (Lippert & Prager, 2001; Sanderson & Cantor, 2001). Conversely, a lack of intimacy and intimate interactions in one's marriage is cited as the most common reason for divorce in America (Moss & Schwebel, 1993). Thus, the presence or absence of intimacy and intimate interactions in

romantic partnerships can be seen as key in determining the level of success and

satisfaction in any marriage/committed partnership (regardless of whether a couple is

raising a child on the autism spectrum or not), and speaks to Moss and Schwebel's (1993)

assertion that "people typically evaluate their romantic relationship in terms of its level of

intimacy" (p. 31).

In addition to these general findings related to intimacy and romantic

relationships, research focused on couples raising children with ASDs brings to the fore

important questions regarding the role of intimacy and intimate interactions within the

romantic relationships of these couples. As mentioned, some research suggests that

couples raising children on the autism spectrum experience more intimacy in their

marriages and committed partnerships, including higher levels of commitment (Brobst,

Clopton, & Hendrick, 2009) and closeness (Hock et al., 2012), while other research

maintains that couples raising children with ASDs experience less intimacy, including

decreased levels of commitment and closeness (Hartley et al., 2010; Myers et al., 2009).

Interestingly enough, in each of these studies, participants reported that caring for their

children with ASDs played a key role in their experiences of intimacy with their

spouses/partners. In some cases, being a couple in the context of raising a child on the

autism spectrum was seen as helping partners feel closer and more committed to one

another (Brobst et al., 2009; Hock et al., 2012) while, in others, the many unique stressors

associated with having an autistic child were viewed as factors that kept partners from

feeling close and committed to each other (Hartley et al., 2010; Myers et al., 2009).

Given these discrepancies among studies of couples raising children on the autism

spectrum, questions once again arise regarding why some couples with children on the

autism spectrum appear to experience more and deeper levels of intimacy while others experience less, what leads certain couples to have more profound intimate interactions than others, and how these couples negotiate issues related to this study's definition of intimacy when caring for children with ASDs.

Although these questions with regard to intimacy and intimate interactions would be relevant for any romantic relationship, they are of particular relevance to couples raising children on the autism spectrum. Again, this is because these couples face unique strains on their relationships related to raising children with ASDs (e.g., ambiguous loss, behavioral issues, financial concerns, lack of couple time; Gray, 2002; Higgins et al., 2005; O'Brien, 2007) that other couples raising typically-abled children do not necessarily experience. In addition, because, as Schaefer and Olson (1981) note, engaging in intimate interactions in romantic relationships is a process that never fully ends and which requires a great deal of "time, work, and effort" (p. 50) to maintain, couples already suffering from the physical and emotional exhaustion commonly associated with caring for children on the autism spectrum (Hock et al., 2012) may have more difficulty finding ways to foster intimacy in their relationships than couples without such strains. Case in point, a couple who feels they are just barely holding their family together may not have the time nor the energy to actively promoting intimacy in their relationship. Thus, an investigation of how couples caring for children with ASDs negotiate intimacy in their romantic relationships is needed to develop a deeper understanding of how these couples facilitate, or struggle to facilitate, issues of intimacy in their relationships while at the same time managing the distinct stressors that come alongside caring for children on the autism spectrum. The findings of just such a study

could go far in assisting couples to identify and extinguish interactions that keep them from experiencing intimacy as well as to develop and promote interactions that help them experience more intimacy in their relationships.

Importance of Study

In addition to the relevancy of intimacy to couples raising children with ASDs, especially with regard to the role of intimacy in the development and maintenance of stable and satisfying couple relationships, there are a variety of other reasons why a study of how couples raising children with ASDs negotiate intimacy would be important not only to these couples and their families, but also to the professionals who service them and researchers who study them.

First, understanding how couples "do" intimacy in the context of raising children with ASDs could allow for the development of pyschoeducational and psychotherapeutic intervention strategies to help these couples better negotiate issues of intimacy in their relationships. In turn, helping these couples find ways to experience more intimacy in their marriages/committed partnerships could also have broader systemic implications. For example, although studies on the effects of divorce on children suggest that some children adjust quite well in the wake of their parents' divorce and demonstrate increases in maturity, self-esteem, and empathy (Coontz, 1997; Gately & Schwebel, 1993), children on the autism spectrum may experience their parents' divorce as a particularly trying process to adjust to. This is not to say that children with ASDs are necessarily less able to adapt to parental divorce than typically-abled children (as little to no research has been done on this subject). Rather, because many children with ASDs often require a great deal of stability and predictability within their environments, as well as more time

to adjust after both major and minor life transitions (Jennings, 2005), the family system

changes that necessarily occur in the wake of a separation or a divorce may trigger a

crisis for these children. Namely, struggles in adapting to parental visitation schedules,

following different rules in each of their parents' homes, and becoming accustomed to

stepparents and stepsiblings may cause children with ASDs to become frustrated, throw

temper-tantrums, or act violently toward themselves or others because they have been

forced to deviate from their established routines (CDC, 2012). Thus, helping to foster

closeness and commitment in their parents' relationships may have the ripple effect of

helping these children to avoid the upheavals and unpredictability of separation and

divorce, and experience more safety and stability for themselves.

Furthermore, as no couple relationship occurs in a vacuum, developing an

understanding of the contextual and environmental issues that factor into how couples

raising children with ASDs negotiate intimacy will allow couples, professionals, and

researchers alike to better tease apart which issues are directly and/or indirectly related to

how couples deal with caring for their developmentally disabled children. Finally,

because of the noted gap in the literature with regard to what leads some couples raising

children with ASDs to have greater experiences of intimacy and intimate interactions

than others, the generation of theory around this topic may be the first step for couple and

family researchers looking to develop a more robust understanding of how couples adapt

and adjust to raising children with ASDs, laying the foundation for more specific studies

related to the topic.

Purpose of Study

Given the aforementioned information regarding experiences of intimacy among

couples raising children on the autism spectrum, the purpose of my study was to conduct an investigation ultimately leading to the generation of a theory on how couples negotiate intimacy in the context of caring for children with ASDs. Developing a sense of how these couples negotiate intimacy (including what outside contexts influence these negotiations and how they change over time) is a first step toward understanding what helps keep couples together or drives them apart in the face of the stressors related to caring for special needs children. Another central purpose of this study is to use the emerging theory related to couples' negotiations of intimacy as a launching pad for the creation of psycho-educational and/or psychotherapeutic interventions that can assist couples in promoting behaviors that encourage deeper levels of intimacy and in extinguishing behaviors that block intimacy and intimate interactions in their relationships. Such interventions could be of great use to couples raising children with ASDs, given that 1) greater intimacy in romantic relationships equates to greater individual mental health and well-being (Moss & Schwebel, 1993; Prager, 1995, 2000), 2) lack of intimacy in relationships is the most common reason for divorce in the United States (Moss & Schwebel, 1993), 3) intimate interactions play a major role in the level of satisfaction experienced in one's intimate relationships (Lippert & Prager, 2001), and 4) autism scholars maintain that couples raising children on the autism spectrum are more susceptible to lower levels of relationship satisfaction (Higgins et al., 2005) and higher incidence of divorce (Hartley et al., 2010) than couples raising typically developing children. For instance, by comprehending the mechanisms that lead certain couples to have more or less intimacy in their relationships, partners could learn new relational skills to better maintain and/or improve the quality of their marriages and intimate partnerships.

Even partners raising children with ASDs who already experiences strong levels of

intimacy in their relationship may benefit from understanding and improving upon the

adaptive processes by which they negotiate intimacy with one another.

CHAPTER 2: LITERATURE REVIEW

In the following chapter I will discuss the theoretical framework guiding my study, followed by a review of ASDs and the common stressors for those who care for children on the autism spectrum. I will then review the literature related to the systemic effects of caring for children with ASDs as well as the literature on how intimacy is fostered or hindered in romantic relationships. I will conclude with a discussion of the rather scarce relevant literature related to experiences of intimacy among couples raising children on the autism spectrum.

Theoretical Framework

The interpersonal model of intimacy (Reis & Shaver, 1988; Reis & Patrick, 1996), family systems theory (Cox & Paley, 2003; Watzlawick, Bavelas, & Jackson, 1967), and ecological systems theory (Bronfenbrenner, 1979) make up the integrative conceptual framework for my study. A visual depiction of this study's theoretical framework is found in Figure 1 on page 12.

I think of my framework as moving from the core to the peripheral issues in seeking to understand to how couples negotiate intimacy while raising children on the autism spectrum. That is, I view the center circle as housing the theory I believe to be most proximally associated with how these couples negotiate intimacy—the interpersonal model of intimacy (Reis & Shaver, 1988; Reis & Patrick, 1996). The next circle includes family systems theory (Cox & Paley, 2003; Watzlawick et al., 1967)—the theory that allows one to be sensitive to broader family system concerns, including caring for a child with an ASD, when examining couples' negotiations of intimacy. The final circle includes ecological systems theory (Bronfenbrenner, 1979)—the theory that I believe

attends to societal, cultural, and temporal contexts in which couples raising children with ASDs are situated. Additionally, I conceptualize my framework as involving arrows pointing both out from the center and in from the periphery in order to connote reciprocal relationships among the different levels of my proposed framework. Finally, I believe my framework to be holistic in that it allows me to attend to various relevant proximal, distal, and temporal factors in my study of how couples negotiate intimacy in the context of caring for children on the autism spectrum.

Interpersonal Model of Intimacy

Unpacking each of the three models I have chosen as part of my integrative theoretical framework, the interpersonal model of intimacy (Reis & Shaver, 1988; Reis & Patrick, 1996) views intimacy as a transactional process between two individuals involving self- disclosure and partner responsiveness (Baucom & Atkins, 2013). Within this model, self-disclosure is defined as "the communication of personally relevant or revealing information to another person" (Manne et al., 2004, p. 590). Such self-disclosing communications may be both verbal and nonverbal, with verbal disclosures
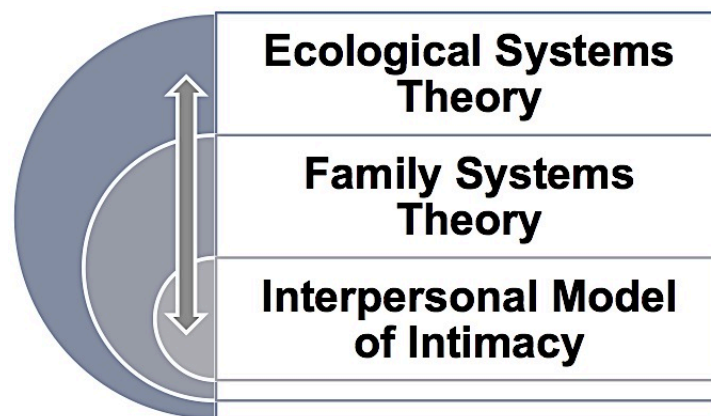
Figure 1. Theoretical framework for the study of how couples raising children with ASDs negotiate intimacy.

encompassing the communication of factual information as well as one's own thoughts and feelings and nonverbal disclosures ranging from the sharing of facial expressions to physically touching one's partner (Manne et al., 2004; Prager & Buhrmester, 1998). Partner responsiveness involves responding (either verbally or nonverbally) to the disclosing partner in a way that directly addresses the disclosing partner's communication. In particular, the responding partner must both express an understanding of the specific content of the disclosing partner's communication and convey a sense of validation of and care for this communication (Reis & Shaver, 1988; Laurenceau, Barrett, & Rovine, 2005).

For such self-disclosure and partner responsiveness to be defined as an intimate interaction, the disclosing partner must also perceive the responding partner's response as understanding, validating, and caring (i.e., "responsive"). When the self-disclosing partner perceives his or her partner's response to be truly responsive, the result of the exchange will be "a feeling of closeness, or intimacy" (Manne et al., 2004, p. 590) with the responding partner. Furthermore, self-disclosure from one partner may elicit a response from the other that includes the other's own self-disclosure (Laurenceau, Barrett, & Pietromonaco, 1998), begetting a cycle of interaction in which each partner becomes understood, validated, and cared for by the other and thus creating an experience of mutual intimacy (Laurenceau et al., 2005).

There are a number of benefits to including the interpersonal model of intimacy as a part of the theoretical framework for my study. Namely, this model allows for me to be sensitive to intimacy as a process and an interaction involving both self-disclosure and partner responsiveness. It also assists in developing an understanding that for any

communication between partners to be considered intimate, the self-disclosing party

needs to perceive his or her partner as responding in a way that demonstrates

understanding, validation, and care. This model also fits well within my study's

definition of intimacy as being a process that involves commitment, affective closeness,

cognitive closeness, physical closeness, and mutuality. This is because it frames intimacy

as an interaction between two partners; details self-disclosing communications in ways

that coincide with the explanations provided for affective closeness (e.g., sharing one's

own feelings with one's partner), cognitive closeness (e.g., sharing thoughts and other

factual information with one's partner), and physical closeness (e.g., physically touching

one's partner); and notes the importance of mutuality in the fostering of intimate

interactions between partners.

Family Systems Theory

Family systems theory (Cox & Paley, 2003; Watzlawick et al., 1967) provides

any theoretical framework with a richer understanding of the ways in which individual

members of, and subsystems within, a family influence and affect one another. In relation

to my study, this theory offers up several concepts that are helpful in constructing my

theory of how couples negotiate intimacy while raising children with ASDs. One such

concept is non-summativity, or the idea that the whole of a family system is greater than

the sum of its parts. This means that a family system "cannot be understood simply from

the combined characteristics of each part" (Cox & Paley, 2003, p. 193). For couples

raising children on the autism spectrum, this aspect of family systems theory brings to

light two important points. First, and more generally, it allows one to see that these

couples are not dealing with "autistic" children, per se, but rather that they are part of a

larger family system dealing with the challenges associated with caring for a member of the system who has an ASD. Therefore, negotiations of intimacy in such marriages/committed partnerships are best understood in the context of a family system in which one or more children are on the autism spectrum. Second, and more specifically, the notion of non-summativity frames a couple relationship as greater than the two individuals who comprise the couple. As such, although each partner may bring different ways of viewing and addressing issues of intimacy in their relationship, how couples negotiate intimacy is best viewed as a dyadic process rather than simply a combination of how partners as individuals feel about and deal with issues of intimacy in their relationship.

Another concept a family systems perspective provides for my study is that of homeostasis. Simply put, homeostasis suggests that members of a particular system interact in ways that work to maintain the stability of the larger system as a whole (Watzlawick et al., 1967). In family systems, this means that various individuals and/or subsystems (e.g., the sibling subsystem, the couple dyad) will put forth effort in order to keep the family unit intact. Additionally, a family system's ability to maintain homeostasis depends upon its ability to adapt to various life circumstances and transitions, developing new patterns of interaction around these situations. Failure to do so, according to family systems theory, occurs when a system becomes either too rigid (and experiences too little ability to change and interact in new ways) or too chaotic (and cannot stop from changing its patterns of interaction; Cox & Paley, 2003). In either of these instances, a family system's inability to adequately adapt to new circumstances can lead to both individual and systemic problems. For couples raising children with ASDs,

the role of homeostasis can shed light on how the degree to which a family can adjust to having a member on the autism spectrum may impact how couples are able, or unable, to successfully negotiate issues of intimacy in their marriages/committed partnerships. For example, if a couple is not able to reorganize themselves and create new patterns of intimate interaction around the stressors related to raising a child with an ASD (either because they are unable to take on new roles and ways of relating or because they are perpetually changing their roles and ways of relating), they are at risk for experiencing less intimacy and intimate interactions. However, if they are able to reorganize and develop new rules and roles around how they interact, they will be better able to negotiate intimacy while caring for a developmentally disabled child.

Ecological Systems Theory

Although family systems theory provides a context for understanding how couples raising children with ASDs negotiate intimacy within the larger family system, ecological systems theory allows me to take into account extrafamilial issues and further contextualize these couples' negotiations as existing within each family's unique and dynamic ecological environment (Bronfenbrenner, 1994). Specifically, ecological systems theory posits that a family's ecological environment is conceived of as "a set of nested structures, each inside the other like a set of Russian dolls" (Bronfenbrenner, 1994, p. 39). The innermost "doll" is referred to as the microsystem, which encompasses the interactions a family system has with its immediate surroundings; the outermost "doll" is the macrosystem, which includes a family's larger sociocultural context. When faced with any number of environmental demands, this theory views family systems as having differing levels of opportunity and constraint based upon their relationships to the

various levels of their ecological environments. Families with more opportunities and less constraints within a particular ecological niche may experience a greater range of possible responses to environmental demands than those who are afforded less opportunities and have more constraints (Bronfenbrenner, 1994).

With regard to couples raising children on the autism spectrum, ecological systems theory allows me to understand how the larger environments in which these couples live may cause them to negotiate intimacy in their relationships in very different ways. For instance, a couple whose proximal environment (i.e., microsystem) does not include extended family or close friends may miss out on the support experienced by other couples who do have access to outside help and, therefore, this couple may have less opportunities to successfully foster intimacy in their relationship. Additionally, a couple whose more distal sociocultural environment views having a child with an ASD as a result of parental shortcomings may feel more social stigma that another couple who live in a culture where autism is viewed as a developmental disorder over which parents have no control. The couple experiencing the stigma of having a child with an ASD may have more difficulty negotiating intimate interactions in their relationship because they feel alone and isolated from outside help. However, it may also be true that such stigma pushes the couple closer together as they rally around an issue for which they have little support. Whatever the case, this theory assists me in being sensitive to the quality of both the proximal and distal environments in which couples are raising children with ASDs, as environmental factors may influence the processes by which these couples negotiate intimacy in their marriages/committed partnerships.

One final point regarding the relationship of ecological systems theory to my

study is that there exists a temporal aspect to how individuals influence and are

influenced by their environments. Bronfenbrenner (1994) refers to this as the

chronosystem, or the patterning of environmental events and transitions over the life

course. Adding a temporal aspect to a study of how couples raising children with ASDs

negotiate intimacy raises my awareness of how a couple's negotiations may change over

time, depending, for example, on how long they have been caring for a child on the

autism spectrum or how long they have been aware of the child's diagnosis.

Theoretical Integration

Although each of the three models making up this study's integrative framework

have their own strengths in developing a theoretical understanding of how couples raising

children on the autism spectrum negotiate intimacy, no one model attends to all of the

necessary variables. For example, although the interpersonal model of intimacy (Reis &

Shaver, 1988; Reis & Patrick, 1996) focuses on intimate interactions between partners

and suggests that in examining intimacy in couple relationships one must be particularly

sensitive to both intimacy-related interactions and each partner's perceptions of those

interactions, it does not sensitize the researcher to explore how larger systemic issues

(e.g., the role of a child on the autism spectrum or one's larger social context) come to

bear on how partners manage intimacy in their relationships. Additionally, although

ecological systems theory (Bronfenbrenner, 1979) allows for both a broader

contextualization of couples raising children on the autism spectrum and the knowledge

that couples living in different contexts may negotiate intimacy in very different ways, it

does not speak to intrafamilial relations and how these may influence couples'

negotiations of intimacy. Furthermore, although family systems theory (Cox & Paley,

2003; Watzlawick et al., 1967) provides for a rich understanding of the ways in which individual members of, and subsystems within, a family affect one another, it is not able to offer any sense of what intimacy looks like in the context of a couple relationship. Because of the theoretical shortcomings of each of the three theories, it was not possible for me to pick one to use in isolation from the others. As such, it became necessary for me to create an integrative framework of these aforementioned models and theories, so that I might be able to attend to the various relevant proximal, distal, and temporal factors in my study of how couples negotiate intimacy in the context of caring for children on the autism spectrum.

Finally, it remains to be noted that I have employed this study's integrative framework with the understanding that, when developing theory around a particular phenomenon, such frameworks are only to be used as "points of departure from which to study the data" (Charmaz, 2003, p. 259) and not necessarily as lenses through which data are interpreted. This is to say that my aforementioned framework serves only to sensitize me to relevant phenomena, issues, and processes related to how couples raising children with ASDs negotiate intimacy. Thus, this framework has been for me a "tentative tool" (Charmaz, 2006, p. 17) that I have used for developing ideas about the processes defined in my data as opposed to a device with which I have imposed certain preconceived notions and beliefs directly onto the data I have collected.

Understanding Autism Spectrum Disorders

History of Autism

Leo Kanner, child psychologist at Johns Hopkins University, introduced the notion of autism and "autistic" individuals in 1943 to explain the behaviors of children

who demonstrated "extreme aloneness from the beginning of life and an anxious, obsessive desire for the preservation of sameness" (Kanner, 1943, p. 217). He created the diagnostic category of autism to differentiate between childhood schizophrenia and the differential symptoms he observed in the children he studied. Namely, Kanner noted that autistic children began displaying symptomatic behavior (i.e., isolating themselves from others, engaging in rigid and repetitive behaviors, and exhibiting speech and language impairments) before the age of three, whereas the onset of childhood schizophrenia began in later stages of childhood. Additionally, Kanner observed that autistic children did not experience hallucinations like children who had been diagnosed with childhood schizophrenia, and that families of autistic children tended to demonstrate much less psychotic behavior than those of children with schizophrenia.

In terms of its etiology, Kanner (1943) held the belief that autism was a socio-emotional disorder that was based in both biological and environmental factors. Nonetheless, for a number of years researchers tended to ignore the possible biological basis for autism and instead concluded that, because autistic children suffered from an innate inability to love others without the presence of any other physical deficits, their disorder must be the result of being raised in an environment in which their parents—their cold, distant, unemotional mothers, in particular—had failed to properly nurture them (Sanua, 1986). These mothers, referred to as "refrigerator mothers" in Bettleheim's (1967) study of autistic children, were thus viewed to be the primary cause of autistic symptomatology in children. Said differently, in response to a refrigerator mother's detached and unloving ways, autism was seen as a child's psychological defense against maternal neglect and rejection. More specifically, by withdrawing into a world of fantasy

and self-absorption, it was believed these children were able to protect themselves from the pains they had suffered in the real world at the hands of their mothers (Bettleheim, 1967). However, the price children of refrigerator mothers had to pay for withdrawing into their own worlds was quite high: their language skills deteriorated; they became preoccupied with maintaining order, sameness, and routine; and their social skill development grew stagnate.

This belief that parents were to blame for their children's autism was first refuted in 1964 by Bernard Rimland in his work on infantile autism. Here, Rimland maintained that autism was a purely biological disorder, and that mothers had nothing to do with the onset of autistic symptoms in their children. Kanner himself furthered Rimland's point in 1971 when he censured those researchers who had failed to pay heed to the portion of his hypothesis regarding the etiology of autism that involved inborn, biological characteristics. He also contradicted he previous stance on the relationship between parenting practices and the presentation of autism in children by cautioning researchers from suggesting a "direct cause-and-effect connection" between parental behaviors and the onset of autism (Kanner, 1971, p. 141).

Etiology of Autism Spectrum Disorders

Today, despite the view of autism as rooted in pathological parenting having long been rejected as a legitimate contributor to the onset of the disorder, experts are still unclear as to the exact cause of autism spectrum disorders (ASDs). What is known is that there are a number of genetic, biological, and environmental factors that may contribute to the presence of ASDs.

On a genetic level, research has demonstrated a strong heritability factor

associated with ASDs. Namely, individuals with siblings or parents on the autism

spectrum are more likely to have an ASD themselves (CDC, 2012b; Muhle, Trentacoste,

& Rapin, 2004). In addition, ASDs tend to occur more in individuals who also have other

genetic disorders, such as fragile X syndrome, Down syndrome, or other chromosomal

syndromes (CDC, 2012c). On a biological level, available data suggest that autism may,

in part, be caused by developmental abnormalities within the central nervous system and

various parts of the brain (e.g., the cerebellum, the temporal lobe, the limbic system;

Bachevalier, 1994; Kemper & Bowman, 1993; Trottier, Srivastava, & Walker, 1999).

And, on an environmental level, some studies suggest that exposure to certain toxins

(e.g., mercury and other heavy metals), vaccinations (e.g., MMR), or prescription drugs

(e.g., thalidomide) may also trigger the onset of ASDs in children (Autism Society of

America, 2012; CDC, 2012c). Lastly, recent longitudinal studies on the etiology of ASDs

have begun to point back to Kanner's hypothesis that parents' behaviors may, in fact,

impact the presentation of ASDs in their children. As Baker, Seltzer, and Greenberg

(2011) maintain, emerging evidence indicates that "parenting can influence autism-

related behavior, even if the etiology of such behavior is largely neurodevelopmental in

nature" (p. 2).

As such, in reviewing the literature on the etiology of ASDs, it is evident that: 1) a

number of different factors may influence the onset of ASDs in children and 2) no one

root cause has been found for the presence of these disorders to date.

Typology and Presentation of Autism Spectrum Disorders

Although autism experts disagree on the etiology of ASDs, they do agree on the

major types of ASDs, how these disorders present themselves, and that at this time there

is no known cure for any type of disorder on the autism spectrum.

ASDs are particular types of developmental disabilities that manifest themselves through the following criteria: impairment in social interactions (e.g., expressing little emotion, displaying little interest in playing with others, avoiding eye contact), impairment in language and communication skills (e.g., repeating words and phrases over and over, experiencing delays in speech, talking in an unexpressive tone), and repetitive and stereotyped interests and/or behaviors (e.g., not wanting to deviate from certain routines, obsessing over particular objects or ideas, engaging in self-stimulatory behaviors; American Psychiatric Association [APA], 2000; CDC, 2012d).

From the publication of the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) in 1994 until the spring of 2013, there were three primary types of ASDs (differentiated by the presentation of the criteria of impairments mentioned above): autism, Asperger syndrome, and pervasive developmental disorder, not otherwise specified (PDD-NOS). Under these old diagnostic criteria, individuals diagnosed with autism (also called "autistic disorder") were viewed as presenting with impairments from each of the aforementioned categories. These individuals could range from being very high functioning (with minimal impairments in social interactions, language and communication skills, and interests and behaviors) to very low functioning (with multiple deficits in each of the diagnostic categories and, often times, other comorbid conditions [e.g., mental retardation]). As distinct from individuals with autism, those with Asperger syndrome were categorized as having challenges with social interactions and unusual behaviors and interests, but did not typically present with language and communication issues or intellectual disabilities. Individuals given a

diagnosis of PDD-NOS (also known as "atypical autism") were considered to meet some but not all the criteria for autism and Asperger syndrome. Typically, those diagnosed with PDD-NOS presented only with impairments in social interaction and communication (CDC, 2012b).

However, in May of 2013, the latest iteration of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) was published. In the DSM-5, each of the three previously mentioned diagnoses was folded into one umbrella diagnosis of "autism spectrum disorder," which included only two domain criteria: 1) impairment in social communication and/or interaction and 2) restricted and/or repetitive behaviors (APA, 2013). In addition, the DSM-5 also added a new diagnostic category termed "social communication disorder" (SCD). According to the DSM-5, individuals falling into the category of SCD exhibit difficulties in the "pragmatics" of social communication, basically meaning they have trouble understanding and following socially sanctioned rules for both verbal and nonverbal communication, but do not present with any restricted and/or repetitive behaviors (APA, 2013).

Some in the autism community have been concerned over the changes in the latest iteration of the DSM, citing fears that certain individuals who were once considered to have an ASD would no longer qualify for the diagnosis and therefore lose the support services they had been receiving. However, a recently published study by Kim and colleagues (2013) conducted in the wake of the DSM-5 changes found that almost all individuals with a DSM-IV diagnosis of autism (98%) and Asperger syndrome (92%) still met the DSM-5 criteria for an autism spectrum disorder diagnosis. Additionally, the study also found that 71% of those with a DSM-IV diagnosis of PDD-NOS retained an

ASD diagnosis according to the DSM-5 criteria, while a further 27% qualified for a SCD diagnosis (Kim, Koh, Kim, Cheon, & Levanthal, 2013). As such, according to this study, it appears that concerns that individuals might lose an ASD diagnosis in the wake of the new diagnostic criteria for ASDs, have been largely unfounded.

Regardless of whether one follows the DSM-IV criteria for ASDs (as I will do in this study, given the fact that most lay people are not yet fully familiar with the DSM-IV criteria) or that of the DSM-5, given the different types of ASDs and the variability of functioning within each diagnostic category, it is evident that individuals on the autism spectrum may vary greatly in terms of the autistic symptoms and impairments they experience.

Prevalence of Autism Spectrum Disorders

As noted in the introduction to this study, ASDs affect one out of every 68 children in the United States, and these numbers are on the rise (CDC, 2012a). Moreover, ASDs tend to be much more common among males than females, affecting one out of every 42 boys but only one in every 189 girls in the United States (CDC, 2012a). However, the reasons for which more boys than girls are affected by these disorders are yet unknown. Some suggest this is because girls present ASD symptomatology in less familiar ways than boys and thus are not properly diagnosed with ASDs (Gould & Ashton-Smith, 2011); others argue that girls are less genetically vulnerable to acquiring ASDs than boys (Skuse, 2000).

Gender notwithstanding, ASDs are often viewed as non-discriminatory with regard to their prevalence. To this point, most extant research maintains that neither race, nor ethnicity, nor socioeconomic status, nor educational level, nor lifestyle is a significant

predictor of the occurrence of autism in children being raised in the United States

(Autism Society of America, 2000; CDC, 2012a). However, other researchers have raised

concerns over the claims that ASDs are ubiquitous in nature, arguing that more empirical

support is required to confirm that, gender aside, ASDs do not favor one race, ethnicity,

social class, education level, or lifestyle over another (Dyches, Wilder, Sudweeks,

Obiakor, & Algozzine, 2004).

Common Familial Stressors Related to Autism Spectrum Disorders

Research has revealed several common stressors for families of children on the

autism spectrum. These include ambiguous loss, behavioral issues, and financial

concerns.

Ambiguous Loss

Unlike other developmental disabilities such as Down syndrome or cerebral palsy,

ASDs, as mentioned, have no known cause and are not apparent at birth. Rather, children

with ASDs develop typically for the first 14 to 24 months of life. Only after this initial

period of typical development do impairments associated with disorders on the autism

spectrum become evident (Landa & Garrett-Mayer, 2006). As such, parents and other

primary caregivers are often taken by surprise when their children begin showing signs of

retarded social and communicative development. Many refer to this experience as an

ambiguous loss (Boss, 1999, 2006) in that these children are still physically present in

their parents' lives but are no longer socially and emotionally who they used to be.

Families may experience additional ambiguity due to the fact that the etiology of

ASDs is largely unclear and that diagnosing a disorder on the autism spectrum is often a

long and drawn out process of eliminating other possible disorders before confirming the

presence of an ASD (Siklos & Kerns, 2007). Furthermore, children with ASDs do not typically have any physical disabilities that accompany their developmental delays and do not appear any different than typically-abled children (O'Brien, 2007). Therefore, on top of trying to determine what could have caused their loved ones to develop an ASD in the first place, family members experience even more ambiguity in trying to make sense of whether the symptoms their loved ones exhibit do, in fact, point to the presence of an ASD or are simply signs of their child's misbehavior.

In addition, families often experience difficulty in accepting a diagnosis of a disorder on the autism spectrum because of the day-to-day variability in functioning of children with ASDs (O'Brien, 2007). That is, many children with ASDs may demonstrate particular impairments in certain areas while excelling in others (e.g., a child who is unable to maintain eye contact and hold conversations with others is, nonetheless, able to perform complicated mathematics unassisted). Such inconsistency in a child's abilities can "keep family members feeling off-balance, never quite certain whether the child is truly unable—or just unwilling—to learn certain basic skills" (O'Brien, 2007, p. 136).

Taking together the aforementioned information, for many families of children with ASDs, the various ways in which they experience the loss of their children keep them from moving along with the grief process, and stuck in a paradox of the simultaneous absence and presence of these children—the very definition of ambiguous loss (Boss, 2006). Simply put, for families of children with ASDs ''the child they thought they had is not the child they must learn to live with'' (O'Brien 2007, p. 135).

Behavioral Issues

On top of the experience of ambiguous loss, as these children grow older their

parents, other primary caregivers, and siblings must deal with the presentation of disruptive, and sometimes harmful, ASD-related behaviors. One of the most common set of behavioral issues among children on the autism spectrum relates to self-stimulatory and stereotypic behaviors. These are repetitive, rigid, and fixated types of behaviors that may be verbal or nonverbal, involve fine or gross motor skills, occur with or without the use of objects, and frequently serve to either engage one's senses or self-soothe when one is on sensory overload (Cunningham & Schreibman, 2008; Smith, Press, Koenig, & Kinnealey, 2005; Turner, 1999). Examples of self-stimulatory and stereotypic behaviors may include: hand flapping, body rocking, walking on one's toes, spinning objects and watching them go in circles, repeating the same word or phrase over and over again, and repeatedly watching objects pass across one's peripheral vision (Schreibman, Heyser, & Stahmer, 1999).

Cunningham and Schreibman (2008) also note other, more complex, types of self-stimulatory and stereotypic behaviors. These deal with "restricted and stereotyped patterns of interest or the demand for sameness" and involve "a persistent fixation on parts of objects or an inflexible adherence to specific, nonfunctional routines or rituals" (p. 470). Children engaging in these types of behavior may pay attention to only a specific part of an object (e.g., the wheels on a toy car), or may require playing with their toys in only certain, specific ways (e.g., repeatedly having to line up one's toy figurines in a particular and unchangeable fashion). Forcing children with ASDs to deviate from these routines and ritualized forms of play may incite temper tantrums and other aggressive behaviors, thus creating stress for their families (Abbeduto et al., 2004; Lecavalier, Leone, & Wiltz, 2006).

In addition to self-stimulatory and stereotypic behaviors, children with ASDs may present other disruptive and harmful behaviors, often related to sensory integration issues or the disruption of self-stimulatory and stereotypic behaviors. These include self-injurious behaviors (e.g., repeatedly pounding one's head against the wall), sexually inappropriate behaviors (e.g., public masturbation, attempting to touch others in a sexual manner), temper tantrums, and behaviors causing harm to others (Gray, 2002; Higgins et al., 2005, Tuzikow, 2012). All of these behaviors have the potential to cause great public embarrassment to families as well as to create a sense of stigma around themselves and their developmentally disabled children, leading to social isolation (Gray, 1994, 2002). Also, because problem behaviors for children with ASDs may increase in frequency and/or intensity over time, families must be very adaptable in how they respond to and deal with such behaviors. This constant need to adapt and adjust to their children's behavioral issues has the potential to engender stress, frustration, and exhaustion in caregivers and the family systems in which they exist (Ramisch, 2012).

Financial Concerns

Having a child with an ASD diagnosis can be financially taxing to families as well. A recent study on the average annual medical costs for Medicaid-enrolled children with ASDs found that these children accrued $10,709 in medical expenses per child, nearly six times higher than the average costs for children without ASDs ($1,812; Peacock, Amendah, Ouyang, & Grosse, 2012). These figures corroborate the findings of Shimabukuro, Grosse, and Rice (2008) who report that yearly medical expenditures for individuals with ASDs are four to six times greater than those for individuals without an ASD. Additionally, Ganz (2007) notes that direct medical costs associated with caring for

a child with an ASD average $35,000 annually through the first five years of the child's

life, while direct nonmedical costs (e.g., behavioral therapy, occupational therapy,

sensory equipment) vary from $10,000 to $16,000 per year over the first 20 years. More

intensive behavioral interventions for children with ASDs (e.g., in-home therapies) may

range in cost between $40,000 and $60,000 per child per year (Amendah, Grosse,

Peacock, & Mandell, 2011) and, in many instances, are not covered by insurance

(Linscheid, 2006).

Financial concerns for families raising children on the autism spectrum derive not

only from out-of-pocket costs for medical and therapeutic treatment. These concerns also

arise from the fact that parents must often times reduce their time at work in order to stay

at home with their children because they cannot find anyone willing and/or able to care

for their children's special needs (Gray, 2002). As such, many families lose the potential

of earning more income because they must take time off work to care for their children.

Thus, on top of all the other previously mentioned stressors related to raising children on

the autism spectrum, caring for the needs of children on the autism spectrum is also a

very expensive endeavor.

Systemic Effects of Autism Spectrum Disorders

Given the common stressors for families of children on autism spectrum, ASDs

can be seen as having an affect not only on the children who have been diagnosed with a

disorder on the autism spectrum but also on those who have been charged with caring for

them.

Parents of Children on the Autism Spectrum

Research demonstrates that parents raising children on the autism spectrum

experience more stress than both parents of typically-developing children (Allik et al., 2006; Brobst et al., 2009; Higgins et al., 2005; Mugno et al., 2007) and parents of children with other types of developmental disabilities (Bourma & Schweitzer, 1990; Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Rodrigue, Morgan, & Geffken, 1990). For instance, as compared to parents of children with typical needs, mothers and fathers of children on the autism spectrum report lower levels of marital happiness and relationship satisfaction (Brobst et al., 2009; Higgins et al., 2005; Rodrigue et al., 1990), lower levels of social support (Higgins et al., 2005; Mugno et al, 2007), greater parenting stress (Brobst et al., 2009), and greater individual emotional distress and sense of isolation (Hamlyn-Wright, Draghi-Lorenz, & Ellis, 2007; Woodgate, Ateah, & Secco, 2008). When compared to parents of children with other types of developmental disabilities, parents of children with ASDs were found to have higher levels of stress and depression and lower levels of relationship satisfaction (Fisman et al., 1989). Moreover, literature on the effects of autism on the family system has shown that raising a child with an ASD can lead to heightened experiences of both parental depression (Benson, 2006; Gray, 2002; Hastings et al., 2005; Parkenham, Samios & Sofronoff, 2005) and anxiety (Gray, 2002; Parkenham et al., 2005).

     Mothers of children with ASDs. Extant research also suggests that mothers of children on the autism spectrum appear to be particularly vulnerable to psychological and relational distress when compared to mothers of children with other types of developmental disabilities, and mothers of typically-developing children. For instance, in a study by Rodrigue and colleagues (1990) using self-report questionnaires to compare 20 mothers of children with ASDs, 20 mothers of children with Down syndrome, and 20

mothers of typically-developing children, mothers of children with ASDs reported less parenting competence, less marital satisfaction, and less family adaptability than the other groups. Mothers of children on the autism spectrum also were found to experience more caretaker burden, more family burden, and more frequent use of self-blaming as a coping strategy than mothers of typically-developing children. Nonetheless, mothers of children with ASDs did report a greater degree of family cohesion than mothers from the other groups. Furthermore, a study conducted by Estes and colleagues (2009) comparing parenting and psychological stress between mothers of children with ASDs ($n = 51$) and mothers of children with a developmental delay other than ASD ($n = 22$) found that mothers of children on the autism spectrum experienced significantly more parenting stress and had significantly higher levels of psychological distress (i.e., symptoms of depression and anxiety) than mothers of children with other types of developmental delays. However, in contrast to the many findings suggesting poorer outcomes for mothers of children with ASDs, in a survey of mothers caring for children with autism ($n = 102$), Down syndrome ($n = 126$), or schizophrenia ($n = 292$), Greenberg and colleagues (2004) found no significant differences in overall levels of maternal depression, psychological wellbeing, or physical health among the three groups.

When compared to fathers of children with ASDs, mothers of children on the autism spectrum have also been found to experience a number of more negative outcomes. Namely, mothers of children with ASDs have greater levels of stress (Herring et al., 2006; Wolf et al., 1989), anxiety (Hastings, 2003), and depression (Wolf et al., 1989), and poorer physical health (Allik et al., 2006) than fathers of children on the autism spectrum. One explanation of these differences relates to the fact that, although

mothers and fathers share parenting roles, mothers of children with ASD often take on the vast majority of the caregiving responsibilities for their developmentally disabled children (Gray, 2003; Hastings, 2003).

Fathers of children with ASDs. Despite the many studies focusing on mothers raising children on the autism spectrum, very little research has been devoted to the study of fathers caring for children with ASDs. Instead, existing studies on fathers have tended to explore the differences between how mothers and fathers are affected by caring for a child with autism (Allik et al., 2006; Hastings, 2003; Mugno et al., 2007).

As noted above, fathers raising children with ASDs generally experience less psychological and physical health issues than their partners. However, in a study of parents of 48 children with ASDs—including 41 pairs of mothers and fathers—conducted by Hastings and colleagues (2005), the researchers found no statistically significant differences in the levels of stress and psychological wellbeing reported by mothers and fathers. What Hastings et al. (2005) did find was that, although the outcomes for mothers and fathers were the same, the sources of stress were different. Namely, the primary source of stress for mothers emanated from their children's behavior problems, while paternal stress "was not associated with child characteristics but was positively predicted by their partner's depression" (Hastings et al., 2005, p. 641). These findings by Hastings and his colleagues corroborate Gray's (2003) qualitative inquiry of gender differences in parents of children with ASDs. In his investigation, Gray found that, although mothers reported their emotional wellbeing to be greatly affected by the demands of caring for children on the autism spectrum, fathers were not personally affected by their children. Rather, fathers maintained that "the most serious impact that their child's autism had on

them was through the stress experienced by their wives" (Gray, 2003, p. 634).

Although most studies on fathers of children with ASDs have tended to compare if and how mothers and fathers are differently affected by raising children on the autism spectrum, a handful of studies investigating the differences among fathers of children with ASDs, fathers of children with other types of developmental disabilities, and fathers of typically-abled children do exist. Interestingly, although these studies suggest that there are a number of significant differences in how fathers of children with ASDs and fathers of typically developing children adapt to the stressors of parenting (Baker-Ericzen, Brookman-Frazee, & Stahmer, 2005; Wolf et al., 1989), there are few significant differences between fathers of children with ASDs and fathers of children with other developmental disabilities (Rodrigue, Morgan, & Geffken, 1992). Namely, in their interviews of fathers of children with ASD ($n = 20$), fathers of children with Down syndrome ($n = 20$), and fathers of developmentally typical children ($n = 20$), Rodrigue and his colleagues (1992) found no empirical evidence to support the idea that ASDs contribute more to paternal stress than Down syndrome. Another noteworthy finding from Rodrigue et al.'s study was that, although both fathers of children with ASDs and fathers of children with Down syndrome reported more disruption in family planning and increases in financial burdens because of their developmentally disabled children, their levels of perceived parenting competence, marital satisfaction, and social support were not significantly different than those experienced by fathers of typically-abled children. As such, it seems that, as a general trend, fathers of children on the autism spectrum experience less severe and fewer hardships than mothers of children with ASDs.

Couples Raising Children with Autism Spectrum Disorders

Although the majority of research conducted on the impact of ASDs on parents has focused on the impact of autism on individual family members, there are a handful of studies that investigate how caring for children on the autism spectrum impacts parents of children with ASDs as a couple dyad.

As mentioned, the literature related to couples of children with ASDs offers very different pictures of how couples are affected by having children on the autism spectrum. On the one hand, a number of studies suggest that these couples are susceptible to negative relationship outcomes, including decreased levels of relationship satisfaction and stability, due to stressors related to raising children on the autism spectrum (Fisman et al., 1989; Hartley et al., 2010; Higgins et al., 2005; Rodrigue et al., 1990). On the other hand, other research indicates no significant differences in levels of relationship stability among couples raising children with ASDs (as compared to couples raising typically-abled children; Freedman et al., 2012), and that these couples may experience increased levels of relationship satisfaction as a result of raising children on the autism spectrum (Bayat, 2007; Cowan, 2010).

Aids and Barriers to Intimacy in Romantic Relationships

Having evaluated the nature of ASDs, common stressors reported by those caring for children on the autism spectrum, and how these stressors may impact parents and couple dyads, I will now turn to examine the topic of intimacy in romantic relationships. The literature on this topic offers a wealth of information regarding that which can promote and that which may inhibit intimacy and intimate interactions in couple relationships. I will begin with a review of the most common factors that aid the

development of intimacy in a marriage/committed partnership as well as those factors viewed to be barriers to deepening intimacy in the context of romantic relationships. I will conclude with an exploration of the literature related to intimacy among couples raising children on the autism spectrum and expound upon the literature introduced in the "Couples Raising Children with Autism Spectrum Disorders" segment of this review.

Aids to Intimacy in Couple Relationships

My review of the literature related to the fostering of intimacy and intimate interactions in romantic relationships revealed several dynamics leading to more and deeper experiences of intimacy among partners. In line with the interpersonal model of intimacy (employed in the theoretical framework for my study; Reis & Shaver, 1988; Reis & Patrick, 1996), a number of studies indicated that self-disclosure (Heller & Wood, 1998; Laurenceau et al., 2005; Lippert & Prager, 2001) and partner responsiveness (Debrot, Cook, Perez, & Horn, 2012; Heller & Wood, 1998; Laurenceau et al., 2005; Lippert & Prager, 2001; Manne et al., 2004) were key to the development of intimacy in couple relationships. Furthermore, in Laurenceau and colleagues' (2005) study of factors that predicted intimacy among married couples, it is interesting to note that the multivariate multilevel modeling the authors developed based on data from 96 participant couples revealed that wives tended to view intimacy as much more strongly tied to feeling "understood, validated, accepted, and cared for" (i.e., partner responsiveness; p. 321) by their husbands, while husbands tended to experience intimacy when they were able to share personal and private information with their wives (i.e., self-disclosure). Adding to the literature on partner responsiveness, in their evaluation of the interpersonal process model of intimacy in a sample of 98 women with breast cancer and their partners,

Manne and colleagues (2004) observed a very strong association between not just partner responsiveness, but also perceived partner responsiveness, and intimacy among their participant couples. As such, it was not enough for an individual to respond to his or her partner's needs; rather, that partner needed to also perceive the response in order for the interaction to foster intimacy within the couple dyad. However, Debrot and his colleagues (2012) noted in their study of 102 non-married, heterosexual Swiss couples that, even after controlling for the perception of partner responsiveness and earlier experiences of intimacy, concrete acts of responsiveness to one's partner had a direct and positive effect on the partner's feelings of intimacy. The authors interpreted this finding as indicating that "the responsive deeds of the partner do not necessarily need to be perceived by the partner to have an impact on the intimate process inside the relationship" (Debrot et al., 2012, p. 623).

Apart from self-disclosure and partner responsiveness, a number of other factors were found to promote intimacy in couple relationships. Heller and Wood (1998), in their study of 50 American couples based on the personal assessment of intimate relationships (PAIR; Schaefer & Olson, 1981), found that married couples experienced more intimacy when spouses could better predict one another's feelings and behaviors. This accuracy of prediction may be better stated as partners knowing each other well and understanding one another's reality, leading to an ability to intuit the feelings or actions of one's partner before he or she ever feels or acts. Also, Gordon and her colleagues (2012) in a study seeking to validate a process model for appreciation and relationship maintenance found that gratitude for one's partner was essential in developing greater intimacy among couples. In the same vein, Stafford and Canary's (1991) study of 956 married or dating

individuals revealed that positivity, or having realistic expectations for and fighting against disillusionment in one's intimate relationship, was associated with maintaining a romantic relationship. Their study also found that having shared foundational beliefs about committed relationships, social support, sharing activities with one's partner, and experiencing openness and honesty in one's relationship were all elements necessary to support a romantic relationship.

Adding to this list of factors aiding in the development of intimacy in romantic relationships, in their study of 113 cohabitating couples, Lippert and Prager (2001) noted partners who reported more pleasantness in their interactions, expressed positive feelings toward one another, and evaluated their interactions close to the time at which the interaction took place tended to experience greater degrees of intimacy in their partnerships. To the latter point, the authors pointed out that evaluating interactions relatively soon after they occur is important for facilitating intimacy in that this prevents both an individual's preconceptions about his or her relationship and/or his or her current psychological state from coloring the interaction in either too negative or too positive a light. Finally, based on their qualitative analysis of 22 Israeli married couples, Ben-Ari and Lavee's (2007) conceptual framework for dyadic closeness reveals more keys to fostering intimacy in one's marriage/committed partnership. On top of certain factors already mentioned (i.e., self-disclosure, partner responsiveness, sharing activities with one's partner), Ben-Ari and Lavee's model found friendship (defined as unconditional support, mutual understanding, appreciation, respect and trust), caring (defined as recognizing a partner's needs and providing for them) and physical closeness (of the sexual or non-sexual variety) as variables that promoted closeness and intimacy in

romantic relationships.

Barriers to Intimacy in Couple Relationships

As one might imagine, many of the things that serve as barriers to intimacy in romantic relationships are simply the opposite of the processes that have been demonstrated to encourage the deepening of intimacy and intimate interactions in couple relationships. Several of these blocks to greater intimacy can be seen as relational, while others are more inherent to the individuals involved in the couple relationship.

On a relational level, Fife and Weeks (2010) lay out various barriers to intimacy. Among these are neglect, or diverting time and energy away from one's relationship to focus on other things (e.g., work, hobbies, children, other relationships); violations of trust (e.g., infidelity, not following through on one's commitments to one's partner); poor communication and conflict-management skills; or any of Gottman's (1994) four horsemen of the apocalypse: contempt, criticism, defensiveness, and stonewalling (i.e., withdrawing as a way to avoid conflict). Other obstacles to relational intimacy relate to what family therapist Lyman Wynne (1988) refers to as caregiving and attachment behaviors. Stated differently, Wynne argues that it is the little things, such as taking out the garbage or buying your partner flowers for no particular reason, which promote intimacy in relationships and prevent the breakdown thereof. Thus, from Wynne's perspective, it is the absence of such caregiving and attachment behaviors that keep couples from experiencing greater intimacy with one another. Lastly, it may be the case that couples have varying perceptions on what constitutes intimacy and intimate interactions in a romantic relationship (e.g., men may equate intimacy with sex while women expect their husbands to approach intimate interactions as they would; Rampage,

1994) and that these differences prevent partners from perceiving each other's attempts to interact intimately as really being intimate.

On an individual level, barriers to greater intimacy in couple relationships also relate to a number of differing issues. As Alperin (2006) notes, not all people have the same capacity for intimacy. For many individuals, a fear of intimacy exists based on either childhood or adult attachment injuries (Alperin, 2001). Such fear may inhibit one from being very vulnerable (e.g., self-disclosing) with his or her partner, which may keep the couple from experiencing greater depth of intimacy in their relationship. In addition, Fife and Weeks (2010) mention that individual fears of becoming dependent upon another, being consumed by another, expressing anger before another, or losing control or being controlled by another may serve to hijack the intimacy process in one's romantic relationship. Alperin (2001) states these fears more succinctly by asserting that many couples are barred from experiencing more intimacy in their relationships due to the fact that one or both partners fears either being exposed before the other or being separated from, rejected, or abandoned by the other.

Intimacy Among Couples Raising Children on the Autism Spectrum

Research on relational outcomes for couples raising children with ASDs is scant at best, and even more scarce when considering how couples raising children on the autism spectrum negotiate issues of intimacy in their romantic relationships. However, there are a handful of studies published in the last few years that have begun to provide some evidence of that which either supports or inhibits the fostering of intimacy in these couples' relationships.

Greater Experiences of Intimacy

Several articles investigating the effects of caring for children with ASDs on couples' relationships have found that these couples may experience more intimacy in light of raising a child on the autism spectrum (Bayat, 2007; Cowan, 2010; Hock et al., 2012; Myers et al., 2009). For example, Bayat (2007), in his qualitative analysis of resilience among 175 parents and caregivers in families of children with ASDs, found that some participants reported to have experienced more cognitive closeness and mutuality with their partners as they rallied around the demands of caring for a child on the autism spectrum. Furthermore, Cowan (2010), in her in-depth, open-ended interviews of five couples raising children with autism found four of the five couples she interviewed to have reported that the difficult times they had experienced in relation to caring for a child on the autism spectrum had strengthened their marriages and allowed them to experience more affective closeness as partners.

Diminished Experiences of Intimacy

Despite the findings of the aforementioned studies, other studies found couples raising children on the autism spectrum to experience less intimacy due to the stressors of raising a child with an ASD (Fisman et al., 1989; Gau et al., 2012; Hartley et al., 2010; Myers et al., 2009). These studies seem to fall in line with Freedman and Naseef's (2012) observations that "while marriage is often on the back burner for parents of young children, when there is a child with ASD the marriage may often not even be on the radar" (p. 12).

Of the studies suggesting that couples raising children on the autism spectrum are at risk of experiencing less intimacy in their relationships, Hartley and colleagues' (2010)

study on risk and timing of divorce among couples raising children with ASDs is one of the most recent and insightful. The results of this longitudinal study of 391 parents of children on the autism spectrum found that married couples raising children on the autism spectrum experienced less commitment to one another and were at least 10% more likely to divorce than couples whose children had no known disabilities. Hartley et al. also found that although the risk of divorce for parents of typically-abled children decreased as their children reached young adulthood, the risk of divorce remained high for parents of children with ASDs. Reasons given for the higher rate of divorce among parents of children with ASDs included the extraordinary levels of stress these families experience, high levels of parenting demands over prolonged periods of time, and lack of attention (i.e., mutuality) devoted to one's spouse (Hartley et al., 2010). However, more mixed results were found in a study by Myers and her colleagues (2009). Namely, in their qualitative content analysis of the responses of 493 parents of children with ASDs to the question "How has your child in the autism spectrum affected your life and your family's life?", the authors found that for some participants raising a child on the autism spectrum led to lessened experiences of both mutuality and relationship commitment from or to their partners; for others, this same phenomenon led to more affective and cognitive closeness with their partners.

How Couples Maintain Intimacy

A review of the literature on intimacy among couples raising children on the autism spectrum also revealed two articles that begin to address issues related to processes in couples' relationships that can lead them to experience either more or less intimacy in light of caring for children with ASDs (Huck et al., 2012; Ramisch et al.,

2013).

First, Ramisch and her colleagues (2013) conducted qualitative interviews with 12 couples raising children with ASDs. The focal question the researchers asked participants sought to understand how these couples maintained strong marriage relationships despite the demands of caring for children on the autism spectrum. The authors then used a cluster mapping methodology to pictorially display common couple responses. Cluster maps for both wives and husbands were then created and examined for similarities and differences. This process revealed that both husbands and wives found communication, defined as being able to "openly discuss topics related to their children as well as other feelings and concerns" (p. 7), and shared ideas about what marriage is and means helped them to overcome the challenges of caring for the needs of children with ASDs. In other words, communication and foundational expectations for marriage helped couples foster more commitment and mutuality in their relationships. In addition, husbands and wives agreed that making decisions together, developing and making use of their support networks, and relying on God and their faith systems were key components of having intimate couple relationships when raising children with ASDs.

However, husbands and wives varied on a number of other ideas regarding the maintenance of healthy marriage relationships. Namely, wives reported that having time to spend both with their husbands and by themselves was central to having a strong marriage while husbands focused on caring for and loving their spouses as important acts in the maintenance of their marital relationships. What remains to be noted in Ramisch and colleages' (2013) study is that, although much information was provided on how couples with children on the autism spectrum maintain their relationships, nothing was

noted regarding how these couples may either enhance or experience barriers to enhancing the quality of their relationships.

Another study important in the development of a deeper understanding with regard to how parenting children with ASDs impacts couple relationships was conducted by Huck, Timm, and Ramisch (2012). This grounded theory study of 19 parents (9 couples and one wife) explored different relationship phases that couples raising children on the autism spectrum experience. Broadly, this study found that the relationships of these couples changed in three principle ways over time, which the authors referred to as "the autism crucible," "tag team," and "deeper intimacy and commitment." In the autism crucible phase, couples were found to have experienced a great deal of pressure on their relationships (e.g., physical and emotional exhaustion, financial strains, and social isolation) that forced them to adapt to the demands of raising a child on the autism spectrum in new ways. Based on the fact that they had less energy and more responsibilities, couples used the language of "sinking or swimming" and "make it or break it" to define this stage of their relationship. The next phase involved couples having adjusted to and reorganized around the special needs of their autistic children. The phase was primarily characterized by couples focusing more on parenting concerns than on themselves or their relationships. This defocusing on the romantic aspects of couples' relationships led to difficulties in preserving and fostering intimacy and connection with one another. The final phase of deeper intimacy and commitment was found to be borne out of the dissatisfaction and lack of intimacy partners were experiencing in the tag team phase of their relationships. In this phase, couples began to see that taking time for their marriages/intimate partnerships could actually be helpful to their children. This

paradigmatic shift in thinking then led couples to work hard to find time alone together

and to seek outside social support in order to do so. Couples who had arrived at this phase

also reported that they had come to have a greater depth of closeness and commitment to

one another as a result of getting through the autism crucible and tag team phases of their

relationships.

The value Huck et al.'s (2012) study lies in the fact that it offers a beginning

sense of the nodal points of couples' experiences throughout the process of parenting

children with ASDs. However, because participants of this study were recruited from

autism support groups and were primarily white and middle or upper middle class it

could be the case that other couples with less resources or social supports may have

different experiences in managing their relationships while caring for children with

ASDs. Additionally, no information was provided in this study with regard to what might

lead couples to not make it out of the autism crucible or tag team phases. Such

information would be very important to have in terms of developing interventions not

only to foster intimacy and intimate interactions but also to stop couples from relating to

each other in ways that railroad the development of intimacy in their relationships.

Areas for Further Study

As noted in this literature review, ASDs present in a variety of ways and cause a

variety of stressors to a variety of family members. Also noted was the fact that extant

literature on the intimate relationships of parents caring for children on the autism

spectrum is limited—especially with regard to how these couples navigate issues of

intimacy in their relationships. Those studies which do exist point to the possibility that

couples may experience less intimacy as a result of having children on the autism

spectrum, more intimacy, or experience no difference in intimacy than if they were caring for typically-abled children. Furthermore, no known literature to date has offered an account for the ways in which couples may arrive at these differing experiences of intimacy. Thus, given the varied results found in the literature on these matters, along with the fact that the processes that lead some couples to have very different experiences of intimacy than others have yet to be clearly elucidated, the purpose of this study was to examine how couples to raising children on the autism spectrum negotiate intimacy as well as to identify the contextual and temporal variables that come to bear on these negotiations.

CHAPTER 3: METHODOLOGY

Given the purpose of this study to develop a theory, grounded in participant data, of how couples raising children on the autism spectrum negotiate intimacy in their marriages/committed partnerships, as well as the contextual and temporal factors that influence these processes, I have chosen to use a methodology principally informed by constructivist grounded theory (Charmaz, 2006). This methodology, best suited for studies of social processes for which existing theories or areas of research are "under-defined or patchy" (Tweed & Charmaz, 2012, p. 134), fits well with my interest in understanding the processes by which couples raising children with ASDs negotiate intimacy, especially in light of the fact that little previous theorizing and research has been done in this area.

Research Questions

Based on my theoretical framework and the extant literature related to intimacy in the context of couples raising children with ASDs, the following research questions guided my study:

1. How do couples raising children with autism spectrum disorders negotiate intimacy in their marriages/committed partnerships?

2. What contextual or environmental factors (proximal and/or distal) influence couples' intimacy negotiations?

3. How do couples' negotiations of intimacy change over time?

Constructivist Grounded Theory

Constructivist grounded theory grew out of the traditional grounded theory methodology first defined by Glaser and Strauss in 1967 as a means to move qualitative

inquiry "beyond descriptive studies into the realm of explanatory theoretical frameworks, thereby providing abstract, conceptual understandings of the studied phenomena" (Charmaz, 2006, p. 6). In simpler language, what Glaser and Strauss developed was a specific type of qualitative inquiry in which the researcher attempted to derive a "general, abstract theory of a process, action, or interaction grounded in the views of participants in the study" (Creswell, 2003, p. 14). Also important to note is the fact that the original intention of conducting a grounded theory study was to "discover" a theory related to a specific social phenomenon in areas where no previous theories had existed (Glaser & Strauss, 1967). Thus, by generating new theory, the argument was that grounded theory studies would be able to greatly contribute to the understanding of various social phenomena (Charmaz, 2006).

For the purposes of my study, in which I have attempted to generate theory around how couples raising children with ASDs negotiate intimacy in their marriages/committed partnerships, I decided to take a methodological approach more in line with constructivist grounded theory (Charmaz, 2006) than with classical/traditional grounded theory. This was because constructivist grounded theory, unlike classic grounded theory, does not hold as an assumption that theories are "discovered" by researchers. Rather, viewing researchers as part of the worlds they study and the data they collect, constructivist grounded theorists maintain that "we construct our grounded theories through our past and present involvements and interactions with people, perspectives, and research practices" and that any theory one generates only offers "an interpretive portrayal of the studied world, not an exact picture of it" (Charmaz, 2006, p. 10). Said differently, any rendering of theory regarding social phenomena reflects only a

construction of reality according to how it has been interpreted by researchers and

research participants, and is not a discovery of an objective reality per se. Thus, the end

of a study informed by a constructivist grounded theory methodology is about

understanding how a certain set of individuals make sense of a certain phenomenon, as

opposed to uncovering the objective truth regarding that particular phenomenon

(Charmaz, 2006). With these thoughts in mind, a constructivist grounded theory approach

to the study of how couples raising children with ASDs negotiate intimacy not only fits

well with my own epistemological leanings, but it also allows me to stay close to my

data, continuously questioning my own (as well as my participants') assumptions the

phenomenon of couples' negotiations of intimacy in the context of caring for children on

the autism spectrum.

Sampling and Selection

Sampling Procedures

A hallmark of grounded theory research is the emphasis placed on theoretical

sampling (Charmaz, 2006; Corbin & Strauss, 2008). The main idea behind theoretical

sampling is that a researcher seeks pertinent data to help develop his or her emerging

theory (Charmaz, 2006). In this study, my employment of theoretical sampling followed

a two-step procedure. First, following Charmaz's (2006) recommendations for selecting

research participants for grounded theory studies, I began with an initial (selective)

sampling of couples raising children with ASDs. This stage of theoretical sampling led

me to seek out participants who met the selection criteria for this study (see the

"Selection Criteria" section of this chapter for participant inclusion criteria and the

justification thereof) and to ask these couples interview questions (based on the

theoretical assumptions guiding my study and my research questions; Echevarria-Doan & Tubbs, 2005) that could lead to the emergence of a theory regarding how couples raising children with ASDs negotiate intimacy.

After interviewing ten couple participants and having developed a rather robust understanding of the categories surrounding the phenomenon of how couples raising children with ASDs manage intimacy, I moved on to engage in what I view as the second step of theoretical sampling. My research team and I began this step after conducting and analyzing ten couple interviews and determining we had reached a point of theoretical saturation, defined as the point at which "(a) no new or relevant data seem to be emerging regarding a category, (b) the category is well developed in terms of its properties and dimensions demonstrating variation, and (c) the relationships among categories are well established and validated" (Strauss & Corbin, 1998, p. 212). Thus, in this last round of data collection, the team and I decided to conduct two additional interviews in hopes of continuing to hone our emerging theory by 1) enriching the categories that had emerged in our analyses and 2) further understanding the relationships between the different categories that had emerged in our analyses (Charmaz, 2006). As such, the focus of the final two interviews was more on soliciting couple participants' understandings of the emergent categories and the relationships between these categories.

Sample Size

Generally speaking, at the beginning of a grounded theory study there are no limits on sample size. Only when the researcher reaches theoretical saturation of the emergent categories, properties of categories, and patterns related to the phenomenon being explored does he or she discontinue data collection (Cutcliffe, 2000). Typically in a

grounded theory study, the actual sample size lies somewhere between 12 and 20 participants. Guest, Bunce, and Johnson (2006) suggest that 12 interviews is a generally sufficient sample size, based on their examination of the number of interviews required to reach data saturation in nonprobabilistic studies. They also maintain that grounded theorists may begin to see the emergence of categories in as few as six interviews. However, Creswell (2007) and Starks and Brown Trinidad (2007) take a more conservative view and suggest a sample closer to 20 participants in order to reach theoretical saturation in grounded theory studies. In my study, I had originally proposed to reach a point of saturation within the first 12 to 15 couple interviews. But, as I have already mentioned, after having conducted and analyzed the first ten interviews for this study it became evident to my research team and me that no new relevant data seemed to be emerging from the interviews. Nonetheless, we decided to conduct two further interviews with a view to obtain the targeted minimum sample size for this study of 12 participant couples and to further round out our findings.

Selection Criteria

Those couples that qualified to participate in my study had to meet the following criteria:

1. The participants must be married or, if unwed, in a committed relationship and cohabitating.

2. At least one of the participants must either be the biological parent of, or have formally adopted, a child under the age of 18 with an autism spectrum disorder.

3. The child on the autism spectrum must live with the participants the majority of the time (i.e., more days that not in a given week).

4. Both participants must have conjointly raised the child on the autism spectrum for
   at least the past two years.

5. The child must also have an official autism spectrum disorder diagnosis made by
   a qualified professional in accordance with the criteria for autism, Asperger
   syndrome, or PDD – NOS (as specified in the DSM-IV-TR; APA, 2000).

Essentially, the reasoning behind my criteria had to do with the fact that I wanted to
ensure that both partners were sharing in the experience of raising a child on the autism
spectrum and that they had been doing so for long enough to develop a deep
understanding of what it meant negotiate intimacy in the context of raising a child with
an ASD. In addition, I also wanted to verify my study participants were actually raising a
child on the autism spectrum and not simply self-diagnosing a difficult child as having
autism.

Recruitment Procedures

Because families raising children with ASDs can be a hard population to access
due to their limited social networks (Neely, Amatea, Echevarria-Doan, & Tannen, 2012),
for the purposes of this study I tried to cast a fairly wide net in my recruiting of potential
participants. I recruited potential participants for my study from a variety of both autism-
related organizations and non-autism-related community groups or services. (This was
done in an effort to diversify and reduce bias my study sample by including both couples
who were actively involved in the autism community as well as couples who were not a
part of this community.) In addition to contacting autism-focused support groups and
family service providers, I also focused my recruitment on community centers, parent
groups, churches with specific programs for disabled individuals, and day care services—

all places that I believed likely to be frequented by families with children on the autism spectrum.

Originally, my intent was to recruit participant couples located in the tri-cities area of suburban Chicago. I targeted this area not only due to the fact that it is close to where I live and work, but also because, taken together, this area is fairly racially, ethnically, and socio-economically diverse. However, when the first of my three rounds of recruitment in late October of 2013 led me to only about half the amount of couples I was hoping to interview for my study, I then decided I needed to expand my recruiting area from just the tri-cities to the surrounding communities of Wheaton, Glen Ellyn, Naperville, and Aurora. This decision allowed me, in mid-November, to contact more organizations, community groups, and service providers that might possibly be working with couples raising children on the autism spectrum. This round of recruitment helped me to find a handful more participant couples. My last round of recruitment took place in early January of 2014 and involved me contacting a few more places I had overlooked in my first two rounds of recruitment as well as my reconnecting with those who had already participated in my study to solicit their assistance in finding other couples that might be interested in my research opportunity. All in all, I contacted 28 autism-related organizations and non-autism-related community groups or service providers, 18 of which were support groups, four were churches that explicitly serve special needs individuals and their families, and four were community educational centers.

In connecting with these sites, I contacted each via an email in which I introduced myself, the purpose of my study, and my interest in partnering with them in finding potential couples to interview. I also attached to my email a recruitment flyer that I had

created for my study (see Appendix E) which included information about the scope of and time commitment involved in participating as well as the form of compensation qualified participants would receive. About one third (10) of the sites followed up with me either by phone or email with further questions for me about my study before they advertised my study to any members of their communities. A further four sites responded, without question, that they would be happy to advertise on behalf of my study. I did not receive any response from nearly half (13) of the sites I contacted; however, some of my study participants later reported having heard about my study from some of these sites.

Shortly after beginning my first round of recruitment, I began receiving calls and emails from individuals interested in participating in my study. When asked how they had heard about my study, one third (n = 6) of callers reported having been referred to me by word of mouth, while another 26% (n = 5) reported being uncertain as to how they had heard about my study. Another five callers (26%) stated having heard about my study from their local church. These findings led me to believe that I had done well to saturate the local ASD community with news of my study and that word of my study had gotten around, especially given the fact that over half (n = 11) of those individuals who contacted me did not identify any one particular referral source. My list of referral sources also led me to conclude that those area churches with specific programs for disabled individuals must have also developed rather tight-knit communities due to the degree to which word of my study spread among these programs. Table 1 on page 55 provides a full listing of referral sources for this study's potential participants.

I noted my correspondences with each interested party on a screening and

Table 1

Referral Sources for Potential Participants

Referral Source Type	Number of Couples Referred by Source	Percentage of Total Couples Referred
ASD Support Group	1	5%
Church	5	26%
Community Center	1	5%
Parent Group	1	5%
Uncertain	5	26%
Word of Mouth	6	33%

recruitment tracking form (where I also kept track of participant contact information and selection criteria; see Appendix F for the full form). Additionally, if I was originally sent an email from a potential participant, I scheduled a time to talk to that individual over the phone. During my initial phone contact with these individuals, I provided a brief background to and purpose for my study, explained what would be expected of those who participated, and answered any additional questions they had about my study. After discussing these matters, if an individual still expressed interest in participating, I then verified that the potential participant met the inclusion criteria for participating in my study. For those who did qualify to participate, I next asked them to go back and ensure that their partners were willing to be a part of my study and, if so, to follow up with me via phone or email regarding best times and locations for us to meet for the data collection interview. Overall, out of 19 individuals who contacted me regarding participation in my study, only 15 qualified to be interviewed. For those four that did not qualify, one was not married or in a committed relationship while the other three had children on the autism spectrum that fell outside the qualifying age range (i.e., under 18 years of age) for this study.

Furthermore, out of the 15 couples who did qualify to participate, two couples never responded to my attempts to set up a formal interview and one other individual reported that her husband, after hearing about the study in more detail, was no longer interested in being involved. For the other 12 couples, after confirming the time and location of the interview, I sent them a copy of the consent form for my study (see Appendix G for the full consent form) to review prior to our meeting.

Of final note, prior to recruiting and selecting any participants for my study, I had my study's design, as well as its sampling and selection procedures, data collection procedures, and data analysis procedures approved by the Institutional Review Board at Virginia Tech (see Appendix D for this study's IRB Approval Form).

Data Collection Procedures

Interview Setting

I gave couples participating in my study the option meeting for the formal data collection interview in their own home, in my office, or at another private location of their choosing. Eight couple participants preferred to meet in their homes, two wanted to meet with me at my office, and another two couples requested we meet at their local church. Ultimately, my aim was to meet with couples face-to-face and to make sure that we met in a place where they felt both comfortable and free to speak their minds.

I found several compelling reasons for conducting interviews on a face-to-face basis in a location of the couples' choosing. Namely, holding a data collection meeting in a location chosen by my participants allowed for the establishment of a less formal atmosphere. This, as LaRossa, Bennett, and Gelles (1981) point out, has the ability to foster a sense of openness and trust from the participants toward the researcher, leading

to greater participant self-disclosure. In the same vein, interviewing couples in a location of their choosing allowed for me as the researcher to "join" with couple participants, connecting with them in a genuine way, taking leadership for the course of the interview, and entering deeply into their own experiences of how they negotiate intimacy (Minuchin, 1974). Moreover, interviewing couples face-to-face provided me with opportunities to observe and comment on couple interactions (e.g., non-verbal gestures and cues) that would not be possible if interviews were not conducted in person (Bjornholt & Farstad, 2012). Such face-to-face interviews also offered me the chance to observe how some couples interacted with their children on the autism spectrum (when I met with participants in their homes and their children were present), despite the fact that this was not the central focus of my proposed study. Finally, by conducting face-to-face interviews, I was also able to offer my participants the option of requesting that another member of my research team attend the interview in order to provide childcare for the participants, as needed; however, no one took me up on my offer.

Interview Modality

As previously stated, I chose to conduct conjoint data collection interviews with the couples raising children with ASDs who participated in my study. I chose this particular modality because of the fact that I believed the benefits of conjoint interview to far outweigh the potential drawbacks.

Benefits of conjoint interviews. Although I looked at a number of different options for collecting data for my study, including interviewing couples separately and simultaneously (Hertz, 1995), interviewing couples separately and consecutively, interviewing one partner only (Taylor & de Vocht, 2011), and letting participants choose

whether to be interviewed conjointly or separately (Taylor & de Vocht, 2001), interviewing couples conjointly seemed most appropriate for my study for a variety of reasons. First, given that the couple dyad was the unit analysis for my study, that my research questions related to the process of negotiating intimacy (a couple interaction necessitating a couple interview in order to be able to see and discuss this process), and that my study's theoretical framework was systemic in nature (i.e., viewing the whole of a couple's relationship to be greater than the sum of each partner's role, and understanding that change to one part of a family system changes the whole system; Cox & Paley, 2003; Watzlawick et al., 1967), I believed it to be theoretically fitting that I engaged in conjoint interviews with my participants.

Furthermore, I was not alone in holding a belief that richer data and thicker descriptions of phenomena can come out of conjoint interviews than from individual accounts (Allan, 1980; Bjornholt & Farstad, 2012; Valentine, 1999). For example, Taylor and de Vocht (2011) note that in conjoint interviews couples can corroborate, challenge, modify, or add to each other's stories by virtue of the fact that they are being interviewed together. This, according to the authors, can promote disclosure of information that may not have been shared in individual interviews. Bjornholt and Farstad (2012) also maintain that a "cueing phenomenon" occurs in conjoint interviews, which does not take place in individual interviews. That is, in conjoint interviews, one partner's thoughts may spur on ideas from the other, creating a generative process by which a couple's description of a particular phenomenon may be both enlivened and enriched.

An additional strength of my preferred interview modality related to the fact that in conjoint interviews a researcher may be exposed to couple dynamics and processes

that would not be evident in individual interviews (Allan, 1980; Taylor & de Vocht, 2011). As Valentine (1999) points out, interviewing participants conjointly may allow the researcher to observe tensions or conflicts in the couple relationship, if disagreements were to arise in the interview process. And, as already mentioned, this interview modality may reveal communication patterns between partners and offer the researcher the ability to collect observational as well as interview data (Bjornholt & Farstad, 2012).

Lastly, I had several practical reasons for electing conjoint over individual interviews. Namely, I was in agreement with Daly's (1992a) assertions that interviewing couples together allows for greater historical accuracy of their accounts and also saves the researcher both time and money by not having to conduct separate interviews for each partner. I also concurred with Bjornholt and Farstad's (2012) argument that conjoint interviews provide a solid method for finding male participants, who may be less inclined to volunteer for a research study independent of their partners.

Risks related to conjoint interviews. Despite the fact that conducting conjoint interviews with couples provided me with many benefits, there were also a handful of risks that I needed to account for as I prepared to facilitate my interviews. Principle among these was the risk that power differentials might arise during the interviews (either between the researcher and one or both participants, and/or between the participants themselves) causing a number of problems for my research participants. For instance, it could have been the case that one partner in a couple relationship was the more dominant and tended to speak for the other, or one partner may have been afraid to express any dissenting opinions or raise any controversial points for fear of later retribution by the other (Hertz, 1995; Taylor & de Vocht, 2011). In these situations, the power of one

partner could serve to silence the other from making known to the researcher certain sensitive issues related to the couple's relationship, let alone any fears or frustrations the silenced partner may harbor (Daly, 1992b). Moreover, this type of power differential might put the less dominant partner in harm's way if he or she were to disclose something that angered the dominant partner, especially if the dominant partner did not want that information shared publically, had no previously knowledge of the information, or felt the information was presented in a distorted manner (Taylor & de Vocht, 2011).

Another area of concern for me with regard to the power differentials involved in conjoint interviews related to the topic of informed consent. Here, Allan (1980) notes that it may be the case that one partner may be eager to participate in a conjoint study and the other is not. In this type of a situation the less interested partner could be seen to have been coerced to participate in the study by his or her partner and, thus, to have never really consented to be interviewed. On a separate but related note, LaRossa and his colleagues (1981) raise the point that informed consent in the context of conjoint interviews will invariably prove to be a bit of a sticky wicket in the sense that couples can never really be sure of what points each other will raise before the interviewer. In this way, what one partner had believed he or she was consenting to discuss in the interview may be different from that which the other partner actually chooses to share.

A last potential risk related to conjoint interviewing for which I needed to be aware had to do with the richness and depth of the data I collected. For example, Hertz (1995) points out that when interviewing couples together, it can be difficult to detect differences in each partner's story and that interviewees are offered no privacy with which to express secrets that they do not want to share in front of their partners. As such,

the researcher may only have access to a couple's "official family account" (Hertz, 1995, p. 435) of the phenomenon in question. Echoing these concerns, Taylor and de Vocht (2011) state that conjoint interviews may not allow for each partner's unique point of view to be expressed.

Mitigating conjoint interviewing risks. For the purposes of my study, I did several things to mitigate the aforementioned risks involved in conjoint interviewing. Regarding issues of informed consent, I emailed a copy of the study's informed consent form to each couple participant prior to the data collection interview, reiterating via this mailing that if one partner strongly desired to participate in the study and the other did not, then the uninterested partner was under no circumstances required to participate. I also requested that each partner read over the informed consent form prior to the formal interview so that both parties would be able to understand what the study involved, as well as the potential risks and benefits of participation, prior to the actual data collection interview. Lastly, I began my face-to-face interviews of each couple by reviewing the informed consent document, confirming that both partners were individually consenting to participate, and noting that either partner could ask to table a particular discussion area or terminate the whole of the interview at any time—an offer none of the couples I interviewed ever invoked.

Another potential risk area related to issues of power between participant couples. In order to assure that one partner did not dominate the discussion, I employed my skills as a marriage and family therapist to, as necessary, balance the conversation, interrupt an overly talkative partner, and/or elicit feedback from a less verbal partner. I also prefaced particularly sensitive areas of discussion by informing couples that it was perfectly okay

to skip over certain issues and monitored both partners for signs of distress (e.g., redness in the face, scowling, frowning, tears) when engaging sensitive topics. Also, in order to ensure that if, in fact, one party did feel silenced or otherwise unable to raise a certain issue in the formal interview, following the interview I emailed each partner a post-interview questionnaire (see Appendix C) that they could fill out and email back to me if they so desired. Thus, the post-interview questionnaire gave each partner the opportunity to privately respond to their experience of the formal interview process.

Regarding this final risk area related to conducting conjoint interviews, the fact that this interview modality may negatively affect the richness and depth of the data collected, I would simply refer back to the arguments made at the beginning of this section in which I cite several authors who have pointed to the idea that interviewing couples together actually adds to, rather than detracts from, the richness of the data and the depth of understanding one can derive about a particular phenomenon—I certainly believe this was the case for me.

Instrumentation

Three different measures were used to collect data for this study: pre-interview questionnaires, semi-structured interviews, and post-interview questionnaires.

Pre-interview questionnaires. Prior to beginning the formal interviews with my participant couples, I had each individual fill out a brief pre-interview questionnaire. In these questionnaires, I asked participants to provide a bit of basic demographic information about both themselves and their children on the autism spectrum in order to gain an understanding of the greater context for the findings of this study. The full list of this study's pre-interview questions are found in Appendix A.

Semi-structured interviews. The primary means of data collection for this study involved in-depth 60 to 90 minute ($M = 69.5$) semi-structured interviews with couples either in their homes or another private location of their choosing. I asked couples a series of questions aimed at developing an understanding of the processes by which they negotiated intimacy, what the steps in these processes were, what contextual factors influenced these processes, and how they changed over time. I created each question for my semi-structured interview in such a way that I could relate participants' responses directly back to one (or more) of the research questions guiding my study. Table 2 notes the relationship between each of my 11 interview questions (following the order in which these questions are numbered in Appendix B) and my overarching research questions.

Post-interview questionnaire. After the conclusion of the semi-structured interview, I invited participants to also fill out a short post-interview questionnaire. The post-interview questionnaire gave each partner the opportunity to respond individually to their experience of the formal interview process and to comment on anything related to the topic of how couples raising children on the autism negotiate intimacy they had thought of after the fact. Specifically, in the post-interview questionnaire I asked each partner if there was anything about their situation they felt they could not speak about in

Table 2

Relationship Between Research Questions and Semi-Structured Interview Questions

Research Questions	Interview Questions
1. How do couples raising children with autism spectrum disorders negotiate intimacy in their marriages/committed partnerships?	1, 2, 3, 4, 5, 6, 10, 11
2. What contextual or environmental factors influence these processes?	7, 10, 11
3. How do these processes change over time?	8, 9, 10, 11

front of their partner, if there was anything surprising to them about how their partner

responded to the interview questions, or if there was anything else I needed to know

about negotiating intimacy while caring for a child with and ASD that they did not

express at the time of the formal interview. The full list of this study's post-interview

questions are found in Appendix C.

Data Collection Procedures

After having verified the inclusion criteria for my participant couples as well as

both partners' interest in participation in my study, a formal interview date and location

was set. At the time of the formal interview I began by reviewing the informed consent

document and noting that the couple could terminate the interview at any time, if they so

desired. If the couple raised no further objections and had no further questions about the

study, I then asked them to sign the consent form. After they had done so, I handed each

partner a copy of my pre-interview questionnaire to fill out.

Once each partner had completed the pre-interview questionnaire, we then began

the formal interview. I informed the couple that they did not have to answer any question

that made them feel uncomfortable. I also, with the knowledge and consent of each

couple, audio recorded each interview in order to later transcribe and analyze the data

provided. After having concluded the formal interview, I gave each couple a $20 Target

gift card as compensation for their time and effort and asked that they sign a document

indicating that they had received the gift card (see Appendix H for the receipt of

compensation form).

As a follow-up to the formal interview, within two days of meeting with each

couple I emailed both partners the post-interview questionnaire. Interestingly enough, out

of 24 individual participants in this study, only four (17%) returned to me completed post-interview questionnaires. And, out of those four, none reported being surprised by anything their partner said, nor that there was anything they felt they could not say about their relationship in front of their partner.

Finally, immediately after completing each interview, I also made note of any other thoughts, observations, or personal reactions to my participants as well as any ways in which the data provided by the participants seemed to either relate or not relate to other data collected from couples I had already interviewed. Appendix I offers an example of one of my reflexive field notes.

Data Analysis

In order to analyze the data collected from my interviews, I formed a research team with two graduate students from the psychology department at Wheaton College. The team and I made use of the constant comparative method of data analysis (Strauss & Corbin, 1998) and employed the commonly used qualitative coding scheme of open, axial, and selective coding (Creswell, 2007; LaRossa, 2005; Strauss & Corbin, 1998). Throughout this process of data analysis, the team and I also took several steps to ensure the trustworthiness of the study.

Research Team

My research team consisted of a 25-year-old Caucasian female who was a masters student in marriage and family therapy and a 38-year-old male doctoral student from Azerbaijan. I trained my team members on how to conduct a qualitative analysis of participants' responses to my interview questions via use of the constant comparative method and a three-tiered coding scheme of open, axial, and selective coding. In addition,

I trained team members on how to both transcribe the interviews I conducted and make use of NVivo, a qualitative data analysis software. In spite of the aforementioned ways in which I made use of my research team, I was the only team member responsible for recruiting for my study, corresponding with potential participant couples, and conducting the data collection interviews. Being in charge of these tasks provided a sense of continuity for my study participants throughout the recruitment and interview processes, and also ensured the uniform collection of data across all study participants.

Constant Comparative Method

In grounded theory research, a recursive relationship exists between the processes of data collection and data analysis. As Rosenblatt and Fischer (1993) note, throughout the process of data analysis there is "a great deal of back-and-forth work between a developing picture of what the data mean and the data" (p. 172). In this sense, it was necessary for my research team and I to begin data analysis while data were still being collected. Data collection for this study did not stop until the research team members all agreed that we had arrived at a point of theoretical saturation (i.e., when the data being collected no longer provide new information for the researcher's emerging theory; Echevarria-Doan & Tubs, 2005).

For this study, making use of a constant comparative method of data analysis (Strauss & Corbin, 1998) meant that the research team and I systematically reviewed and re-reviewed participants' data, comparing these data across the data provided by other study participants for the purpose of identifying commonalities, themes, and emergent categories in what participants reported in relation to the phenomenon of how couples raising children on the autism spectrum negotiate intimacy. We used the coding

procedures detailed below to aid us in this endeavor.

Coding Procedures

Before beginning any data analysis of the formal interviews, members of the research team transcribed each interview word for word and entered electronic copies of the transcribed interviews into NVivo. The team members and I then read and reread each transcript in order to better familiarize ourselves with the content and general themes included in each couple interview before we made any attempt to formally code the interview data. For the actual coding of each transcript, we followed the commonly used coding scheme for grounded theory studies of open, axial, and selective coding (Creswell, 2007; LaRossa, 2005; Strauss & Corbin, 1998).

Open coding. After each member of the research team had independently read and reread each couple interview transcript, analysis of the interview data for this study began with open coding. Strauss and Corbin (1998) describe this phase of coding as one in which "data are broken down … [and] closely examined" (p. 102). For the purposes of this study, such breaking down and close examination signified that my research team and I conducted a line-by-line analysis of each couple's interview transcript. More specifically, we broke the data down into discrete segments (i.e., words, phrases, and sentences), coded these segments, and searched for similarities and differences among the codes that we had developed (Strauss & Corbin, 1998).

For the first few transcripts we reviewed, team members met together in order to develop a consensus on the codes we were creating for each discrete segment of text. In creating the codes, each member of the research team worked to maintain a critical and analytical stance toward the processes being discussed. Practically speaking, this meant

that the team looked at more than just the words in each discrete segment of data we coded; rather, we also looked to analyze the context and tone of couples' statements so as not to make the mistake of coding a particular segment independent of the larger conversation taking place. In addition, we attempted to code segments of text in the gerund verb form (to keep the data active rather than passive) and we used, when appropriate, "in vivo" codes, or codes that made use of participants' own words (Charmaz, 2006), to capture meanings behind certain discrete segments of data. This type of coding allowed us to remain close to the data by preserving the voices of interview participants in the initial codes we created.

Next, we created a codebook of the codes we had generated from our collective open coding analysis of the first three interviews (Hruschka et al., 2004). This codebook served to guide the research team as subsequent transcripts were assigned a "lead coder" who was responsible for taking charge of the open coding process for each of the remaining transcripts. For each new transcript that was analyzed, the lead coder used the codebook as a reference, but also created new codes for discrete transcript segments that did not align themselves to already existing codes. After coding each new transcript with both new and existing codes, the lead coder then sent his/her coding to the other members of the research team to review independently. During this time of independent review, the other members of the research team raised questions about the lead coder's coding, adding to and subtracting from the codes originally created by the lead coder. Later, the entire research team reconvened to discuss the lead coder's coding, at which point the open coding codes to be applied to each transcript were finalized and any new codes were added to the codebook.

The research team followed this method of open coding for the first ten interview transcripts. At the end of the tenth interview we had amassed a codebook with 895 codes. The challenge then became how to distill this list of codes into something more manageable before moving on to the next phase of coding. Following Auerbach and Silverstein's (2003) guidelines for categorizing similar ideas in the open phase of coding, I desired to condense all of the original codes that had been established during the line-by-line coding process down to somewhere between 40 and 80 sets of codes. After removing all of the duplicate codes and those that did not ultimately appear to aid in developing an understanding of the phenomenon being studied, the research team and I reviewed and then re-reviewed the codebook, looking for larger themes under which individual codes could be subsumed. We agreed to 24 theme areas under which to list individual codes, ranging from "babysitting and respite care" to "conflict" to "sex and physical intimacy." In each of these areas, we listed the codes that we believed spoke to one or more aspects of each theme and did not limit codes to being used in only one area. Thus, a code like "accepting couple time may not happen as often as expected" was able to fall under the theme areas of both "couple time" and "adjusting expectations/adapting."

After we had placed each remaining open coding code into one or more theme areas, the team and I next worked to unpack each theme area and group the codes therein into categories that spoke to the various aspects of each area. For a theme area with fewer codes, this process was simpler than for a theme area with dozens of codes attached. For example, we were able to distill the theme area of "child behavioral issues," which included only 10 codes, to one set of codes entitled "viewing opportunities for couple

time as dependent upon child behaviors"; however, for a larger theme such as "communication," which included 55 codes, we needed to create six sets of codes from "proactively communicating" to "experiencing communication difficulties" in order to capture all the information included in this area. Ultimately, we reached a consensus over 80 sets of codes that related to various aspects of negotiating intimacy while raising a child on the autism spectrum. These 80 sets formed the basis for the next step in our coding process, axial coding.

Axial coding. Axial coding is a second level of coding which often times occurs while open coding is still ongoing (Echevarria-Doan & Tubbs, 2005). This phase of data analysis involves coding that seeks to bring back into a coherent whole, and to provide a working framework for, data that has been broken down into separate pieces and distinct codes during the open coding phase (Corbin & Strauss, 2008). Thus, in axial coding, the researcher works to create categories and subcategories that encompass large swaths of data which flesh out the properties and dimensions of a particular category or subcategory (Corbin & Strauss, 2008). This coding is referred to as axial due to the fact that these comparisons of data occur around the "axis" of a category, thus linking data together (Strauss & Corbin, 1998).

Through the process of axial coding, my research team and I attempted to begin to identify central categories emerging from the data. More specifically, we looked for categories of: 1) conditions that influenced how couples negotiate intimacy while raising children with ASDs, 2) actions and interactions that resulted from couples' experiences of these negotiations, 3) contextual issues that informed how couples manage matters of intimacy, and 4) consequences of the ways couples addressed intimacy in their

relationships (Creswell, 2007). Basically, we looked to answer to the "who, what, where, when, why, how" questions of the study during the axial coding phase. From a practical standpoint, this meant that my research team and I examined each of the 80 sets of codes that we had created to determine which sets fit together and just how they could be clustered into larger categories and subcategories of information. In the midst of performing these tasks, we regularly returned to the interview transcripts in order to pull out examples and descriptive quotes for each category and subcategory that we developed, as well as to ensure that the categories we were creating accurately reflected the data that study participants had shared with us.

At the completion of this phase of analysis, the team and I had compiled five central categories comprised of 13 subcategories related to how couples raising children with ASDs negotiate intimacy (see Appendix L for a detailed list of the categories and subcategories pertaining to this study, as well as a data saturation matrix indicating which participant couples endorsed which particular categories and subcategories). We also gathered together the data that related more specifically to the second and third research questions guiding this study (i.e., "What contextual/environmental factors influence how couples raising children with ASDs negotiate intimacy?" and "How do these processes change over time?") into two other distinct categories of information with five related subcategories.

After completing the steps enumerated above, the research team and I went back to code the final two transcripts of the study, but did so at the axial level. That is, we did not do a line-by-line coding of these transcripts, but instead combed through these for data that could provide us with further information regarding the categories and

subcategories we had established. At this same time, the team and I also went back

through the transcripts of the first ten interviews we had analyzed to look for any

information we might have previously overlooked regarding our emerging categories and

the relationships among them (Corbin & Strauss, 2008). Ultimately, our aim at this point

in the data analysis process was to "elaborate and refine" (Charmaz, 2006, p. 96) the

categories constituting this study's theory of how couples raising children on the autism

spectrum negotiate intimacy.

Selective coding. After all the necessary data for the study had been collected,

coded, and placed into the appropriate parent categories and associated subcategories, my

research team and I then began the final phase of coding—selective coding of the data.

This is the point at which we established what LaRossa (2005) calls "the main story

underlying the analysis" (p. 850) for understanding both 1) the processes of how couples

negotiate intimacy while raising children with ASD and 2) the contextual factors that

affect these processes over time. Specifically, the story that we developed during this

phase of coding attempted to integrate (e.g., specify the relationships between) the

categories that had emerged for us during the axial stage of our coding process (Charmaz,

2006). In other words, the selective coding phase was where we put together a "theory"

for making sense of how couples raising children with ASDs negotiate intimacy.

For the purposes of this study, the selective coding phase involved the research

team coming to a consensus over how the particular categories we had previously

established related to one another in creating a cohesive narrative regarding the

phenomenon in question. These conversations took place after all the interviews had been

completed and all the emergent categories had been saturated. In creating this narrative,

the team and I reviewed various aspects of the categories and subcategories we had

developed and experimented with many different visual depictions of best to make sense

of the processes by which couples negotiated intimacy when raising children with ASDs.

Throughout this process we went back and forth between the data and our prospective

theoretical models to check the degree to which the stories we were putting forth actually

fit the data we had collected and analyzed. After much trial and error, we ultimately

agreed upon a theory, well grounded in participant data, of how couples caring for

children on the autism spectrum negotiate intimacy.

<div align="center">**Assuring Methodological Rigor**</div>

During the data collection and data analysis phases of this study, I took several

measures to guarantee the methodological quality and rigor of my study. Using Guba and

Lincoln's (1989) three criteria for establishing the trustworthiness of qualitative inquiries

as a guide, I will demonstrate the tactics I employed to ensure the credibility,

transferability, and dependability of my study.

Credibility

The credibility of a qualitative study relates to the degree to which a study's

results are consistent with the data collected. Stated another way, credibility in qualitative

research has to do with the accuracy with which a researcher has recorded the specific

phenomenon under study (Shenton, 2004). In my study, I took several steps to make

certain that the work I have presented closely reflects couples' experiences of negotiating

intimacy while caring for children with ASDs. Specifically, I formed a research team to

help me in the interview coding process, I adopted a well-recognized research method, I

openly discussed my research biases, I worked to ensure participant honesty, and I

engaged in member checks to verify my findings.

Use of multiple coders. Throughout the data analysis process of this study, I employed two additional coders (both of whom were graduate students from different backgrounds and with differing perspectives on the interview data) in order to limit the degree to which I allowed my own biases and preconceived notions to influence how I interpreted the data. Thus, for each step in the coding process, I had two additional individuals who were just as familiar with the data as me and who could add their own analytic perspectives to that which I was bringing to the table. These members of my research team were very helpful in keeping me "close" to the data, preventing me from imposing too much of myself on participants' thoughts and experiences, and honing the precision of the codes we created. For example, during the process of open coding, there were multiple occasions on which my team helped me to see that imposing a previously existing code on a particular discrete segment of interview data would not capture the heart of what the participants were trying to communicate, at which point we would work together to create a new code that better fit the participants' thoughts. As such, more than anything other measure I employed to ensure the trustworthiness of my study, having a research team assisting me served to limit my own biases from negatively impacting the data analysis process (Patton, 2002).

Discussion of researcher bias. I also took several steps to raise my own awareness regarding the biases I held about my topic of study (Koch, 1994). For example, I wrote a reflexivity statement (included later in this chapter) in which I made note of how my own social location and previous experiences in working with the population under study could affect my view of my work. In this statement I also

discussed the steps I took to keep my biases from sullying the ways in which I collected

and analyzed participant data. Furthermore, after the conclusion of each interview I

conducted, I made a reflexive journal entry in which I wrote out my personal reactions to

the couple I had just interviewed (Rodgers & Cowles, 1993). Prior to beginning the

analysis of each interview transcript with my research team, I went back and read my

reflexive journal entry to the rest of the team so that they (and I) could be aware of my

personal response to each couple and how this response could influence the way I

interpreted the data I had collected.

Member checks. A final way in which I attempted to solidify the credibility of

my study was through member checks (Koch, 1994; Shenton, 2004). In these member

checks, I went back to previous study participants to ask them if my emerging theory of

how couples raising children with ASDs negotiate intimacy both made sense to and fit for

them. Although I aspired to meet with more couple participants to verify my findings,

only two couples responded to my invitation to get their feedback on the results of this

study. In these meetings, I shared the categories and theory emerging from the data I had

collected for my study and then asked for these couples' opinions on my work. In both

cases, the couples I followed up with reported that they 1) believed I had developed a

strong sense of what negotiating intimacy looked like for a couple raising a child on the

autism spectrum and 2) had no further feedback for me with regard to how I might further

hone my findings.

Transferability

In qualitative research, transferability has to do with the degree to which a study's

findings relate to the experiences of others. More aptly stated, Marshall and Rossman

(1989) describe transferability as "the burden of demonstrating the applicability of one set of findings to another context" (p. 145). For the purposes of my study, transferability means that other couples raising children with ASDs can relate to my findings regarding intimacy negotiation and view these as fitting well with their own life situations (Koch, 1994).

Background data and thick description. One of the ways in which I worked to make my study transferable was to provide amble background data in order to offer a strong context for my study, including a rich literature review and well-explained theoretical framework (Shenton, 2004). In addition, in writing up this study's findings, I used a variety of quotes in order to provide a thick description of each category included in my emerging theory. In this sense, I created a space for my readers to access the participants' own voices so that they might decide for themselves whether or not they agree with my conclusions and determine if my findings may apply to other couples raising children with ASDs (Patton, 2002). Furthermore, by holding in-depth interviews with 12 couples raising children with ASDs, I was able to gather the data necessary to build a theory grounded in the lived experiences of my participants.

Theoretical saturation. As mentioned, theoretical saturation occurs when, in the process of data analysis, new categories and subcategories no longer emerge from the data being collected (Strauss & Corbin, 1998). Theoretical saturation further added to my study's transferability in that it allowed the research team and I to conclude that there were no new major theoretical insights to be garnered from the data that had been collected (Charmaz, 2006). As such, when my research team and I arrived at the point of theoretical saturation, we were able to conclude our data collection and analysis process

under the assumption that we had captured the salient points regarding the phenomenon of how couples raising children with ASDs negotiate intimacy. Arriving at this point of saturation added to the transferability of this study in that the results of this work could be seen to apply to other couples raising children with ASDs as well.

Dependability

Dependability in qualitative inquiry addresses the extent to which one can assess that proper research practices were followed (Shenton, 2004). A best practice for maintaining the dependability of a qualitative study is to leave an "audit trail" so that individuals outside the study may be able to clearly follow the decisions made by the researcher during the process of data collection and analysis (Koch, 1994).

Audit Trail. One of the key ways in which I tried to ensure the dependability of my study was to keep a variety of documents readily available for others to inspect after I completed my study. These included reflexive field notes, theoretical memos, and records of my methodological decision making processes (Rodgers & Cowles, 1993).

As already reported, I kept notes of my thoughts, feelings, and reactions to each data collection interview (Patton, 2002). This process, known as "bracketing", served as a means for me to acknowledge my assumptions about and responses to both my interview participants and the larger phenomena in question. This is because bracketing is a reflexive process that allowed me to be better aware of my own biases and how these biases could impact my interpretation of the data. Thus, implementing this practice enabled me to approach my interview data with more of an open mind (Starks & Brown Trinidad, 2007). In addition, my research team and I engaged in theoretical memo writing during analysis of the data (see Appendix J for an example of a theoretical memo created

by the research team during the data analysis process). Theoretical memo writing offered us a means to engage on a deeper level with the data, to raise questions about the data, and to consider similarities and differences across the data as we endeavored to understand the ways in which couples raising children with ASDs negotiate intimacy (Tweed & Charmaz, 2012). This type of memo writing also helped to further establish an audit trail, whereby my team and I were able to keep track of both our emerging impressions of the data as well as how we viewed the data to be related to one another (Cutcliffe, 2000). Furthermore, I kept methodological records of each step in the data analysis process (i.e., open, axial, and selective coding). I viewed doing so as a way to make my research processes more transparent as well as to open the door for others to inspect these processes, replicate my study, and verify my findings (see Appendix K for an example of the study's methodological records; Marshall & Rossman, 1989; Rodgers & Cowles, 1993).

Adoption of a well-recognized research method. Another key way in which I ensured the dependability of my study was by making use of a very well known and regarded methodology—grounded theory (Charmaz, 2006; Glaser & Strauss, 1967). In doing so, I was able to stand on the shoulders of others who came before me in employing analytical strategies that have been successfully utilized by grounded theorists in the past (e.g., the constant comparative method, triadic coding, theoretical sampling; Shenton, 2004).

Reflexivity Statement

I have a great deal of personal interest in the study of couples raising children with ASDs, which I believe to be borne out of some key life experiences. Namely, I grew

up in a home where my mother was a middle school special education teacher for the

majority of my childhood. Thus, at an early age I was exposed to individuals with

physical, emotional, and cognitive disabilities. I remember thinking as a child that my

mother's work was important but not quite knowing why. Later, during my

undergraduate years, I had the chance to work as a behavioral therapist for a young boy

who had been diagnosed with autism. I worked with this boy from the time he was four

years of age until he was six. I visited him in his home three to four times a week, spent

time with his family, and greatly enjoyed my work. By the time the boy had stopped

receiving behavioral treatment, he no longer tested on the autism spectrum.

　　　　After my graduation from college, I found myself looking for work similar to that

which I had done on a part-time basis while still a student, as I had found great value in

doing such work. I happened to find employment as a case manager at a non-profit

organization that served individuals with developmental disabilities and their families.

During my time with this organization I worked with many families raising children with

ASDs. I was happy to provide these families with case management support for their

children, but over time I came to develop a sense that they needed more help than I could

(or was qualified to) offer. This was because many of these families were struggling with

a number of issues related to having a child with a developmental disability that I had no

idea how to address. I would hear stories about families' financial constraints, the stress

caring for their children had caused them, and the systemic ramifications of raising

children with disabilities.

　　　　Only years later, when I learned about marriage and family therapy (MFT), did I

come to understand that the help I had wanted to provide the families I served as a case

manager related to not only the child with a disability, but the family system as a whole.

As a graduate student in MFT I even had the opportunity to work with a few families

who had children on the autism spectrum. I enjoyed this work greatly and finally felt that

I was doing the work that was really needed for these families. So began the journey that

has led me to pursue my doctoral studies in MFT, and to conduct research on the impact

of ASDs on the family system.

Despite my seemingly altruistic reasons for studying couples raising children with

ASDs, I also need to examine how my previous experiences with the population I have

chosen to study, in conjunction with my position of power and privilege (as a White,

married, heterosexual, educated, physically healthy Christian male working at a well-

renowned institution of higher learning), might impact my interactions with study

participants and affect the responses they give to my interview questions. Thus, given

these previous expeirences and my social location, I decided it would be important for me

to explore any biases (either latent or explicit) that I held about couples raising children

with ASDs in hopes of ferreting these out before they had the opportunity to negative

impact my data collection and analysis. In contemplating these matters, I arrived at four

central biases (although I believe that there are certainly many others that I have not yet

been able to unearth within myself) regarding these couples.

First, when considering couples raising children on the autism spectrum, I have

historically held the belief that "the apple does not fall too far from the tree." Namely, I

have tended to presume that there is a biological link to ASDs and that one can simply

look to the parents (the father, in particular) of a child on the spectrum to see from

whence the child's disorder has come. More specifically, I conceptualized fathers of

children with ASDs as tending to be a bit aloof, difficult to converse with, and maybe even somewhere on the autism spectrum themselves. I think this bias came from the work I did in college with a young boy on the autism spectrum, as the boy's father was very socially awkward and hard to communicate with. I have never forgotten this boy's father, nor the link that I made at that time between the boy's autism and his father's social awkwardness. Left unchecked, I think this bias could have errantly caused me to link deficits in a couple's experiences of intimacy to an undiagnosed ASD in one of the parents, as opposed to seeing the interactive components of intimacy negotiation among these couples. I tried to mitigate this bias from influencing my findings by both engaging in reflexive field notes immediately following my interviews and by forming a research team with two other individuals who had not shared my previous experiences with families raising children on the autism spectrum.

Second, in reflecting on my biases I also came to see that I had a picture of what families raising children on the autism spectrum looked like. In particular, I found that I believed these families to be rather well-off, White, residing in a big house in the suburbs, and technologically savvy. I did not have much room in my mind for other, different looking, families. Again, I think this bias developed from my work in college, in which the family I served was relatively wealthy, and in my experience with my wife's male relatives, many of which are well-to-do computer programmers with pretty significant deficits in social skills for whom I have often wanted to offer various ASD-related diagnoses. Relatedly, I found myself holding a belief that individuals with financial means do not experience any contextual/environmentally-related problems as they can simply throw money at these difficulties to make them go away. These thoughts,

taken together, could have caused me to overlook the contextual factors that the couples I interviewed were reporting to influence their intimacy negotiations, especially if I deemed these couples to be fairly affluent. As such, I made sure to ask all of my participants about how they conceptualized various external factors (including any financial constraints) to be playing a role in their ability to experience intimacy in their relationships.

Lastly, I found myself to be holding on to an idea that, when raising children with ASDs, mothers should be the primary caregivers, because fathers certainly would not be able to handle all responsibility of raising a child with an ASD. Instead, I held the belief that fathers should play more of a supportive role and allow mothers to take on the majority of the responsibility for caring for the child on the spectrum. I think this belief stemmed, in part, from my previous experiences with fathers of children on the autism spectrum, whom I found to be less expert (or maybe just too scared) at dealing with their children than their spouses. Because this bias could have kept me from attending to various gender-related concerns for couples attempting to negotiate intimacy in their relationships, I asked couples in each interview I conducted about their division of household labor. I then inquired about the degree to which partners were satisfied with their divisions of labor and if they perceived this division as having any impact on how they navigated issues of intimacy in their marriages/committed partnerships.

CHAPTER 4: FINDINGS

Demographic Information

In hopes of better understanding the context out of which my study has emerged, along with conducting semi-structured interviews with couple participants, I requested that each participant to complete a brief pre-interview demographic questionnaire (see Appendix A). In these questionnaires, I asked participants to provide a bit of basic demographic information about both themselves and their children on the autism spectrum. In the following sections I have provided an overview of relevant couple and child demographics, while Table 3 offers a demographic profile of each couple and includes pseudonyms for each study participant that I will use throughout this chapter. Appendix M includes biographical profiles for each participant couple.

Participant Couple Demographics

The sample for my study consisted of 12 couples (24 total participants) raising children on the autism spectrum. All 12 of the couples I interviewed were married and heterosexual. All except one of the couples were the biological parents of their child or children on the autism spectrum. The remaining couple adopted their child with autism when he was just an infant. Participants ranged in age from 37 to 58 ($M = 46.9$). The average age of the women who participated was 45.4 years old; the average age of male participants was 48.3. With regard to race and ethnicity, the vast majority of participants identified as Caucasian (n =22, 92%). One (4%) participant identified as Hispanic, and another (4%) as Asian. In terms of education level, three fourths (n = 18) of participants had at least a college degree, with 42% (n = 10) having completed some type of graduate education. Out of 18 participants who had completed college, exactly half were male and

Table 3

Selected Demographic Profile of Couple Participants

Participant Number	Pseudonym	Age	Race/ Ethnicity	Child's Age	Child's Race/Ethnicity	Child's Diagnosis
001	Tricia	44	Caucasian	9	Caucasian	PDD-NOS
	Leo	43	Caucasian	--	--	--
002	Megan	43	Caucasian	9	Caucasian	PDD-NOS
	Matt	44	Caucasian	--	--	--
003	Pam	47	Hispanic	12	Hispanic	PDD-NOS
	Ben	56	Caucasian	--	--	--
004	Erin	40	Caucasian	10	Caucasian	Autism
	Nathan	37	Caucasian	--	--	--
005	Cindy	40	Asian	9	Asian-American	Autism
	Tom	54	Caucasian	7	Asian-American	Autism
006	Samantha	43	Caucasian	8	Caucasian	Autism
	Robert	52	Caucasian	--	--	--
007	Laura	44	Caucasian	15	Caucasian	Autism
	Todd	43	Caucasian	--	--	--
008	Carla	56	Caucasian	14	Mixed Race	Autism
	Derek	57	Caucasian	--	--	--
009	Harper	46	Caucasian	7	Caucasian	Autism
	Wes	43	Caucasian	--	--	--
010	Kristen	46	Caucasian	15	Caucasian	Asperger's
	Jared	51	Caucasian	13	Caucasian	Autism
011	Ashley	42	Caucasian	13	Caucasian	Autism
	Max	42	Caucasian	--	--	--
012	Fran	54	Caucasian	17	Caucasian	Autism
	Ted	58	Caucasian	--	--	--

half female; however, out of the 10 who had a graduate degree, 70% (n = 7) were female.

The annual household income of couples that participated in my study ranged from under

$25,000 per year to more than $100,000. Nine couples (75%) reported annual household

incomes of greater than $50,000, and five (42%) stated making more than $100,00

annually. Only one couple (8%) reported an annual income of less than $25,000 per year.

Couples also reported having been together for an average of 19 years; however,

83% (n = 10) endorsed being together for between 11 and 20 years. Two (8%)

participants (one male and one female) also stated having been married previously, with

each of these individuals having been married only once before. In terms of family

structure, the number of children couples had ranged from one to five (*M* = 2.83). Two

couples (17%) had only one child (i.e., their child with an ASD), while 58% (n = 7) of

couples had either two or three total children in the family. The remaining three (25%)

couples had either four or five children. Regarding religious affiliation, 23 out of 24

(96%) participants identified as having some religious affiliation. One quarter (n = 6) of

participants identified as Catholic, while another 25% (n = 6) reported themselves to be

Protestants. The 11 (46%) remaining participants who identified as being religious stated

themselves to be Christians unaffiliated with a particular denomination.

Child Demographics

Study participants also shared demographic information regarding their children

with ASDs. Of the 12 participant couples, 10 (87%) couples reported having one child on

the autism spectrum, while two (13%) couples reported having two children with ASDs.

All of the 14 total children with ASDs being raised by couples who participated in my

study were male. They ranged in age from seven to 17 years old (*M* = 11.3). Just over

half (57%, n = 8) of these children were between the ages of seven and 12; the remaining

six (43%) were teens between the ages of 13 and 17. Not surprisingly, much like their

parents, the majority (72%, n = 10) of these children were identified as Caucasian. Two

children (14%) were identified as Asian-American, one (7%) as Hispanic, and one (7%) as mixed race. In terms of their diagnoses, ten (72%) children were reported to have autism, while three (21%) had PDD-NOS and one (7%) had a diagnosis of Asperger syndrome. Full details of the demographic information collected as a part of this study may be found in Appendix N.

An Emerging Theory of How Couples Raising Children on the Autism Spectrum Negotiate Intimacy

As mentioned in the methodology chapter for this study, based on the data we collected and analyzed, the research team and went through several iterations of trying to visually depict how couples raising children on the autism spectrum negotiate intimacy. After much discussion and debate, we arrived at a tentative model of these processes, found in Figure 2 on page 87. We believe that this process model attends to all the major aspects of how couples negotiate intimacy when caring for children with ASDs and encompasses all the categories of data that emerged from our study.

The model starts with the nodal event of a couple finding out that they have a child who has been diagnosed with a disorder on the autism spectrum. This is a fixed moment in time at which point a couple becomes aware of, and is finally able to give a name to, the nature of their child's problems. From this point forward, negotiations of intimacy among these couples begin to change.

Following the ASD diagnosis is a line pointing to cognitive shifts. Cognitive shifts refer to the adjustments in cognition and perception that couples must make together related to the nature of their relationship and their expectations for what it looks like to be a couple in the context of raising a child on the autism spectrum. Making these

cognitive shifts together with one's partner is a necessary, but not sufficient, step in the

process of negotiating intimacy in one's marriage/committed partnership. This is due to

the fact that the way a couple appraises the nature of life with a child on the autism

spectrum will influence each partner's ability to foster intimacy with the other. For

example, a couple in agreement over the fact that raising a child with an ASD will mean

that their relationship will look different from other couples who do not have a

developmentally disabled child will be better able to adjust their expectations for

intimacy in their marriage/partnership and, therefore, be better prepared to make the

necessary relational shifts found to assist couples in experiencing intimacy than a couple

who cannot accept the fact that having a child with an ASD will mean they may have to

readjust what it means to be a couple. Couples who are unable to make such shifts in

cognition (because either one or both partners are struggling to do so) will have greater
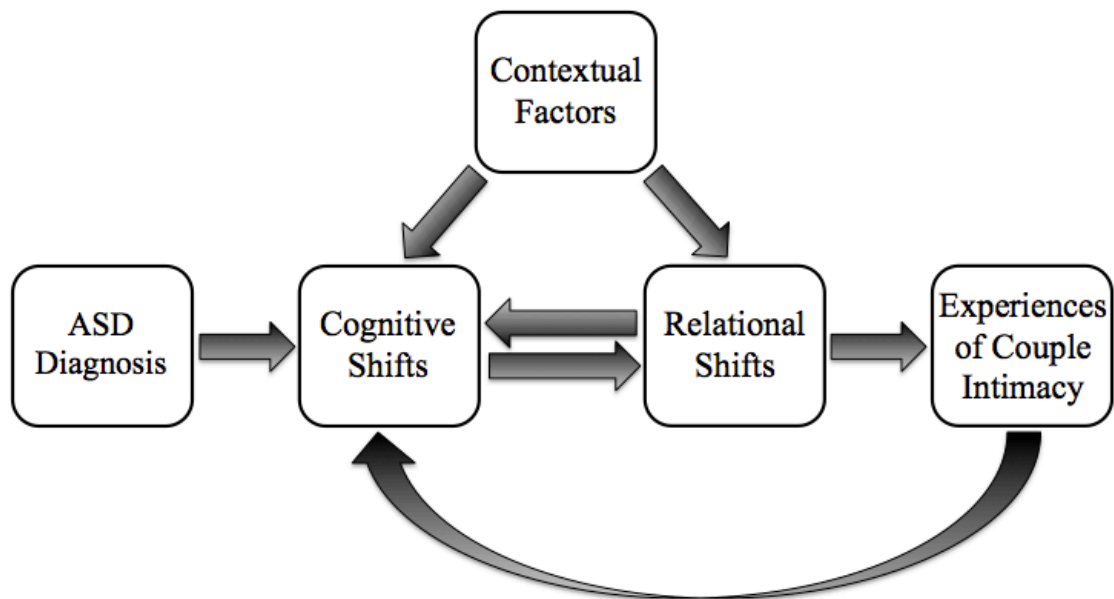
Figure 2. A process model of how couples raising children on the autism spectrum

negotiate intimacy.

difficulty in acting upon the relational shifts required to experience more intimacy when raising children with ASDs.

Relational shifts have to do with the interactional tasks in which couples must engage when raising children with ASDs. This study found four key categories of relational shifts that impact these couples' experiences of intimacy (which will be further unpacked later in this chapter). They relate to couples consciously working as a team to care for their children on the autism spectrum and each other, practicing enhanced communication skills, overcoming unique barriers to couple time, demonstrating heightened levels of sensibility toward one another. No one particular category related to relational shifts is more important than another, nor do any of these four categories precede or follow from any other.

Although in our study we found that negotiations of intimacy among couples raising children with ASDs involved making the necessary cognitive shifts before making the necessary relational shifts, we also noted that a recursive relationship existed between these two processes. Thus, in our process model two arrows have been placed back and forth between the "cognitive shifts" and "relational shifts" boxes as a way to indicate the fact that not only do the ways in which couples make shifts in cognition influence the ways that they make the aforementioned relational shifts but that the ways in which couples make relational shifts may also go back and influence the ways they make cognitive shifts, and so on. For instance, when partners successfully work together as a team or overcome their barriers for time together, they are then able to go back and have greater expectations for the degree to which they can experience intimacy with one another which may help them have a positive expectancy for succeeding in making

relational shifts necessary for fostering intimacy moving forward. Conversely, if a couple struggles to do something like demonstrate heightened levels of sensibility to one another's experiences, this may cause each partner to reconsider the possibilities for what they can expect with regard to experiences of intimacy in their relationship, making it even harder to make the necessary relational shifts in the future.

Our model also accounts for the various contextual factors and other outside influences that may come to bear on the ways in which couples make both shifts in cognition and shifts in their ways of relating to their partners. (Key contextual and environmental variables related to the negotiations of intimacy among couples raising children with ASDs will be addressed later in this chapter.) More specifically, the cognitive and relational shifts couples must make in negotiating intimacy in their relationships can be either aided or blocked by the degree to which such contextual factors impede upon or facilitate these negotiations. For example, a couple in which one partner suffers from clinical depression—a contextual factor—may have greater difficulty making the necessary cognitive shifts together because the depressed partner cannot come to see the positives in the couple's lot in life than a couple in which neither partner has any mental health concerns. Because making cognitive shifts together with one's partner is a necessary step in the process of fostering intimacy in one's relationship, the couple dealing with depression might have more difficulties in experiencing intimacy together than another couple where mental health issues are not a concern. As another example, a couple with a strong social support system—also a contextual factor related to this study—may have less problems with finding quality childcare than a couple who experiences a great deal of social isolation and who have no way to overcome their

barriers to couple time. Thus, the couple with the strong support network experiences

fewer barriers to finding time together as a couple (one of the four key relational shifts

related to couples' experiences of intimacy) than the couple who has little outside

support. To note the fact that couples' negotiations of intimacy do not occur in a vacuum,

arrows pointing down from the "contextual factors" box to the "cognitive shifts" and

"relational shifts" boxes have also been included in Figure 2.

The result of the degree to which couples raising children with ASDs navigate the

necessary cognitive and relational shifts, also taking into account the influence of any

contextual factors on these processes, is a couple's experience of intimacy. Couples who

are able to make the necessary shifts and who do not have an undue amount of contextual

factors impeding their path to intimacy will likely have less difficulty fostering intimacy

in their relationships than those who struggle to make the necessary shifts or who must

deal with contextual factors that inhibit them from making these shifts. However, it

remains to be noted that intimacy is not a fixed point at which a couple one day arrives.

Rather, intimacy, as conceptualized in this study, is a process. This means that for

couples raising children with ASDs (as for any other couple), intimacy is an iterative

process that takes place over time. Thus, an arrow pointing from the "experiences of

couple intimacy" box back to the "cognitive shifts" box has been included to connote that

how couples negotiate intimacy is best understood as a cycle taking place over time.

(Although the research team discussed the notion of having an arrow pointing back from

the "experiences of couple intimacy" box to the "relational shifts" box as well, we

ultimately decided that what our findings bore out was that couples' experiences of

intimacy caused them to shift their cognitions and perceptions, but did not necessarily

bypass these shifts and directly link back to their relational interactions.) Conceptualizing

couples' negotiations of intimacy as our model has offers hope for couples struggling to

find closeness in their relationship that they can work over time toward something better

than that which they are currently experiencing. It also reminds those couples who are

presently satisfied with their experiences of intimacy that they cannot simply rest on their

laurels, given that intimacy is a process that requires work to maintain.

<div align="center">**Core Categories Related to Couples' Negotiations of Intimacy**</div>

The findings of this study suggest that there are five core categories to consider

when discussing how couples raising children on the autism spectrum manage intimacy

in their relationships. The first category relates to cognitive shifts, or how partners make

meaning of their couple relationship in the context of caring for children with ASDs. The

other four categories have to do with relational shifts, three of which relate to actively

working together with one's partner, and the final category to demonstrating emotional

sensitivity toward one's partner.

Making Necessary Cognitive Shifts Together

One of the strongest threads running through the interview data analyzed for this

study had to do with the need for each partner in a couple relationship to make some key

cognitive shifts (i.e., adjustments in expectations and perception) with regard to the

amount of time they would have together as a couple, the impact of their autistic child/ren

on their couple relationship, and the unique challenges associated with caring for children

with ASDs. As shown in this study's process model, each partner's ability to make these

fundamental shifts in conceptualizing what it means to be a couple raising child on the

autism spectrum is a key component in couples' negotiations of intimacy and relates back

to the notion of cognitive closeness (Moss & Schwebel, 1993), noted in the definition of intimacy employed for the purposes of this study. In a general sense, study participants noted that intimacy was promoted between partners when both were able to make these shifts and hindered when either one or both partners were unable to do so.

Time together as a couple. Ten of the 12 couples I interviewed noted that it was important for them to adjust their expectations for the time together as a couple, both now and in the future, and to accept the fact that they might not have as much time alone together as other couples raising children who did not have special needs. The prevailing sense was that developing a more realistic picture of what one's couple relationship could look like in the context of raising a child on the autism spectrum helped couples to appreciate the time they did have together which, in turn, assisted them in navigating the relational shifts necessary to fostering a greater sense of intimacy in their relationships. However, as one husband noted, failure to make these adjustments around couple time could lead to a partner "blaming the other person for not being able to spend time with you because you have a child that has special needs" and thereby inhibit a couple's ability to work together successfully negotiate particular relational shifts.

Time and again, couples stated that they had to drastically reduce their expectations for the amount of time they would have with their significant others. For example, as Carla and Derek noted, it could be quite difficult for them to have any time alone together at all:

Carla: I mean, it is not like you are going to sit on the couch for two hours and watch a movie together.

Derek: Yeah, there is none of that.

> Carla: No.
>
> Derek: Yeah.
>
> Carla: That is not happening. He [our son] would never—he did not stay asleep
>
> for two hours, for years.

Later in the interview, Derek went on to say that sometimes couple time might only occur for "five minutes out of a month," but that "you got to be okay with that."

Cindy and Tom also echoed Carla and Derek's sentiments regarding a lack of time spent together as a couple, sharing how they had to make peace with the reality that they would never have any extended period of time away from their two children with autism:

> Tom: We do not have enough time, us time, is pretty much what it is.
>
> Cindy: Yeah, the vacations, like, I have seen my friends go, "Oh yeah, we are
>
> going to Las Vegas with another couple for four days." And that is never going to
>
> happen.
>
> Tom: No.
>
> Cindy: That is never going to happen for us. You know we are never going to get
>
> that big European vacation on our 20th wedding anniversary like a lot of people
>
> do. That is not going to happen.

Laura and Todd extrapolated out even further into the future and discussed how they had had to come to terms with the reality that they would always be responsible for caring for their son with autism and, thus, would never be empty nesters. As Laura stated:

> We are never going to be empty nesters. So, what does that look like for life? You
>
> know a lot of married couples get to have that time again alone and we are not

going to have that. And so, how does that impact our relationship? But I think we

have both come to accept the fact that we are okay with that. It is going to be okay

that we never have that time alone again.

Laura also went on to add that, despite the fact that she and Todd would always have to

take care of their son, as far as they were concerned there was still "life as an older

couple with a special needs child."

Although the argument could me made that these couples are not really talking

about intimacy, per se, but rather about the impact of raising children with ASDs on

couples' time alone together, within the context of this study these participant statements

set the table for a couple's future negotiations of intimacy. That is, making these

cognitive shifts regarding expectations for and perceptions of time together with one's

partner was found to be a foundational element in a couple's ability to make the relational

shifts necessary for fostering intimacy in their relationship. Some good examples

highlighting this point relate to how couples who had made these shifts in cognition were

then able to redefine what it meant to have time together, given the difficulties of finding

time alone as a couple. For instance, Tricia and Leo shared how they had to change their

expectations for dating in light of raising a child with PDD-NOS:

Tricia: Well, we don't go out—like some couples go out like once a week. No, no.

Once a month at the most.

Leo: Yeah, less than that even.

Tricia: Which, I mean I would like more—

Leo: We go to Sam's Club—

Tricia: Yeah we try to do, even if there's a little, "Let's go to Sam's Club

together." Just a little—

Interviewer: A shopping date?

Tricia: Yeah, exactly.

Ashley and Max also noted how they had readjusted their expectations for going out on a

date from dinner and a movie to even simply having the opportunity to run to the grocery

store together:

Ashley: I look at it this way, too, is that if we go grocery shopping, that is still by

ourselves, okay? … Yea, it is kind of couple time even though it is not really

"couple time."

Max: Mm-hmm.

Ashley: Because, at least we are by ourselves and we are not going that

crazy…because we are out of the house and we are not with the other two

[children].

Furthermore, Pam discussed how despite the fact that she and Ben did not have many

opportunities for time together leading to sexual intimacy, they still were able to reframe

small acts of physical affection as times of intimate connection. As Pam stated, "A lot of

times when we go to bed…we'll hold hands or we'll have a little moment before we go to

sleep and that's basically it. I think that's the time of connection."

Thus, by redefining small snippets of time together as couple time, these couples

were able to "find" time alone together, even if this time did not involve going out to eat,

a couple-only vacation, or an extended period of time together after having launched their

children out of the family home. And, as will be elucidated later in this chapter, finding

time together as a couple and overcoming barriers to couple time are core aspects of

fostering intimacy in one's relationship when raising children with ASDs.

In sum, participants maintained that if couples raising children with ASDs could not adjust their expectations for couple time and change their perceptions of what time together as a couple might look like, they would face more difficulties in experiencing intimacy in their relationships. However, if couples could make these shifts, they could come to a place of deeper appreciation for the time they did actually have with one another and as a result experience more closeness and connection to their partners.

Child's impact on the couple relationship. In addition to having to make cognitive shifts regarding time together as a couple, seven of my participant couples reported that couples raising children with ASDs also had to think differently about how their children impacted their relationships. In particular, participants noted the importance of partners being able to reframe the role their child on the autism spectrum played in a couple's ability to find intimacy in their relationship.

Namely, participants maintained that couples raising children with ASDs needed to guard themselves from over-focusing on how their children's negative behaviors took away from opportunities to foster intimacy as a couple and, instead, focus on the ways in which having a child on the autism spectrum could actually help to bring a couple closer together on both cognitive and affective levels. For example, Megan and Matt noted how, despite some of the struggles they have had with their son with PDD-NOS, they continued to view their child as a gift that has helped them be closer to one another rather that a curse that has kept them from experiencing more intimacy in their marriage. As Matt maintained:

We've had so many wonderful moments that involve [our son] in our whole life

that have brought [Megan and I] closer and made us that we can both smile and be

life-affirming. I mean, I just don't accept the idea that just because we have a

child with autism that means we're doomed to have to suffer our whole lives.

Megan went on to reiterate Matt's point, stating that:

There are challenges with [having a child with autism]—there are a lot of things

that are challenging and difficult. I don't want to sugar coat it because I'd be

misrepresenting. But on the flip side, there's just wonderful moments that I think

people may not understand either. Because I think to a certain extent it's brought

[us] closer together.

Todd and Laura also shared Megan and Matt's sentiments about accentuating the ways in

which having a child with autism can bring a couple closer together. However, they also

shared about how they both had to make a conscious decision (i.e., a shift in cognition) to

focus on the ways in which having a son with autism could help them experience

intimacy with each other:

Todd: And so I believe [having a child with autism] is actually a glue that made

us stronger together rather than something that was divisive. But there is a time

when you make a choice—[having a child with autism] could be a divisive thing

or something that pulls you together. And I think we both agreed that it is

something that [was going] to pull us together.

Laura: We were going to be stronger together.

Todd: Yeah. Stronger together.

In a similar vein, participants also mentioned how it was important for couples not

to view their children with ASDs as having the power to destroy their capacity for

intimacy and intimate interactions. For example, Erin and Nathan mentioned that although it was difficult not to lose track of finding ways to foster intimacy in their relationship due to the special needs of raising a son with autism, they had deliberately deciding to not view their child and his behaviors as stronger than their ability to foster intimacy in their relationship:

> Nathan: Yes, [raising a child with autism] is tough. But if you do not loose focus it can even bring you closer together than if that was not there.

> Erin: But you have to make the conscious effort that your marriage and your couplehood is worth fighting for, because you cannot let yourself get so lost and so overwhelmed and so overburdened with the needs of your child.

Therefore, Erin and Nathan were able to experience more intimacy in their relationship (in terms of commitment, cognitive closeness, and mutuality) by acknowledging the fact that raising a child with an autism spectrum disorder was no easy task and refusing to let the associated challenges have the power to tear them apart.

Childcare challenges. All 12 participant couples I interviewed also maintained that in order to help foster intimacy in their marriages/ committed partnerships, couples raising children with ASDs needed to make cognitive shifts related to the particular challenges associated with caring for children on the autism spectrum. (Again, although making these shifts may not always directly link to experiences of intimacy for couples raising children on the autism spectrum, participants noted that they do set the table for couples to be better prepared to make the relational shifts necessary to enhance experiences of intimacy in their relationships.) With regard to these challenges, couples reported that they needed to be able to expect the unexpected with regard to their

children's behaviors, make light of these behaviors, and accept the fact that life is not fair

when dealing with issues that parents of typically-abled children might never have to

address. Couples who were unable to make these shifts were deemed to have greater

difficulty in fostering intimacy in their relationships than those who were able to together

change their expectations for and perceptions of the challenges related to raising children

with ASDs.

Tricia and Leo noted the importance of expecting chaos—and using humor in the

face of it—when raising a child with PDD-NOS:

Tricia: Well, you have to have some humor in there. I mean like, "Oh, there's

another poop mess." Or, I don't know. That's only humor for probably us, but—

Leo: It's not always funny.

Interviewer: But you need to make light of it?

Tricia: You need to joke around about, "Oh, there he [our son] goes naked again."

You know what I mean? He likes to be naked. He's outside jumping on the

trampoline naked.

Leo: Sometimes climbing up on our highest point in the back yard.

Tricia: So the cars going by can see his naked butt, I mean you have to have

humor in there, like, "Yep, this is our world…"

Leo: Yeah.

Thus, for Tricia and Leo, shared humor over these types of situations helped the couple

not to become overwhelmed by their child's behaviors and to normalize these situations

as part and parcel of raising a child on the autism spectrum. As relates to the topic of

intimacy, Tricia and Leo went on to share that coming to a mutual understanding that

they will have to face some unique childcare challenges on a regular basis helped them to have more realistic expectations for, in Leo's words, "taking care of each other."

Ultimately, couples noted that if they were not going to let these types of childcare challenges affect their experiences of intimacy in their marriages/intimate partnerships, they needed to accept them as simple matters of course when raising children on the spectrum. For example, after detailing various episodes involving their two sons with autism, fecal matter, syrup, and the deceased, Cindy and Tom stated that they could not dwell on these issues too much, nor consider how unfair it is that they have to deal with these unique childcare challenges that other couples raising typically-abled children will never face:

> Tom: And if you look at it that way instead of, "Well that is not fair." It never is really going to be fair. You do what you do and fairness does not come into it at all. You do what you got to do and you move on.
>
> Cindy: Well, yeah, and if you are waiting for life to be fair then the whole autism thing is just going to blow your world apart anyway…
>
> Tom: It is not fair. We know it is not fair and we are going to work through it [together].
>
> Cindy: Yeah.

In this way, Cindy and Tom maintained that for couples to be able to foster commitment, closeness, and connection in their relationships, it was important each partner to make a shift in cognition, letting go of the idea that they have been given the short end of the stick in having a child on the autism spectrum and working to find a shared perspective on how to best move forward as a couple despite their childcare challenges.

Similarly, Pam and Ben shared the thought that accepting the fact that life is not fair and moving on is a process that requires a fundamental shift in expectations for one's couple relationship:

Pam: I think changing expectations, you know, kind of learning to live with, you know, kind of shifting in expectation of life or your picture for your family—

Interviewer: Tell me a little bit more about that. What expectations would need to shift?

Pam: You know, that things aren't going to be perfect, that there's going to be added stressors [related to having a child with autism], that there's going to be—

Ben: Surprises.

Pam: That [raising a child with autism] will be taxing on [your] relationship, but yet—and you're going to have rewards—but they're going to look different. You know what I mean? Your highs are going to look different from other peoples' highs…

Ben: Yes. Yeah…

Pam: Yeah, and I think it's the couple—where they have to kind of agree on that, because I think it would be really hard for one person to be still, like, pushing for something that's maybe not realistic.

In this sense, Pam and Ben, shed light on the fact that when one or both partners in a couple relationship could not adjust their expectations for experiencing relational "highs" with one another, they would have more difficulty in fostering intimacy in their relationship than when a couple could reframe their relational "highs" in light of the unique challenges associated with raising a child on the autism spectrum.

Consciously Working as a Team

Aside from making the aforementioned necessary cognitive shifts, this study found four categories of relational shifts that were essential to negotiating intimacy in their relationships while raising children on the autism spectrum. Teamwork among partners was the first of these more action-oriented categories. Within this category, couples identified three specific aspects of working as a team that they perceived to be most key to helping foster intimacy in one's marriage/intimate partnership: sharing the childcare workload, finding "me time," and learning about and advocating for ASDs together.

Sharing the childcare workload. Although sharing the childcare workload with one's partner may not appear at first blush to relate to how couples raising children with ASDs negotiate intimacy, 11 couple participants—the female partners, in particular— noted that the more they felt supported by their partners in caring for their children with ASDs, the more intimacy they experienced in their marriages/intimate partnerships. As such, this particular finding seems to relate to the idea of mutuality, or the level of give-and-take in one's relationship (Moss & Schwebel, 1993), which was included as a component of intimacy, as defined in this study. For example, Fran shared about how early on in caring for her son with autism she felt distant from Ted because she did not perceive him to be coming along side her to care for their son; however, Fran noted that in recent years this dynamic has changed for the better:

Fran: Probably his [our son's] first 13 or 14 years were really challenging. Thirteen years where I feel like I carried most of the load and Ted was like an appendage, you know—

Ted: An arm.

Fran: But the last few years…that has really changed—

Ted: Yay!

Fran: A lot. Because Ted has made a concerted effort, like an intentional effort, to

make more of a connection with him [our son], and so that has helped me to have

more trust in him as a partner.

Fran went on to mention a time in the recent past when she was going out of the country

on business and leaving Ted alone with their son for almost three weeks:

Fran: Even when you [Ted] were driving me to the airport…his [our son's] care

was not even on my mind, because I just felt confident that you were going to

take care of him well. And so I felt really free to go without having that. That was

my major worry.

Ted: Yeah, yeah.

Fran: And so without having that as a worry at all because, you know, you had

proven yourself in your relationship with him, and so I felt comfortable with that.

Ted: That helped you be close to me?

Fran: Yeah!

Laura and Todd had a similar experience; however, theirs was more about reflecting back

on some tough parenting tasks they tackled together during the early years of raising their

son, for which they are now reaping the rewards:

Todd: I feel closer to Laura because I feel like we have—as far as our parenting,

we decided to make some tough decisions as far as disciplining and not giving in

and so forth. And it was hard. We had a lot of hard times, you know, with him

throwing fits when we would not allow him to bring toys to certain things or do certain, whatever.

Laura: [Our son] has sensory issues as well.

Todd: But, the fact that we kind of conquered all these different things through it, the fact that he is potty trained, the fact that he can go to church and leave his toys in the car and not throw a fit—I mean, that was not easy to do, but now he does it. And he does it well and he is pretty well emotionally. But I feel proud, like that is something we did together.

Laura: Mm-hmm

Todd: It is like, it draws me even closer to Laura like, "Wow, we actually are good parents. We are doing some good things together."

As such, for Fran and Ted and Laura and Todd, working together to care for one's child was viewed as fostering couple intimacy (especially in terms of cognitive closeness and mutuality).

By contrast, Harper and Wes reported experiencing more closeness to and connection with one another by taking a "divide and conquer" approach to sharing the childcare work. In this way, the couple could play to one another's strengths. As Harper pointed out, although she does most of the hands on care for the couple's son (because Wes works long hours and often comes home exhausted), "he [Wes] is an avid reader, and the support that he shows towards our relationship and towards me in working with [our son] is how much you [Wes] have read books. I have a hard time reading." Moreover, Harper reported felt close to Wes via his engagement in researching the best childcare options for the couple's son and acknowledging that "her job is harder" than

his, while Wes felt close to Harper in relation to all the work she did day-in and day-out to care for their seven-year-old son with autism.

Whatever the tack taken, as long as couples could agree on the childcare workload distribution, they were able to feel closer and more connected to one another for having shared the experience. But when this distribution was not balanced or not agreed upon, partners reported feeling like single parents, ignored by their significant others, and resentful at their partners for not helping with the care of their own children. Needless to say, these were all experiences that kept couples from feeling a deeper sense of intimacy in their relationships. To this point, Laura noted that she could see how "if you had a couple [where] one was in denial or was hands off, and one person was left to deal with [caring for a child with autism] totally, then you are going to get some animosity big time. And it is really going to be divisive."

Taking "me time". In addition to sharing the childcare workload with one's partner, nine couple participants also highlighted the importance of partners providing one another with the opportunity for respite from childcare responsibilities, viewing this time away as a "valuable commodity." Allowing one's partner the opportunity for such breaks (or "me time," as a few participants called it) was seen as fostering intimacy among couples raising children with ASDs. This was because giving one's partner a break was viewed as demonstrating both a partner's sense empathy for the needs of the other (i.e., affective closeness) and the fact that there was some degree of give-and-take in the couple's relationship (i.e., mutuality). Conversely, not giving one's partner a break when needed was seen as something that could lead to the build up of resentment and, thus, inhibit the experience of intimacy with one's partner.

Speaking specifically to the point that allowing one another to get a break from childrearing could promote a sense of intimacy in one's couple relationship, Laura and Todd shared about how this process worked for them in light of the fact that Laura was the primary caregiver for the couple's child with autism:

Todd: I think one thing that helped us with the intimacy, even just connecting to each other, is just knowing when each of us was at the end of our rope. And so we would know—I could read her, like, "Okay, she is pretty frazzled here. It has been a long day. It is time for me to step in and take over and let her have a break." And then vise-versa, she would do the same thing for me. And just realizing that we needed to tag-team when we needed to do that…

Laura: But it made me feel closer to him as well, because there were a couple of nights that I met him at the door with my purse on my shoulder and I am like, "I got to get out." And he said, "Okay. I get it. Go." And I came home and he had not only fed the kids, you know, taking care—had mopped the kitchen floor, done the dishes, had them bathed, and in bed. And when I came home, we were just able to have time together. And that actually made me feel closer to him because he was willing to step up and do that for me. And realizing, "Okay, even though he had had a long day at work, realizing that I had been dealing with this chaos for hours on end and he was willing to step up and do that for me" just meant a lot to me.

Therefore, for Laura and Todd, Laura taking some "me time" can be viewed as an intimate interaction in that Todd was both aware of and responsive to Laura's request for respite from her childcare responsibilities. This led the couple to experience a sense of

mutuality and affective closeness with one another.

Relatedly, Erin and Nathan made note of the fact that part of what made finding "me time" an intimate interaction for them related to actually encouraging one another to take breaks from family life. As Erin stated, "I have been trying to encourage him [Nathan] to actually take a little more time on the weekends. Go hang out with his guy friends, or go away for a couple of days." Nathan also pointed out that although he used to think it was not good for couples to have too much time apart, he has now come to understand that "time apart helps make the time together more special" because it allows each partner to gain some perspective on the work the other does for the family and the relationship. Despite Erin and Nathan's desire to encourage one another to find some "me time," Erin also mentioned how, as the primary caregiver to the couple's ten-year-old child with autism, part of feeling close and connected to her husband meant that he be able to accommodate her need for "me time" at just a moment's notice: "There were some days, by the time he got home, he walked in and I walked out."

More than anything, participants maintained that there should be no quid pro quo attached to giving and receiving "me time," as having provisos attached to such free time took away all things that made these types of interactions intimate (e.g., exhibiting empathy toward one's partner, demonstrating a level of give-and-take in one's relationship). Rather, the most important idea was for partners raising children with ASDs to give each other a break in spite of who got the last break, who was more tired, or who worked harder during the day. Stated differently, participants found it to be important for couples raising children with ASDs to exhibit a sense of selflessness with regarding to giving one another a time of respite from caregiving. When this was not the

case, participants believed there to be negative consequences regarding the possibilities

for intimacy in couples' relationships. For example, Tricia reported that on some

occasions in the past she felt a sense of distance in her relationship with Leo due to the

fact that he had been unwilling to give her a caregiving break because he, also, had

worked all day long. However, the couple went on to discuss how that had been working

to find a better approach taking "me time" that did not create distance in their marriage:

> Leo: I think we've actually, even in the last year, gotten a lot better with [giving
>
> one another breaks]. We've both—
>
> Tricia: Yeah. And [you're] a little better at saying, like when I'm reaching my
>
> maximum, you're better at saying—
>
> Leo: Well, I think we've both been getting better and working on giving more in
>
> that realm.
>
> Tricia: Yeah. I think so…
>
> Leo: We're getting better at…pick[ing] up more of the slack for the other person.
>
> Tricia: Yeah, definitely on the good days…
>
> Interviewer: Have you always been pretty good at giving each other a break, or is
>
> that something you've learned throughout the years?
>
> Leo: Well, I think we've gotten better lately. Yeah, so I don't know that we—I
>
> mean, we've argued somewhat in the past more about kind of comparing work
>
> load distribution and…trying to sometimes compare and argue about [who
>
> deserves the break] where we're less focused on that now, I think. There still can
>
> be times when maybe we'll both want to do a certain thing and we'll have to have
>
> some friendly negotiation about [who gets to take a break].

Thus, Tricia and Leo showed their desire to grow more in terms of giving and taking "me time," given that their past experiences with finding "me time" only fostered distance in their relationship.

ASD education and advocacy. A final way in which participants discussed working as a team for their children with ASDs and each other related to ASD education and advocacy. Namely, ten of the 12 couples interviewed for this study mentioned how sharing together in the process of learning about ASDs as well as advocating together on behalf of their children's needs helped them feel connected to one another on a cognitive level, like, as one participant mentioned, they were "in it together" (with the "it" referring to the task of raising a child on the autism spectrum). In fact, participants' statements about how conjointly educating themselves on ASDs and advocating on behalf of their children fostered intimacy in their relationships were quite similar to those statements which participants made about sharing the childcare workload.

Namely, in response to a question about what advice they would have for couples raising children with ASDs who are struggling to experience intimacy in their relationship, the first things Cindy and Tom noted was that these couples needed to find a way to work together to educate themselves on ASDs. This was because of the fact that in Cindy and Tom's perspective, getting on the same page as one's partner was a key component in being able to work as a team to deal with all that comes along with raising a child on the autism spectrum. As Cindy went on to explain:

> You have to find a way to exchange information that works for both people. I read books, and a lot of the information I get for the kids is involved in reading books. [Tom] does not read books. It is hard for me to hand him a 300 page book and

say, "You know what, this has got great information on autism. Read it." So what

I started doing was buying him CDs. Fortunately, we live in a multimedia world,

and a lot of times you can get the books as audios. So I would get him the audios,

and be like, "On your way back and forth to work you really need to listen to this

because there is good information." And he will.

On top of learning together about ASDs, some couples found that their

engagement in ASD advocacy groups helped them experience more intimacy as a couple.

For instance, Megan and Matt found shared meaning in fundraising activities and

working to help other families caring for children with ASDs. As Megan reported:

We started getting really involved in Autism Speaks [a national autism advocacy

organization] because we had the diagnosis, we started doing the walks, we

started fundraising, we started, you know—we are hoping to make it into a

foundation [for our son]. You know, we sell t-shirts every year. It's just—we kind

of broke through, and it's like our thing we do together. You know, to celebrate

[our son] and to celebrate what we go through.

Later in the interview, Megan noted that, as a result of their advocacy work together,

"[Matt] and I are closer" and are now better equipped to "move forward" and not feel

stuck trying to be a couple raising a child with PDD-NOS.

Other couples, like Erin and Nathan, viewed advocacy as something they did on a

more local level, and just for their own son with autism. For them, advocacy meant

making sure that they worked together to get the best services they could for their son in

school, with a fringe benefit of feeling closer to one another in the process:

Erin: [Nathan] is taking this Thursday and Friday off. On Thursday we go write

the IEP [an individualized school education plan for the couple's son]. Weee!

Interviewer: Talk about fostering intimacy in your marriage, right?!

Erin: Yes!

Nathan: Yes!

Erin: Nothing says fostering intimacy like—

Nathan: An individualized education plan [meeting]!

Erin and Nathan later went on to mention that writing their son's IEP together did, in fact, help them experience more closeness and commitment to one another in their own marriage as it gave Nathan an excuse to take a couple days off of work and allowed the couple to spend quality time together (going shopping, going out to lunch, going to the movies) after the IEP meeting and while their children were still in school.

Practicing Enhanced Communication

How couples communicated comprised a second major relational shift category for this study. In particular, study participants noted that hearing and being heard by one another, finding ways to effectively communicate with each other (given the unique challenges of raising children with ASDs), and successfully managing conflict were central variables in negotiations of intimacy among couples raising children on the autism spectrum. Despite the fact these were skills that one could argue to be necessary for fostering intimacy in any marriage/intimate partnership, participants believed that because couples caring for children with ASDs faced situations and relational challenges that other couples would never have to address, it was all the more important to develop an enhanced ability to practice these skills with one's partner. Thus, participants noted that a couple's ability to communicate well with one another could go far in fostering

intimacy in their relationship, while difficulties in communication could create distance or rifts in one's marriage/intimate partnership.

Hearing and being heard. One chief communication concern for 11 of the 12 participant couples dealt with a couple's capacity to both hear and be heard by one another. Thus, partners needed to not only express themselves and their needs to each other but also receive and understand one another's expressions and needs—themes of particular importance to couples raising children with ASDs because of the fact that these couples were viewed as having so many more responsibilities, stressors, and distractions in their lives than other couples raising typically-abled children. Generally speaking, male participants highlighted the fact that it was important for them to be able to really listen to their wives and demonstrate to them that they had heard what their spouses had said; female participants reported that it was most important for them to be able to express themselves and their needs to their husbands, and in ways that their partners could hear and understand. These findings resonate with this study's conceptualization of intimacy as an interaction involving both self-revelation and partner responsiveness (as highlighted in Chapter 1).

One interesting aspect of hearing that several participants mentioned related to the idea that truly hearing one's partner did not necessarily translate into doing anything about what was being communicated. That is, for intimacy to be fostered between partners, all the disclosing partner needed what for the receiving partner respond in a way that showed comprehension of what the disclosing partner had shared. To this point, Todd mentioned that in his conversations with Laura, Laura actually felt more heard by, and emotionally connected with, him when he did not take action on what she was saying

to him. As the couple reported:

> Todd: For me it was learning to listen…As the typically male "fixer," wanting to
> fix everything, so—and again we have not arrived, we are still a work in progress,
> but I hope to believe that we are doing better—but just to listen, "Okay, she needs
> to vent…" So I just need to let her say what she needs to say…and then once that
> is all said and done we can—and knowing that I am listening and paying attention
> and so forth, then we can come to an understanding and so forth and I think it is
> helpful.
>
> Laura: Yeah, and I think, you know, he has gotten really good about asking,
> "Okay, do you want me to listen or do you want me to fix?" And so giving me
> that option, but there are also times when I have told him, "I need you just to feel
> this with me for the next five minutes. If I am wrong, we will deal with that later.
> But if I am angry because I have been hurt, or whatever, just be angry with me for
> five minutes. Listen. Then we will deal with that if I need to ask for forgiveness or
> whatever. Just in this minute, just be there with me in the moment." And [Todd]
> has gotten really good about doing that.

As such, by showing Laura that he had heard what she was trying to communicate to him,
Todd helped to nurture a sense of intimacy—affective and cognitive closeness,
specifically—in his marriage with Laura.

On a related note, Matt made the point that hearing one's partner did not
necessarily mean agreeing with one's partner:

> It's not about agreement. You're not going to agree on everything. It's about
> hearing each other, and really listening—an active listening. Because sometimes

you'll be like, "Yeah, yeah, yeah." No. You have to really understand where each

other's coming from, 'cause definitely it can be a very bumpy road, and you have

to understand what each other is dealing with.

As such, Matt believed that to foster intimacy in one's relationship it was important for

partners to realize that the process of hearing and being heard was more important than

the content of the conversation. However, as will be discussed in the section on conflict

resolution, participants also maintained that if a couple could never come to an agreement

on the context of the conversation (especially if the conversation was about childcare

matters), then this discord could negative impact the couple's sense of intimacy with each

other.

       Finding ways to effectively communicate with partner. Another important

factor related to promoting intimate interactions among couples raising children with

ASDs had to do with the development of strategies for effective communication between

partners. As previously mentioned, although finding ways to communicate effectively is

critical to the growth of intimacy in any couple relationship, study participants deemed

this aspect of practicing enhanced communication to be particularly vital to couples

raising children with ASDs due to the many unique stressors they face they have the

potential to keep them out of touch or cause them cross wires with one another. With

these thoughts in mind, ten couple participants shared a bevy of different, and very

creative, ideas regarding how couples could "do" communication with one another so as

to foster intimate interactions in the context of caring for children on the autism

spectrum.

       Many couples reported that one of the ways they worked to safeguard against

drifting apart, given the many directions in which parents of children with ASDs could be

pulled, was to place a priority on regular communication. For instance, Matt and Megan

discussed their need to do whatever it took to make sure they had space to communicate

with each other on a regular basis:

> Megan: Well, I think we both still put a priority on just regular communication
>
> and sometimes we'll have different goals in mind about how to communicate
>
> those frustrations or needs, but I think that we, overall, still have communication
>
> as a goal to get back to center…
>
> Matt: Yes, and I think we just have found we need to really spend some time to, I
>
> think, more than anything…we really try make regular time to talk…because life
>
> is very busy—life can be a little crazy for us—and you need to spend that time
>
> kind of connected, for us to feel intimate.
>
> Megan: Right.

In discussing this topic, participants mentioned some very specific ways in which they

were able to prioritize regular communication in their relationships. Erin and Nathan

stated that they would send each other texts throughout the day to keep in touch and that

they made sure they had time to reconnect after their children were in bed. For them,

these strategies allowed for small moments of intimate interactions, of connecting

through demonstrations of affective closeness, at various points during the day. Likewise,

Megan shared one of the strategies she and Matt employed in order to connect with one

another and keep the outside distractions at bay:

> He'll always call me on the way from work. And sometimes I'm like, "Ok, I'm
>
> making dinner, I am this and that." But that used to be our time to kind of like run

through the next two hours, three hours of our life when he got home, because he

wasn't being attacked by the kids and I had his undivided attention. I would

sometimes go lock myself in the car, and make sure everybody was safe, to talk to

him for a couple of minutes. You know, just so we could have that time.

In response to Megan's description of locking herself in the car just to have a few

minutes to connect with him, Matt responded that the couple went to such lengths

because "if you don't touch base that regularly, you drift apart fast."

On top of discussing how they worked to prioritize opportunities to communicate

with their partners, participants also gave accounts of the many different ways they found

to effectively communicate with their partners. Carla and Derek discussed the necessity

to plan in advance for time to communicate, because if it was not on the calendar then

other issues related to their son's care would certainly get in the way of them connecting

with one another. They also reported that a couple raising a child on the autism spectrum

needed to be willing to connect with one another whenever there was opportunity to do

so. As Derek stated, "You have to be willing to make time for each other when you can."

Matt shared a similar idea, maintaining that couples needed to "be ready to talk"

whenever they had the chance and that men, in particular, needed to "show up

emotionally and be ready to talk through a lot of stuff" during these conversations. Cindy

and Tom also reported several ideas regarding effective communication, one of which

involved considering the timing of their conversations with one another:

Cindy: You have to know when—the timing. You have to get the timing right

because, like I said, if I try to tell him something when he has just come home

from work he is going to tell me that he has heard what I have said, but he has not

processed it.

Tom: I have not. No.

Cindy: He has not gotten to the point of—so we are going to have the same

conversation three times because I did not wait, and that is just going to frustrate

me.

These ideas, according to my study participants, were helpful ways for couples to find the

space for intimate connections with one another when dealing with all that comes along

with raising children on the autism spectrum.

Resolving conflict together. Given the many appointments, therapies, behavior

issues requiring immediate attention, and the fact that many couples raising children with

ASDs have to work extra jobs or longer hours to pay for their children's medical and

therapeutic services, participants believed that levels of stress and opportunities for sitting

down and communicating with one's partner were fewer and farther between for couples

raising children with ASDs than for other couples who were not. As such, 11 couple

participants also viewed conflict resolution as an area of communication in which couples

raising children on the autism spectrum needed to be particularly skilled. Participants

discussed several ways they had dealt with conflict in their own relationships, both

successfully and unsuccessfully, including how these various ways of managing conflict

impacted their experiences of intimacy in their couple relationships.

However, before discussing methods of conflict resolution, it remains to be noted

that participants also pointed out that resolving conflicts well was especially important

when dealing with one particular aspect of caring for children with ASDs that tended to

incite a great deal of conflict, distance, and detachment between partners—when their

children on the autism spectrum acted out in public. For example, Carla and Derek shared about the difficulties of taking their son in public, how their different approaches to dealing with him had the potential to create conflict and distance in their relationship, and how they had to work very hard to not allow their son's public outbursts to drive a wedge between them:

> Derek: You cannot look at [our son] and say, "Oh, he has got autism." No, he looks normal just like any other kid. And so when he blows up or has a meltdown in the middle of the store, the people are acting like, "This kid is a brat. Holy Cow!" You know? And giving us the eye.
>
> Carla: Making us feel bad and that we need—
>
> Derek: That makes—it gets us upset. And then she wants to deal with him in one way and I want to take him out to the car, whatever. It is just very, very hard not to push each other away.

As such, just like Carla and Derek, in considering the topic of conflict management, many participants shared their thoughts in light of their children's public misbehaviors.

Regarding successful ways of resolving conflict, many couples mentioned that it was important to nip any sense of resentment toward one's partner (something participants viewed as antithetical to fostering intimacy in all its forms) in the bud, thus keeping conflict from erupting in the first place. For example, Ashley reported that for her marriage it was important for her and Max to share even difficult things with each other. As she explained, "If you have a feeling about something, no matter what it is, let the other person know. Do not think they are going to look at it the wrong way and explain it as best you can." Ashley went on to add putting off a conversation with one's

partner did not make it any easier to build trust in one's relationship, which she viewed to be the "most important thing" in developing a sense of intimacy between partners. Fran added to this idea, stating that she and Ted learned the hard way that couples needed to openly and honestly "talk to each other about [their] child, talk about options together, [and]…not avoid talking together about it" because avoidance would only build up resentment between partners and make it even more difficult to communicate effectively and "feel bonded" with one another down the road. Another helpful way to stop conflict before it started was discussed by Laura, who mentioned that it was crucial for her to remember that Todd could not read her mind and that she needed to talk to him if she had a problem:

> Just learning that just because he could not read my mind and did not know what I needed at every second and every moment did not mean that he loved me less. He just could not do it. He is wired differently than I am…and so I had to learn, "Okay, I need to not yell or not give the silent treatment. I need to just tell him how I am feeling." And I think for both of us, that was actually a big thing. Me just learning to express myself, not in hatred or in anger, but effectively.

Laura's statement was communicated in the context of a larger discussion around what she thought made Todd feel distant from her. In response to this thought, Todd then shared that he was working on doing a better job of learning "not to do the blame thing," whereby he would attribute to Laura all of the couple's negative interactions and any of their son's outbursts. Thus, the couple reported that working through these issues had helped them to develop a "solid relationship" in which they felt a strong sense of love and commitment to each other.

Less successful ways of addressing conflict had to do mostly with allowing antipathy to build up toward one's partner. Participants maintained that permitting negative affect to accrue inhibited one's ability to engage in intimate interactions with one's partner. This was because having a storehouse of resentment toward one's partner was seen as keeping one both from being willing to disclose anything personal to one's partner and from responding to anything personal disclosed by one's partner. Kristen and Jared spoke to this point, noting that years of conflict around the cares of their two sons on the autism spectrum had brought them to a place in which Kristen would distance herself from engaging in arguments with Jared while Jared would try to force Kristen to talk to him when he felt he had not yet had his peace. As the couple reported:

Kristen: I turn things inward.

Jared: But if you turn things inward, I am this kind of person where when I see you turning inward I go, "Well, okay what is wrong?" And then, you [say], "No nothing!" And then we will get into this thing. I will pry it out of you and it will cause a fight.

Jared went on to state that the result of these types of interactions with Kristen led her, in his estimation, to distance herself from him: "I would…try to get close to her. She always seems to maintain this little bodily distance from me, like, 'I do not trust you.'"

As such, for study participants, productive conflict resolution involved clear and dispassionate communication while ineffectual attempts to resolve their conflicts tended to involve either unclear communication or overly aggressive attempts to communicate. The former strategies were seen as fostering intimacy while the latter were deemed to be strategies that caused partners to put up walls between one another and, therefore, inhibit

a couple's ability to find ways to intimately interact with one another.

Overcoming Unique Barriers to Couple Time

The third major relational shift category emerging from this study pertained to how couples were able to overcome the barriers to couple time that were seen as unique to the experience of raising children with ASDs. Although any couple with children has barriers to couple time that they must overcome in order to find time to engage in intimate interactions, as highlighted below, participants noted that couples raising children with ASDs had more and harder barriers to overcome on the road to experiencing intimacy in their relationships than couples who did not have children on the autism spectrum.

Participants stated several unique barriers to couple time for those raising children on the autism spectrum, including difficulty finding qualified and experienced childcare support; the fact that children with ASDs could not often tolerate being apart from their parents for an extended period of time; and needing to remain constantly vigilant of their children so that they did not try to run away from home, harm themselves, harm others, or destroy property. For example, Pam noted that even if she and Ben could find appropriate childcare for their son, this did not mean that their son would be able to handle the time apart from them. As Pam reported, "Even when we [Ben and I] have gone someplace for a…night, [our son] can't tolerate it after a while, so we've never been able to do those couple trips or whatever." Instead, Pam mentioned that she and Ben had to limit their times away from their son to a night away at most in case "we're far away and there's a problem and we need to get back." Moreover, Carla and Derek stated that they could not even let their son with autism out of their sight, let alone get away together

for a night, because their son had tried to run away from home on a number of previous occasions:

> Derek: He [our son] would just go outside and take off.
>
> Carla: He would escape.
>
> Derek: I would find him six blocks away…You cannot let him out of your sight. And it puts a very big strain on what you are doing, whether it is trying to watch a movie or a ballgame or whatever.

The couple went on to share how this strain mentioned by Derek related to the fact that they could never really let their guard down and find time to relax with one another as a couple because the moment they did so, their son would always seem to get himself into trouble.

Creatively carving out time together. As a way to combat the aforementioned barriers to couple time and find more time to foster intimacy in one's relationship (especially intimacy in terms of affective and physical closeness [Moss & Schwebel, 1993]), every couple I interviewed reported in some form or another that couples caring for children with ASDs needed to get creative. One major aspect of the creativity required dealt with finding snippets of time together as a couple, especially because it was so hard for these couples to find extended periods of time together away from their children. As Cindy and Tom shared:

> Tom: You take it [couple time] when you can. You take 15 minutes here, ten minutes there.
>
> Cindy. And sometimes we do not. Sometimes, three or four days will go by—
>
> Tom: Will go by—

Cindy: We will look at each other and be like, "I feel like I have not seen you in a

month!"

Tom: She is like, "Yeah, I have not seen you in a month." And I am like, "Yeah, I

know!"

Erin also spoke to this point, adding:

I think you need to devote time together even if it is just in the evening playing a

video game together…just the two of you…You cannot live in the ideal world of,

"Well, since we're not getting out of the house, it's not worth the time and it's not

worth the date."

As can be seen in Erin's statement, finding snippets of time with one's partner relates

closely to the previously mentioned cognitive shifts couples need to make regarding their

time with one another. That is, the relational shift of carving out snippets of time with

one's partner (e.g., finding a few minutes to play a video game with one's partner at the

end of the day) only aids in overcoming the barriers to couple time so long as both

partners deem these small moments of time together as being sufficient to foster intimacy

in their couple relationship (e.g., rejecting the notion that intimacy in one's relationship

was only fostered by getting out of the house for a romantic evening with one's partner).

Another way in which participants believed couples could creatively carve out

time with one another actually involved including their children with ASDs as part of

their couple time activities. Ben and Pam told about bringing their son with them on

dates, because a date with their son was better than no date at all:

Pam: And we do go out a lot, but he's with us. We've got him right there. So, like

we do, really—it's not like we stay at home all the time. We're actually out a lot,

but he's going to be there.

Ben: Well, that's been since he was—that's always been true, since he was little.

That's just the way we've—

Pam: And so then, you know, like, yeah, you're out, but you have—it's not like

the same conversations.

As such, although Pam and Ben admitted that taking their son with them on a date felt like bringing a "chaperone" along with them, going out with their son ultimately allowed them to have a degree of time together as a couple that they might not otherwise have. Laura and Todd also discussed the fact that they had become so used to including their son as a part of their marital relationship, that they could almost not imagine a marriage with their son involved:

Laura: But I kind of feel like [our son] has almost become an extension of us, you

know? We know that it is going to be the three of us, and so, you know, I do not

know. I just look at it as, not just [the two of] us going forward into the future, but

the three of us.

Todd: Right.

Again, these ideas of involving one's child in couple time activities relates not just to relational shifts but also to the aforementioned shifts in cognition necessary to foster intimacy in one's relationship. This is because, as Pam and Ben pointed out, including one's child in one's couple time activities and still framing such activities as intimate experiences means that partners must also view their child on the autism spectrum as just another facet of their couple relationship.

Yet other ways couples reported being able to carve out couple time together

included waking up early in the morning before one's children arose, giving sedatives to

an active child so that the child would fall asleep and allow for the couple to have some

alone time (because, as Harper noted, she and Wes "desire to have sex a lot more than it

happens"), and planning in advance time together as a couple (even if, according to Erin,

this made couple time "unspontaneous, unsexy, and all that"). Lastly, Harper and Wes

talked about how, for them, it was important to guard their couple time from outside

distractions. As Harper said:

> We try to do things in the evenings, especially the weekends. [Our son] goes to
>
> bed at seven. We do not take phone calls, for the most part, after seven. It is like,
>
> that is, I think it is kind of an unspoken thing that that is our time.

In all of these instances, participants shared how going the extra mile in finding time to

be together was key in keeping them feeling close and connected to, and like they

"actually have a relationship with" their partners.

Locating quality childcare help. In addition to finding creative ways to get some

time together as a couple, every one of my study participants mentioned that getting good

and trustworthy babysitting support was a huge hurdle to overcome in actually making

couple time—and therefore opportunities to foster affective and physical closeness in

their relationships—a reality. Participants maintained that if they did not feel completely

confident in the person in whose charge they had left their children they could not

actually enjoy their time away. For example, Tricia shared about how when she and Leo

left their son with a new babysitter, she had some trouble not worrying about him: "Even

when we went to the movie last week, I mean, I [felt] stressed and amped up. But

then…when you're together and out a little bit, assuming that he's [our son] physically

okay, you just relax together."

Apart from their own worries about leaving their children in the care of another, participants also reported that finding a babysitter or respite care worker who came with experience in dealing with ASDs made a huge difference in the quality of care their children received and the peace of mind couples experienced. As an example of how things could go wrong, Harper and Wes shared the story of a nice, but inexperienced, teenage girl they had hired to watch their son:

Harper: When [our son] was younger, that is when he was—we did not change his diaper fast enough, it is like he had even eaten his poop. [We] came home…there is a 15-year-old neighbor girl babysitting [our son] and she was not experienced enough…

Wes: And that is one of the reasons why we do not have much respite, because there is not a whole lot—

Harper: Well, I came home and [our son] had done the fecal smearing all over his wall, his dresser, all over the window and it smelled like a farm. And the girl just left and she never came back.

Thus, Harper and Wes maintained that they now took less chances on going out and spending time together as a couple in part because of their concerns over someone else not being able to handle their child's behaviors while they were away.

However, not all babysitting experiences were reported to end in disaster. As Cindy and Tom noted, finding someone trustworthy and with experience made all the difference in a couple's ability to get out and enjoy their time away together:

Cindy: Our respite care worker is really good. She will come in and I will say to

her, "[This one] has been grumpy all day long. He has been stemming all day

long." Or, "This one has been crying all day because he does not want me to go

out." And she is like, "Oh, it will be fine. Go ahead." So we have a really good

respite care worker.

Tom: Yeah

Cindy: And we will just go.

Tom: And you know what? It is usually okay.

Cindy: And I always say to her, "If it is a problem, send me a text. We will come

back. We will just go to dinner and then we will come back." And…once we are

out the door…it is fine.

The couple went on to share how having trustworthy childcare help allowed them, after

having made it out their front door, to transition into just being a couple out on a date

very quickly.

Consequently, given the unique barriers to couple time for partners raising

children on the autism spectrum, being creative in finding opportunities to spend time

together and acquiring qualified childcare support when going out together were viewed

as key components in the recipe for experiencing intimacy when caring for children with

ASDs.

Demonstrating a Heightened Sensibility toward Partner

Having and expressing a heightened sensibility toward one's partner encompassed

the final category related to relational shifts emerging from the data regarding how

couples raising children with ASDs negotiate intimacy. Within this category, participants

noted that empathizing with the experiences of one's partner (especially as they related to

one's childcare experiences) and showing appreciation for a partner's contributions to the family were of particular import in the development of intimacy in one's marriage/intimate partnership. Again, as with some other aspects of negotiating intimacy while raising children on the autism spectrum, participants pointed out that expressing empathy for and appreciation toward one's partner were not novel tasks for couples raising children with ASDs; rather, they simply became more essential for these couples given all that comes along with caring for children on the autism spectrum (e.g., feeling overwhelmed by one's childcare responsibilities, feeling like no one understands what it actually means to raise a child on the autism spectrum).

Empathizing with partner's experiences. Ten of the 12 couples I interviewed reported that partners raising children with ASDs who had a strong sense of empathy for one another would experience more intimacy in their relationships—especially with regard to affective closeness to one's partner—than those that did not. Stated differently, because so few outsiders really understood what it was like to be a couple caring for a child with an ASD, it was critical for partners to feel as if they could empathize with one another's experiences. Moreover, participants believed that if an individual did not feel like his or her partner understood and related to what he or she was experiencing in relation to raising a child on the autism spectrum, then this lack of understanding could drive a wedge between the couple and keep them from feeling close and emotionally connected to one another.

Speaking to these points, Matt and Megan discussed how empathizing with each other was a process that was sometimes difficult for them, especially given the fact that Matt worked out of the house all day while Megan stayed home with their son with PDD-

NOS. According to Matt:

> I think that the hardest thing particularly has been in times when Megan is going
> through something [with our son] that I can understand but I'm not feeling it to
> the same level she does. And you could say, "I can understand how that feels,"
> but it doesn't feel adequate enough—like when something really hurts. Because,
> you know, someone, she's been in a spot where someone said something about
> [our son]…in public context, or something like that.

Thus, in Matt's example, although he was trying to empathize with how Megan felt upset by someone else's comments about their son's behavior, Matt believed that Megan was not satisfied with the degree to which he understood her experience. Matt went on to state that he believed his difficulties in fully empathizing with his wife's feelings kept the couple from experiencing more emotional connection to each other:

> You can't always be on the same spot emotionally…I think, particularly when
> there can be stuff with the child with autism that can be hard and you can't always
> be 100 percent in exact same spot with that. I think that sometimes is what can
> [create] a little bit of a distance.

Jared also spoke to the idea of how a lack of empathy for one's partner, especially when one's partner was the primary caregiver for one's child with autism, could inhibit any sense of emotional connection in one's relationship:

> And since I was not there all day, I did not—I could not identify enough with the
> trouble [of raising two children with ASDs]. So, perhaps there was a little
> distance there between [Kristen and me] because we could never share the same
> vision.

Despite these struggles to empathize with one another's experiences, especially as related to caring for children on the autism spectrum, participants also noted that a little empathy for one's partner could go a long way toward couples feeling intimately connected to one another. For example, although Matt shared a great deal about his struggles in understanding Megan's childcare difficulties, he later maintained that in order to develop more intimacy in his marriage he and Megan were consciously working at fostering empathy for one another: "Particularly with [Megan] being home a lot…it is really important for us to be connected for me to really hear her experience, because otherwise you aren't connected, you are not understanding each other."

Appreciating partner's contributions. Participants stated that expressing empathy was only one part of the equation in demonstrating a heightened sensibility toward one's partner. The other part had to do with expressing gratitude for what each partner contributed to the family. As such, 11 couples I interviewed noted that appreciating what one another contributed to their marriage and family life (especially as related to caring for children on the autism spectrum) promoted a sense of emotional connection and mutuality between partners. This was seen to be particularly true for couples in which one partner took on more childcare responsibilities that the other. For instance, Harper shared how just one kind word of appreciation from Wes could go far in drawing the couple closer together. To highlight this point, Harper told of how it made her feel when Wes thanked her for all that she did as the primary caregiver for their son: "I am like, 'Wow! He really values me and values the way I am doing with [our son]— sees how important it is, you know, that I am helping a child to develop.'" Harper began to cry after making this statement and when asked what her tears were about, she

responded that she felt very loved by Wes when he showed his appreciation for her hard work with the couple's son.

In addition, Laura and Todd each shared about occasions in the past where one partner's act of apprecation toward the other engendered a great deal of intimacy for their marriage. According to Todd:

> I just realized after awhile I was pretty selfish, that, "Wow I do not realize how much she has to work with and deal with all the time" when I only had like a short window in the evening that I had to deal with everything. So I guess I always appreciated, even looking back, how much she had to deal with and so forth. But I think when I finally got it, that she was struggling and that I needed to step up and do things, then I realized, "Oh, okay. She needs a lot more from me than what I am giving."

Todd's realization led him to do more things around the family home to show his appreciation for all that Laura had to deal with all day long. Laura stated that, for her, Todd doing something as simple as mopping the floor "met my emotional needs" and brought her closer to Todd in the process. Conversely, Laura also shared how she would try to go out of her way to show Todd that she also appreciated all the hard work he did as an athletic trainer to provide for the family:

> There were times when I would load up all three of the kids in car seats and diapers and all that stuff just so I could take him a coffee when he was on the football field in the cold. And I do not know, or it is just the little things that I think he appreciated that effort, that I would think of him and go through all the trouble to do that because getting [our son with autism] in a car seat was an

experience in itself. Truly. But just trying to do the little things in the midst of all

the chaos to make him think that I still remember him and I want him to feel

special and meet his needs.

In response, Todd reported that these types of expressions of gratitude from Laura made

him feel loved by Laura and "close to her."

Contextual/Environmental Factors Influencing Couples' Negotiations of Intimacy

Couple's negotiations of intimacy never take place in a vacuum. As such, a

secondary research question for my study explored what contextual and environmental

factors, if any, came to bear on how couples navigated intimacy while raising children on

the autism spectrum. The factor most closely related to these negotiations of intimacy

was couples' experiences of outside support, followed by the degree to which couples

shared the same (or similar) foundational commitment to their relationships.

Additionally, there were a handful of other lesser considerations that related to

intrapersonal and institutional issues that were reported to impact the ways couples were

able to make the cognitive and relational shifts necessary to foster intimacy in their

relationships.

Experiences of Outside Support

On the whole, study participants reported that experiences of outside support

(including the support of friends, family, and professionals/helping organizations), or

lack thereof, played an important role in the ways in which couples raising children with

ASDs were able to negotiate intimacy. Namely, participants noted that having a good

support system helped couples navigate the cognitive and relational shifts necessary to

foster intimacy in their relationships, while a scarcity of quality support made it more

difficult for couples to manage these shifts.

More specifically, couples mentioned that it was important to surround themselves with people—especially others in the ASD community—who could understand their situations and help them to find intimacy in the face of raising children with ASDs. For example, Wes shared about how when he and Harper were able to spend time with other couples raising children with ASDs it allowed the couple to be more open about certain aspects of caring for their own son with autism: "It is not just normalizing, it is—you are sharing experiences with each other and you are able to talk about things freely." In this way, Wes viewed his and Harper's participation in the ASD community as a way for them to be more emotionally intimate with one another in ways that they may not have been able to do on their own. However, when seeking support from others in the ASD community, Laura noted how she and Todd had to be careful about not surrounding themselves with others within the community who held only a negative outlook:

> We have been around some special needs couples that all they talk about is how bad things are or how the school district is screwing them over or their kids. And, I mean, we can advocate for each other and we can learn from each other. And I want to sympathize with other people, but it seems like the only conversations we have is how horrible things are…You just really do not want to be around those people.

The couple then mentioned that it was important for them to stay away from those couples with negative perspectives on having children with ASDs because they did not want to get sucked in to the same way of thinking. As such, they made the concerted effort to surround themselves with others who had more positive outlooks and who

helped them to make the cognitive shifts necessary for finding intimacy in one's marriage/committed partnership when raising children on the autism spectrum. As Todd stated: "When you can get with other couples that, yes, they are going through special needs—but then they can laugh, then we can have joy and have some, 'Oh yeah! There are some positive things!'"

On top of finding support from others in the ASD community, participants also mentioned a number of other avenues of support that assisted them in the process of fostering intimacy (in all the ways it has been defined for the purposes of this study) in their marriages/committed partnerships. Family and close friends were viewed as trusted sources of respite for couples looking to find some time together away from their children with ASDs. For a few participants, their local place of worship was a place to both find childcare support (especially if that community had any experience in serving families of children with disabilities) and counseling for the difficulties they faced in their couple relationships. Support groups or online chat rooms were also places where partners could get help regarding what it meant to be a couple in the context of raising a child with an autism spectrum disorder. Even individual and couples counselors were mentioned as professional ways for individuals and couples to get help in dealing with the strains of being a couple raising a special needs child. To this final point, Jared was adamant about how couples trying to keep their marriages afloat in the midst of raising children with ASDs needed to "get MFT [marriage and family therapy] and get it fast" so that they would be able to "establish a means of communicating the stresses of their situation early on" before their relational difficulties led to the decay of their relationships.

In spite of the many ways in which couples reported having benefitted from

outside support, participants also pointed out how it was sometimes more common to experience a lack of understanding and support from friends and family. They stated that such a lack of understanding and support could make it harder, in certain ways, to foster intimacy in their relationships. For instance, some study participants told of how they had no one to rely on but themselves in caring for their children, and that this lack of support made it hard to get a break from their parenting responsibilities to find quality time together as a couple. As Cindy and Tom reported:

Cindy: I think if we had more family support it could take some of the burden, some of the stress, off of us, which would help [us find time together]. But we know that is not going to happen, either.

Tom: Yeah, we are on an island.

Cindy: Yeah, we are an island.

Tom: We are an island.

Other participants mentioned that, even if they did have access to outside support from friends and family, feeling misunderstood by these individuals in terms of what it really meant to deal with a child on the autism spectrum could also negatively impact a couple's ability to foster intimacy in their relationship. In this vein, Carla and Derek shared about how Derek's extended family's misunderstandings of the decisions the couple made regarding family outings (usually based on their son's behaviors) often led to conflict between the couple:

Derek: We may have to leave a situation and they [Derek's extended family] do not understand why we cannot go at all to whatever…thing is going on with the family or whatever. And so they get aggravated with us for not showing up or

having to leave early or whatever. They do not understand. So that puts, again, a

wedge between the two of us.

Carla: Mm-hmm.

Derek: And it makes it stressful for us.

The couple later noted that the conflict arising from these situations with extended family

made it hard for them, at times, to feel like they were working well as a team and on the

same page about all that came along with being a couple raising a child with autism.

Foundational Commitment to Partner

The degree of commitment to the relationship that partners held prior to having

children on the autism spectrum were also seen by participants as a contextual factor that

influenced the ways in which couples negotiated intimacy. This particular finding also

relates closely to this study's definition of intimacy, which involves commitment to one's

partner as a central factor of intimacy in romantic relationships (Moss & Schwebel,

1993).

More specifically, participants reported that coming to the experience of raising a

child on the autism spectrum with an already established, strong commitment to one's

relationship was a great asset in a couple's ability to find ways to stick together when

times got tough—which they inevitably would when raising children with ASDs. For

example, Erin and Nathan shared about how their commitment to be married for life has

helped them deal with all that comes with raising a child with autism:

Nathan: We made a commitment before we even had [our son] that nothing was

going to come between us. It has been a bit of our guiding light through it all.

Erin: Being Catholic, you know, really divorce is not an option for us. And I am

not going to lie—some days it is harder than others. Some years it is harder than

others…but I think one of the main things is that when we went into this marriage

it was with the plan that this was forever. 'Til death do us part.

Nathan: Yeah.

Erin: And there is no back outs, and there is no take-backs.

Nathan: There was no "Okay, I love you but if it gets too tough, well, I just cannot

deal with it."

Erin: Right. And I think that is part of why we have done so well, is that, you

know, we go on with the mindset that it is "for better or for worse," "'til death do

us part." I mean, we have had some really low times, we have had some really

high times.

Thus, Erin and Nathan saw their foundational commitment to each other and their

relationship as key in not letting the stressors of caring for a child with autism be able to

pull them apart as a couple. Similarly, Kristen and Jared told of how their foundational

sense of commitment kept them from ever truly being able to walk out the door when

times got tough. As Jared reported:

We have this bottom line commitment to each other…and I think no matter how

tough things have gotten, no matter what I have said, you know, "I am walking

out, I am walking out, I am walking out"—nobody could ever do it.

Also, speaking about commitment in a more religious sense, Derek shared that before

adopting their son he and Carla held the belief that God was not "going to give us more

than we can handle." He added that this belief helped the couple to not "let this situation

[raising a child with autism] tear us apart."

Other Intrapersonal and Institutional Considerations

Although experiences of outside support and having a foundational commitment to one's partner were viewed as the two primary contextual variables that influenced negotiations of intimacy among couples caring for children with ASDs, participants also shared a number of other intrapersonal and institutional factors that could have an effect on a couple's ability to make certain cognitive and relational shifts necessary in fostering more closeness and connectedness in their relationship.

With regard to intrapersonal factors, participants noted that partner physical and mental health played a significant role in couples' abilities to experience intimacy in their marriages/committed partnerships. For example, Ashley shared about how her epilepsy made it hard for her and Max to carve out time together as a couple—even just to touch base at the end of the day—because she was constantly exhausted and had to put all the energy she could muster into her children: "With my seizure issue…it is going to take half my body away. So, it wipes me out completely. And so then the kids take over." Ted also discussed how his mental health concerns, sometimes exacerbated by his son with autism, played a major role in his ability to be emotionally and cognitively close with Fran:

> For the last 15 years or so I have been—I have had this major depressive stuff in
> my life which I am sure is somehow related to [my son with autism], but it is not
> rooted in [him]. It is triggered at times by things with [him], but that is not—so I
> have had that big animal [depression] here which has negatively affected our
> [Fran's and my] relationship in a big way.

Thus, if one or both partners were ailing, either physically or psychologically, it became

all the more difficult for couples to share the childcare workload, practice effective

communication, and find snippets of time together.

In addition, the severity and type of behavioral issues exhibited by children with

ASDs was also seen as having an impact on couples' negotiations of intimacy, especially

regarding their ability to work as a team. Harper and Wes shared one very poignant

example of a behavior their son exhibited which put a great strain on their relationship:

Harper: Some of his [our son's] problems started when he got a virus from me at

11 months old. His autoimmune—the diarrhea, over five years of diarrhea,

chronic daily diarrhea started—

Wes: It was horrible, because if you did not catch him right away—

Harper: It would go up his back, and would—

Wes: I do not know—have you heard of fecal smearing?

Interviewer: Yes.

Harper: I mean like, just everything would be smeared—

Wes: You had to catch him, like, right away and it was very, very stressful.

This stress, the couple later reported, had to do in part with their disagreements over why

the fecal smearing occurred, who was responsible for cleaning it up, and how they could

prevent future such incidents from taking place.

In reporting on other extrafamilial and institutional factors affecting couples'

experiences of intimacy, participants focused their sights on expenses associated with

raising children with ASDs, issues with the schools their children attended, and other

work-related issues (e.g., working long and/or odd hours). Regarding monetary concerns,

Cindy reported that raising children with ASDs cost "ten times" as much as raising

typically-abled children when factoring in extra medical and therapeutic costs. She added that she had begun working extra hours and taking on extra jobs to help make ends meet, and that this took away from her ability to find regular time to connect with Tom:

> Cindy: With the kids too, because it is an extra expense, I had to work weekends. And it was the best way we could do that. So it was like seven days a week we are going.
>
> Interviewer: That does not leave a lot of time for you guys as a couple, then?
>
> Cindy: No.
>
> Tom: No, we get like 20 to 30 minutes together [a week].

School-related difficulties were also seen as having an influence on a couple's capacity to focus on their relational needs. Erin mentioned how she and Nathan felt they had to expend a lot of energy to get their son's school to give him the services he needed. In turn, this lack of energy was viewed, in part, as keeping the couple from making the space in their lives for more opportunities to do couple-related activities. According to Erin, "We might be fighting for with the schools in terms of accommodations or insurance referrals. All of that takes a lot of energy out of us. And with a lot of energy going there leaves less energy for other things."

Lastly, participants talked about how their jobs, in general, caused them added stress and often kept them from having more time with their partners. This was the case even if they were not making a conscious choice to work longer hours to pay for their childcare expenses. For example, Cindy and Todd discussed how Todd's job was the biggest external factor that kept them from having more opportunities for couple time:

> Todd: My job is the biggest obstacle.

Cindy: Yeah, it is.

Todd: I just have really odd hours that goes late.

Cindy: Long hours.

Todd: And weekends and all that sort of stuff. If I had a better job that allowed for family life balance, I think things would have been a lot easier and maybe not as much of a struggle.

How Couples' Negotiations of Intimacy Change Over Time

Because, from a theoretical standpoint, how couples negotiate intimacy is not static, but rather a process, it was also important for this study to explore how the negotiations of intimacy among couples raising children with ASDs changed, if at all, over time. This was the third, and final, research question guiding my study.

In discussing how their negotiations of intimacy had changed over time, couple reported that negotiating intimacy was an iterative process. Namely, participants stated that, in the face of the unique needs and challenges associated with raising children on the autism spectrum, the more they were able to make the necessary cognitive and relational shifts reported in this study, the better they were able to negotiate intimacy in their relationships over time. Additionally, many noted that one of the key factors in this process was to simply "survive the early years" of having a child with an ASD, as getting through these first years gave couples both a sense of accomplishment and a belief that their relationships could thrive in the context of raising children on the autism spectrum. To this point, Laura mentioned how for her and Todd the task of caring for child with autism was "so much harder in the beginning…just the struggle of time and babysitters and resources and all that was much, much harder." Now, however, the couple noted that

it was much easier for them to find the time and space to make some of the

aforementioned shifts:

> Laura: It [being a couple raising a child with autism] has become so much easier.
>
> Todd: Yeah.
>
> Laura: I mean, if we want to have a date night, we have date night now. But in the
>
> beginning, you have to have the support system first before that can happen.

Carla shared a sentiment similar to that of Laura and Todd, noting that "if you can get

through the early years and figure out how you are going to make this [caring for a child

with autism] work, when you come out on the other side things are better than before you

had [your child]." Thus, Carla believed that for her marriage, surviving the early years of

unpredictability with her son actually helped her have a closer relationship with Derek

later on in that the couple had be forced to made the necessary shifts in cognition, put

their marriage "on the backburner" for a time, and work together as a team to care for

their son—all skills that continued to help them foster intimacy in their relationship in the

present. As another example, Cindy and Tom shared that through surviving the early

years of raising two children with ASDs, they learned how to move very quickly from

being in parent mode from being in couple mode. This viewed this skill as assisting them

in taking advantage of the time they could actually find together as a couple:

> Tom: We go very easily from "autism mode" to "regular mode."
>
> Cindy: And I do not think it has always been like that.
>
> Tom: No.
>
> Cindy: I think when they [our sons] were younger, it was much harder.
>
> For those couples who successfully navigated the early years of caring for

children with ASDs, participants pointed out that this did not mean all the hard work of

negotiating intimacy was over. Instead, participants maintained that couples needed to keep working at all the relational skills already mentioned (i.e., working as a team, communicating well, finding couple time, and demonstrating sensibility toward one's partner) in order to continue fostering intimacy in their relationships over time. Participants also made note of the fact that while it was true that the more hard work couples did in the early years, the easier their relational shifts would become in subsequent years, it was also the case that the more difficulty couples had in surviving the early years, the harder it would be to make the necessary relational shifts in later years.

CHAPTER 5: DISCUSSION

Having detailed this study's emergent theory of how couples raising children on the autism spectrum negotiate intimacy, I will conclude with a discussion of how my findings contribute to the related literature as well as what they mean, practically speaking, for couples raising children with ASDs. I will then highlight some key practice implications based on the results of this study, address the limitations of my study, and discuss potential future research directions associated with the topic of couples raising children with ASDs.

Intimacy as an Interactional Process

The findings of this study indicate that, for couples raising children on the autism spectrum, experiencing intimacy is best understood as an interactional process. That is, this study found that both partners in a couple relationship together need to be able to make the cognitive and relational shifts mentioned in this study as key components of fostering intimacy among couples raising children with ASDs for the couple to experience intimacy in their marriage/committed partnership. For example, if only one partner is attempting to make key relational shifts such as practicing enhanced communication with or demonstrating a heightened level of sensibility toward the other partner, then this couple will have more difficulty experiencing intimacy in their relationship (because there is no interaction between partners in these processes) than another couple who are actively working together to make the shifts necessary in experiencing intimacy in their relationship. This finding coincides with the interpersonal model of intimacy (Reis & Shaver, 1988; Reis & Patrick, 1996) employed as a part of the theoretical framework for this study, which suggests that intimacy exists as an interaction

between partners and not something that one partner can experience independent of the other. It also relates to the notion of non-summativity, drawn from the family systems theory component of the theoretical model for this study (Cox & Paley, 2003; Watzlawick et al., 1967), which suggests that the whole is greater than the sum of its parts. In this sense, understanding intimacy as a dyadic process, as opposed the sum of two individual experiences, clarifies the point that intimacy does not exist as an individual state but rather as part of a larger set of interactions between two partners in a couple relationship. Furthermore, viewing intimacy as an interactional process expands upon previous literature related to the relationships of couples raising children with ASDs in that highlights the fact that the health and maintenance of one's marriage/committed partnership is about more than just the variables that each partner brings to the relationship (e.g., commitment to the other, respect for the other, level of parenting stress, style of coping, perception of partner's support with caregiving responsibilities; Brobst et al., 2009; Higgins et al., 2005; Ramisch et al., 2013).

This study also found that not only is intimacy for couples raising children with ASDs an interactional process, but it is also iterative and ongoing over time. More specifically, this study's findings suggest that a couple's experience of intimacy is not an end in and of itself but instead feeds back into the ways in which a couple perceives their ability to foster intimacy in their relationship, beginning the cycle of intimacy negotiation over again. As such, for couples raising children with ASDs, greater experiences of intimacy will beget greater experiences of intimacy, while absences of intimacy and intimate interactions will beget even more such absences over time. For example, a couple that has historically had difficulty fostering closeness in their relationship might

begin developing a larger and larger sense of hopelessness with each missed opportunity

for connection, while another couple that had been more successful in fostering intimacy

in their relationship might lean on the knowledge that they had been successful in the past

in order to do so again in the future. This finding corresponds to yet another component

of the theoretical framework guiding this study, ecological systems theory's concept of

the chronosystem (Bronfenbrenner, 1994), which posits time as being an important

consideration in developing a contextualized understanding of any family systems-related

phenomenon.

This study's finding regarding the iterative and ongoing nature of intimacy

negotiation among couples raising children with ASDs also both relates and contributes

greater depth to the one extant article regarding how relationships among these couples

change over time (Hock et al., 2012). Although this article, by Hock and colleagues

(2012), provides an excellent theory for how relationships among couples raising children

on the autism spectrum change over time, their model is linear and finite. More

specifically, Hock and colleagues' study suggests that couples move from experiencing

the "autism crucible," or the stage of first coming to terms with all that comes along with

raising a children with ASDs, to a stage in which they primarily focus on parenting at the

expense of their own relationships, to an end point of deeper intimacy and commitment to

one another. In presenting their model in this fashion, the authors show intimacy to be a

fixed point at which a couple one day arrives by virtue of simply having moved from one

stage to the next in a linear fashion. As such, this present study adds to Hock et al.'s

(2012) work in that it demonstrates change over time for couples raising children with

ASDs to be not just a linear and finite process but rather cyclical and recurrent over time,

meaning that couples looking to experience deeper intimacy and commitment in their relationships need to actively work together to achieve and maintain these "deeper" places of intimacy and commitment.

Multifaceted Nature of Intimacy Negotiations

This study also found intimacy negotiations among couples raising children with ASDs to be multifaceted, involving several key cognitive and relational shifts. No one shift, either cognitive or relational, was found to link directly to couples' experiences of intimacy. Rather, as noted in the process model for this study, experiences of intimacy among these couples were found to be dependent upon the degree to which they were able to navigate each and every cognitive and relational shift. That this study found intimacy negotiations to be multifaceted in nature parallels with the conceptual definition of intimacy helping to guide this study, which conceives of intimacy as also being multidimensional (involving commitment, affective closeness, cognitive closeness, physical closeness, and mutuality; Moss & Schwebel, 1993).

Cognitive Shifts

One of this study's key findings regarding the process of intimacy negotiation for couples raising children with ASDs relates to the ability of each partner in a couple relationship to make the necessary cognitive shifts with regard to the amount of time they have together as a couple, their view of the impact of their child with ASD on their couple relationship, and their perceptions of the unique childcare challenges that come with raising a child on the autism spectrum. In essence, making such shifts is all about reframing, also defined as one's ability to "redefine stressful events in order to make them more manageable" (Lustig, 2002, p. 18). For couples raising children with ASDs,

such reframing might involve partners being able to come to terms with a lack of couple time and appreciate the time they do have together, look for the ways in which their children have drawn them together instead of over-focusing on the many ways in which their children might pull them apart, and accept (and even make light of) the fact that they will have child-related issues to deal with that are very much unique to caring for children on the autism spectrum. However, it remains to be noted that these shifts can be difficult to achieve and that participants in this study often noted that it took time to be able to see the glass as half-full versus half-empty when considering what it meant to be a couple in the context of raising children with ASDs.

As previously stated, although these cognitive shifts do not provide a direct link to couples' experiences of intimacy, per se, this study did find them to be the first steps in the process of intimacy negotiation. This was because making these shifts in cognition and perception set the table for a couple's ability to actually take action and "do" the relational shifts mentioned in this study. As such, a couple looking to foster intimacy in their relationship first needs to be able to see some good in their situation, some potential for the future of their marriage/committed partnership, before they can successfully engage in making the relational shifts necessary in fostering intimacy in their relationship, let alone appraise their work in making these shifts as progress.

Additionally, although making these shifts could well be viewed as individual and intrapsychic—rather than dyadic and relational—activities, the findings of this study maintain that they are actually processes in which both partners need to engage. That is, couples need to make these cognitive shifts together to be able to experience intimacy in their relationships. For example, if a wife has resolved herself to the fact that couple time

will not look the same for her relationship as for another couple that does not have a child on the autism spectrum while her husband refuses to come to the same conclusion, this couple will inevitably struggle to do something like carve out a few minutes of couple time (a key relational shift) because, in the husband's eyes, that limited amount of time together is not nearly enough to constitute "proper" couple time. Thus, one partner's inability or unwillingness to make the necessary cognitive shifts mentioned in this study's findings has the potential to inhibit the couple's ability to make the subsequent relational shifts that are part of the intimacy negotiation process for couples raising children with ASD.

Making cognitive shifts conjointly with one's partner as a necessary step in the process of intimacy negotiation among couples raising children with ASDs is a finding that resonates with Bayat's (2007) study of resiliency among families raising children on the autism spectrum in which she found that a change in worldview was a chief factor in promoting resiliency for these families. More specifically, Bayat found that resiliency was fostered among families who could positively reframe the impact of their children with ASDs on family life. However, Bayat's study was not focused on couples, nor on the topic of intimate relationships. Nonetheless, the fact that positively reframing was part of the process of promoting resiliency among families caring for children on the autism spectrum helps to corroborate this study's finding that making positive reframes (i.e., cognitive shifts) is also an important aspect of promoting intimacy among couples raising children with ASDs. Furthermore, this study's findings regarding the primacy of cognitive shifts in couples' intimacy negotiation processes also coincides with Hock et al.'s (2012) aforementioned study in which partners' "cognitive reactions" to the

demands of raising a child on the autism spectrum was determined to be a key component in a couple's ability to move toward deeper intimacy and commitment in their relationship. Despite this similarity between these two findings, this present study extends upon Hock and colleagues' (2012) description of cognitive reactions by framing a couple's cognitive responses as conjoint, rather than individual, processes and by noting that cognitive appraisals are not simply "responses" to the experience of caring for children with ASDs but are actively negotiated between partners within the context of caring for children on the autism spectrum.

Relational Shifts

Although this study's finding regarding making cognitive shifts with one's partner can be seen as standing on its own in terms of how it relates to negotiations of intimacy among couples raising children with ASDs, the other four categories related to how these couples negotiate intimacy are best viewed together under the larger heading of relational shifts. This is because working as a team, practicing enhanced communication, overcoming barriers to couple time, and demonstrating sensibility toward one's partner are all action-oriented, relational tasks that involve both parties in a couple relationship. Moreover, these categories have been placed together under the same heading because of the fact that the findings from this study did not indicate that one specific category was more important than another, nor that any one category came before or after any other category, nor that a couple could avoid one of these categories and still fare the same as a couple that works to attain mastery over each of the four categories related to relational shifts. For example, a couple that succeeds at working as a team, communicating effectively, and showing sensibility toward each other but that cannot overcome barriers

to couple time might be more at risk of drifting apart from one another more than a couple who manages to find a way to put all four relational shift categories into practice. Also, as previously mentioned, these tasks can been seen to succeed or fail to the degree to which a couple has already been able to make the necessary cognitive shifts related to being a couple raising a child on the autism spectrum.

This study's findings concerning the relational shifts couples must make in the process of negotiating intimacy in their marriages/committed partnerships can also been seen to substantiate and add to other related literature. For instance, with regard to the finding that couples raising children with ASDs must consciously work as team as a part of their intimacy negotiation processes, a number of other studies also found teamwork to be important for these couples. Huck and colleagues (2012) found that taking a tag-team approach to parenting when dealing with children with ASDs was a necessary step in the process of developing a deeper sense of commitment and intimacy in one's marriage. Additionally, Bayat (2007) and Ramisch (2012) reported that partners who worked together in caring for their children with ASDs would have stronger marital relationships/committed partnerships as a result. Lastly, Cowan (2010) found that couples who worked together to overcome some of the more difficult aspects of raising a child on the spectrum reported having more marital satisfaction and feeling "stronger as a couple" (p. 107). Thus, while this present study also highlights the importance of teamwork among couples raising children with ASDs, it also adds greater depth to previous related works in that unpacks the core components of teamwork for these couples (i.e., sharing the childcare workload, taking "me time," and learning about/advocating for ASDs together) and notes the relationship between teamwork and couples' experiences of

intimacy.

Additionally, in relation to this study's findings regarding practicing enhanced communication with one's partner, a clear link exists between the interactive nature of these skills (especially the idea of "hearing and being heard") and the model of intimacy that serves as part of the theoretical framework for this study. That is, the communication skills found to foster intimacy in this study relate closely with the interpersonal model of intimacy (Reis & Shaver, 1988; Reis & Patrick, 1996), defined earlier as a transactional process between two individuals involving self- disclosure (e.g., "being heard") and partner responsiveness (e.g., "hearing"; Baucom & Atkins, 2013). This connection helps to further contextualize intimacy as an interactional process between partners and reemphasizes the idea that, four couples raising children with ASDs, both partners need to be engaged in making the shifts mentioned in this study for a couple to come to experience intimacy in their relationship. This finding regarding practicing enhanced communication also expands upon previous findings related to communication among couples caring for children on the autism spectrum. Namely, although Ramisch and her colleagues (2013) found that communication was a key factor in maintaining a strong marital relationship in the context of raising children with ASDs, this study did not make mention of the type of communication process that helped couples keep their marriages strong. As such, this present study provides an important contribution to the literature on couples raising children with ASDs by noting the ways in which particular communication skills can either help or hinder couples' intimacy processes.

There is less related literature to how couples raising children with ASDs overcome barriers to couple time; that which does exist coincides with this study's

findings that these couples do not have as much time together as they would like (Cowan, 2010; Myers et al., 2009). Nevertheless, these studies did not share the findings of this study that couples needed to be creative in overcoming their barriers to couple time, nor that finding quality childcare help was a key factor in the process of finding couple time with one's partner. As such, another contribution of this study comes in presenting ways for couples raising children with ASDs to find time together—despite their unique barriers to couple time—rather than simply stating that certain barriers to couple time exist.

Lastly, this study's finding that demonstrating a heightened level of sensibility toward one's partner is a major component in the process of negotiating intimacy for couples raising children on the autism spectrum is consistent with the findings of a few other studies. In particular, with regard to extant research investigating how couples, in general, develop and maintain intimacy in their relationships, Gordon and colleagues (2012) found that expressing and receiving gratitude in one's close relationships fosters intimate bonds between partners, while Ben-Ari and Lavee (2007) maintained that appreciation and respect for one's partner promoted marital closeness. Additionally, in Hock et al.'s (2012) study on parenting children with ASDs, the authors made mention of the fact that providing emotional support for one's partner was an important factor helping each other cope with the stress of caring for a child on the spectrum. However, the present study extends upon the findings of Hock and colleagues in finding that emotional support for one's partner is not just about helping to cope with stress but is also about a larger process of promoting intimacy in one's relationship.

Contextual Factors

The contextual factors emerging from this study help to shed light on the fact that couples' negotiations of intimacy may also be influenced by outside forces. Thus, the cognitive and relational shifts couples must make in negotiating intimacy in their relationships can be either aided or blocked by the degree to which such contextual factors impede upon or facilitate these negotiations. This finding coincides with Bronfenbrenner's (1979) ecological systems theory, part of the theoretical framework for this study, which suggests that family systems have differing levels of opportunity and constraint based upon their relationships to the various levels of their ecological environments. Thus, for couples raising children with ASDs, some contextual factors, such as access to outside personal and professional support, were found to facilitate couples' negotiations of intimacy, while others, like a partner in poor physical or mental health, were found to constrain these couples' negotiations.

This study's findings regarding contextual factors and their influence on the processes by which couples negotiate intimacy when raising children on the autism spectrum also corresponds to a number of other related works. For instance, the finding that having a foundational commitment to one's relationship aids couples in fostering intimacy in their relationships is in line with Ramisch and colleagues' (2013) finding that sharing foundational ideas about marriage with one's spouse helped couples to maintain sound relationships in the face of raising children on the autism spectrum. Additionally, this study's contextual findings are consistent the work of Hock and his associates (2012), who made note of how physical and emotional exhaustion, as well as financial strains, placed a great deal of pressure on couple relationships and restricted an

individual's ability to find more intimacy in his/her marriage. The finding that the amount

of outside supports available to families raising children with ASDs can have an

influence over a couple's functioning, also resonated with Hock et al.'s (2012) work in

which the authors noted that social isolation could hinder the ability of couples raising

children on the autism spectrum to foster intimacy in their relationships. In addition to

these comparisons to the impact of contextual factors on experiences of intimacy among

couples raising children with ASDs, this study also added to the contributions of the

previously cited studies in demonstrating that each of the aforementioned contextual

factors do not directly impact couples' experiences of intimacy, but rather serve to

influence other mechanisms (i.e., key cognitive and relational shifts) by which couples

raising children on the autism spectrum negotiate intimacy.

Practice Implications

At this onset of this study, one of my great hopes was to be able to extrapolate out

from my work a set of practice implications for marriage and family therapists and other

helping professionals who may come in contact with couples raising children with ASDs.

Based on the findings of my study, I believe there are a number of implications to be

drawn, both in a general sense for various types of helping professionals (e.g., support

group leaders, clergy and other faith-based organization leaders, social service providers)

working with these couples, and in much more specific ways for clinicians who serve this

population.

General Suggestions for Helping Professionals

This study's findings suggest that helping professionals working with couples

raising children on the autism spectrum would do well to engage these couples in a few

key ways. First, based on this study's findings that making a few key shifts in cognition are the first steps for couples in the process of fostering intimacy and that surviving the early years of raising children with ASDs is an important factor in a couple's ability to foster intimacy in their relationship over time, if a couple has recently found out that their child has a disorder on the autism spectrum (or is simply less educated than they would like to be regarding ASDs, what it means to be a parent of a child on the spectrum, or what it looks like to be a couple raising a child with an ASD), helping professionals should be prepared to offer the couple some psychoeducational resources. Examples of informative, yet easily digestible, psychoeducational materials include Sicile-Kira's (2008) brief review regarding the common effects of autism in family and partner relationships or Abbott's (2013) therapeutically-oriented article entitled "Love in the time of autism." Professionals may also help a couple still looking for more information about ASDs by helping to normalize the chaos they are experiencing and reminding them that many other couples who have been in similar situations report that the first few years of raising a child on the spectrum are just about surviving. However, these professionals should also share that many couples have found that after getting through the early years they feel closer to one another as partners for what they have accomplished together.

Another important aspect of working with couples raising children with ASDs could be to help these couples develop a more robust support system (Neely et al., 2012). That is, because external factors, such as the amount and quality of couples' outside supports, was shown to influence the degree to which they experience intimacy in their relationships, it is important to work to help these couples consider how they can expand their access to and utilization of both informal and formal supports. Examples of such

supports helping professionals could help a couple to access (if these are not capacities in which professionals are already working with the couple) include: support groups for parents of children with ASDs or other developmental disabilities, church and other spiritually-based communities, respite care services, psychotherapeutic services, financial assistance services, school advocates, and neighborhood associations, among many others. In the event that a couple reports that they cannot rely on family to support them, professionals could also help the couple to consider how to build a family of choice (i.e., a family of non-blood relations) to surround and assist them with their unique needs and challenges. Building such a family could go far in helping couples to acquire the outside support found by this study to mitigate difficulties in making certain relational shifts (e.g., overcoming unique barriers to couple time) related to developing intimacy in one's marriage/committed partnership.

Lastly, and again based on the findings of this study which suggest that the quality of a couple's outside supports can have an effect on the couple's ability to successfully negotiate intimacy in their relationship, one other general way that professionals could assist couples raising children with ASDs would be by helping partners to advocate together on behalf of their child. Helping a couple to advocate together could both support the couple in working together as a team (one of the necessary relational shifts noted in this study's findings) and in actually obtaining the types of ASD-related services that could serve as formal supports for promoting intimacy in the couple relationship. For example, assisting a couple in advocating for respite care for their child on the autism spectrum could free the couple up to find some more time alone together as a couple (another relational shift as part of this study's process model of

intimacy negotiation). Additionally, aiding a couple in finding more financial assistance for their child could also help the couple to pay for the type of quality childcare that this study found to be a necessary component in overcoming the unique barriers to couple time (ultimately found to be barriers to experiencing intimacy with one's partner) when caring for children with ASDs.

Specific Therapeutic Interventions

On top of to the aforementioned general suggestions for helping professionals working with couples raising children with ASDs, there are also a number specific ways in which psychotherapists may intervene to assist these couples in fostering more intimacy in their marriages/intimate partnerships.

Externalizing the problem. If one or both partners in a couple relationship is struggling with making the necessary cognitive shifts related to being a couple raising a child on the spectrum, narrative therapy's externalization technique (White & Epston, 1990), in which a therapist works to help a couple see a problem in their lives as something outside of themselves, might be a very useful intervention. More specifically, this intervention could aid partners in viewing their child's ASD-related behaviors as something external to the child as opposed to part of the child's intrinsic character— especially given the fact children are not born with ASDs, but only acquire them after their first 14 to 24 months of life. In addition, externalizing autism could not only help a couple to have a more positive outlook regarding the nature of their child and his or her behaviors, but could also assist the couple to consider how autism has impacted their ability to make the relational shifts necessary to foster intimacy in their marriage/ committed partnership. Helping a couple to reflect on autism's impact on various

relational shifts can then allow partners to think about how they might work together to mitigate the effects of autism on their intimacy-related interactions and outsmart its future efforts to hinder the processes by which they experience intimacy in their relationship.

As a part of this process, the therapist could assist both partners in looking for unique outcomes (White & Epston, 1990), or times when their problem (i.e., autism) was not a problem. Questions that could help a couple determine when autism did not impede on their ability to experience intimacy in their relationship might include (adapted from Freedman & Combs, 1996):

1. When was a time that autism was not able to get between the two of you and disrupt your attempts to foster intimacy in your relationship?

2. When autism is not able to block your attempts to promote intimacy in your relationship, what does your relationship look like?

Furthermore, once a couple has been able to pin down times when autism has not hindered their attempts to foster intimacy in their relationship, they may move on to explore how they had been able to outwit autism in those instances. After unpacking the ways in which they have successfully outwitted autism, the couple can then use those same strategies to keep the negative effects of autism at bay and, thus, promote the relational shifts found by this study to assist couples in experiencing intimacy in their relationship.

Encouraging shifts in attributions and schemas. Another intervention for partners who are experiencing difficulty in making the necessary cognitive shifts related to being a couple raising a child on the spectrum has to do with assisting couples in adjusting 1) the ways in which they conceptualize having a child with an ASD as having

impacted their ability to experience intimacy and 2) their schemas for what a happy, healthy, and intimate relationship looks like. In this sense, employing guided discovery, an intervention derived from cognitive-behavioral couple therapy (Baucom, Epstein, LaTaillade, & Kirby, 2008), may be of use. Thus, if one or both partners in a couple relationship are struggling to see the impact of their child on their relationship as anything other than negative, or if one or both partners cannot let go of a particular unrealistic schema for what an intimate relationship should look like (especially as relates to how much time a couple should have alone together), the therapist may use the guided discovery technique to help the couple to question particular attributions and schemas in order to develop a different, more adaptive, perspective on their child and their relationship. More specifically, leading couples along a journey of guided discovery would involve the therapist asking one or both partners to describe their existing standards for what type of impact children should have on their parents' relationships and what intimacy in a couple relationship should entail. Having detailed these matters, the therapist would then inquire the couple about the various advantages and disadvantages of these existing standards and then address the possibility of developing new standards or adapting previously existing standards as needed (Baucom et al., 2008).

For example, with a couple in which one partner has expressed a belief that come hell or high water couples in intimate relationships should go out on a date at least once per week, the therapist may ask about the benefits and drawback of holding this belief. If the partner describes the benefits of going out once a week as making sure that quality couple time occurs on a regular basis and the drawbacks as experiencing a great deal of frustration when all that comes with raising a child on the autism spectrum gets in the

way of the couple's weekly date, the therapist could then ask the partner about the possibility of developing a different standard that did not lead to so much frustration but still ensured that couple time was prioritized as taking place regularly. Making this adjustment in standards could thus help the couple to experience more cognitive closeness by honoring the desire to spend time together while being realistic about the frequency with which such time together could occur.

Enhancing effective communication. Helping partners to build their communication skills and manage their conflicts well is yet another chief way in which psychotherapists may assist couples raising children on the autism spectrum. Enhancing effective communication with one's partner is especially important to these couples because of this study's findings suggesting that practicing enhanced communication between partners was one of four key relational shifts necessary to promote intimacy in one's marriage/committed partnership.

For partners that are struggling to hear and be heard, a therapist could help them to work toward more effective communication with one another by making use of Markman, Stanley, and Blumberg's (1994) "speaker-listener technique." Using this technique, a therapist can train partners to talk to each other in ways that are both clear (so each truly understand what the other is saying) and safe (so that neither has to fears the conversation will get out of hand). More specifically, a therapist can help partners to take turns engaging in conversation, with one partner acting as the "speaker" and the other as the "listener." Speakers are instructed to speak only for themselves, be brief, and stop so that the listener can paraphrase what is being said. Listeners are prompted to paraphrase what they heard and not offer any rebuttal. Additionally, each partner is

taught to take turns having "the floor," or being in the position of speaking, as well as to focus on simply having a good conversation rather than trying to problem-solve anything. Thus, the therapist may help a couple to practice these tasks in therapy with the hope that they can later be generalized to the home environment, enhancing the couple's abilities to hear and be heard by one another.

On the level of effective problem solving, one of the subcategories related to this study's findings related to the practice of enhanced communication, psychotherapists can help couples raising children on the autism spectrum by teaching and then practicing with them Gottman and Silver' (1999) five-step model for resolving conflicts. These research-based steps involve helping partners to 1) start conversations without criticism or contempt; 2) make and receive "repair attempts," or actions or statements that deescalate tension between partners; 3) soothe themselves when getting heated during a conversation by taking a "time out" (i.e., a 20-minute break necessary to calm oneself down); 4) take each other's thoughts and feelings into account; and 5) be tolerant of one another's flaws and faults. An additional component of Gottman and Silver's model is for couples to determine which of their problems are solveable and which are not. For couples raising children with ASDs, a therapist could again be of assistance by helping them to determine which problems are worth grappling with and which are matters that they may never be able to solve.

Promoting emotional attachment. Another important relational shift found by this study to be an integral part of couple's negotiations of intimacy when raising children with ASDs has to do with demonstrating a heightened level of sensibility toward one's partner. This shift was found to be key in these couples' intimacy processes due to the

fact that study participants reported they felt emotionally distant from one another when expressions of empathy and appreciation were absent from their relationships, and felt emotionally close to one another when such expressions were regularly demonstrated in their relationships. Thus, because couples raising children with ASDs may require support in empathizing with and appreciating one another, therapists working with these couples should also consider taking an emotionally focused couple therapy (Johnson et al., 2005) approach when sensitivity to and sensibility toward one's partner is a presenting concern. This perspective on couple therapy helps couples to identify the negative cycles of interaction that keep them from being more open with one another, to expand upon the possibilities for emotional expression in their relationships, and to restructure their interactional cycles in more positive and loving ways. As such, when working with a couple raising a child on the autism spectrum, a therapist may help a couple to acknowledge and discuss the ASD-related hardships they face, to work to unearth that which keeps the couple from working with and not against each other, and to develop new ways of relating to each other that better meet one another's emotional needs in light of all that comes along with caring for children on the autism spectrum. Intervening in these ways can then help couples to be more sensitive to each other's emotional needs, leading them to engage in more successful negotiations of intimacy in their relationships.-

Addressing gender-related concerns. This study, as well as others (e.g., Hock et al., 2012), have found that, among couples raising children with ASDs, mothers tend the primary caregivers for their children, either staying at home on a full-time basis or only working part-time outside the home. Although this study found that a number of couples

in which the wife stays home believe this division of labor to be helpful to the family

system, it could still be important for a therapist working with these couples to explore

matters related to gender and power within the couple relationship (Mac Kune-Karrer &

Foy, 2003). To this end, Haddock, Zimmerman, and MacPhee, (2000) offer a number of

very good questions to ask couples when attending to gender in couple therapy. More

specifically, these authors share a number of questions related to decision-making,

work/career life, housework, money, and sex that may be important to ask of couples

raising children on the autism spectrum who are in more traditional relationships. The

answers provided to these types of questions could shed a great deal of light on whether

or not partners see their division of labor, and other issues of power and gender, as

problematic or not. Exploration of these types of gender-related issues may, in turn, help

couples to work more equitably as a team—one of the relational shifts this study found to

be central in the negotiations of intimacy among couples raising children with ASDs.

Limitations of the Study

While this study has contributed important information related to the processes by

which couples raising children with ASDs negotiate intimacy, it is not without

limitations. First, my sample included only married couples and was fairly homogeneous

in terms of race, socio-economic status (SES), and religious affiliation. As such, it could

very well be the case that my findings would not apply as well to racial minority couples,

couples of lower SES, non-married partners, and/or couples that are non-religious. I say

this because a wealthy, White, Christian married couple would, ostensibly, not have

nearly the number of outside stressors as a couple that has not been imbued with such

power and privilege. For example, a poorer couple may be more impacted by more

financial constraints, or a non-White couple by institutional racism, than what is reflected in my findings. As such, I would suspect that in a less homogeneous sample, couples' might report social support to be a more central factor in their negotiations of intimacy In addition, due to the fact that 23 out of 24 of my participants endorsed having some religious affiliation, one must question the degree to which being involved with organized religion serves as either a protective or a risk factor for couples raising children with ASDs. Thus, it would be interesting to study couples who do not affiliate themselves with any particular religious tradition, or a non-Christian religious tradition, to assess if the ways they negotiate intimacy look different than for the couples interviewed for this study. Namely, I would wonder if, among a more religiously diverse sample or a sample that included more non-married couples, one's foundational commitment to one's partner may be a less prominent contextual factor in the process of negotiating intimacy, or if the division of caregiving responsibilities would be less traditional and more egalitarian and, therefore, impact the degree to which couples might need to make the relational shifts related to working together as a team.

Second, in my study, I interviewed couples who were, at present, all still in a committed marital relationship to one another. I did not accept as participants individuals raising children with ASDs who had separated from or divorced their partners. As such, the couples that participated in this study had all managed (to greater or lesser degrees) to find ways to stay together in the face of all that comes along with caring for children on the autism spectrum. Had I also included separated or divorced individuals in my study, my results may have looked different based on the fact that I could have potentially gathered more information on what does not help couples to negotiate intimacy while

raising children with ASDs. In particular, I would wonder if hearing more about what kept couples from successfully fostering intimacy in their relationships, might have led to richer negative case examples related to teamwork, communication, conflict, and emotional closeness between partners. I also wonder if individuals who have separated or divorced from their partners in the midst of raising a child on the autism spectrum would resonate with the intimacy negotiation processes in this study or if they might deem these processes to only relate to partners who were still in relatively stable relationships with each other.

Third, I chose only to interview couples conjointly regarding their experiences of navigating issues of intimacy in their relationships. Although I believe I gave sound reasoning for my decision to interview couples together, and worked to ensure that these conjoint interviews did not keep important information regarding couples' negotiations of intimacy from being attained, it might still be the case that some participants held back from sharing certain information in front of their partners. Therefore, it is possible that my study findings have not included more sensitive information that participants chose not to share in front of their partners, despite the fact that I later gave them the opportunity to follow up with me via email regarding anything they felt they could not, or did not, voice during the conjoint interview process.

Fourth, as a part of my interviews with couples, I asked them to reflect back on experiences they had had in the past. Thus, it may be the case that some participants' recollections of their past experiences were not entirely accurate or, at least, had been colored by the passage of time. This is a phenomenon commonly referred to as "recall bias," defined as occurring when the accuracy or completeness of a study participant's

recollections regarding events or experiences from the past may be called into question (Last, 2001), particularly in instances in which a good amount of time has passed between the original event or experience and the time at which the participant is being interviewed about said event/experience. In addition, I asked couples to reflect on their experiences over the entirety of their time raising children with ASDs, while only collecting data from these couples during a single interview. As such, I may have missed out on gathering the depth of information that could have been provided in a more longitudinally-oriented study.

Finally, couples raising children on the autism spectrum may experience quite a variety of levels of caregiver burden, depending on the severity of the ASD-related symptoms their children exhibit. However, in this study, I made no attempt to determine the degree of caregiver burden that the couples I interviewed were facing. Therefore, it could be the case that couples negotiate intimacy in different ways based on the amount of caregiver burden they are experiencing and that the model presented in this study does not fully account for how couples with varying levels of caregiver burden negotiate intimacy. For example, understanding intimacy processes for couples with high levels of caregiver burden may require a model that places social supports not just as an external factor impacting the various cognitive and relational shifts that need to be made, but rather as a central factor in the process of experiencing intimacy among these couples. This is because of the fact that these couples would, ostensibly, need more outside support in creating a space for them to make the cognitive and relational shifts required to foster intimacy in their relationships than couples reporting low levels of caregiver burden.

Future Research Directions

One area of future research in a vein similar to that of this study relates to the notion of conducting longitudinal research on couples raising children on the autism spectrum to explore how their negotiations of intimacy change over time. As participants in this study pointed out, as has other related research (Hock et al., 2012), the early years of raising a child on the autism spectrum can be particularly difficult for couples. Thus, tracking with couples over time to see how they work through the early years of caring for children with ASDs, and having multiple data points for how their negotiations of intimacy evolve, would be quite helpful in developing a more robust sense of how these couples manage their intimate relationships over time. Namely, it would be interesting to examine over a period of time a couple's level of perceived caregiver burden and/or the level of autism-related symptoms their child exhibits in relation to partners' perceived level of intimacy in their relationship. More specifically, a couple's level of perceived caregiver burden could be measured by the Caregiver Burden Scale (which addresses issues of time-dependence burden, developmental burden, physical burden, and social burden; Zarit, Reever, & Back-Peterson, 1980), the level of autism-related symptoms their child exhibits by the Autism Diagnostic Interview-Revised (which measures one's level of social interaction, communication skills, and behavioral issues; Lord, Rutter, & Le Couteur, 1994), and each partner's perceived level of intimacy in their relationship by the Personal Assessment of Intimacy in Relationships Scale (measuring the level emotional, social, sexual, intellectual, and recreational intimacy in one's relationship; Schaefer & Olson, 1981). Ultimately, a longitudinal study like this could go far in isolating specific areas of intimacy for couples to address as specific stages in caring for

children with ASDs and also provide very specific practice implications to those working

with couples at varying stages in the process raising children on the spectrum.

Another area for future research could involve a cross-cultural study, quantitative

or qualitative, of how couples raising children with ASDs compare across cultures. Given

that different cultures have very different perspectives on what it means to have a child

with an autism spectrum disorder (Daley, 2002; Dyches et al., 2004; Wang & Casillas,

2013), it would be interesting to explore how these different perspectives hold influence

over how couples manage their relationships while caring for children with ASDs. In

particular, a cross-cultural study could address questions related to the validity of this

study's process model outside of the homogeneous sample from which the data for this

work were drawn, such as the role of outside supports or the degree to which each of the

cognitive and relational shifts noted in this study really are essential to the negotiations of

intimacy among couples from distinct sociocultural backgrounds.

Furthermore, a great deal of further insight related to how couples raising children

with ASDs negotiate intimacy could be gained by conducting interviews with post-

divorce individuals. That is, because this present study only looked at intimacy

negotiations among married couples (a fact that could very well limit the range of

responses to how intimacy is negotiated among those raising children on the autism

spectrum), studying that which kept couples from successfully experiencing intimacy in

their relationships could also be of great importance in developing an understanding of

how couples raising children with ASDs manage issues of intimacy in their relationships.

As such, a future study could focus on couples who ended their relationships in the midst

of all that comes along with raising children on the autism spectrum, which could add

some necessary depth and diversity to the findings related to intimacy negotiation in this present work.

In addition, future research into areas related to functioning among couples raising children with ASDs would do well to employ Pauline Boss's (2002) family stress management model in working to develop an understanding of how and why couples raising children on the autism spectrum experience more stressors and less relationship satisfaction and stability than couples raising children with typical needs and those caring for children with other types of developmental disabilities (DDs; e.g., Down syndrome, cerebral palsy, mental retardation). Namely, Boss's (2002) model could assist future researchers in tying their findings back to Boss' theoretical assumptions, which posit that 1) even strong families can experience crises given enough stress, 2) various family values and beliefs will influence how different families define and make meaning of stressful life events, 3) contextual variables (e.g., age, class, gender, and race) may also impact meanings families make of various stressful situations, 4) individuals stressors can impact an entire family system, 5) some family members will exhibit more resiliency than others when under distress, and 6) some families who seem to fall apart in the face of a crisis may actually become stronger for it in the long run. As such, this model could be particularly useful sensitizing a researcher to what factors impact how couples make meaning of having a child on the autism spectrum, the individual and contextual variables that may serve to mitigate or exacerbate a couple's experiences of stress, and how relational issues in the midst of a crisis may actually make individuals and/or couples stronger over time (i.e., meaning that partners who decide to end marital/committed relationships while raising children with ASDs are not necessarily destined to experience

worse individual and relational consequences than those who stick together through thick and thin).

One final thought regarding future research relates to the idea of testing whether the theory emerging from this study could generalize to couples raising children with other DDs. Namely, in light of various studies which have found that parents raising children on the autism spectrum experience more stress than those raising children with other types of developmental disabilities (Bourma & Schweitzer, 1990; Dunn, Burbine et al., 2001; Fisman et al., 1989; Rodrigue et al., 1990), it would be interesting to note if the same process employed by couples raising children with ASDs in negotiating intimacy applied to couples caring for children with other types of DDs. I would hypothesize that intimacy processes for couples caring for children with other types of DDs might look different from couple raising children with ASDs in that couples of children with other DDs would not have experienced the ambiguous loss related to their children and, therefore, have less significant cognitive shifts to make than couples of children with ASDs. Given that children with other types of DDs tend to present with less severe behavioral issues than children with ASDs, I would also think that couples raising children with DDs would have fewer caregiving burdens to navigate in their attempts to foster intimacy in their relationships than couples raising children with ASDs.

Conclusion

This study has explored how couples raising children on the autism spectrum negotiate intimacy in their marriages/committed partnerships as well as what contextual factors influence these process and how they change over time. Twelve couples currently raising children on the autism spectrum were interviewed conjointly regarding their

experiences of intimacy negotiation. A methodological approached based on constructivist grounded theory was used to analyze the data collected from these couples. The results of this study indicate that intimacy negotiation for couples raising children on the autism spectrum is an interactive process in which both partners must work together to make several key cognitive and relational shifts. Necessary cognitive shifts include reframing how partners perceive their access to and experience of time together as a couple, their autistic child's impact on their relationship, and how they view the unique challenges associated with raising a child on the autism spectrum. Relational shifts include partners working as a team, practicing enhanced communication, overcoming the unique barriers to couple time, and demonstrating a heightened sensibility toward one another. Although cognitive shifts were found to precede relational shifts, a recursive relationship was found to exist between these shifts in that, while cognitive shifts could lead to relational shifts, relational shifts could also lead back to cognitive shifts, and so on. In addition, the cognitive and relational shifts couples must make in negotiating intimacy in their relationships were found to be either aided or blocked by the degree to which contextual and environmental factors impeded upon or facilitated these negotiations. The result of the degree to which couples raising children with ASDs navigate the necessary cognitive and relational shifts, also taking into account the influence of any contextual factors on these processes, was found to be a couple's experience of intimacy. However, this study found also that intimacy was not a fixed point at which a couple one day arrived, but was instead an iterative process taking place over time and requiring work to maintain.

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Appendix A: Pre-Interview Questionnaire

1.   First name: _____

2.   Partner's first name: _____

3.   Your child's name: _____

4.   Your child's age: _____

5.   Your child's gender: _____

6.   Your child's race/ethnicity: _____

7.   Your child's diagnosis (e.g., autism, Asperger's, PDD-NOS): _____

8.   Your relationship to your child (e.g., mother, stepfather, etc.): _____

9.   Total number of children in the family: _____

10.   Your age: _____

11.   Your gender: _____

12.   Your race/ethnicity: _____

13.   Your religious affiliation (if any): _____

14.   Your occupation: _____

15.   Your highest level of education achieved: _____

16.   Your combined annual household income (please check one): ____Up to $25,000

____$25,000 - $49,999 ____ $50,000 - $74,999 ____ $75,000 - $99,999 ____ More

than $100,000

17.   How many years have you been married to/in a committed relationship with your

partner? _____

18.   Have you ever been married previously? If so, how many times? _____

19.   How did you hear about this study? _____

Appendix B: Formal Interview Guide

1. What does the idea of intimacy for your marriage/partnership mean to you in the context of raising a child with ASD? What do you think this idea means to your partner?

2. Tell me about a time, since taking on the responsibility of caring for a child on the autism spectrum, when you felt especially close to your partner. How did you find this level of closeness?

3. Tell me about a time you felt particularly distant from your partner, due to the responsibilities related to caring for a child with ASD. How did this distance occur? What did you do about it?

4. Imagine you have had a particularly trying day with your son/daughter on the autism spectrum, but are scheduled to go out later that evening on the first date you have had with your spouse/partner in a long time. What do you do? Why?

5. If I were to interview your closest friend/family member about your marriage/ partnership, what would they tell me about how well you manage issues of intimacy (i.e., commitment and closeness) in your relationship in light of raising a child on the autism spectrum?

6. Now pretend I was to ask your son/daughter with ASD about your marriage/ partnership. What would he/she tell me? What advice would he/she have for you in order to foster intimacy in your relationship? What would he/she say got in the way of your experiencing more intimacy with each other?

7. On a day-to-day basis, what outside/external factors do you notice help you to foster intimacy in your relationship with your spouse/partner? What factors hinder

this process?

8. Thinking back to when you first learned that your son/daughter had an ASD, how, if at all, have you and your spouse/partner changed the ways in which you care for your marriage/partnership? How have these changes helped/hindered your growth as a couple?

9. What would you recommend to a couple that just learned they have a child with an ASD?

10. If you were to direct a movie about a couple trying to navigate the ins and outs of their own relationship while raising a child with ASD, what would be a few of the key scenes in the film?

11. Is there anything else I need to know about how couples raising a child on the autism spectrum manage issues of intimacy in their marriages/partnerships?

Appendix C: Post-Interview Questionnaire

1. Were there any aspects of the interview you had difficulty discussing in front of your partner? Is there anything you felt you could not say in front of your partner?

2. Was there anything your partner said in the interview that surprised you?

3. Was there anything that I did not ask during the interview that you think might be important for me to know about couples raising children with autism spectrum disorders?

4. Did anything I brought up during the interview raise the need for you or your family to speak with a therapist? (If so, I have a list of counselors in the area that I can send to you.)

Appendix D: IRB Approval Letter
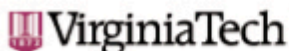
VirginiaTech

Office of Research Compliance
Institutational Review Board
North End Center, Suite 4120, Virginia Tech
300 Turner Street NW
Blacksburg, Virginia 24061
540/231-4606 Fax 540/231-0959
email irb@vt.edu
website http://www.irb.vt.edu

MEMORANDUM

DATE:	October 21, 2013
TO:	Jacob Johnson, Fred Piercy
FROM:	Virginia Tech Institutional Review Board (FWA00000572, expires April 25, 2018)
PROTOCOL TITLE:	How Couples Raising Children on the Autism Spectrum Negotiate Intimacy
IRB NUMBER:	13-874

Effective October 18, 2013, the Virginia Tech Institution Review Board (IRB) Chair, David M Moore, approved the New Application request for the above-mentioned research protocol.

This approval provides permission to begin the human subject activities outlined in the IRB-approved protocol and supporting documents.

Plans to deviate from the approved protocol and/or supporting documents must be submitted to the IRB as an amendment request and approved by the IRB prior to the implementation of any changes, regardless of how minor, except where necessary to eliminate apparent immediate hazards to the subjects. Report within 5 business days to the IRB any injuries or other unanticipated or adverse events involving risks or harms to human research subjects or others.

All investigators (listed above) are required to comply with the researcher requirements outlined at:

http://www.irb.vt.edu/pages/responsibilities.htm

(Please review responsibilities before the commencement of your research.)

PROTOCOL INFORMATION:

Approved As:	**Expedited, under 45 CFR 46.110 category(ies) 6,7**
Protocol Approval Date:	**October 18, 2013**
Protocol Expiration Date:	**October 17, 2014**
Continuing Review Due Date*:	**October 3, 2014**

*Date a Continuing Review application is due to the IRB office if human subject activities covered under this protocol, including data analysis, are to continue beyond the Protocol Expiration Date.

FEDERALLY FUNDED RESEARCH REQUIREMENTS:

Per federal regulations, 45 CFR 46.103(f), the IRB is required to compare all federally funded grant proposals/work statements to the IRB protocol(s) which cover the human research activities included in the proposal / work statement before funds are released. Note that this requirement does not apply to Exempt and Interim IRB protocols, or grants for which VT is not the primary awardee.

The table on the following page indicates whether grant proposals are related to this IRB protocol, and which of the listed proposals, if any, have been compared to this IRB protocol, if required.

Invent the Future

VIRGINIA POLYTECHNIC INSTITUTE AND STATE UNIVERSITY
An equal opportunity, affirmative action institution

Appendix E: Recruitment Flyer

Are You and Your Spouse/Partner Raising a Child with an Autism Spectrum Disorder?

If You Can Answer "YES" to this Question, We Need Your Help!

We are currently conducting interviews of how couples, like you, manage your own marriages or committed partnerships while caring for children on the autism spectrum.

Interviews will last between 60 and 90 minutes and take place either in the convenience of your own home, or another private location of your choosing. Also, *free* childcare during the time of the interview may be provided, upon request.

To express our thanks for your participation in the study, qualified couples will receive a **$20 gift card** to Target.

If you are interested in being a part of this research study, please call us at **630-752-5431** or email us at **jake.johnson@vt.edu** for more information.

Principal Investigator: Fred Piercy, Ph.D., LMFT
Department of Human Development, Virginia Tech
Phone: (540) 231-9816
Email: piercy@vt.edu

Appendix F: Screening and Recruitment Tracking Form

SCREENING & RECRUITMENT TRACKING FORM

HOW COUPLES RAISING CHILDREN ON THE AUTISM SPECTRUM NEGOTIATE INTIMACY

Investigator: Fred Piercy, Ph.D., LMFT
Co-Investigator: Jake Johnson, M.S., LMFT

Department of Human Development
Virginia Tech

PARENT/GUARDIAN #1 NAME: _____

PARENT/GUARDIAN #2 NAME: _____

NAME OF CHILD WITH ASD: _____

CHILD AGE: _____ (< 18 years old)

CHILD SEX: _____ MALE _____ FEMALE

ADDRESS: _____

_____

_____

TELEPHONE: _____

EMAIL: _____

HOW DID THE PARTICIPANTS LEARN ABOUT THE STUDY?

VERIFY THE INCLUSION CRITERIA:
(Check the box to indicate that you have verified this information with the parent/guardian.)

❑ The parent/guardian must be married or, if unwed, in a committed relationship and cohabitating.

❑ At least one of the parents/guardians must be the biological parent of, or have formally adopted, the child with an autism spectrum disorder.

❑ Both parents/guardians must have conjointly raised the child on the autism spectrum for at least two years.

❑ The child on the autism spectrum must live with the parents/guardians the majority of the time (i.e., more days than not in a given week).

❑ The child must also have an official autism spectrum disorder diagnosis made by a qualified professional in accordance with the criteria for autism, Asperger's syndrome, or PDD – NOS.

❑ The child on the autism spectrum must be under 18 years of age.

PLEASE RECORD *EVERY* CONTACT WITH THE PARTICIPANT:

DATE	NATURE OF CONTACT & ACTION NEEDED	INITIALS

PRE-INTERVIEW QUESTIONNAIRE AND FORMAL INTERVIEW SESSION:

Date: _____

Time: _____

Location: _____

POST-INTERVIEW QUESTIONNAIRE:

PARENT/GUARDIAN #1 NAME: _____

DATE RECEIVED: _____

PARENT/GUARDIAN #2 NAME: **_____**

DATE RECEIVED: _____

NOTES:

Appendix G: IRB-Approved Consent Form

VIRGINIA POLYTECHNIC INSTITUTE AND STATE UNIVERSITY

Informed Consent Form for Participants in Research Projects Involving Human Subjects

Title of Project: How Couples Raising Children on the Autism Spectrum Negotiate Intimacy

Principal Investigator:	**Co-Investigator:**
Fred Piercy, Ph.D., LMFT	Jake Johnson, M.S., AMFT
Professor, Dissertation Advisor	Doctoral Candidate
Department of Human Development	Department of Human Development
Virginia Tech	Virginia Tech

I. Purpose of this Study

This is a research study associated with the department of human development at Virginia Tech investigating how couples parenting children with autism spectrum disorders (ASDs) manage their own marriages/committed partnerships while also dealing with the stressors that come alongside caring for children with ASDs.

The purpose of this study will be to develop a theory of how couples raising children on the autism spectrum negotiate matters of intimacy in their marriages/partnerships, including any outside factors that either aid or inhibit the intimacy process. The results of this study will offer a first step toward understanding what helps keep couples together or drives them apart in the face of the stressors related to caring for children with ASDs. Additionally, the results of this study will highlight a variety of strengths and areas for growth regarding how couples raising children on the autism spectrum maintain and grow, or fail to maintain, intimacy in their relationships. Ultimately, this study's results will offer useful educational information to therapists and other mental health workers who serve the needs of couples raising children with ASDs.

About 12 couples (or 24 total individuals) caring for children on the autism spectrum will be interviewed for the purposes of this study. All of the couples interviewed for this study have been primarily responsible for raising at least one child under the age of 18 with an ASD for at least the last two years. In addition, all couples participating in this research study live in or around the tri-cities area (St. Charles, Geneva, and Batavia, IL) of suburban Chicago.

II. Procedures

You will complete a pre-interview questionnaire, a formal interview, and a post-interview questionnaire. The pre-interview questionnaire asks participants to respond to several brief questions related to demographic information. The formal interview involves a series of open-ended questions aimed at understanding the processes by which couples raising children on the autism spectrum negotiate matters of intimacy in their relationships. This includes the specific ways in which couples manage intimacy, what factors outside the couple relationship influence the intimacy process, and how this process changes over time. In the post-interview questionnaire, study participants will individually respond to questions related to that which they felt might have been left unsaid during the formal interview.

Both the pre-interview questionnaire and the formal interview will take place either in your home or in another private location of your choosing (e.g., the private office of the co-investigator of this study). The pre-interview questionnaire is a paper form that should take no more than five minutes to complete and the formal interview will take between 60 and 90 minutes, depending on the depth of the answers you provide to the interview questions. You have the option of requesting childcare during the time you and your partner are participating in the pre-interview questionnaire and the formal interview. If you do ask for childcare, the research team will make every reasonable effort to provide a safe environment while watching your child. However, in the case of an accident or other medical emergency involving your child, neither the researchers nor Virginia Tech have financial resources set aside to pay for emergency or long-term medical treatment; therefore, you would be responsible for paying for those costs.

After you have completed of the pre-interview questionnaire and the formal interview, you and your partner will each individually complete the post-interview questionnaire at a later time and location of your choosing. Once you have completed the post-interview questionnaire, you may submit your responses to the researcher either by mail (in a self-addressed, stamped envelope provided by the researcher) or by email. This questionnaire should take between five and 25 minutes to complete. After you complete the post-interview questionnaire, you are done with the study.

Before beginning any of these steps in the research process, you and your partner will give your consent (permission) to be in the study, signing one copy of this form to be kept by the investigators of the study and another that you will keep.

III. Risks
The risks of being in this study are very small. However, it is possible that certain study questions may cause you to feel sadness or anger. In addition, you may learn something about your partner during the course of participating in the study that you did not previously know about him/her and which causes you some distress.

You do not have to answer any study questions that make you feel uncomfortable and you can stop at any time, without penalty. Also, if you would like any further assistance with feelings that have come up for you while participating in this study, the researcher will provide you with contact information for mental health resources in your community. Please note that you will be solely responsible for playing any and all costs associated with seeing a mental health professional.

IV. Benefits
While we cannot promise that you will benefit from being in this study, you might learn more about yourself and your partner that may assist you in having more intimacy in your marriage/partnership. In addition, participating in this study may also create a space for you and your partner to talk about certain issues important to your relationship that you might not have otherwise discussed. Finally, the information you share may be used by researchers in the future to help other couples raising children with ASDs. You might feel good knowing that the information you provide in this study may be of future benefit to other couples in similar positions.

V. Extent of Anonymity and Confidentiality
Your participation in this study is confidential. This means that no one, except the researchers, will see or hear your responses to the pre-interview questionnaire, the formal interview, or the post-interview questionnaire.

After you finish the formal interview, the audio recording of your answers will be separated from the paper forms that have your name on them. When this happens, your interview will be assigned a code number and it will not be possible to match your name to your answers to the interview questions.
People on the research team will type out your answers to the formal interview questions. When we do this, we will take out your name, the names of your family members, or any other information that could be used to identify you. The written copy of your interview answers will also get a code number. Additionally, your responses to the post-interview questionnaire will be assigned the same code number as your typed-out answers to the formal interview questions and will any personally identifiable information removed from them.

All information from this study will be stored in locked file cabinet or password-protected computer in a locked office. Only members of the research team will be able to open the office and file cabinet and use the computer. When the study is over, the audio recording of your formal interview will be destroyed. Other forms will be kept for 5 years. After that time, they will be destroyed. We will keep your answers to the formal interview questions that we have transcribed and from which we have removed any information that could identify you as a participant in this study. Only people on the research team will be able to use this information.

We will protect your confidentiality unless we learn about current child abuse or elder abuse. If we do learn of any instances of emotional, physical, or sexual abuse, we must provide this information to the appropriate government authorities. Also, if we think you are a threat to cause harm to yourself or someone else, we must tell the proper authorities. These are the only times when your confidentiality would not be protected.

Finally, it is possible that the Institutional Review Board (IRB) may view this study's collected data for auditing purposes. The IRB is responsible for the oversight of the protection of human subjects involved in research.

VI. Compensation
While it is not possible to fully repay participants for their time and effort, as a small token of appreciation for helping with the study, participant couples will receive one $20 Target gift card. Upon receipt of the gift card, participants will be asked to sign a form indicating they have, in fact, received the card.

VII. Freedom to Withdraw
You are free to withdraw from the study at any time. There will be no penalty for choosing to end participation in the study, and you will still receive the $20 Target gift card if you decide to stop being in the study. In addition, you may choose to refrain from answering any question asked of you, whether in the pre-interview questionnaire, the formal interview, or the post-interview questionnaire. There is no penalty for deciding not to answer any particular question.

VIII. Subject's Responsibilities
I voluntarily agree to participate in this study. I have the following responsibilities:

1. To allow my responses to the pre-interview questionnaire, the formal interview, and the post-interview questionnaire to be used for the purposes of this research project.
2. To permit the disclosure of my identity to the researcher with the understanding that my identity will remain confidential in any professional publications or presentations derived from this study.
3. To let the researcher contact me after having completed the pre-interview questionnaire, the formal interview, and the post-interview questionnaire if there are any discrepancies in the data that require further clarification.
4. If I choose to make use of the childcare provided by the research team, to understand the limitations of the liability of both the researchers of this study and Virginia Tech in the event that my child is injured while under the care of a member of the research team.
5. To inform the researcher as to any other questions or concerns I may have related to being in this study.

IX. Subject's Permission
I have read and understand this consent form and the conditions of this project. I have had all my questions answered. I hereby acknowledge the above and give my voluntary consent:

_____   _____
Subject Signature   Date

_____   _____
Subject Signature   Date

Should I have any pertinent questions about this research, I may contact:

Fred Piercy, Ph.D.   Jake Johnson, M.S.
Principal Investigator   Co-Investigator
540-231-9816   630-752-5431
piercy@vt.edu   jake.johnson@vt.edu

If I should have any questions about the protection of human research participants regarding this study, I may contact:

Dr. David Moore
Chair, Virginia Tech Institutional Review Board for the Protection of Human Subjects
(540) 231-4991
moored@vt.edu

Appendix H: Receipt of Compensation Form

RECEIPT OF COMPENSATION

HOW COUPLES RAISING CHILDREN ON THE AUTISM SPECTRUM NEGOTIATE INTIMACY

Investigator: Fred Piercy, Ph.D., LMFT
Co-Investigator: Jake Johnson, M.S., LMFT

Department of Human Development
Virginia Tech

I, the undersigned, acknowledge receipt of compensation in the amount of **one $20 Target Gift Card** for my time as a participant in the above research study.

_____   _____
Participant #1 Signature   Date

_____
Participant #1 Name (PRINTED)

_____   _____
Participant #2 Signature   Date

_____
Participant #2 Name (PRINTED)

_____   _____
Researcher's Signature   Date

Appendix I: Reflexive Field Note Example

Interview 001
11/8/13

As this was my first interview conducted for my dissertation, I found myself quite nervous upon entering the home of my participant couple. A part of me felt frozen by my "imposter syndrome," as that old refrain about my being to dumb and unsophisticated to be in a doctoral program in the first place echoed in my head. I was also unsure of how things would go over with the couple, and if I'm honest, I was also a bit fearful of meeting the husband, who was the head of the SWAT team for the local police force.

The couple was nice enough, but I quickly realized that jumping into the formal interview with the question "What does marriage mean to you in the context of raising a child with autism?" was a bad idea. Both partners seemed a bit taken aback by this, I think because I did not first "prime the pump" with something less intrusive to start the interview process—I'll have to remember to start off slower in my future interviews.

Nonetheless, the couple was warm and very forthcoming with me about very sensitive aspects of their relationship. Despite their warmth, I also found myself feeling frustrated with the fact that the wife kept asking me to rephrase my questions and seemed to have a really hard time understanding what I was asking of her. I didn't think my questions were too difficult to understand, and did not get why she couldn't follow them. I was also thrown off a few times when the couple's son with autism would enter the room, grab his mom, and carry her away into the other room, leaving his father and I to make small talk until she returned. I guess that is life with a child on the autism spectrum. I don't know why I should expect anything different when conducting these interviews in families' homes.

Another point worth mentioning is the fact that I actually observed this couple actively "negotiating" their relationship during the interview. They, on more than one occasion, discussed and questioned one another on different topics related to the interview questions. They also held each other's hands during emotional moments in the conversation, which left me feeling hopeful for their future despite the difficulties they had reported facing as a couple as a result of caring for a child with ASD.

Also, at the end of the interview, both partners shared with me that they felt that it had been helpful to have such an in-depth conversation of their relationship as related to parenting a child on the autism spectrum. The MFT in me was glad to hear this news and I left heartened by the couple's reminder to me that my work is and can be important to a great number of couples raising children with ASDs.

I wonder how my future interviews will compare to this first one…

Appendix J: Theoretical Memo Example

February 14th, 2014

In continuing on with the axial coding process, the team and I have hit an impasse with regard to the emergent category of "Developing a Heightened Awareness of and Appreciation for Each Partner's Contributions and Needs." Namely, we are wondering if we are trying to pack far too much information into one place. We are also questioning if awareness and appreciation really even fit together, given the fact that awareness seems to be more of an emotional state and appreciation an action to be taken. However, in considering the possibility of splitting this category into two discrete parts, we also feel as if 1) there is not enough data to justify the split and 2) we are not certain that creating a category around awareness and another around appreciation will actually even be all that discrete. The team and I also wondered if we needed to distinguish between each partner's contributions and each partner's relational needs. Again, we felt uncertain of how best to proceed given the fact that if we divide the category further we risk losing a sense of data saturation.

After debating these matters for some time, I challenged the team to think about keeping this category as is, especially if we could justify the conglomeration of the development of a heightened awareness of and appreciation for each partner's contributions and needs under the larger umbrella of empathy. I was curious to know if this also made sense to the rest of the team, especially given the fact that the conceptual definition of intimacy being used for this study includes a component that directly speaks to empathy between partners as an experience of intimacy.

Appendix K: Methodological Memo Example

January 30th, 2014

Breaking down 895 open coding codes/indicators is proving to be a daunting task. The initial plan was to comb through all of the codes to look for any duplicate codes (or codes that were essentially conveying the same idea) and combine them and to also delete any other codes that at the end of the day did not relate to any of the three research questions guiding this study. However, this process proved to be too cumbersome and so I decided to take a different tack. Now, the research team and I will be looking to lump codes under broad umbrella headings such as "communication" and "couple time" and "conflict." After placing each of the 895 open coding codes into one (or more) of these larger headings it will be much easier to go back and cluster the codes into more manageable chunks of data before moving on to axial coding and the creation of categories and subcategories of information related to how couples raising children with ASDs negotiate intimacy. This process, I think, will be much like the creation of "tree nodes" in NVivo, in which you gather individual pieces of data into a "set" of information.

Appendix L: Data Saturation Matrix

Major Finding	Interview Data Source											
	001	002	003	004	005	006	007	008	009	010	011	012
Category 1: Making necessary cognitive shifts together												
Time together as a couple	X	X	X	X	X	X	X	X	X	X	X	X
Child's impact on the couple relationship	X	X	X	X	X	X	X	X	X	X	X	X
Childcare challenges	X	X	X	X	X	X	X	X	X	X	X	X
Category 2: Consciously working as a team												
Sharing childcare workload	X	X	X	X	X	X	X	X	X	X	X	X
Taking "me time"	X	X	X	X	X	X	X	X	X	X	X	X
ASD education and advocacy		X	X	X	X	X	X	X	X	X	X	X
Category 3: Practicing enhanced communication												
Hearing and being heard	X	X	X	X	X	X	X	X	X	X	X	X
Finding ways to effectively communicate with partner	X	X	X	X	X	X	X	X	X	X	X	X
Resolving conflict together	X	X	X	X	X	X	X	X	X	X	X	X
Category 4: Overcoming unique barriers to couple time												
Creatively carving out time together	X	X	X	X	X	X	X	X	X	X	X	X
Locating quality childcare help	X	X	X	X	X	X	X	X	X	X	X	X
Category 5: Demonstrating heightened sensibility toward partner												
Empathizing with partner's experiences	X	X	X	X	X	X	X	X	X	X	X	X
Appreciating partner's contributions	X	X	X	X	X	X	X	X	X	X	X	X

Appendix M: Participant Biographical Profiles

Couple 001: Tricia and Leo

Tricia is a 44-year-old stay-at-home mom and also a part-time freelance writer. Leo is a 43-year-old police officer who is also the head of his precinct's swat force. The couple, both Caucasian, live in a nice, well-kept suburban home with their two boys, the younger of whom is a 9-year old with PDD-NOS. They have been together as a couple for 20 years and have lived in the same home since before their 14-year-old son was born. Tricia presents as very emotional while Leo presents as rather stolid. The couple hold hands throughout the interview process, but also appear at times to be unsure of the state of their marriage or the degree to which they are actually able to foster intimacy in their relationship. Nonetheless, they are eager to participate in my study and strive hard to understand my interview questions. Part of me wonders if they are trying to give the "right" answers to my questions. They state several times that they hope that their participation in my research project will be of help to other couples raising children on the autism spectrum.

Couple 002: Megan and Matt

Megan is a 43-year-old part-time instructional aide to special needs children. Matt, 44, works in insurance. Both partners are Caucasian and have masters degrees. They have been together for 16 years and have three children, the youngest of which (a 9-year-old boy) has PDD-NOS. The family lives in a very nice home in a wealthy Chicago suburb. Despite having a child on the autism spectrum, they seem like the perfect suburban American family. Throughout the interview, I am surprised how much Megan and Matt are on the same page about every area of strength and weakness in their attempts to find intimacy in their marriage. Both partners also repeatedly mention the fact that they do not look at their son with PDD-NOS as any different than either of their other children. I find myself wishing that I could be as kind, giving, patient, and selfless as both partners present themselves as being.

Couple 003: Pam and Ben

Pam is a 47-year-old Hispanic social worker with two masters degrees who serves families of children with developmental disabilities. Ben is a 56-year-old Caucasian computer engineer with no advanced degree work. Pam has been married once previously and Ben was never in any long-term relationship prior to meeting Pam. The couple, who have been together for 17 years, live in a middle-class subdivision on the very edge of suburbia, where farmland meets townhomes. Their only child in their 12-year-old boy with PDD-NOS. Near the beginning of my interview, I am surprised to hear Pam report that she thinks her husband is somewhere on the autism spectrum (although this is a thought that I had also entertained). I am more surprised to hear Ben agree with Pam's statement. I also notice that the couple couldn't be sitting farther apart from one another in their living room. However, this seems to coincide with the fact that both partners report their lives to revolve around their son and that this has come at the detriment of

their marital relationship. I leave the interview without having much hope for this couple to be able to find ways to draw closer to one another after years spent drifting apart focusing on the care of their child.

Couple 004: Erin and Nathan

Erin is a 40-year-old stay-at-home mom and Nathan is a 37-year-old consulting actuary. Both are Caucasian. The couple have been together 16 years (13 as a married couple) and have a 13-year-old daughter and a 10-year-old son with autism. They live in a rather modest, if not a bit messy, home. During the interview, I find it hard to get a word in edgewise with Erin, let alone create a space for Nathan to share his thoughts as well. I also find it difficulty to keep the couple, and Erin especially, on track as at various times both partners seem more inclined to talk about parenting a child with autism as opposed to discussing what it is like trying to foster intimacy as a couple raising a child on the autism spectrum. Moreover, I wonder to myself if Erin wants me to be impressed by her, as she mentions on several occasions all of the hardships she, personally, has overcome related to having a child on the spectrum; she also reminds me more than once that she has a masters degree while her husband does not. Regardless, I get the sense that Erin and Nathan have found a way to make their marriage work despite the many stressors they report facing.

Couple 005: Cindy and Tom

Cindy is a 40-year-old Asian-American who works part-time as an after school tutor while Tom is a 54-year-old Caucasian municipal worker. Tom has been married once before and has two adult children from his previous marriage. Together, Cindy and Tom have two sons, ages nine and seven, both of whom have autism. The couple has been married for 11 years and live in a subdivision on the outer edges of suburban Chicago. Their family home is rather chaotic with clothes and toys strewn about. As I interview the couple, their two boys regularly interrupt us to hug their parents and show me tricks— like how one can drink a large glass of water and then spit it all back into his cup after having positioned the cup on a table a couple of feet away. (It is really quite impressive.) At another point in the interview, Cindy and Tom's older and more heavy-set son jumps on my back and squeezes me as hard as he can. The couple laugh together and tell me that this is the way their son shows affection. It is clear to me that Cindy and Tom have found good ways to remain close and connected to one another despite the often hectic environs in which they live.

Couple 006: Samantha and Robert

Samantha is a 43-year-old Caucasian stay-at-home mom who also homeschools the couple's five children. Robert is a 52-year-old Caucasian retail sales worker who also has cerebral palsy. Although Robert does not use a wheelchair, he has difficulty ambulating and making use of his fine motor skills. His speech is also rather delayed, though comprehensible with some effort. The couple have been together for 13 years and live in a run-down townhome in a lower-class suburb of Chicago. I have no idea where all seven

family members fit, especially given the omnipresence of the family's giant Labrador and the fact that the front room of the family home is dedicated to the care and tutelage of the couple's 8-year-old son with autism. I notice that Samantha is always interrupting Robert. I wonder if this is a reaction to years of having to wait for him to slowly labor through his speech. I fairly consistently have to redirect the couple to talk about couplehood as opposed to best practices in parenting a child with autism. I walk away from the interview with the sense that the couple never fully grasped what I was asking them to comment on.

Couple 007: Laura and Todd

Laura, 44, and Todd, 43 are both employees of the college at which I work (Laura as a part-time fundraiser and Todd as an athletic trainer). Therefore, we all agree to meet in my office for the interview. Both partners are Caucasian and have been together for 20 years. They have three children, the middle of whom is a 15-year-old boy with autism. Both Laura and Todd understand the focus of the interview and speak openly and honestly about what it is like to try to foster intimacy as a couple with a child on the autism spectrum. They also give many real-life examples to paint a picture of what their marriage looks like (the good, the bad, and the ugly) in the context of caring for a child with autism. Throughout out conversation, I notice the couple holding hands, and actively affirming one another's points of view. After the interview is over, I find myself wishing that every other interview I conducted could be as seamless as this one.

Couple 008: Carla and Derek

Carla is a 56-year-old stay-at-home mom and Derek is a 57-year-old auto mechanic. Both partners are Caucasian. We meet in the reception area of the couple's church as Carla reports the couple has company in town and that the couple's house is too crowded to meet there. Carla is very chatty and Derek is a little bit more reticent to speak. However, he begins to warm up after a few minutes of conversation about local sports teams. The couple share with me that they raised two children, now adults, before they felt "called by God" to adopt another child. They had no idea when they took custody of their now 14-year-old mixed race (Filipino and African American) son when he was just a newborn that he had any type of developmental delay. The couple offer some very interesting insights as they compare and contrast their first round of parenting children who are typically-abled versus their second round of parenting with a son who has autism. It seems that the couple's shared religious beliefs are a large factor in how they have been able to find even a modicum of intimacy in their relationship, given the many difficult situations they have experienced as a result of having a child on the autism spectrum.

Couple 009: Harper and Wes

Harper is a 46-year-old stay-at-home mom and Erik is a 43-year-old software engineer. Both Harper and Wes are Caucasian and both have masters degrees. At the couple's request, we meet at the coffee bar area of the couple's church, as Harper reports the couple's home to be too messy to host me. Harper presents as very anxious and at times

seems to be over-sharing about her past experiences of sexual abuse. By contrast, Wes seems somewhat distant and aloof, although he also reports that he is just getting over a cold. The couple, who have been married for 13 years, have one child, a 7-year-old boy with autism. Although there are moments in the interview when Wes and Harper offer up some very good thoughts regarding what it means to negotiate intimacy in the context of raising a child with autism, there are many other instances when they follow tangents regarding medical treatments for autism, the health concerns of their son, and the true etiology of ASDs. It feels to me as if having a child with autism has railroaded this couple's marriage and that they have not yet found, and may not ever find, ways to become closer and more connected to one another.

Couple 010: Kristen and Jared

Kristen, 46, is a Caucasian stay-at-home mom. Jared, 51, and also Caucasian, is currently unemployed. The couple, who have been together for 20 years, have three children—two boys and a girl. The elder boy, 15, has Asperger syndrome, and the younger boy, 13, has autism. The family live if a ramshackle home in a small farming community 20 miles west of the nearest Chicago suburb. Upon my arrival at Kristen and Jared's house, I notice next to the front door a discarded Thanksgiving turkey carcass rotting under some snow in the front lawn. I try to not let this sight be the basis upon which I judge the couple. During the interview, I noted that Jared is better able to focus on discussing issues of intimacy in the couple's relationship than Kristen is, as she tends to want to discuss parenting issues as opposed to marital ones. As the interview progresses, I also feel more and more like the couple is in a very fragile place. Both Kristen and Jared have each been hospitalized on different occasions during the past several months for mental health concerns. They discuss how the overwhelming stressors of caring for two children on the autism spectrum can get the better of them from time to time and really negatively impact their ability to find intimacy as a couple. I leave the family hope really hoping that they follow up on my suggestion to see a couple therapist to get some additional help for their relationship.

Couple 011: Ashley and Mark

Ashley and Mark are a Caucasian couple who have been married for 18 years and who are both 42 years of age. Ashley is a stay-at-home mom, but a Lutheran minister by trade. In her words, she cannot work or drive because of the grand mal seizures that accompany her epilepsy diagnosis. Mark is an account who also has a bipolar disorder. I meet the couple at my office, as they report this is more convenient for them than meeting at their home. Ashley is very talkative and sometimes talks over, or for, Mark. Conversely, Mark is quiet and when he does speak, I have some difficulty understanding him as he talks very quickly and tends to slur his speech. Neither partner seems to understand the focus of the interview is intimacy negotiation and not parenting concerns, despite my attempts to refocus the conversation. At the end of the interview, I am not sure how much of the dialogue will be helpful in developing a theory of how couples raising children with ASDs negotiate intimacy.

Couple 012: Fran and Ted

Fran is a 54-year-old counselor and Ted is a 58-year-old non-profit recruiter. They are both Caucasian and have been married for 32 years. They live in a modest and clean home with their 17-year-old son with autism—they have already launched their other four children. I note how both partners take their time in formulating their responses to my questions. Part of me appreciates their thoughtfulness, but another part wonders if they are trying to find answers that are more socially acceptable than others. Regardless, the couple were also clearly actively interacting with one another throughout the interview process, often working together to craft their responses about how they negotiated, or failed to negotiate, intimacy in their marriage. It seems to me that they are just now coming up for air after a decade or more of just barely hanging on as a couple, given the many stressors related to raising a son with autism.

Appendix N: Participant Demographic Information

Parent Characteristics and Context Variables

Characteristic	N	%
Age		
35 to 39 years	1	4.2
40 to 44 years	12	50.0
45 to 49 years	3	12.5
50 to 54 years	4	14.6
55 to 59 years	4	14.6
Race/Ethnicity		
Asian	2	8.3
Caucasian	21	87.5
Hispanic	1	4.2
Highest Level of Education		
High School	3	12.5
Some College	3	12.5
College	7	29.2
Some Graduate School	1	4.2
Graduate School	10	41.7
Years Together with Partner (Per Couple)		
0 to 10 years	0	--
11 to 15 years	4	33.3
16 to 20 years	6	50.0
21 to 25 years	0	--
26 to 30 years	0	--
31 to 35 years	2	16.7
Annual Household Income (Per Couple)		
Up to $25,000	1	8.3
$25,000 to $49,999	2	16.7
$50,000 to $74,999	4	33.3
$75,000 to $99,999	0	--
More than $100,000	5	41.7

Child Characteristics and Context Variables

Characteristic	N	%
Age		
6 to 8 years	3	21.4
9 to 11 years	4	28.6
12 to 14 years	4	28.6
15 to 17 years	3	21.4
Race/Ethnicity		
Asian	2	14.3
Caucasian	10	71.4
Hispanic	1	7.1
Mixed Race	1	7.1
Diagnosis		
Autism	10	71.4
Asperger Syndrome	1	7.1
PDD-NOS	3	21.4