PARENTS IN RELATIONSHIPS WITH THEIR CHILDREN WITH AUTISM:

A QUALITATIVE STUDY

by

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STATEMENT OF DISSERTATION APPROVAL

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ABSTRACT

Research suggests that the social and communication deficits associated with autism make it difficult for affected individuals to participate in relationships. In light of this research, I sought to explore how parents perceive and experience their relationships with their children with autism. Specifically, I sought to understand parent perceptions of how they create and sustain relationships with their affected children, and how those relationships grow and change over time.

This research was guided by developmental theories that suggest human development occurs through social interaction. Using this perspective as a conceptual framework, I conducted in-depth interviews with 34 individuals, including 24 mothers, 9 fathers and 1 grandmother. I analyzed the data using interpretative, phenomenological methods. The preliminary findings were critically reviewed by participants to increase the validity of the analysis.

Five themes emerged from this study: 1) parent perceptions of early bonding and attachment ranged from “highly unusual” to “unremarkable and normal”; 2) an overwhelming majority of parents described their relationships as non-reciprocal; 3) a large majority of parents identified significant barriers to creating relationships with their children; 4) parent strategies for creating connections with their children ranged from very limited to successful and well-established; and 5) an overwhelming majority of parents described their relationships as “growing and changing” over time, although they recognized they would remain their children’s caretaker. From a synthesis of these themes, an overall finding emerged that a majority of parents in this study described having relationships that were close and satisfying, despite the numerous challenges of having a child with autism.

Findings from this study can be used to support families affected by autism and to enrich the education of professionals who work with them. It may also serve as a guide to explore how relationship development between parents and their children with disabilities differs from relationship development between parents and their typically developing children.

For my boys – Rick, Finn and Keene

“Do not fear.”

--Emily Thurber

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ACKNOWLEDGEMENTS

This dissertation is a tribute to the families who invited me into their lives to listen to the stories of their joys and sorrows in their relationships with their children with autism. Because of their candid insights, I know more today about love, perseverance and parenting than I did before I began this project. This work is also a tribute to all the teachers and mentors I have had through the years who have helped shape how I write, how I think and what I believe, especially Christina Gringeri, Brad Lundahl, Alan Fogel, David Derezotes, Rosey Hunter and Joel Millard. I owe much as well to friends and colleagues who have supported me through the years with whatever I might have needed at the time, including advice, support, perspective and encouragement, especially my dear friend, Rita Mangum, to whom I also give absolute credit for getting my dissertation through the thesis editor. I am indebted to the friendship and working relationship that evolved with Holly Godsey, a colleague who was also striving to complete her dissertation. Our regular “work dates” provided the structure and nurturance for both of us to complete our work. I thank my family, especially my parents, who have never stopped believing in me, and my sister, Emily, who invented the phrase “Do Not Fear” to get me through the inevitable self doubt that plagues a writer. Finally, I thank my very dear, very patient and immeasurably generous spouse, Rick Golden, who could not have been a more perfect partner with whom to travel this journey.

CHAPTER I

INTRODUCTION

This study is a qualitative exploration of parent perceptions and experiences in their relationships with their children diagnosed with autism spectrum disorders (ASD). The study illuminates how parents create and sustain relationships with their children who have been diagnosed with a disorder that impairs participation in social relationships. Findings from this study can be used by mental health and education providers who support and provide treatment to families who are affected by autism. Findings can also inform developmental theories by providing insight on how relationship development progresses between children with disabilities and their parents in contrast to typically developing children and their parents.

Using qualitative methods, I conducted in-depth interviews with a purposeful sample of 34 parents who had a child (or children) who had been diagnosed with an ASD. I completed all data collection and analysis. Preliminary findings were reviewed by a subset of my research participants to increase validity. Five important themes emerged from this study: 1) parent perceptions of early bonding ranged from “highly unusual” to “unremarkable and normal”; 2) an overwhelming majority of parents described their relationships as nonreciprocal; 3) a large majority of parents identified significant barriers to creating relationships with their children; 4) parent strategies for creating connections with their children ranged from very limited to successful and well-established; and 5) an overwhelming majority of parents described their relationships as “growing and changing” over time, although they were aware they would remain their children’s caretaker. An overarching finding was that a majority of parents had meaningful avenues for connecting with their children and perceived and experienced their relationships as close and satisfying, despite the challenges of raising a child with autism.

This chapter begins with an overview of the context and background that situates my study. Next, the problem statement, the statement of purpose, and my specific research questions are presented. I also introduce my research approach and personal interest in conducting the study. The chapter closes with a discussion of the significance of this study. In order to streamline language, henceforth all references to “parents” will refer to “parents of a child with an ASD”. If I am referring to parents of typically developing children, I will note this, or it will be evident from the context. While I have chosen to use the word “parent” to describe my participants, this category includes one grandmother who participated in the study. In addition, I will use the words autism and ASDs interchangeably, unless referring to a specific child’s diagnosis.

Background and Context

Autism has been described as a neurobiologically based, developmental disorder with current prevalence estimates as high as 1 in 100 children (Knapp, Romeo & Beecham, 2007). First described by Leo Kanner in Baltimore in 1943, and 1 year later by Hans Asperger in Vienna, autism's hallmark feature is impairment in social relatedness. Both Kanner and Asperger described this cardinal feature as "aloneness."

In 1943, psychiatrist Leo Kanner interviewed a number of young, Caucasian boys who appeared to have a constellation of symptoms and behaviors not yet identified as a specific syndrome. According to Kanner, the most striking symptoms were the boys' lack of interest in other human beings coupled with an obsessive interest in objects. Observations revealed these boys seemed oblivious to the presence of adults. They were intrigued by seemingly unimportant details of their environment, such as a pencil being used during the interview, the legs of the table and chairs, or perhaps the doorknob. As if "lost in their own world," it took a great deal of effort for interviewers to capture and focus the boys' attention onto subjects expected to be relevant for typically developing children.

The parents of these boys wrote lengthy diaries about experiences with their children. They remarked on their children's aloofness, disinterest in people, strange obsessions with select objects and the pursuit of odd preoccupations like spinning the wheels of a stroller turned onto its side or lining up toy trains rather than rolling them around a track. These parents knew their sons' behaviors and their parent-child relationships were not typical, yet they did not understand their children's condition or how to help.

Kanner labeled this constellation of symptoms “autism” – from the Greek, “alone.” Since his initial paper (Kanner, 1943), interest in and understanding of autism has exploded. In fact, autism in the 21st century is now considered an “epidemic,” with estimated prevalence at 1 in 100 (Knapp, Romeo & Beecham, 2007). Our current understanding is that autism is a spectrum disorder, such that one may fall along a continuum of severity with differing symptom constellations.

Based on available research, autism does not appear to be a culturally relative condition (Berry, Poortinga, Segall & Dasen, 1992) but rather a universal psychiatric disorder found in cultures worldwide (Daley, 2002). Such is the case because autism is understood to be a predominantly biological disorder (Shaked & Bilu, 2006). Autism experts have asserted, “There is no other developmental or psychiatric disorder of children for which such well-grounded and internationally accepted diagnostic criteria exist” (Cohen & Volkmar, 1997, p. 947). Despite its universality, the expression, course, treatment and impact of autism on families remains susceptible to a degree of cultural influence (Daley, 2002).

According to the CDC research on autism in Utah (2002), there are approximately 7.5 individuals per 1,000 who have been diagnosed with an autism spectrum disorder. In Utah, autism occurs in boys over six times more frequently than girls, with boys at 12.7 per 1,000 and girls at 2.0 per 1,000. Unfortunately, the etiology of autism remains unknown and treatments, while numerous, are effective in 50% or less of cases (Goin-Kochel, Mackintosh & Myers, 2009; Goldstein, 2002; Parikh, Kolevzon & Hollander, 2008). Of the 50% who progress with treatment, the gains often appeared to be limited to a child completing their formal education but not extending to independent living once the child is done with formal schooling (Gutstein, 2005/2007).

Much of the initial research on autism was on the individual affected by the disorder and its etiology, course and treatment. More recently, researchers have focused on how parents and other caregivers are affected by having a child with an ASD. Studies examining the impact on caregivers tend to be quantitative with findings falling broadly into six categories: 1) positive and negative impact of having a child with autism; 2) parents as both providers and consumers of treatment interventions; 3) parental coping strategies; 4) heritability of the disorder; 5) parent perceptions of the child; and 6) nonheritable risk factors, such as age of parent at child's conception.

Because autism is a disorder in relating, understanding how a parent relates to a child on the spectrum is important. Even with typically developing children, parent child relationship development is a rich and complex undertaking (Lollis & Kuczynski, 1997; Maccoby & Martin, 1983). Once a child is affected by social relatedness challenges, it may be that the parenting experience becomes different and more difficult than when raising a typically developing child (Bristol & Schopler, 1984; Hastings & Johnson, 2001). A number of questions arise: How does a parent approach a child who is socially unengaged? How does a parent read the signals of a child who communicates atypically? Without a well-established relational foundation, how do parents become a guide and mentor to their child? Does the experience of love and connection differ for parents in these circumstances?

The psychiatrist Donald Cohen interviewed a young man with autism about his memories of childhood relationships. According to the young man, “I really didn’t know there were people until I was seven years old. I then suddenly realized that there were people. But not like you do. I still have to remind myself that there are people. I never could have a friend. I really don’t know what to do with other people” (Cohen, 1980, p. 388). The question that drives this study is, what would the young man’s parents have said about their experience relating to their son? What was it like to live with a child who “didn’t even know there were people” until he was 7 years old?

Williams (2004) conducted an interpretative phenomenological analysis of the autobiographical writings of 10 adults diagnosed with an ASD. His research suggests that adults with autism experience feelings of distance from other people. The social and emotional cues necessary for interaction seem inaccessible to them. They reported they had to develop explicit coping strategies to negotiate the interpersonal interactions that come more easily and naturally to individuals without an ASD diagnosis.

Given the interpersonal difficulties described by adults with autism, it is possible that parents have similar difficulties relating to their child with an ASD. The adult with autism who describes himself as an “alien from outer space in need of an orientation manual” (Sinclair, 1992, p. 300), may once have been the “alien” child of a confused and disoriented parent, also in need of some kind of interpretative guide to make sense of a child whose behaviors and emotions were socially, culturally and developmentally unrecognizable. Parent autobiographies and memoirs describe these kinds of experiences for parents, but research data on this topic are limited.

Problem Statement

Research suggests that the social and communication impairments of children with autism create difficulty and psychological distress for parents. These impairments appear to make it difficult for parents to establish normative parent child bonds between themselves and their children. There is little research, however, exploring how parents overcome the difficulties of the social relatedness impairments, to create and sustain relationships with their children.

Statement of Purpose and Research Questions

The purpose of this study was to investigate how parents experience and participate in their relationships with their children. I examined how the social relatedness impairments of autism affected interactions, and how parents overcame challenges to forge close and satisfying relationships. To address the purpose of this study, I posited the following three research questions:

1. How do parents perceive and experience the nature and quality of their relationship with their children?

2. What are parents’ perceptions of how they develop and sustain relationships with their children?
3. What are parents’ perceptions of how their relationships with their children grow and change over time?

Research Approach

To explore parent experiences, I chose qualitative methods. I conducted in-depth, semistructured interviews with 34 participants. I personally conducted the interviews, transcribed the audiotapes, and analyzed the data using an analytic procedure outlined by Marshall and Rossman (2006). I asked participants to examine my preliminary findings, and ensuing conversations helped sharpen the findings to produce better representations of parents’ experiences and perceptions.

Qualitative methods suited this study for two reasons. First, few studies have investigated how parents develop relationships with their children with ASDs. It is appropriate to use qualitative methods when areas of inquiry are fairly new and when developing testable hypotheses would be premature (Marshall & Rossman, 2006). Second, qualitative data collection methods allowed me to explore a wide array of responses from parents, including emotions, thought processes, reactions, beliefs, biases and preferences. The conversational style of personal interviews gave me greater access to these multiple areas which could be unwieldy to tap into using traditional survey instruments (Strauss & Corbin, 1998).

Researcher Perspective

I came to this topic by way of personal experience, being the parent of a child who was diagnosed with an autism spectrum disorder very early in life. I spent a lot of time reflecting on my own experience, and often wondered what it was like for other parents. My personal experience and continued reflections were the foundation of this research.

I used the practice of bracketing to keep my own experiences separate from my understanding of the parents I interviewed (see Chapter III). By bracketing my perspective, I could listen more clearly to parents who had experiences that were different from mine. I kept a reflections journal during the research process guided by the reflexivity outline presented in APPENDIX A.

Significance of the Research

Helping Parents

Foremost, I hope the findings from this study will benefit parents. The process of relating to a child with autism is complex. My goal is to share diverse stories that parents can read or listen to. I hope they can find themselves somewhere in those stories, and find comfort if needed as witnesses to other’s experiences. I want these findings to be accessible to all parents, regardless of gender, culture or socioeconomic status.

Informing Professionals

Second, I believe the findings will benefit professionals in fields such as social work, psychiatry, developmental medicine, mental health and education who work with children with ASDs and their families. Deeper understanding of the personal and private experience of parents with an emphasis on the diversity of experience will help professionals be more effective in their work.

Contributing to the Literature

The findings in this study will contribute to the now anemic literature in this area. At present relatively little is known about parents' perceptions of how they create and sustain relationships with their children and the levels of closeness and satisfaction they experience in those relationships.

Guiding Theory

This research is guided by developmental theories that suggest human development occurs in the context of relationships. While early developmental theorists posited that development unfolded from a genetic blueprint, it is now more generally accepted that individuals do not develop in isolation, but rather in relation to others (Beebe & Lachman, 2002; Fogel, 1993; Stern, 1985; Tronick, 1998). Further, the development of individuals – while marked and dramatic in infants – continues throughout the lifespan. Parents evolve and develop in relation to their children, just as children are evolving and developing in relation to their parents. The findings from this study can help guide further research in this area by focusing interest on how parent child relationships between parents and disabled children develop, how they may be different and the same as normative relationships, and how those relationships can help or hinder development of both child and parent.

Summary

Research suggests the social relatedness impairments in children with autism place emotional, social, psychological and practical strain on parents across cultures. Scant research has examined how parents respond to these social relatedness impairments. Using qualitative methods, I explored this area with a sample of 34 parents who have a child diagnosed with an autism spectrum disorder. My research was informed and guided by personal experience, and has both practical and theoretical significance. The dramatic increase in the diagnosis of autism in our population over the past decade makes this an essential area of inquiry.

CHAPTER II

LITERATURE REVIEW

Overview

The purpose of this qualitative study was to explore parents' perceptions and experiences in developing and sustaining relationships with their children, given the social relatedness impairments of the autism disorder. Specifically, I explored how parents create and sustain relationships with their children when the very nature of the disorder impedes (to varying extents) the ability of the child to develop relationships. I also examined the degree to which parents feel close, connected and satisfied in these relationships. To carry out this study, I completed a critical review of current literature. As is normative in qualitative research, the literature review will be ongoing throughout the data collection, data analysis and synthesis phases of the study.

In this review, I focus first on the developmental literature to establish a context of normative parent child relationships, and how children are thought to develop through these relationships. I explore this area because I am proposing that the relationship development of parents and their children with autism diverges from this normative path. I then move to a more specific review of features of relationships between parents and their children with autism. In the final section, I explore how the literature currently describes how parents experience their relationships with their children.

To conduct this review, I used multiple sources of information, including professional journals, books, unpublished dissertations, periodicals and general internet resources. I accessed these resources through Academic Search Premier, CINAHL, Digital Dissertations, TREVOR, Family and Society Studies Worldwide, MEDLINE, PubMed, Primary Search, PsycARTICLES, the Psychology and Behavioral Sciences Collection, PsychInfo (Ebsco host), Women's Studies International and Google. While I focused primarily on the past 2 decades of research (1990-2010), I also used seminal studies from earlier decades when the information contributed to a better understanding of the literature.

I conclude the chapter with an interpretative summary describing how the literature has informed my understanding of the topic and how this understanding contributed to the unfolding of the project.

The Parent Child Relationship

In its earliest stages, the parent-child relationship can be described as a pair bond in which both participants provide the other with primary, physiological rewards – warmth, contact, food, tension release and positive endocrinal changes (Waterhouse, 1988). Very quickly, parent and child learn their partners are a source of pleasure (Hofer, 1987; Waterhouse, 1988). The pleasure is received primarily through the sensory processing systems and can be described as thermal, olfactory and tactile (Monmaney, 1987; Waterhouse, 1988).

From conception of the relationship, the partners are involved in a dynamic feedback system such that both individuals adjust, react and respond to the other communication behaviors (Fogel, 1993; Rice, Collins & Berscheild, 2000). Parent and child are interdependent and mutually influential (Fogel, 1993; Kuczynski, 2003; Lollis & Kuczynski, 1997). The process of mutual adjustment and influence is believed to be adaptive, “helping all animals survive, and it depends on both innate propensities and learned skills in the behavioral repertoire of individuals” (Waterhouse, 1988, p. 103). It has been suggested there is “no feeling or behavior in infants that is not in some way coupled with a parental feeling or behavior” (Fogel, 2000, p. 316). The parent child system is a “mutually regulated process between two people who move together, apart, and then back again” (Fogel, 2000, p. 317). To try to view or understand the relationship as a discrete interaction between separate individuals within an environment misses the idea that the relationship is a transactional system, dynamic and multidimensional (Fogel, 1993/2000; Stern, 1977).

Fogel (1993) defines the dynamic system interaction between parent and child as co-regulation: “Mutual social coordination requires that there be a continuous unfolding of individual action that is susceptible to being continuously modified by the continuously changing actions of the partner… [Co-regulation] is a social process by which individuals dynamically alter their actions with respect to the ongoing and anticipated actions of their partners” (Fogel, 1993, p. 34). He illuminates co-regulation in an example between a British mum and her 6-month-old son, Paul, who has begun to cry when his parent enters the room:

> Mother: Oh, now what’s up, hey? Oh dear, oh dear, what’s the matter? [Mom picks Paul up.]
>
> Mother: Are you thirsty, is that what it is? Do you want a drink? [She sees and picks up his bottle and offers it to him. He refuses it and continues crying.]
>
> Mother: Hungry? Are you? Do you want something to eat? No? Sleepy then, do you want to go to sleep? [She puts him in his pram but he continues to cry. She picks him up again and walks about comforting him. She stops at the window. Paul apparently looks out but continues crying. Mother tries to attract his attention and then to direct it.]
>
> Mother: Look, there’s a pussycat, can you see him? Do you know what pussycats say? Do you? They say ‘meow’ don’t they, yes, of course they do. [Paul stops crying during this speech.]
>
> Mother: There, that’s better, down you go then. [She places him back on the floor.] (Fogel, 1993, p. 16).

Fogel comments that this discourse is characterized by relative uncertainty on the part of the mother who must intuit what her son needs as he cannot yet communicate through language. Her responses vary based on the cues he gives her through crying, body language and facial expressions. The parent invests herself into the interaction with voice, expression and physical responses, all of which contribute somewhat mysteriously to Paul calming down and returning to his play. This type of exchange unfolds thousands of times between infants and their caregivers, giving rise to the child’s development and the parent’s increased understanding of the infant (Fogel, 1993).

Developmental psychologists generally accept that infants develop through social engagement with their caregivers (Hobson, 2003). Genes are believed to contribute by giving us the “equipment to benefit from social experiences” from which our emotional development and capacity to think like humans arises (Hobson, 2003).

Much observational work has been done on interactions between parents and their infant children. Trevarthen (1979) describes one such observation:

> As soon as the mother begins to talk to the baby, her movements become regular and subdued. She speaks more quietly and more gently and becomes highly attentive, spending as much time waiting and watching as speaking…In summary, mothers’ responses to two month old infants are stimulating, attentive, confirmatory, interpretative and highly supportive (Trevarthen, 1979). As long as the mother is sensitive and responsive, her actions may “dovetail in such a way with her infant such that the two behave in complete concert as if dancing together.” (Trevarthen, 1974)

Tronick and colleagues focus on the coherent nature of “episodes” that occur between parents and children during prolonged social exchanges (Tronick, 1977). An episode may begin with an initiation phase (started by either parent or child), followed by a phase of mutual orientation, then greeting, then an active period of play and dialogue, and finally a lessening of the affective engagement until the connection appears to be temporarily “broken” (Tronick, 1977). These episodes wax and wane throughout the course of the day. Particular episodes are never carried out in exactly the same way, but the nature of the episode remains cohesive and recognizable, despite small variations (Fogel, 1993).

Thousands of interactions between parent and child accumulate into a history of interactions and the capacity of both partners to anticipate future exchanges

(Fogel, Garvey, Hsu & West-Stroming, 2006; Laursen & Bukowski, 1997). It is this history in the context of a dynamic system that becomes the relationship between parent and child. The relationship is ever changing in response to developmental changes within the individuals and contextual factors (Fogel, 1993; Fogel et al., 2006). In this model, both parents and children contribute to the development of the relationship.

The parent child relationship diverges from other types of relationships in several ways (Maccoby, 2000). In the parent child relationship, the partners take on many different roles. The parent is never just “parent,” but also teacher, guide, mentor, playmate, moral guide and provider of nutrition and shelter needs (Maccoby, 2000). Accordingly, the child is student, apprentice, playmate and a mouth to feed and a body to shelter. Over time, roles may reverse, such that a child takes on parent roles, and a parent takes on the roles of a child (in old age of the parent, for example) (Maccoby, 2000; Maccoby & Martin, 1983).

The enduring quality of the relationship also sets it apart from other relationships (Collins, 2000; Maccoby, 2000). While mutual influence exists in all relationships, the mutual influence in the parent child relationship may be relatively stronger. Each person’s reactions deeply matter to the other and partners are vulnerable to each others’ pressures. Because of the intimacy and enduring nature of the relationship, there may be significantly greater cooperation and conflict depending on whether goals are shared or conflicting (Kuczynski & Hildebrandt, 1997; Maccoby, 2000; Maccoby & Martin, 1983).

For both partners, there is an inherent desire to contribute to shared feelings of closeness and pleasure (MacDonald & Carroll, 1992). Mutual enjoyment is derived from companionship, shared ideas, play and conversation. Both parent and child have a need for the relationship to be mutually rewarding (MacDonald & Carroll, 1992; Olsson & Granlund, 2003; Wilder & Granlund, 2003).

There is evidence suggesting universal processes in parent child interaction modified by local culture and custom. For example, the use of baby talk or “parentese,” while not absolutely universal, has been documented in a wide range of languages, including Arabic and Xhosa, Comanche, Warlpiri, Mandarin, Japanese, Gilyak, Bengali, Hindi, Marathi, Sinhala, French, German and Latvian (Das, 1989; Dil, 1971; Ferguson, 1964; Fernald, 1992; Kelkar, 1965; Meegaskumbura, 1980).

Similarly, there is some evidence suggesting there are culturally universal patterns of play between mothers and their 20-month old children (Cote & Bornstein, 2009). In this case, South American Latino immigrants, Japanese immigrants, and European Americans in the United States were studied. The researchers found that regardless of culture, children’s exploratory play was significantly positively related to both maternal demonstrations and solicitations of exploratory play (Cote & Bornstein, 2009).

Another developmental process believed to be universal is the acquisition of social competence (Feldman & Masalha, 2010). Regardless of culture, children must be prepared by adults and other mentors to participate in group activities, develop friendships and learn meaningful information about cultural values and practices (Mead, 1934; Rogoff, 2003; Vygotsky, 1978). While the content of the socialization process is culturally constructed, the universal necessity of the process appears to be an evolutionary adaptation (Feldman & Masalha, 2010).

In summary, parent child relationships across multiple cultures, parent and child co-exist in a dynamic, multidimensional communication system driven by physiological and psychological rewards. While the parent child relationship can be viewed as the vehicle through which a child develops, the system mutually impacts and affects the development and actions of the parent, feeding back into the parent's influence on the child, and round again. Both partners must have the ability to decipher communication cues that may appear and disappear with astonishing rapidity and that occur in multiple bands of communication. Partners learn to perceive patterns despite small, ongoing changes and variation that may "flavor" the interaction to discern the pattern's original intent or meaning.

In the rapid exchange of communication behaviors, partners learn to regulate their own internal states in order to maintain fluidity in the exchange. Infants are apprentices in the communicative exchange, but through their relationships with caregivers, build up their communication repertoire to become more fluid, self-regulated partners (Fogel, 1993; Rogoff, 1990). Each partner develops the capacity to be flexible in their roles, both in any given moment and over time. The question arises, how might this process differ when a child has a disability?

The Case of Children with Disabilities

The parent-infant emotional feedback system is said to be established within the first few months of life (Fogel, 1993; Sroufe, 1996). Parents of typically developing children help this feedback system unfold by participating in thousands of daily interactions, ranging from feedings and diaper changes to more structured games like peek-a-boo and pat-a-cake (Fogel, 1993; Gutstein, 2005). This feedback system appears to cut across cultures. Across the world in cultures in which social games are found, for example, some variant of peek-a-boo exists that shares common structural features and dynamics of the English language version (MacDonald, 1993). In the Ciskei homeland of South Africa, for example, in Xhosa (a Bantu click language), the parents chant “Uphi? Uphi? Na-a-a-a-a-n Ku (Where? Where? Here!). In Tokyo, parents chant “Inai Inai ba!” while pulling a cloth away from their face. Words and vocal melodies may differ across cultures, but the “rhythm, dynamics and shared pleasure” appear to be the same (Fernald & O’Neill, 1993, p. 259).

Parents use their infants’ facial expressions, vocalizations and gestures to fine-tune their interactions so that encounters can remain emotionally rewarding (Rogoff, 1990; Sroufe, 1996). Typically developing children, when securely attached, will use their attachment figure as a “safe haven” when distressed, and as a supporter of discovery and play in times of low distress (Bretherton & Munholland, 1999).

In a dyad between parent and a child with a disability, the communication feedback system can be altered. The disabled child may be unable to use certain behaviors that a caregiver can respond to intuitively, making it difficult for a parent to interpret the child’s communicative intent (Dunst & Wortman Lowe, 1986; Olsson, 2004;Trad, 1994). Parents of disabled children may have to change their communication style to better fit the communication of their child (Goldbart, 1994; Iacono, Carter & Hook, 1998; Mar & Sall, 1999; Olsson, 2004). Parents can use their historical interactions with their child to infer what a child might be trying to communicate (Grove, Bunning, Porter & Olsson, 1999). They might rely on more subtle cues from their children to derive meaning (Olsson, 2004; Pettersson, 2001; Wilder & Granlund, 2003).

For parents of children with disabilities, their culturally driven expectations about the type and intensity of behaviors their infants will display are not met (Fogel, 1993). Infants who are limited in their ability to use a common repertoire of behaviors to communicate are likely to confuse and frustrate their parents (Harding, 1983; Lacono et al., 1998). In turn, infants who are unable to derive meaning from normative social expressions from their parents may themselves feel confused and frustrated. Unable to read signals from one another, communication may be experienced by both parent and child as unrewarding, unproductive and distressing. In the next section, I review the autism specific literature.

Parents and Their Children with Autism

Research over the past decade has established that raising a child with autism impacts parents in global and pervasive ways (Pisula, 2003). The constellation of symptoms associated with an autism spectrum disorder appears to impact the parent child relationship, the parent’s emotional and physical self, comfort with parenting, perspective on the parenting role, and core beliefs, priorities and values, both about themselves, their family and the broader world. For parents, raising a child with autism is a life altering experience.

In individuals with autism, joint attention, enjoyment sharing, conjoint pretend play, declarative communication, social referencing and perspective taking are all examples of communication abilities found to be underdeveloped or absent (Baron-Cohen et al., 1996). Consensus has emerged suggesting autism spectrum disorders (ASDs), despite their heterogeneity, interfere with the development of emotional engagement and social relatedness (Hobson, 1993; Mundy & Crowson, 1997; Mundy, Sigman & Kasari, 1993; Trevarthen, Aitken, Papoudi & Robarts, 1996). Children with ASDs are much less able to provide clear emotional and social feedback to their parents due to a number of underlying neurobiological deficits (Gutstein, 2005).

Research has established, for example, that children with autism express less positive emotion (Kasari, Sigman, Mundy & Yirmiya, 1990; Snow, Hertzig & Shapiro, 1987); more negative and neutral emotion (Bieberich & Morgan, 1998); and they may not accurately interpret their parents’ emotional expressions

(Capps, Kasari, Yirmiya & Sigman, 1993; Dawson, Hill, Spencer & Galpert, 1990). Parents of young children with autism perceive their child as significantly less emotionally engaged and less expressive than typical peers (Wimpory, Hobson, Williams & Nash, 2000). They are less likely than typically developing children to combine smiles with eye contact, and less likely to smile in response to smiles from their parents (Charman et al.,1997). Children with autism appear to be less engaged with and affected by other people's expressions of feeling (Hobson, 1993; McGee, Feldmen & Chernin, 1991), including distress (Bacon, Fein, Morris, Waterhouse & Allen, 1998). Children with ASDs also display more atypical facial expressions of positive emotion, marked by asymmetry, reduced movements in the eye and mouth regions, shorter duration, higher lability and lower intensity (Loveland et al., 1994).

Using the Strange Situation protocol, researchers investigated whether attachment in children with autism is comparable to attachment in typically developing matched peers (De Wolff & van IJzendoorn, 1997; Rutgers, Bakermans-Kranenburg, van IJzendoorn, & van Berckelaer-Onnes, 2004). Attachment was defined as the affectional bond that infants form between themselves and their parent figure (Bowlby, 1969/1982; Cassidy & Shaver, 1999). Researchers found that attachment rates between parents and their children with autism is roughly equivalent to attachment rates between parents and their typically developing children. More specific research revealed that as the severity of autistic symptoms increases and cognitive functioning decreases, rates of attachment development are less than those of both children with high functioning autism and typically developing children (Rutgers et al., 2004).

Using the Child Domain Subscales of the Parenting Stress Index, Abidin (1995) found that parents of children with autism experience relationships that are “less close” as compared to typically developing matched peers. In the same study, based on responses on a different subscale (Attachment Subscale), the researchers conclude that parents of children with autism have relationships with their children that are “as close” as parents of neurotypical peers. The researchers suggest that the contradictory findings may be a function of social desirability in response sets on the second subscale. They also suggest parents’ guilt or denial could contribute to overstating feelings of closeness (Hoffman et al., 2009).

In qualitative works, most parents report they do not feel close to their children. They report feeling distant, constrained, limited, shut out and unacknowledged (Cashin, 2004; Cullen & Barlow, 2002; Cullen-Powell, Barlow & Cushway, 2005). They describe feeling rejected, pushed away, ignored and avoided (Escalona, Field, Singer-Strunk, Cullen & Hartshorne, 2001). They universally state the desire to increase feelings of closeness and connection, both physically and emotionally (Field et al., 1996). For parents in these studies, relationship satisfaction was low (Cashin, 2004; Hoffman et al, 2009).

In two qualitative works in which touch interventions were conducted (Cullen & Barlow, 2002; Cullen-Powell, Barlow & Cushway, 2005), researchers found they could teach parents touch and massage techniques that were well-liked by their children. All participants in both studies reported feeling closer to their children following the touch-based interventions. They reported increased satisfaction with their relationships and increased ability to relax with their children. Despite their successes, parents reported that their relationships continued to feel one-sided, with the child in control of when and where the massage was delivered. This aspect of one-sidedness is described in other literature as a lack of reciprocity or mutuality in the relationship (Cashin, 2004; Gutstein, 2007; Williams, Kendell-Scott, & Costall, 2005).

Some literature suggests that the parenting experience appears to be qualitatively different from parenting a typically developing sibling (Williams, 2003; Williams, Kendell-Scott & Costall, 2005). Parents reported their children did not rely on them to guide their learning. In learning how to use a fork and knife, parents described that their children did not watch their actions or try to imitate them. They used the utensils in idiosyncratic and nonfunctional ways, ignoring and at times actively rejecting guidance (Williams, 2003). The child with autism does not appear to be able to take advantage of socially mediated learning offered by parents, a response that is bewildering and upsetting (Lewis & Boucher,1988; Park, 1983; Williams, 2003).

Parents interact with their children with autism for shorter periods of time as compared to parents of children with other types of disabilities and parents of typically developing children (Crawley, & Spiker, 1983; Konstantareas, 1991;

Konstantareas & Homatidis, 1988/1992). This may be due to the child's tendency to actively reject, ignore or negatively respond to parental bids for interaction. Parents may spend less time in interactions that are not rewarding (Konstantareas & Homatidis, 1988/1992).

For many parents, their primary role is to obtain treatment for their child (Coultard, 2001; Tehee, Honan & Hevey, 2008). Their time may be highly structured, and limited to driving to appointments, obtaining assessments and services, and managing the myriad of treatment providers who are involved in their child's treatment (Hastings & Johnson, 2001).

In the first years after a diagnosis, parents experience a tremendous array of emotions, with negative responses generally outweighing positive ones (Dumas, Wolf, Fisman & Culligan, 1991; King et al., 2006; Williams, Kendell-Scott & Costall, 2005). Parents generally have elevated levels of depression as compared to parents of typically developing children (Carter, Martinez-Pedraza & Gray, 2009; Davis & Carter, 2008; Dumas, Wolf, Fisman & Culligan, 1991; Yirmiya & Shaked, 2005). They also report more parenting stress and psychological distress (Epstein, Saltzman-Benaiah, O'Hare, Goll & Tuck, 2008; Estes et al., 2004). These results not only hold when parents are compared to parents of typically developing children, but also when compared to parents of children with other kinds of disabilities, such as Down's Syndrome, psychiatric disorders, behavior disorders, developmental delays and chronic medical illness (Bouma & Schweitzer, 1990; Donovan, 1988; Estes et al., 2009; Hoffman et al., 2009; Sanders & Morgan, 1997). There appears to be something unique about the experience of parenting a child with autism that intensifies the difficulties (Bromley, Hare, Davison & Emerson, 2004). Researchers have offered explanation as to why this may be the case. A consensus has arisen that the social relatedness impairments of children with autism may make it uniquely difficult and emotionally painful to raise a child with autism (Davis & Carter, 2008; Dumas et al., 1991).

For most parents, feelings of loss and grief are common reactions to a diagnosis of autism in their child (Chu & Richdale, 2009; Dumas et al., 1991; Estes et al., 2009). The child they thought they had is transformed into a child who is likely to have lifelong, severe disabilities. Dreams for their child vanish, replaced by fear, anxiety and confusion (Bursnall, Kennedy, Senior & Violet, 2009; Cashin, 2004; Kanner, 1943; Trigonaki, 2002; Williams, Kendell-Scott & Costall, 2005). In the parent child relationship, parents describe longing to feel close to their child, feeling despair that they cannot be the parent they had hoped to be and feeling hurt by their child’s seeming rejection and aloofness (Bursnall et al., 2009; Cashin, 2004; Cullen-Powell, Barlow & Cushway, 2005).

Amidst the sadness, parents do report moments of joy and triumph when they are able to connect with their child (Cashin, 2004; Cullen & Barlow, 2002; Cullen-Powell, Barlow & Cushway, 2005; Trigonaki, 2002). These moments are often so infrequent as to be noteworthy.

Parents describe that parenting feels constrained and unnatural (Cullen-Powell, Barlow & Cushway, 2005). The communicative signals their children give are difficult to interpret (Cullen & Barlow, 2002; Cullen-Powell, Barlow & Cushway, 2005; Epstein et al., 2008; Olsson, 2004; Williams, Kendall-Scott & Costall, 2005). Parents report feeling out of control, and often seek advice and help outside of themselves rather than relying on parental instincts (Bursnall et al., 2009). They might need to be trained by an outside consultant to teach their child ordinary tasks of daily living (Williams, Kendell-Scott & Costall, 2005). For some parents, this leads to feelings of incompetence and reduced self-esteem (Bursnall et al., 2009).

Parents report that some of their roles are amplified. They become treatment provider, caregiver and advocate (Bursnall et al., 2009; Tehee, Honan & Hevey, 2009; Trigonaki, 2002). They may be involved in continued toilet training with an adolescent or adult child. While most children with autism will learn to feed themselves, eating can remain a difficult process. This may require extra vigilance and care on the part of the parent, even as the child enters adulthood (Bursnall et al., 2009; Gray, 1994/2006).

The advocacy role can become all consuming (Bursnall et al., 2009; Gray, 2006; Hastings et al., 2005). It is not unusual for parents to have more information about their child’s condition and treatment needs than the school system. Parents can spend inordinate amounts of time informally “training” teachers and school administrators about what is most helpful for their children

(Bursnall et al., 2009; Tehee, Honan & Hevey, 2009). Rather than being rewarded for this, they may be perceived as intrusive and over-protective (Bursnall et al., 2009). Such negative feedback can be exhausting, wearing a parent down over time (Carter, Martinez-Pedraza & Gray, 2009). While all parents play multiple roles with their children, the parent of a child with autism may feel this more intensely (Bursnall et al., 2009).

For some parents, the enormous emotional, mental and financial resources required in raising a child with autism are associated with sleep disturbance and exhaustion (Chu & Richdale, 2009). Parents describe their experiences as “relentless” – the “never ending story” (Bursnall et al., 2009, p. 94). Parents can remained depressed and stressed over time, even years after receiving a diagnosis.

For other parents, rather than a “wear and tear” effect, they appear to adapt by decreasing their expectations of their children. Parents with reduced expectations are most likely to experience reductions in stress and anxiety over time (Carter, Martinez-Pedraza & Gray, 2009). For these parents, there appear to be shifts in their belief systems and world views (King et al., 2006). They report they learn to enjoy the small moments of pleasure with their children and become more tolerant of others (King et al., 2006).

There are other cultures in which spiritual and religious views may help parents come to terms with their circumstances. In a study of orthodox mothers of children with autism living in Israel, coping mechanisms were deeply rooted in spiritual-religious frames of reference, especially as related to the transmigration of souls, reliance upon which helped the mothers better understand and accept their circumstances (Shaked & Bilu, 2006). In research on younger Latino mothers, coping was enhanced in mothers who accepted that their child is a gift from God, given to them because they have been found to be worthy of such a child. Raising the child will help them become better persons (Skinner, Bailey, Correa & Rodriguez, 1999). In Native Hawaiian culture, the spiritual orientation toward life helps parents appraise their disabled child as a normal and valued member of the community (McCubbin, McCubbin, Thompson & Thompson, 1998). In some Native American communities, a child’s functional abilities are valued over disabilities, and there are often no labels in these cultures for disabilities such as autism (Connors & Donnellan, 1998). The child is referred to by a descriptive label (e.g., “she runs away” or “he gets excited”) rather than a classification denoting pathology (Connors & Donnellan, 1998).

In some communally based cultures (e.g., Native Hawaiians, Filipino American families and Hispanic families), there appear to be strong networks of support in extended families built on cooperation and allegiance where individual desires are sacrificed for the benefit of the family (McCubbin et al., 1998). These support networks may be so strong that the use of professional services may be circumvented and the child becomes the responsibility of extended family and community (Bailey, Skinner, Rodriguez, Gut & Correa, 1999; Skinner et al., 1999). In research on African American families, professional services are accessed only after relying on family, friends and church support (Pruchno, Patrick & Burant, 1997; Rogers-Dulan & Blacher, 1995)

Although there are a growing number of cross-cultural studies, researchers must be vigilant against exaggerating cross-cultural differences and de-emphasizing within-cultural differences (Hewlett, Lamb, Shannon, Leyendecker & Scholmerich, 1998).

Summary

In neurotypical development, parent and child engage in intimate, intuitively driven, dynamic exchanges that function to further the development of both parent and child, and from which both parent and child can derive satisfaction and need fulfillment (Waterhouse, 1988). The parent child relationship is dynamic and transactional, not static or linear (Fogel, 1993). Its complexity is a function of multiple roles, the evolving development of both partners and changing contexts (Maccoby, 2000). The relationship is influenced substantially by cultural molding.

Parents of children with disabilities can be confused by non-normative communication processes by their children. They report distinct and challenging differences in their children's abilities to respond to them socially and emotionally, although their need to have the relationship be rewarding and meaningful persists (Olsson & Granlund, 2003). Regardless of their child's impairments, the relationship is still a system – a mutually regulated process between individuals – but the process is altered due to the child's disability. Over time, parents learn to identify more subtle communication signals and cues based on the history of interactions and develop altered communication to better fit their child's needs (Olsson, 2004).

In relationships with children with autism specifically, an additional burden can be the child's lack of motivation to interact. The child may appear to be without need for connection, guidance and companionship. Parents are bombarded with multiple feelings, from feelings of rejection, confusion and despair, to longings for closeness and connection (Field et al., 1996). For a child with a nonautism disability, the disability can alter communication skills, but does not necessarily decrease the motivation to relate. For a child with autism, the disability appears to not only impact the mechanical aspects of communication, but its underlying function – the creation of bonds between individuals.

The questions that arise from this predicament are numerous and form the basis of the purpose of this project. The primary question remains, how does a parent with a child with autism develop a relationship with his or her child? The motivation to carry out the normal parenting role and functions persist, despite an autism diagnosis. Parents are driven biologically, socially and culturally to connect with their children. But what if the child is not willing or able? How do parents bridge the relational gap? To explore these dilemmas, I posited the following three research questions:

1. How do parents perceive and experience the nature and quality of their relationship with their children?

2. What are parents’ perceptions of how they develop and sustain relationships with their children?
3. What are parents’ perceptions of how their relationships with their children grow and change over time?

In the next chapter, I will outline the methods I used to address these questions.

CHAPTER III

METHODOLOGY

Overview

The purpose of this qualitative study was to explore a sample of parents to better understand how they develop relationships with their children with autism. Specifically, I explored how parents create and sustain relationships with their children and how those relationships change over time. For this study, I posited the following research questions: (1) How do parents perceive and experience the nature and quality of their relationships with their children? (2) What are parents' perceptions of how they develop and sustain relationships with their children? (3) What are parents' perceptions of how their relationships with their children grow and change over time?

In this chapter I describe the research methodology, including discussion of the following: (a) rationale for research approach, (b) guiding paradigm, (c) research design, (d) research participants, (e) data collection methods, (f) data analysis, (g) ethical considerations, (h) criteria of soundness, (i) limitations of the study, and (j) dissemination of results. I will conclude the chapter with a brief summary of this section.

Rationale for Qualitative Research Design

An extensive qualitative analysis of how parents experience their relationships with their children with autism had not been presented before this study. Qualitative methods are useful in understudied areas because they allow for a broad and comprehensive investigation of a relatively unexplored topic (Patton, 1990; Stern, 1980). Open-ended interviewing is effective at generating rich and descriptive stories that include thoughts, emotions, reactions, beliefs and biases. This range of responses might be unwieldy to tap into using traditional survey methods (Strauss & Corbin, 1998). From these stories it is possible to generate a number of themes that connect all of the stories, without losing the nuance and uniqueness of the individual narratives. Every finding can always be relocated into its original context which is the life of the person telling the story. As with all good science, the emphasis is on discovery. The methods used to make those discoveries, however, are not based on traditional, positivist, quantitative inquiry (Maxwell, 2005; Patton, 1990; Strauss & Corbin, 1998).

There are a number of assumptions in qualitative research: 1) knowledge is constructed intersubjectively; 2) the researcher learns from participants to understand the meaning of their lives but should maintain a certain stance of neutrality; and 3) society is reasonably structured and orderly (Burrell & Morgan, 1979; Marshall & Rossman, 2006). From these assumptions it follows that the meanings participants give to their experiences are a valid and constructive way of understanding the world.

Qualitative inquiry is also described as emergent and evolving (Marshall & Rossman, 2006). The ideas that I drew from multiple areas – personal, the literature, parent stories – have been reworked and revisited as the study progressed. My initial proposal has been altered in some ways to better fit the experiences and intentions I had as a researcher, and the processes and findings that were emerging in the earliest phases of the study.

In qualitative inquiry researchers “draw on their own experiences when analyzing materials because they realize that these become the foundations for making comparisons and discovering properties and dimensions” (Strauss and Corbin, 1998, p. 5). It can be seductive, however, to select conclusions that fit with personal experience, rather than seeing how data informs, enriches and makes one’s personal experience more empirical (Marshall & Rossman, 2006). Because of this, most qualitative researchers think of their findings as qualifiable, modifiable and open to negotiation (Strauss & Corbin, 1998).

The practice a researcher uses to avoid an over-reliance on personal assumptions in drawing conclusions is known as bracketing (Crotty, 1996). Bracketing is the process through which a researcher puts aside personal feelings and preconceptions to try to minimize researcher influence in the conceptualization, procedures and analytic processes of a qualitative study (Porter, 1993). The success of bracketing depends on the self-awareness of researchers, often referred to as researcher reflexivity (Ahern, 1999). By being reflective, the researcher brings to awareness how one’s experiences may be influencing the research process, rather than trying unrealistically to eliminate them (Ahern, 1999; Porter, 1993). I practiced bracketing through journaling based on the reflexivity guidelines recommended by Ahern (1999; see APPENDIX A).

Guiding Paradigm

My methods for understanding parent experiences were interpretative and phenomenological. Phenomenology is the study of experience and the way we understand those experiences to develop a worldview (Marshall & Rossman, 2006). The word “phenomenology” is made up of two Greek symbols and can be roughly translated to mean: “to bring to light through speech” (Heidegger, 1927/1964). In a phenomenological study, an everyday experience is examined with the hope of broadening the perspective to what might currently be understood about the phenomenon. For practical purposes, the experience under investigation is considered a discreet phenomenon, but it is understood that in reality no phenomenon exists with clear and distinct boundaries (Cashin, 2004). The contradictory sounding goal of phenomenological inquiry is to achieve clarity through complexity.

In a phenomenological study, it is important that the meanings and interpretations of experience are kept as intact as possible. To discuss the phenomenon, however, we use terms and understandings with which we are already familiar. This requires a researcher to move back and forth between the pure expression of the phenomenon and our current understanding of the phenomenon so we can share and discuss our findings with clarity (Moustakas, 1994).

The term “phenomenology” arose out of philosophical debate but has been concretely applied to human science (Moustakas, 1994). In phenomenological inquiry, the researcher has a personal interest and involvement in the topic. Subjective and objective co-mingle, such that researchers both shape and are shaped by their investigations (Moustakas, 1994). Throughout this study, my own perceptions informed what I understood about this topic. It is accepted in phenomenological inquiry that the researcher’s “thinking, intuiting, reflecting and judging – the data of experience – are regarded as the primary evidence of scientific investigation (Moustakas, 1994, p.59). By combining personal experience with the personal experiences of participants, I developed a more complete understanding of the phenomenon.

Phenomenology rests on the assumption that knowledge is co-created between researcher and participant and that unique and varied worldviews contribute to a valid understanding of a phenomenon (Patton, 1990). As such, the design of this study is based on interactions between myself and parents.

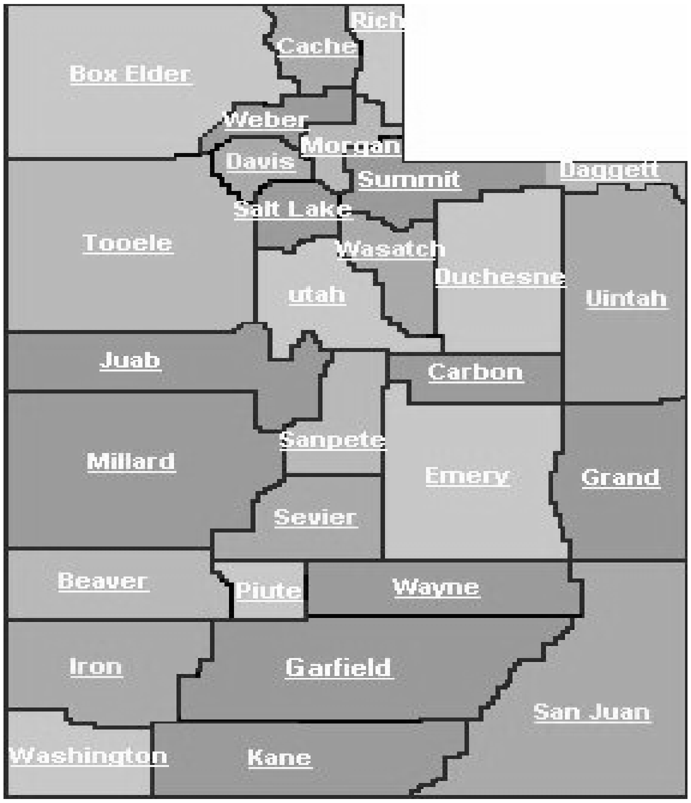
This study cannot be described, however, as purely phenomenological. In pure phenomenology, the goal is to understand a common experience, not to consider how frequently elements of that experience occur and how those elements relate to demographic variables of the participants and social context. Based on the researcher’s background and interest in conjunction with findings that emerged that seemed to diverge from the existing literature, I added the component of counting occurrences and trying to make associations between participant variables and outcomes. That process brings some positivist qualities to this investigation.

Research Design

This study had two phases. During phase I, I conducted in-depth interviews with 34 parents using a semistructured interview format (see APPENDIX B). With this format, each participant was directed to describe their relationship with their child. During the interviews, I used prompts to direct them to areas I perceived as important and meaningful. During phase II, I invited participants to comment on the findings I developed from the interviews.

Research Participants

Participants were 34 caregivers whose children had been diagnosed with an autism spectrum disorder. The study included 9 fathers (26%), 24 mothers (71%), and 1 grandmother (3%). The 34 participants represented 27 families. Of the 34 total, 29 participants self-identified as non-Latino Caucasian (85%). Four parents self-identified as Latino (12%) and one parent self-identified as Pacific Islander (3%). Thirty-two of the 34 parents live in Utah. They were from the following counties – Utah, Salt Lake, Davis, Weber and Box Elder (see Figure 1). Two mothers live in Mexico, one in a small town in the State of Jalisco and the second in a large metropolitan area in the State of Michoacán (see Figure 2).



(This image was imported from OnlineUtah.com)

Figure 1. Map of Utah Counties
(32 participants from this study came from
Utah, Salt Lake, Davis, Weber and Box Elder County)

Parents ranged in age from 26 to 55 with a mean of 39.3 years. Income level ranged from $15,500 to $255,500, with a median of $45,500. Education levels ranged from completion of high school to advanced degrees with the most frequently occurring education level endorsed as “college graduate”. Religious affiliation was divided as follows: 65% of parents endorsed a religious affiliation as Latter Day Saints; 21% reported “none” or “not applicable”; 6% reported Catholic and the remaining 9% were equally divided among Unitarian, Jewish

Figure 2. Map of Mexican States
(Two participants from this study came from the
Mexican States of Jalisco and Michoacán.)

and “generic Christian.” About 8% of the families had three children with autism and two families had two children. The remaining 22 families had one child with autism. Of 34 participants, 33 were partnered and co-parenting. One was partnered and single parenting. Occupations of parents were diverse, ranging from stay at home mothers to engineers and teachers (see Table 1).

Of the 34 children represented in this study, 50% were diagnosed with autism, 35% with Pervasive Developmental Disorder, Not Otherwise Specified, and 15% were diagnosed with Aspergers. Ages ranged from 3 to 23 years with a median

Table 1. Parent Demographics

N = 34		%	*N*
Type of Caregiver:			
	Mothers	71%	24
	Fathers	26%	9
	Grandmothers	3%	1
Gender:			
	Female	74%	25
	Male	26%	9
Racial/Ethnic Identification:			
	Non-Latino Caucasian	85%	29
	Latino	12%	4
	Pacific Islander	3%	1
Educational Attainment:			
	College Graduate	53%	18
	High School Diploma	32%	11
	Advanced Degree	15%	5
Primary Residence:			
	United States	94%	32
	Mexico	6%	2
Religious Affiliation:			
	Latter Day Saint	65%	22
	None	21%	7
	Catholic	6%	2
	Other	9%	3
Age (in years):			
	Mean	39.3	
	Min	26.1	
	Max	55.3	
Family Income (in US Dollars):			
	Median	$45,500	
	Min	$15,500	
	Max	$255,500	

age of 9. About 21% of the children were female (see Table 2).

Averaged across all of these characteristics, this sample could be described as predominantly non-Latino, Caucasian, female, LDS, partnered, college graduate with a median age of 39, a median income of $45,500, living in Utah with one son with autism. A quick guide is provided in APPENDIX C for easy reference to parents and their corresponding children to facilitate ease in reading this

Table 2. Child Characteristics

N = 34		%	*N*
Gender:			
	Male	79%	27
	Female	21%	7
ASD Diagnosis:			
	Autism	50%	17
	PDD NOS*	12%	12
	Aspergers	15%	5
Age (in years):			
	Median	9	
	Min	3	
	Max	23	

*PDD NOS=Pervasisve Developmental Disorder, Not Otherwise Specified

document.

Sampling Procedures

I used purposeful sampling in this study, because purposeful sampling is the procedure used in interview-based research to yield the most information about the phenomenon under study (Bloomberg & Volpe, 2008; Patton, 1990). Purposeful sampling is a process of selecting respondents with a specific purpose in mind. In this case, I used a combination of criterion and snowball sampling (Marshall & Rossman, 2006). Criterion sampling dictated that all participants met a particular set of criteria (Bloomberg & Volpe, 2008; Marshall & Rossman, 2006). These criteria are described below. Once initial participants were identified, a snowball sampling procedure was initiated. In snowball sampling, initial interviewees identified cases that had a high probability of being information rich (Strauss & Corbin, 1998). Five of the parents were interviewed in 2009 as part of an initial conceptualization of this project. The remaining 29 parents were interviewed between February and October of 2011.

Inclusion Criteria

Any parent who had a child or grandchild of either gender with an ASD was considered for the study. In an effort to recruit an inclusive sample, parents of any race, ethnicity, age, and sexual preference were welcomed. Children had to be at least 3 years old because recent research suggests that autism diagnoses are most stable when made at this age or later (Kleinman et al., 2008). The child had to have a verifiable autism spectrum disorder diagnosis – Autism, Pervasive Developmental Disorder, Not Otherwise Specified, or Asperger Syndrome – made by a licensed professional qualified to make such a diagnosis (e.g., developmental pediatrician, psychologist). The participating parent had to be able to attend an in-person interview lasting approximately 90 minutes and be available for a 12-month period for follow-up conversations that could take place in writing, in person and/or by phone, depending on the time, skills and preferences of the participant. Participants agreed to review findings. I endeavored to meet the diverse needs of my participants by providing written materials or oral description, and by translating documents into Spanish for non-English speakers.

Participants were recruited with assistance from the leadership of three Utah based organizations: Utah Families for Effective Autism Treatment, Big Maks (Mothers of Autistic Kids) and El Proyecto Autismo. The leadership of the first two organizations contacted their members via email with an attachment describing the study and the participant criteria. They also posted information on their websites. The leader of El Proyecto Autismo advertised the study directly on the project's website. She also invited me to one of the project's monthly parent support groups to present information about my study.

Parents who were interested in participating were given my email address and phone number and asked to contact me. After being contacted, I collected additional information from parents to determine whether they met inclusion criteria and gave them details about the study to help them decide if they wanted to participate.

No monetary compensation was given to participants. The participants were invited to read the results of the study, or to have me share them in person or by phone if there were literacy or language issues that might make it difficult for a participant to read written findings. My hope was that participants would feel a degree of satisfaction and reward in sharing their stories.

Data Collection Measures

In order to increase the rigor, breadth and depth of this study, I used two methods for gathering data (Denzin & Lincoln, 2000; Patton, 1990). By employing more than one method, I increased the likelihood of obtaining a valid understanding of the phenomenon. The two methods were in-depth interviews and participant review of findings.

Phase i: Individual interviews. Emails were sent by two English-speaking, local autism group leaders to members who might be interested in participating in this study. Attached to the emails was a brief description of my study, including participation criteria and how to contact me. To recruit Latino families, the leader of El Proyecto Autismo posted information in Spanish on her website. Interested participants were asked to contact me either by email or phone. I responded to all interested parents to determine study eligibility. I arranged to meet parents who met the study criteria at a time and location they had indentified as convenient. Two mothers from Mexico unexpectedly expressed interest in the study after reading about it on the El Proyecto Autismo website. Due to travel constraints, I interviewed them by phone using an interpreter.

Of the 32 parents living in Utah, all but 2 chose to meet in their home. Two of the parents chose to meet at a restaurant and coffee shop. For the Utah participants, the consent document was reviewed and signed by the participant before interviews began. The mothers in Mexico received translated copies of the consent document via email. Based on instructions in the document, their participation in the study served as their official consent. Because I was unable to travel to Mexico, I interviewed these two mothers by phone with the aid of an interpreter.

I gave all participants details about the goals of the study and the study procedures. I answered questions and clarified information as requested. As part of the introductory process, I disclosed I am the parent of 7-year-old son with autism. I hoped this disclosure would help interviewees feel more comfortable and potentially better understood because I could relate to at least some aspects of their experience. Interviews ranged in length from about 1 hour to 3 1/2 hours. Interviews increased in length as I was further along in the study. I conducted 28 interviews total (22 interviews with individuals and 6 interviews with couples). All interviews were audiotaped.

Phase ii: Member checking. Member checking is the process by which study participants are invited to critically review the researcher's work at one or more points during the research process (Morse, 1994). Checking with participants is believed to increase the rigor of the study and reduce researcher bias (Lincoln & Guba, 1985). It allows for an interactive, constructivist process between researcher and participant in the development of research findings. During member checking, participants have the opportunity to (1) correct errors and challenge what they perceive as "wrong" interpretations, (2) volunteer additional information that may be stimulated by discussion, and (3) confirm particular conclusions and interpretations by the researcher (Angen, 2000; Creswell, 1998; Lincoln & Guba, 1985; Morse, 1994).

After transcribing and coding the interviews, I proposed a number of preliminary findings. I contacted participants and requested they review and comment on these findings. Of 34 participants, 12 reviewed the findings and gave both supportive and critical comments.

Data Analysis and Interpretation

Qualitative research yields an enormous amount of raw data (Marshall & Rossman, 2006). The key to managing the data is to conduct data collection and analytic procedures simultaneously (Merriam, 1998) to avoid being overwhelmed by huge quantities of raw data. To make the process manageable, I used an analytic procedure outlined by Marshall and Rossman (2006).

Data were analyzed in a six-step process outlined by Marshall and Rossman (2006): (1) data organization; (2) data immersion; (3) theme generation; (4) data coding; (5) interpretation; and (6) a search for alternative understandings. I refined my analysis and interpretation based on participant feedback.

Data Organization

My data consisted of four types: 1) original, digital recordings of interviews with each participant, 2) written transcriptions of each interview, 3) written field notes and 4) preliminary analytic memos. The digital recordings were stored and organized on the recording device, which stored each interview with date, time and length of interview. As a back-up, I also logged information about each interview in a research journal, specifically noting the date, time and location of interview, and with whom the interview took place.

After transcribing the oral interviews, I organized transcripts by keeping them filed alphabetically in a locked file drawer in my home office. I used a separate journal marked “field notes” to record and store thoughts that I had while conducting interviews. I dated these notes for easier management of how they relate to particular interviews. Preliminary analytic memos were notes that I wrote in a word document that was open at the same time as the transcript document. That allowed me to easily reference back and forth between the transcript and my notes. I added additional emphasis by underlining passages, converting text into bold and italics, and starring items with asterisks.

Data Immersion

Immediately after conducting each interview, I listened to the recording of the interview to keep fresh in my mind individual participants’ voices and stories. After transcribing the data, I read each interview two or three times using the side by side Word document approach described above. I underlined passages that seem meaningful, important, intriguing, and serendipitous. So as not be become bogged down or overly influenced by any single interview, I read through all the interviews before rereading each interview. I used this process to simultaneously focus on individual narratives in the context of the larger parent story. Through the process of immersion, I became familiar with the data, and noticed there were people, events and quotations that constantly sifted through my mind (Marshall & Rossman, 2006).

Generating Categories and Themes

The process of generating categories and themes is described as the most "difficult, complex, ambiguous…and intellectually challenging phase of data analysis" (Marshall & Rossman, 2006, p. 159). My plan was to discern recurring ideas, beliefs and language through immersion in the data. I constructed themes from the analysis which served as "baskets" for placing bits of data (the text). According to Guba (1978), a category of meaning, or theme, is a pattern that has internal convergence but is also distinct from other categories. I endeavored to discover patterns, themes and categories that had not been stipulated beforehand (Patton, 2002), although these themes were influenced by prior knowledge and personal experience.

Data Coding

After generating five themes, I designated a color to represent each theme. I reread the transcripts and coded the text by highlighting quotations that related to the theme. During the coding process, new insights emerged, which required I rethink themes and recode. This process took several months to complete.

Analytic Memos

Throughout the research process, I recorded my thoughts, impressions, reactions, insights, emotions and reflections in Word documents labeled "analytic memos." These memos were simultaneously a record of my thoughts but also a stimulus for new thoughts and ideas. As Wolcott (1994) describes, the process of writing, intertwined with the process of thinking and reflection, is the “transformational” process whereby raw data are turned into meaningful findings.

Interpretations

I used interpretative phenomenological analysis to reflect on my findings. During this process, I moved between the specifics of a particular narrative to the more general meaning I derived from the compilation of narratives. The individual themes were integrated into a cogent, unifying understanding of the data. As Patton (2002) describes: “Interpretation means attaching significance to what was found, making sense of the findings, offering explanations, drawing conclusions, extrapolating lessons, making inferences, considering meanings and otherwise imposing order” (p. 480).

Alternative Understandings

For every interpretation, I considered multiple, plausible alternative explanations. I concentrated on noticing how my assumptions and experience might be influencing my analysis. During this stage, I invited participants back into the process as a check on my perspective and to extend my findings. The outcome of shared reflection was an interpretation that was more thoughtful and that more closely reflected participant experience.

Ethical Considerations

It is the primary responsibility of the social scientist to inform and protect research participants (Bloomberg & Volpe, 2008). Because participation in social science research is voluntary, participants were fully informed about the nature and purpose of the study and the study procedures. Identifying information about participants and the information they provided was kept confidential by employing the following safeguards.

Informed consent was obtained prior to any data collection. Participants had the opportunity to both read and hear an oral explanation of the consent documents. Documents were translated into Spanish for non-English speakers. Participants were invited to ask questions and were told they could withdraw from the study at any time.

Consent forms which listed participant names were separated from the interview data. Transcripts were stored on a password protected computer. Interview audiotapes and transcriptions were kept in a locked filing cabinet in my home office.

Interviews were conducted in participants’ homes in a further effort to maintain privacy. Parents who chose to meet in a public place were cautioned about the possible decrease in privacy. Every effort was made in those cases to select a private space within the setting. The two parents who chose this option repeatedly asserted they felt comfortable with the circumstances. Real names were replaced by pseudonyms in all written documents.

In addition to safeguarding privacy of respondents, a significant ethical concern was to represent the voices of my respondents despite the perspective I brought to the project based on my cultural identification, age, gender, values and political perspective (Marshall & Rossman, 2006). As described above, I consistently reflected on how my personal experience and perspectives were impacting all aspects of this study. My goal was to minimize my voice to maximize the voices of my respondents.

In addition to these pragmatic elements of research ethics, I was obligated to consider the moral question of asking questions of others that sometimes evoked emotional pain. I made sure participants were aware that this could be an outcome of participating in this study and gave them options before and during interviews to stop at any time.

Soundness of the Study

While all studies must have a perceived truth value (Lincoln & Guba, 1985), the constructs used to judge the rigor and soundness of this study are criteria which have been developed to more accurately reflect the assumptions of the qualitative paradigm (Marshall & Rossman, 2006). These alternative criteria include the concepts of trustworthiness, transparency, authenticity, minimizing researcher bias and transferability. While the language differs, these constructs attempt to assess what in quantitative research would be referred to as validity and reliability.

Trustworthiness

To the best of my ability, I accurately collected data by using high quality recording equipment. A different kind of trustworthiness was how well and how true I held to my participant stories. I asked myself the question over and over, "What would my participants think about this?" I was able to ask them that directly when they provided feedback on my findings and interpretation, but I kept their presence close through all stages of the study as a kind of super ego holding me accountable.

Transparency

To maintain transparency of this research project, I kept an audit trail of all procedures and processes as I carried them out. This included written notes, recorded data, transcribed data, coded transcripts, key decisions in the research process and feedback from my adviser and committee members.

Authenticity

I used more than one data collection strategy to increase the authenticity of this study. In-depth interviews provided the primary source of data. The secondary source of data was feedback from individual participants on findings and preliminary analysis. Combining these strategies deemphasized researcher bias and increased the likelihood that the final product was reflective of the thoughts and ideas of a group of individuals.

Researcher Bias

As has been clear from introduction of this study, my research interests arose from personal experience. To keep the project from becoming purely autobiographical or self-serving, I practiced bracketing as outlined above. In this practice I identified personal preconceptions, judgments and prejudices and then set them aside. I listened to parents with an open mind with the intention of co-constructing new knowledge.

Transferability

The results of this study are not intended to generalize to all parents with children with autism. The sampling for this project was purposeful, not random, and attempting to extrapolate to a broader population is not appropriate. On the other hand, the findings can be used as a starting point for other projects and for the development of theories and specific hypotheses which might be tested in more quantitative types of projects. This project is an attempt to begin to deeply and richly describe a phenomenon using multiple cases, in the hope that in a collection of such cases, it might be possible to develop a basis for formulating hypotheses (Olsson, 2004).

Study Limitations

This study has limitations. Some of the limitations arose from criticism of qualitative research in general, and some limitations arose from the research study procedures themselves. I carefully considered how to minimize the impact of these limitations on the study findings.

It is suggested that an inherent limitation in qualitative research is researcher subjectivity (Marshall & Rossman, 2006; Patton, 1990). Will my findings mostly reflect personal experience and opinion, or will they represent the combined narrative of many parents? In order to minimize the possibility that the findings will be overly subjective, I practiced bracketing as described above (see APPENDIX A).

A second limitation resulted from one type of sampling error that can occur. In qualitative research, there are no objective criteria for determining a sample size. In my original proposal, I suggested I would interview 20 parents or fewer, depending on when I achieved saturation. My request for participants generated a much greater response than anticipated. I chose to interview all parents who expressed interest if they qualified. In part, this may have come from my perspective as a parent and a personal understanding that it is important for parents to have opportunities to tell their stories. This decision increased my breadth, but also decreased opportunity for additional meetings due to the large size of the sample. In studies with smaller sample sizes, the researcher has the opportunity to gain greater depth from a smaller number. In this study, I may have sacrificed some depth by choosing breadth. To counter this, I used participant review to have additional opportunity for contact with participants to increase the depth of understanding.

A third limitation is the degree to which most literature on autism emanates from Western cultural perspectives (National Research Council, 2001). I tried to counter this by seeking participation by the Latino community in Utah and Mexico. Gaining access to this group has been a much slower and more complex process than anticipated. As a result, the ethnic diversity in my sample is limited to 5 of 34 parents. To counter this limitation, I continued to pursue the opportunity to recruit Latino parents throughout the analysis and writing phases of this study. I also intend to complete additional studies with Latino families after my dissertation process is complete.

Dissemination of Results

The results from this study will be written in a final dissertation paper that will be accessible through the University of Utah Marriot Library. One or more articles describing the study and its results will be submitted to peer-reviewed journals. I will make a summarized version of the final study available to all participants. If there are literacy issues or language barriers which would prohibit a respondent from reading findings, I will make accommodations to have a personal discussion with them about the findings.

Summary

In this chapter I provided a detailed description of my methodology for this research project. I used in-depth interviews and member checking to explore the experiences and perceptions of parents in their personal process of developing relationships with their children with autism. My guiding paradigm was phenomenology, including the practice of bracketing to publicly acknowledge my presuppositions. I analyzed the data in the context of the literature, personal experience and feedback from colleagues and research participants. I established soundness in the study by focusing on trustworthiness and transparency and used the highest ethical standards and practices to protect the privacy of my participants. I kept the limitations of the study in mind, and persevered to reduce the impact of those limitations on the study findings using the strategies outlined above.

In the next chapter I present the five themes that emerged from the interviews. Embedded in these themes is the feedback I received from parents about my findings.

CHAPTER IV

FINDINGS

Overview

The purpose of this study was to explore parents' perceptions and experiences of their relationships with their children with autism. I believe that a better understanding of this phenomenon will allow practitioners and educators who work with families affected by autism to have a more well-defined and precise understanding of the variety of experiences that parents can have with their children. This chapter presents the key findings from in-depth interviews with 34 parents as well as a participant review of those findings. Using interpretative phenomenological analysis, five themes emerged:

1. Bonding: Parent perceptions of early bonding experiences ranged from "highly unusual" to "unremarkable" and "normal."
2. Reciprocity: An overwhelming majority of parents described their relationships as nonreciprocal.
3. Barriers: A large majority of parents identified significant barriers to creating relationships with their children.
4. Connections: Parent strategies for creating connections with their children ranged from "very limited" to "well-established."

5. Change: An overwhelming majority of parents described their relationships as “growing and changing” over time, but with awareness they would remain in a caretaker role with their children.

The following discussion provides details to support and explain each theme. The purpose of this section is for the reader to enter more personally into the study by listening to the voices of participants both in their individual stories and in the larger story they create together. The emphasis throughout this section is to let participants “speak for themselves.” I use illustrative quotations from multiple participant interviews to capture both convergent and divergent perspectives. In this way, the reader is introduced to some of the complexity and richness of the subject.

Theme 1: Bonding

Finding 1: Depending on the parent, perceptions of early bonding experiences ranged from “highly unusual” to “unremarkable” and “normal”

About 61 % of participants described that their children, particularly as infants, did not rely on them for soothing, comfort, security or approval. They did not perceive that they bonded with their children in a “typical” way, and their children did not feel well attached. The attachment they did have was described as “sporadic” and “tenuous.” Some parents perceived their children’s behaviors to be so unusual that the most appropriate descriptor was “alien.”

Some of the parents in this group described an extended period of getting acquainted with their children. It was as if the normative timeframe for initial parent child bonds to be established was stretched from months to years. Their perceived lack of ability to get to know and respond well to their children often turned into self-blame.

Parents also expected their children to hold them above other adults as more meaningful, special and important in their lives. This would be evidenced by fears around the parent's departure, excitement about the parent's return and by placing a higher value on the parent's opinions and reactions. They expected to be treated "like a person," not like a "piece of furniture." For parents in this category, it was disturbing and concerning when their expectations around bonding and attachment were not met.

Rejecting comfort. Some mothers discovered they were not able to soothe or comfort their children. Some children actively rejected their overtures. Mothers found it difficult to understand why intuitive strategies they had used successfully in other circumstances were not working. Jane remarks:

> It was really hard to develop a relationship with her. It just didn't exist in a lot of ways. For a long time, I thought it was my fault. I couldn't sing to her; she would just scream. She didn't like being held. She didn't really connect with us in any way. It was awful. (Jane)

Jane is at a loss to find the strategy that soothes her daughter. She appears to be in great distress, but Jane feels helpless to intercede.

Reba describes her son actively resisting her efforts to comfort him:

> Something knocked something else over, and Matthew was there and it scared him. It made a loud noise. And as a mother the first thing I wanted to do was to pick him up and tell him it's OK. But when I tried to do that, he got mad. He said, "No!" and he pushed me away. He went down to his room and got his silky and sat, and just was holding his silky. He was about two at the time. And I just thought, no, uh uh, that's not right. (Reba)

Neither of these mothers attributed their children's responses to a fussy temperament. Both described feeling like something much more ominous was present.

Children from another world. For some parents, their children seemed so different from what they had expected it was as if the children had come from another world. Joie likens her baby to a "little alien." Her child is mysterious to her. She is looking for guideposts to understand her daughter, but they are missing: "I was thinking I would have a little girl who would be like me when I was a little girl, but it seemed like I had this little alien; this little alien child who didn't do anything I expected." Joie is presented with an enigma. She turns to the autobiographical writings of individuals with autism to help her interpret the girl who is confusing her:

> I read some of the books by Temple Grandin, and I thought, that helped so much because that was really the first clue I ever had about what things might be like for Tess, inside of Tess. When things have been the worst, it's been when I have been thinking like me, and not thinking like her. (Joie)

Like an explorer, Joie needs a map to find her way to her daughter.

Ted expands on the theme of child as alien. He is still very angry and disappointed about his son's disability: "He is a different species from a different planet. He's half robot, half alien and, like, raised by humans." Ted may be joking, but the language he chooses illuminates how greatly his son diverges from what Ted anticipated or has ever known. Using startling language was perhaps the only way to convey the intensity of his experience. I do not believe it is coincidental that parents used the word alien to describe participating in relationships in which they themselves may feel alienated.

Whereas Joie turned to autobiographies to help her understand her daughter, Ted has turned to science. He is extremely well read in neuro- and developmental psychology and the science of autism. He learns about his son by learning what scientists and researchers explain about autism, rather than through an intimate, engaged process of parent child interaction. While this is not to suggest that interactions with his son are absent, it does suggest that his ways of knowing about his son are derived more intellectually than experientially.

<u>The extended acquaintance frame</u>. Parents repeated the refrain that getting to know their children took longer than it did for their other children. The differentness of their children's behaviors, communication patterns, thought processes and emotional make-up conspired to extend the acquaintance-making process well beyond the first couple of years of life when most parents feel that they have come to know and understand a great deal about their children. Jenna asserts that it has taken her years to really feel like she understands her daughter:

> Jenna: Because of Lucy's lack of language skills and lack of understanding and communication, we've spent a lot of years doing a lot of guessing. We've done a lot of problem solving. She didn't have those normal communications you would have with a kid. We didn't have that. I guess my

> point is that my husband and me have spent a lot of years reading Lucy's expressions, reading her actions, reading everything else, so we could understand how to meet her needs emotionally and physically and everything else.
>
> Tracy: It almost sounds like detective work!
>
> Jenna: Yes [emphatically]! We've had to do so much problem solving and things like that with her. I had a friend the other day that said, you know I'm just one of those moms who doesn't like the baby age. I like it when they get older and they can tell me what they want. And I'm like thinking, that would be a nice concept, you know what I mean?! We're still a long way off understanding all of her emotions and stuff. We're starting to get more legitimate about how she's feeling, what she's feeling, but emotions with her have taken a long time. We've established mad. We've established happy, but that's about it.

Jenna's daughter is 8 years old. Jenna gives voice here to the dramatically extended period of time for understanding how her child feels. At 8, Jenna and her husband have been able to detect and establish only two of their daughter's emotional states: mad and happy. Other than that, her daughter's emotional make-up remains remarkably hidden from them.

The intuitive approaches parents brought to these relationships were often thwarted. Some turned away from themselves and their own understandings of children to others for clues about their children's unique behavior and communication patterns. They spent years decoding emotional expression and behavioral patterns to educate themselves about their children. The degree of effort that went into learning about their children cannot be underestimated.

Self-blame. Parent lack of success with their initiatives often left them to wonder what they were doing wrong as parents.

> It was like, OK, what am I doing wrong? What am I missing? Is there a skill I don't have? Is it because I'm at work all day? So I quit working to stay home with him, and then he actually got worse. So then it was like totally personalized. I'm just too young. I don't know how to handle a kid. It was a real struggle. (Gabrielle)

It was not uncommon for mothers who had originally intended to go back to work to change their plans and become "stay at home moms" to try to improve their bond with their children. In other cases, the mother might cut back on her work hours, or choose to work fewer days. As was the case with this mother, the relationship continued to deteriorate, only leading her to wonder even more what she was doing wrong. Interestingly, none of the fathers in the study (0 out of 9) spontaneously remarked that they felt responsible for their children's emerging difficulties.

While some mothers were trying to make sense of their children's unusual behavior by berating themselves for being "bad moms," other moms were being berated by spouses and physicians:

> Everyone was telling me it was my fault – the doctors, my husband. I started to believe it really was my fault, that I was a bad, bad mom. (Selena)

Mothers like Selena, already suffering from feelings of inadequacy as a parent, were not able to turn to their pediatricians for reliable information about why they might be experiencing so many difficulties with their children. This led to an intensification of self-blame and feelings of isolation.

<u>Feeling invisible and irrelevant</u>. Parents generally expected that as their children approached their 1st year, they would become distressed at a parent's departure. This expectation grew out of their experiences with their other

children, or from their understanding of child development. Many parents discovered that their children seemed remarkably unaware of the parents' comings and goings:

> He doesn't really show a difference in affect when I leave for work or come home. He's just focused on what he's doing. It's not an event to him; it's not relevant to his world. (Ted)

Ted interprets that his presence is not interesting enough to warrant his son's shift in attention away from what he is doing to pay attention to his father. Ted feels irrelevant.

Jane recounts a similar pattern when her daughter was an infant. Raine would not appear to notice when Jane and her spouse left the house and returned. Raine did not display behaviors that would indicate that these comings and goings mattered to her:

> We would leave, and she wouldn't care. We'd come back and she's like oh, whatever, and this was from right from the get go, really early on. You know how people say I give my baby to somebody else and they want mommy? Never, we never had that, ever. There was never this special, oh that's mommy, or that's daddy. We never had that. (Jane)

For Jane, feeling unnoticed is combined with perceiving that her daughter does not value her or recognize her status as parent as special or different. There is a perception on Jane's part that she is indistinguishable from other people. Her daughter is not showing her preference for attachment. This type of response requires the parent to devote extra care and effort in pursuing their child and establishing their importance to them. The biologically based, adaptive pattern for parents and child to seek mutual proximity and reward is lacking.

Other parents, like Louise and Marissa, describe the consequences of feeling invisible to and unnoticed by their children:

> Tracy: What is that like for you, to feel like your children aren't interested in you, or don't come to you, or…
>
> Louise: It's so hurtful. Before they were diagnosed, I couldn't get them to engage with me at all. It's kind of a rip your heart out kind of thing, you know, what's wrong with me? I can't make a connection with my child. Am I even going to be part of their life?

When her children were young, Louise feared she might always remain on the periphery of her children's lives. That is an odd and painful position for a parent to find herself in.

In a similar story, Marissa describes the lack of specialness that one expects to feel as a parent:

> It was like we were invisible to him. You know how kids are supposed to think you are the greatest, that you can fix anything? We didn't feel that at all. I didn't feel special to him, the way a mom is supposed to be special. I loved him so much, but I didn't feel that love in return. (Marissa)

Like Jane, Marissa feels indistinguishable.

Ted expanded on the theme of invisibility, describing that his son lived in a "phased out existence" in which people were only "ghosts":

> He literally, he just lives in a phase shifted universe where we're all kind of ghosts and he just exists phase shifted out of our reality and in his own, and kind of pulls us in and communicates through séance when he needs something (Ted)

Using humor, Ted uses the séance metaphor to try to describe the "other worldliness" about his son and how this influences their relationship. He hints that his son uses him instrumentally, "to get what he needs," and not relationally.

Loose attachment. Once children could walk and run, some parents experienced great difficulty keeping their children with them in public places. While it is typical for toddlers to run off, most children become anxious if the separation becomes too great. They are also likely to be wary in new situations, and reluctant to go somewhere with a stranger. Laurel illuminates how this was not the case for her son by describing how she believed he would indiscriminately choose to go with strangers in situations in which children typically show more wariness and concern:

> When he was younger, I felt like anyone could come up and take his hand and he would have just wandered off with them. He would've wandered off with anyone – literally. When we had him assessed at Pingree, Dr. Peterson said, "Will he go with me?" And we said, "Are you kidding? Sure he will!" (Laurel)

For Laurel, her son's attachment felt loose. He seemed unaware of who should be his safe haven and figure of greatest importance. Laurel understands that her son's lack of discrimination between the importance of different adults affects her ability to bond with him. She cannot depend on the instinctual preference children show their parents to maintain closeness and use this as the foundation for relationship building. It is as if the metaphorical attachment *leash* that binds parents and children is absent. This may partially account for why parents with children with autism often consider using harnesses with leashes to keep their children near and safe. They resort to constructing physical connection when socio-emotional and biological connection is impaired.

A number of parents experienced that their child did not seem to differentiate or care that the parents' opinion or response carried more weight than that of a stranger. One father describes what can happen when both he and his wife say "no" to one of his son's requests:

> It's clear he doesn't depend on me for parenting. When he wants something, like a popsicle, after he asks me and my wife, he will even ask a stranger. It's gotten to the point where he'll just ask anyone who happens to be in the room. Dylan doesn't value as parents our approval or disapproval. (Ted)

Ted believes that his son does not really understand or does not care that his opinion as a father has greater value than the opinion of someone who might happen to be sitting in his living room. He expands on the idea of the undervaluing of his opinion through a story about a visit with his son to the planetarium:

> I mean we were at the planetarium, and he took off giggling and running down the big hallway, and I had to just sprint after him. There was nothing I could have said that would make him stop. "Stop, we're gonna go home!" or "You're gonna go to your room!" or "No more popcorn!" he just kept going. He didn't care or hear. He didn't have a reason to stop. What reason would he stop? So I won't get mad at him? He doesn't care about that. (Ted)

Ted perceives that his status as "father" goes unrecognized by his son and will not impact his son's behavior.

<u>Bonding and attachment feel "normal."</u> Whereas 61% of participants did not believe that bonding was typical or predictable, about 39% of participants felt like the bonding experience with their children were "completely normal." One father, who had already raised two other children, did not believe that his son with autism exhibited any kind of unusual bonding or attachment behaviors:

> He and I used to sit and watch TV and he'd just kinda sit like a baby would. He didn't have a lot of strange activity issues, not wanting to do things or wanting to do strange things, at all. He was just more quiet, kinda to himself. Our older boy had to go through some speech therapy, so we just kinda thought maybe he's just a little slow. (Scott)

Eight other parents remarked that their children were very “cuddly” and “loving.” One mom describes how joyful her early interactions were with her son:

> He was a very cuddly, loving, happy, baby. I never felt distant from him. He was a little, joyful ball. I thought he was just spoiled because he would throw tantrums more than my other kids. He always had a huge smile on his face. There was no detachment. I never felt that. Never. That's why I thought autistic, what do you mean, autistic? He always had eye contact. I know we have a bond. There's no question. (Leann)

Another mom remarks that her son was such a cuddly, easy baby:

> Dylan loved to be held all the time, so you could just hold him and he'd like be just totally mellow. He was such an easy baby, so easy, like, as long as he was held. No tantrums, no screaming through Target like his brother does now. None of that stuff. (Gabrielle)

When Gabrielle looks back at her experiences during Dylan's infancy, she does not recall feeling like there was anything unusual or odd about their early interactions.

Alice is emphatic about the early bond she felt between herself and her son:

> I've always felt connected to him then. I have never felt not connected to him, or any kind of disconnect. I always felt like he wanted a relationship and wanted one with me. Basically we've always had that. He had toys he liked that we could play together. He had books he wanted to read with us together. We felt like he was engaging us, besides us just engaging him. (Alice)

Alice notes that the desire to interact was mutual, that her son initiated interaction, and was not just responding to her bids to interact. She adds that she has always felt special to her son, “I have never felt not important to him. I definitely felt like we were special to him." Unlike the parents described in the beginning of this section, these parents perceived a strong bond and normal attachment with their children, including feeling as if their children saw them as special and important.

Two other moms described that their primary connection was through shared play around common interests. Nedra remarks about her son, "He is bright and intense and when he was a little kid, we spent a lot of time playing together. It was the kind of playing I like to do, you know, building with Lego's." She realized only later, after she had two more children, that her son's play was not imaginative or childlike.

Jodi describes that her son did not enjoy typical baby games and could be unresponsive in other ways, but they were able to connect through a mutual interest in cars:

> J: He didn't like to play peek-a-boo, things like that, but I figured that was just his personality. The games that you play with babies and the songs you sing and patty-cake – he just wasn't interested. He wouldn't respond to you…
>
> T: Did you feel a mutual connection, even though he didn't like to play those typical baby games and could be unresponsive?
>
> J: Yea, because we would do other things. He liked lining up cars, and I'm a huge auto racing fan, so I thought he was lining them up like in the start of a car race, so I thought that was great! So we would do that together. (Jodi)

It is only later, after Jodi's son is diagnosed with autism, that she learns that lining up toys can be characteristic of the lack of imaginative play in children with autism. For Jodi, rather than being a cause for concern, lining up toys was an opportunity for relating.

Summary

Parents generally fell into two categories when describing how they perceived they bonded with their infants and how well they believed their infants were attached to them. In the first group, 21 out of 33 parents described highly unusual interactions during their children's infancy and early childhood. They described their children's attachment as tenuous, sporadic and unconvincing. These atypical interactions ranged from a dislike for being soothed and comforted, little or no separation or stranger anxiety, an odd lack of regard for "who they belonged to" and seemingly being unconcerned about their parent's opinion of them and their behavior. In the second group, 13 out of 33 parents detected nothing unusual about their bonding experiences with their children, and experienced that their children were strongly attached to them. They bonded primarily through physical affection and shared interests.

Theme 2: Reciprocity

Finding 2: An overwhelming majority of parents (31 of 34) described their relationships with their children as nonreciprocal

Reciprocity in a relationship is defined as a mutual or cooperative interchange between individuals. Both partners, consciously or not, recognize and participate in a dynamic system in which the actions of one simultaneously influence and shape the reactions and responses of the other (Fogel, 1993). This process takes place across the bandwidth of communication and can involve verbal speech, gestures, turn-taking, shared emotional states and behavioral responses. Between a parent and child, reciprocal interactions begin very early in an infant’s life, beginning as subtle exchanges involving eye contact and touch, and evolving into simple games such as peek-a-boo. Based on the history of exchanges, partners develop expectations about co-participation in these exchanges, while remaining open to the possibility of change and variety in any given circumstance (Fogel, 1993). About 91% of the participants in this study did not experience reciprocity as described above.

One of the most distinct memories of a lack of reciprocity that parents reported was in their early attempts to play “baby games” with their children. Most parents expected that a simple game like “peek-a-boo” would elicit delight in their infants. They believed their children’s enjoyment would be infectious. For many, however, their expectations of mutual enjoyment were not met:

> I think relationships are a reciprocal commitment. And Mary doesn’t understand that reciprocity. I don’t think she would ever go through the motions of peek-a-boo. It was hard enough just to get her to laugh at the peek-a-boo when I did it. It was a lot of work. I didn’t experience that sense of joy and laughter that I had with my other daughter. She would laugh and then it would be like, “we’re done” and then she would move on quickly to something else. (Susan)

Another example of a simple exchange that happens between parent and a young child involves sitting on the floor and rolling a ball together. Most parents expect that their children would quickly catch on that the purpose of the game was to roll the ball back and forth, not merely for a physical outlet, but to share in the enjoyment and rhythm of the exchange. Jane describes how her experience with this activity ran counter to that belief:

> When she was about 12 months old, I would roll her the ball and she would pick it up and toss it away. What the heck am I supposed to do with that? (Jane).

Because the endless hours of practice and repetition with early social exchanges build a foundation for more complex exchanges of later childhood, perhaps it was not surprising that the impaired ability to co-regulate would extend into later play between parent and child. Laurel speaks to the frustration of trying to be involved with her son, Braxton, around playing a television console game. He needed her help, but did not appear to want her for a mutually enjoyable exchange:

> We try to play games with him, but he is hard to be with. He'll get the Sega game out, and he'll act like he wants you to play it. And so we'll say something like, "Oh, you want to play that? OK, let's play together". And he'll want you to turn it to the right channel. And then he'll sit there for a minute and play with it and then he'll give it to you, and he'll want you to play it so he can run around and be excited by the pictures. He doesn't necessarily want to play it together – he wants to be excited by the pictures. And if I want to switch to a different game that I want to play, he's like, "No, no, no!" That's not OK with him, and he'll turn it off. (Laurel)

Laurel makes a point that Braxton did not seem interested in two key components of play, one being the desire for the play to be mutual. The other characteristic of shared games is the creativity that each partner can bring to the interaction (Fogel, 1993). Laurel's son did not welcome that. Laurel perceived that Braxton saw her as an intrusion, or instrument for meeting his needs.

A more abstract form of reciprocity evolves between parent and child in the form of conversation. One would expect a lack of reciprocal conversation between parent and a child who never learned to speak. What was interesting in this study, however, was that even with highly accomplished speakers, the ability for the cooperative exchange of information and feelings was absent:

> There's not that sharing with Brayden. Like with my daughter, there is this back and forth – she talks, I talk, she talks. We're sharing our feelings, sharing our day. It's not like that with Brayden. With Brayden, it's lists. He wants me to repeat what's on his lists, and if I get it wrong, I have to start all over again. There is no intimate sharing of feelings. It's not like we are having a conversation. (Leann)

Leann did not experience an exchange of ideas and feelings when talking with her son. Her apparent function was to fulfill a need on her son's part to repeat the words on a list in the appropriate order. Novelty was strongly discouraged.

A symbolic extension of reciprocity moves from more literal exchanges (e.g., turn taking, shared movements in pat-a-cake, conversation) to the co-participation in emotional states. The emotional state can be synonymous, as in two people feeling love for one another, or opposite but coordinated, as in a child feeling fear when his or her parent is angry. Parents who noted the lack of reciprocity in the more concrete realms of game playing and verbal exchange, noted a similar inability of their children to participate with them in emotional states. Marissa stated it simply, "I loved him so much, but I didn't feel that love in return." Susan describes this further:

> I don't want to say it's been a difficult relationship, but I think maybe it's been very one-sided. I think Mary tries to share things with me like her sister Sarah does. It's hard to explain. You love your child; it's just maybe she's not been

> able to reciprocate. She can't reciprocate the love the way I want her to. (Susan)

Nedra describes the difficulty by contrasting her son with autism with her other children without autism:

> Kevin doesn't always know how that emotional give and take of relationships works, so he doesn't always give you all of that in a relationship. With my other kids, I don't know, you get a little more feedback in the relationship. I don't think Kevin gets that. (Nedra)

Nedra doubts that Kevin can read and understand how she feels. Reba similarly describes her belief that her son does not understand emotional responses: "I think if he saw me crying, he would just wonder why there was water coming out of my eyes. Seriously."

As their children got older, parents expected their children would improve in their ability to pick up on cues that the parent was in distress and in need of help. For many parents, this awareness did not appear to be growing in their children. They did not believe their children would be aware of an accident or plight on their part, even in the most dramatic circumstances. As Susan put it, "I joke that if I fell down the stairs (and cried out for help), Mary would just step right over me and keep going wherever she was going. It's a scary thought. Actually, it's terrifying." For Susan, and others, their children were just not able to pick up on cues and reciprocate with the expected actions to help someone in need.

A number of parents emphasized their role as observer rather than participant with their children. Children often seek out their parents to watch what they are doing – "look at me" becomes a familiar childhood refrain. But "look at me" is usually accompanied by “play with me.” There may be times when a parent is requested to observe, but there are other times when they are quite decidedly sought out as participants. For many of the parents in this study, their role as observer was sought almost exclusively. Leann describes it thus

> This is what it’s like – this is our relationship: We are in a cartoon all day long with Brayden. We are living a cartoon. He is the characters and he’s got all the characters with him. And you don’t necessarily have to be the cartoon; you’re just watching it. But he wants you to look at it. He wants to make sure you are looking at it. (Leann)

Brayden desires Leann to be present – to watch – but not to *contribute*, except, by following his instructions to her about repeating the words on his lists.

About 9% of parents perceived that their relationships had components of reciprocity, at least in some areas. Alice, for example, describes that her son has very good turn-taking abilities:

> When we read together, we do a lot of turn-taking. He’ll read a page and I’ll read a page. Or, if we are picking up toys together – like cars – I’ll try to make it a game. I’ll say, how many can you pick up and put in the tub? I’ll pick one up, and he’ll pick one up. There’s a lot of back and forth like that. When we are reading, or doing other simple tasks – things he enjoys doing – the turn-taking comes pretty naturally. He understands when it is his turn and when it is my turn. (Alice)

Leann was certain that her son could share emotional states, to respond with concern when she was angry and to share feelings of love and closeness:

> I feel very close with him. And he has a sense of like “I love you, mom” and if I raise my voice, he’ll go, Mom, don’t be mad at me. And he senses anger, and frustration cuz that’s a new word, "are you frustrated?" He knows I’m mad. And he’ll say, mom, I’m sorry, I’m sorry, I love you, I love you. We’re very connected that way. (Leann)

This same mom, however, reported that her son could not participate in mutual conversations, highlighting that the reciprocity only occurred in certain areas of their relationship.

One father suggested that for him, reciprocity came mostly through shared play and tasks, rather than through any kind of conversation or emotional relating:

> Yea, you know, I guess, it seems pretty normal (our relationship) for a father son thing. We like to wrestle and I tickle him. He's super playful and he always comes to me for that. He'll frequently take interest in something I'll do. Like if I'm fixing something, he'll be pretty interested, like, even if I'm just hanging a picture, he'll run up and he'll start bringing me tools. (Steve)

For Steve, the relationship had enough reciprocity to qualify as "pretty normal," and what would be expected between a father and son.

Summary

An overwhelming majority of parents perceived that their relationships with their children with autism lacked reciprocity. In this majority, 31 out of 34 parents described having children who were not at all or only minimally interested in infant games, had great difficulty having mutually satisfying conversations, generally lacked the ability to share emotional states, were unaware or non-responsive when the parent needed help, and seemed to prefer that their parent observe and comment on their play, but not necessarily contribute and introduce novelty.

These parents were acutely aware of the responsibility they had in being the architect of the parent child relationship. Their relationships lacked the quality of mutual influence and mutual construction. They could not rely on the inherent desire of both partners to contribute to shared feelings of closeness and pleasure and to seek mutual enjoyment through companionship, conversation and play (MacDonald & Carroll, 1992). If relationships can be described as partners moving toward and away from one another and back again (Fogel, 1993), the relationships of parents in this study are better described as the parent moving toward, and the child moving away. If a relationship was going to be built, the parent had to coax the child into proximity and build the alliance slowly and effortfully.

A very small minority of parents (3 of 34) perceived that their children had some ability in reciprocal interaction. This was most often seen in the ability to take turns, the ability to discern their parents' emotional states (particularly anger and sadness) and to participate in a mutually enjoyable game such as roughhousing and tickling.

Theme 3: Barriers

Finding 3: A large majority of participants (79%; 27 of 34) identified significant barriers to creating relationships

As was anticipated, there were a significant number of parents who identified multiple obstacles in creating relationships with their children. These obstacles fell into four major categories, including social and communication impairments associated with autism, parent focus on their child's deficits, parent's long term expectations for their child, and the time and intensity demands of multiple treatments. While all participants identified some challenges to overcome, about

21% of participants (7 of 34) did not associate these difficulties with creating relationships.

Different ways of being in the world. It was anticipated that the associated social and communication challenges of autism would interfere with relationship development. Tammy mentions that it is difficult to develop a relationship with someone who “can’t ever sit still and who doesn’t make eye contact!” Joie gives voice to a different type of thinking and relating to the world that goes on inside her daughter that is due to her autism and how that kept them apart:

> She was always a little harder to, she’s always felt like she’s just maybe a little bit, just out of arm’s reach, you know? I feel like I’m as close to her as anyone ever is, and that’s kinda the way I’ve always felt, that when she was little, that, I feel like her way of thinking is so different from mine and she’s not aware enough of my way to know that her way is different, so she can’t really breach the gap. It’s up to me to try and see the world through her eyes and, I feel like an interpreter a lot of times, like, um, here’s the bulk of the population and here’s Tess and here’s me trying to make her to make sense for all of them and for all of them to make sense for her. (Joie)

Joie is explaining how these differences in thinking not only affect how she relates to her daughter, but how this complicates how her daughter can relate to the bigger world outside of family. Joie refers to herself often in our interview as her daughter’s “interpreter” or “translator.” The idea that Joie needs to be around to help the world understand her daughter created particular anxiety for her about what her daughter would do when Joie is gone.

Other mothers speak to the tremendous difficulties in understanding what their children wanted and needed due to their inability to speak, point and use facial expressions or gestures. Marissa describes a typical communication interaction with her son before he received treatment and how this interfered with her ability to bond with him:

> I had to do a lot of guessing to understand what Miles wanted. Like if he wanted a drink, he couldn't tell me, it would just be he would go in the kitchen and just cry. So, I knew it was something that was in the kitchen area that he wanted, so I would pull out crackers, I'd pull out other stuff. He couldn't shake his head "yes" or "no". He couldn't use his pointer fingers. He couldn't point, so, finally, when I pulled out a cup and would fill it with water or milk, and he would take it and he would just be quiet. It almost reminded me of Helen Keller. Have you heard of the story? Where she would just walk around trying to find whatever she needed – that's kind of what it was like with him. So, it was very hard to bond with him at that point. (Marissa)

Miles could both see and hear, but his ability to use those senses to communicate was so remarkably impaired that his mother experienced him almost as if he was, like Helen Keller, both hearing and vision impaired.

Some parents found that the challenges their children face with understanding and responding to emotions made relating almost impossible. Laurel describes that her son just does not understand what people are feeling, and that this is a significant obstacle for feeling close to him:

> I don't think he really understands feelings. I don't think he understands "sad" or "happy". If I got hurt and cried out and Braxton heard me, he'd think it was funny. If the baby gets hurt, Braxton won't do anything to help. Braxton doesn't care. He doesn't understand what's going on at all. He's so unaware of other people's feelings and pain. (Laurel)

Ted uses a metaphor about nature to describe his son's lack of empathy:

> Autistic people don't exist as empathetic personalities, I mean a little bit, but not for the most part. Dylan interacts with the world the way we interact with nature. Like if the river comes up and ruins your picnic, you don't talk to the river. That's how Dylan treats people. That's how he treats kids. If it's windy, and it blows over your picnic basket, you don't personalize it, you don't empathize with it. You don't put yourself in the wind's shoes. That's how Dylan acts with people. He doesn't care. (Ted)

Ted perceives that his son does not recognize people as “persons” with minds and feelings of their own. They represent some kind of energy in his world, but he does not construct people out of the raw material he sees. It would be helpful to understand if this is also how Dylan relates to himself. If Dylan lacks concrete self-hood, he has no foundation for understanding the selves of others.

Double vision or consciousness. An unexpected finding was that parents described a deficit focus as interfering with their relationship. Spending large amounts of time focused on their children’s difficulties interfered with their ability to enjoy them for “who they are” and to be present in daily moments. This deficit focus was borne of necessity of believing that in order for their children to eventually attain independence, a parent must work diligently to fix problems in the present. It was as if parents were forced to look at their children with a kind of double vision, or double consciousness (DuBois, 1897). They are always looking at two children: the one with autism, and the one who is just their child. Where they most often rested their gaze was associated with satisfaction in their relationships. The autism acted as a competitor for the parent’s attention, squeezing out the other elements of relating.

Reba compares having a child with autism to having a child with cancer. In both cases, the parent must be vigilant around the child’s illness. In the family narrative, child is victim, autism is villain and parent is hero. As hero, the parent must vanquish the enemy to save the child’s life. This imperative leads parents like Reba to see autism every time they look at their children:

> I feel like I just take him places to get him the help he needs. I guess our relationship feels “normal”, but normal like the parent of a child who has cancer. You are always overshadowed and wondering, is he doing what he needs to be doing? Is he getting the help he needs? Am I getting him where he needs to be? That overshadows our relationship. I think it keeps it from us being, having…that’s a big part of our relationship. It keeps us from having a relationship. (Reba)

Autism becomes an unwelcome third partner in the parent child dyad.

Susan can relate well to how Reba questions whether she is doing enough to help her son because she finds herself thinking similar thoughts about her daughter:

> As a mother, it’s so hard, because it’s so easy to always see the deficits and not the good stuff. I do feel helpless sometimes. Am I doing the best I can? Is there something better I can do? What’s going to happen when I’m gone? I find myself obsessing about those things. I try to take things one day at a time, one year at a time, but a lot goes through my mind. (Susan)

For Susan, the present moment must compete with Susan’s tendency to connect her daughter’s actions with possible underlying elements connected to her disability. She sees her daughter jumping on the bed and engages with her, but another part of her sees the pathology of autism, the fear that her child will become perseverative in the activity.

> In terms of feeling interconnected, sometimes, I might be throwing her on the bed and having fun, but the very next thought is – is she going to start perseverating on this? How many times am I going to have to do this? And what’s going to happen when I want to stop? With my other daughter, it’s just a fun thing that we are doing. These thoughts always haunt me. I don’t know if it’s being cynical about everything my daughter does, like, “what’s behind this?” I am trying to understand it all. It’s a lot of work. I have a tendency to try to “fix” her. (Susan)

Susan is acutely conscious of this double awareness and brings it up repeatedly and spontaneously throughout our interview. It struck me that this was an area that she was experiencing great turmoil over, and that she was able to use our interview as a time for sorting through her thoughts and feelings. She noticed that her gaze was turned most often toward her daughter's impairments which arose from her desire for her daughter to become independent one day:

> My struggle with Mary is wanting her to succeed. I want independence for her. And because of that, I am always looking at her deficits. I don't know that it's ever really happened, that I have just enjoyed being in the moment with Mary since I have known her diagnosis. I think trying to be present with her would be very hard, because for seven years we have been trying to fix things. I just can't imagine it. It kind of makes me sad – that I can't imagine just being in the moment with her – just her and I, having fun. (Susan)

Susan cries as she is telling me this. Her desire to experience her daughter in the present and to enjoy her for who she is a theme she repeats throughout our interview.

Both Susan and Reba toy with the idea that "letting go" is a means to feel more deeply connected with their children. Susan narrates:

> I feel like there is always something nagging at the relationship with her. Is it just my perception of autism? Do I just need to let go of that and just let our relationship flourish the way it should be? Maybe I should let my dreams go…the ones I had for her. You have a baby. You don't think they are going to have any problems, and then this all unfolds and than all your dreams for this child go down the toilet. I think in some ways, all of these issues impact my relationship with Mary. Sometimes I think, maybe I should just love her for who she is and not try to make her into something that is going to be very difficult for her. That maybe I should just love the moments and not always look at her deficits. Sometimes, when she's in her own little world, skipping around or swinging on the swing, and there's this happiness, and she's giggling to herself, I wonder, what does it feel like? You know, she's pulling away from the world, but she seems so happy. I often wonder, am I pushing her too hard? Trying to turn her into something she's not? I sometimes wonder if she is in a school that is too social. Am I asking too much of her? These things haunt me in our relationship. (Susan)

The words that Susan and Reba use are evocative: overshadow, haunting, nagging. “Overshadow” has a double meaning. It evokes the loss of light, but with an element of obscuring something else. Something that overshadows steals the spotlight. Susan’s spotlight should be focused on her daughter, but instead it is focused on her autism. The words haunting and nagging both represent that another force, or person, is intruding. Something that is haunting is ever-present, hovering, inhabiting. In nagging, there is a prodding or an urging to move toward or to do something. There is an element of being scolded. This fits beautifully with Susan’s sense of perpetual guilt that she is not doing enough, not being enough, for her daughter.

Reba, like Susan, toys with the idea that letting go of expectations of wanting her child to be “normal,” might allow the relationship to blossom. Reba compares her own treatment choices for her son to the choices made by a neighbor with a son with autism who has received little treatment intervention except as provided by the public school system. Reba wonders whether there is an emotional pay-off to her neighbor’s choice that she has missed out on:

> I just have always felt – and I still do – when we found out he was autistic, I just started getting all the help I could. And that’s kind of how I’ve looked at him – not the emotional side – but the practical side of him. So I look at my neighbor, and how she’s loved her son, and although he’s still so very delayed – he doesn’t read and other stuff and he’s in 5th grade – but I have to weigh which one is better? That my son knows his academics, or that her son is so in touch with his feelings, and really seems to be more connected? And now, she’s got cancer – stage 4 – and she may die. And I sometimes think, man, just look at the relationship she’s had with her son. (Reba)

It is an odd position to be in, that a parent would have to choose between loving or treating their child. Reba struggles around whether they are mutually exclusive. She ponders this repeatedly throughout our interview. She alludes to this idea when she describes how much treatment her son received when he was very young, and how that treatment took him away from spending time with her.

> But with Matthew, he was three years old going to preschool all the time – all day long! He'd get on the bus at 8:00 and he'd come home at 4:30 in the afternoon. We didn't get to experience Matthew that much. I don't know if I'll ever have that connection that I have with the other kids, like before they started school, and they were home all the time, because Matthew was away so much in treatment. (Reba)

Even if parents do not intend to let treatment interfere with relating, however, autism treatment may be unique in the treatment of mental health and behavioral disorders in that it involves two factors that take children away from parents: the number of hours required to be effective, and the degree to which treatment is often done by professionals rather than the parents themselves. With applied behavioral analysis, for example, the prescribed number of hours of treatment per week is 40. This can either involve the child going to a school to deliver the interventions, or having tutors come into the home for 6 to 8 hour shifts, 5 to 7 days per week. For other mental health disorders, unless a child is hospitalized, treatment is usually only several hours per week.

For Louise, who sent her two children with autism to a special school implementing behavioral treatments, the number of hours spent away from her and her lack of direct involvement in the treatment process eventually took its toll on her self-concept as a mother:

> With so many hours in treatment, I didn't feel like I was raising my children! And then I finally said, "No. Three years old, six hours away from me, four days a week? Uh uh!" I was starting to feel like they weren't even my children anymore! (Louise)

Rose, whose son is now 23, conveys the shock of giving her child over to treatment:

> I mean, it killed me! I'm like, you gotta be kidding me?! So, I would take my two and a half year old, and put him on a bus, and he'd drive the bus up to school and be in school all day. And then they'd come and drop him off and I'd take him, and it was just the weirdest thing. I mean, I remember the first time, they had this big van, and I put my two and a half year old on a van, and I actually remember just thinking, really? He's two and a half! (Rose)

It is crucial to note that while treatment might have decreased parent child contact, parents noted that the gains made in treatment made it more likely that the parent and child could have a meaningful relationship. These comments were not an indictment of treatment – they were a reflection that treatment can have unintended consequences.

Even a treatment that is parent-based and parent-delivered, however, does not guarantee that the parent will find this time enjoyable or as an avenue to relate. In fact, for Cherl, delivering a play-based treatment impeded her ability to have fun with her grandson. She depicts implementing the treatment as "drudgery":

> You would never have believed sitting down and playing with a car with a kid could be so exhausting! I eventually hired a university student to come and help because I thought I just can't do this. It was taking away that enjoyment for me of "grandma". It was drudgery, and I felt like it was taking away from my relationship with him. It was no longer "grandma fun day," it was "grandma drudgery day". (Ruby)

Some parents discovered they could relate more fully and joyfully with their children when they viewed the autism as integral to whom their child was rather than something wrong that needed to be fixed. Several parents described the release of energy they experienced when they participated in this process. Clint talks about his “ah hah” moment when he dropped his expectations about his daughter’s future life:

> I just embraced it. I came to the realization that my child’s not gonna be the president of the United States. My child’s not going to be an astronaut. But by me trying to get into their world and appreciate the world from their perspective, I realized it’s not such a bad place. And so I realized, it’s not the end of the world that my child’s not gonna be president of the United States, and so you know what? I’m gonna stop and smell the roses. She’s giddy, she’s happy, she loves life, she’s joyous, and smiles and for me, that’s enough. That’s the holy grail! It was just embracing the fact that hey, I have an autistic child, and that’s OK! (Clint)

Cindy and James give voice to a similar change in the way they viewed their son:

> James: A lot of those treatments seemed more like torture rather than therapy. And so we set our goal. Our primary goal for Josh is for him to be happy. We’re not gonna go to these extremes to try and “fix” him, because, you know what? He’s not broken. We’re loving him. We’re teaching him to deal with life and to live with life. We’re just not trying to make him be like everyone else.
>
> Cindy: After we decided that, everything became a celebration again! There’s those stories of the people who come out of autism, the one in a billion that gets over it, and you hope for that, you hope that one day they’ll wake up and they won’t be autistic anymore, but it you’re hoping for that and working towards that and that’s all, you’re missing out.

For these parents, releasing their expectations of eventual independence seemed to decrease the intensity of the pursuit of treatment which freed them to focus on what they enjoyed about their children, not what was wrong with them.

Leann, who stood out among participants as having one of the most joyful connections with her son and who described feeling immensely allied and linked with her son narrates her experience of accepting what is, and allowing expectations to drop away:

> I'm not gonna heal him; I'm not gonna change him, this is who he is, and I'm just gonna love him for who he is, celebrate him for who he is. I am very satisfied with my relationship with him. I feel it's different, but it's Brayden. He brings me so much joy! Maybe he'll never contribute anything to society. My biggest thing is that I want him to be happy. He's funny and goofy and nerdy and weird and I adore him. (Leeann)

This description of Leann's attitude toward her son is not intended to imply that other parents don't love and adore their child, because it was clear that all of the parents loved their children very much, regardless of how interconnected or disconnected they felt. It can be illustrative, however, of an energy that is freed when parents accept their child's diagnosis.

Treatment providers often caution parents against letting their children participate in their areas of intense interest. It is recommended that a parent let that happen as little as possible, and to include their child in family activities as much as possible. While this is sound advice from a treatment provider, parents often reported that to actually do this was exhausting. Susan wondered if her efforts to always "pull her daughter back" from her daughter's preoccupations and interests got in the way of being able to enjoy her daughter:

> I always feel like I have to bring her back into the "circle." Like at the pool, we're there as a family, to do things together. For example, to go down the Lazy River together. But it's hard to pull her out of her perseverative behavior if she wants to be doing something else, like going down the waterslide. I am always trying to "pull her in." These issues are always nagging at me. They impact my relationship with Mary. We just don't have those feelings of pure enjoyment like I have with my other daughter. (Susan)

Susan narrates exerting tremendous effort to pull her daughter back into the relational circle and away from the interests that draw Mary magnetically away from the family. It is as if her daughter lacks the *relational endurance* to sustain connection. But the relentless and repetitive nature of Susan's efforts took away from spending enjoyable time with her daughter.

For about 21% of parents (7 of 34), the types of difficulties outlined above did not interfere with developing interconnection with their children. Alice describes that she feels very connected to her son, despite how exhausting their interactions can be, including the fact that he can become physically aggressive:

> I feel like we do have a good relationship. There is a connect there, where I know there are a lot of children with autism where you never know, or you feel like they're not really "there" when you look into their eyes. But with Brad, definitely, we connect. It's just being careful and learning how to relate to him to not set him off. When he has a meltdown, he'll throw things, he hits people, he gets aggressive. It's just a learning process about how to avoid a meltdown. (Alice)

Scott relates that although his son's first two words were "go away," and mostly directed at him, he did not see some of his son's inability to understand how someone else might feel as a barrier to relating:

> I have a really good relationship with my son. Brayden, you know, some of his first two words were: "go away". And he used those all the time on me because I wasn't there. But I didn't take it personally. I don't take any of that stuff personally. He doesn't know what he is saying when he says that. He doesn't know how hurtful those words could be to somebody. But thinking, "Oh, Brayden doesn't like me," I never thought that. So my relationship with Brayden is really good. (Scott)

Scott's understanding of how autism could affect his son's behavior helped him depersonalize potentially hurtful comments.

Jodi remarked throughout our interview that her relationship with her son was strong, and she felt connected to him, despite his autism. She seemed to be able to find ways to appreciate his unique way of connecting, rather than seeing this as a barrier to their relationship.

> I don't know if he reciprocated as much as compared to my other kids. I'm close to Adam, but he's not necessarily close to me. He's Adam, and I love him. You know how little ones usually adore you, and they need you around, you're special; you're mom; you can do no wrong; you solve all the problems; a kiss from you makes it all better; you don't really get that as much from a kid with autism, but once you accept that that's just not how they show their love and affection, then, you know, it's more tolerable, and you look for the other ways to connect. (Jodi)

For multiple reasons, this smaller group of parents appears to be able to separate out the difficulties associated with autism with their sense of connecting to their children.

Summary

A large majority (79%; 27 of 34) of participants in the study identified obstacles to developing and sustaining relationships with their children with autism. Obstacles fell into four broad categories: (1) social and communication impairments of autism; (2) parent focus on children's deficits; (3) parent long-term expectations for their children; and (4) pragmatic features associated with the time and intensity required for autism treatment. Less than one quarter of parents (21%; 7 of 34) also identified similar experiences and difficulties with their children's autism, but did not report that these difficulties got in the way of developing relationships.

Theme 4: Connections

Finding 4: Parent strategies for creating connections with their children ranged from “very limited” to “well-established”

A majority of parents (53%; 18 of 34) perceived they had found and regularly use strategies to feel close and well connected to their children. One channel for connection and relationship satisfaction was through physical closeness and affection. This could be in the form of hugs, kisses and snuggling, but also in physical play such as wrestling and tickling. This strategy for satisfying interaction might persist even as the children were reaching young adulthood or beyond. Parents also described outdoor activities such as hiking and biking which could be done together but did not involve a lot of verbal interaction. Other parents created closeness with their children by engaging regularly around their children’s area of intense interest, even if they themselves had little interest in this area. Some parents also described an avenue of connecting and feeling close that could best be described as “spiritual” or “energetic.”

One father, Greg, talks about how despite having a child with the difficulties that come with autism, his relationship with him is good because his child is emotionally expressive and affectionate, “You know, it’s really, it’s pretty good with all things considered. Because he is affectionate and because he does express his emotion; he is such a loving little boy.” Alice also feels like her 10-year-old son’s ability to be physically close to her is very sustaining and satisfying, “He’s a very snuggly kid. He’ll still sit on my lap. He’s always been like that. He loves to hug, and cuddle and kiss. He would hug and kiss me every day. That's the best. That's what I like." Leann, who describes her son as her "sunshine" and "joy" comments,

> When I am having my morning coffee he comes and cuddles up with me, I mean, he sits on my lap still, and he's 12! But he's very affectionate with me, like he'll come up and give me hugs and kisses when he goes to bed. Every morning when our alarm goes off he comes and climbs in our bed with us and he's like a little monkey. (Leann)

A number of parents experienced a sense of joy and togetherness with their children while participating in simple activities such as walking, hiking or watching television. These activities did not place a high demand on verbal or emotional interaction. They were a way for parents to be with their children without taxing relationship skills. Steve is particularly poignant in his description of time spent with his son:

> I'd scoop him up and we'd go on long walks. We spent a lot of time together that way. There's a canal down at the end of our neighborhood, a playground and stuff like that so we'd go down there and we'd just throw rocks in the water, just to get out of the house and to enjoy each other's company and the peace and quiet. I'd just put him in the big giant stroller [Steve begins to cry], yea, just walk in the sunshine, just enjoy the peace, and watch the trees, and laugh at the ducks that would be in the canal. He just thought they were hilarious when they would quack. We'd just have a nice, pleasant, quiet time together. (Steve)

Steve described many scenes like this during our interview and would often get tears in his eyes as he shared these memories of feeling close to his son. For Steve, relating to his son did not require lots of dialogue.

Some parents, like Clint, would turn a negative situation into an opportunity to "just be close." Clint explains:

> Her sleeping patterns were horrible when she was younger. A lot of times she would be up all night, and I was flat out exhausted, so I had this big recliner and I'd just prop her up on my lap and she'd sit there right next to me and we'd watch television. That opened that door to feeling close. (Clint)

One mom, Leann, felt particularly connected to her son in a number of outdoor activities in which they jointly participated – going for jogs, taking long walks, going on hikes and bike rides. In almost all cases, there was little to no discussion of any kind, despite the fact that her son is able to speak well.

> There's a lot of times when there's just the two of us, the two of us on a bike ride or at the coffee shop. You know, there's long, silent walks; there's long, silent bike rides. We'll ride in the car for a couple of hours and not really talk, the music's on, but it's OK. It's OK. It's being together. (Leann)

For a number of parents, the magic bullet for connection was to engage with their children around the child's area of intense interest. This was seen as a crucial entry point for connection. By engaging with their children on their children's terms and through their particular interests, children showed a measure of willingness to co-participate in interpersonal interaction in some cases, and to remain in simple proximity in other cases. For parents like Cindy and James, before finding this entry point, there seemed to be no way to connect and build a relationship with their son, "So we tried, oh my gosh, we tried everything! We tried farm animals; we tried some cars; just every toy imaginable, and nothing happened. He was just not at all interested." Once they discovered "Monster Jam," however, they felt like their ability to connect with him turned around:

> It wasn't until we discovered Monster Jam that he would interact with us. We credit that with bringing him back, because that was the only thing that had enough pull to drag him out of his world into ours. (Cindy)

As James remarked, Monster Jam gave them a "tow hold," a bridge for crossing a relational space between them and their child that before then felt impassable.

Steve, who described his son as "the world's number one biggest train fan," shares how he uses his son's interest in trains to spend time together:

> I like to take him down to the shows, to the hobby store, and let him look at the trains. Billy loves his trains. There're about three or four model train shows that come to town every year, so I always take him to those. I put a book on tape and head phones and I just follow him around for a couple of hours until I'm just exhausted. (Steve)

Steve describes that he and Billy really do not talk at all on these excursions, but he notes they are walking together, looking together, and spending time together, which Steve perceives as very satisfying. He puts the head phones on so he has something to do to keep himself entertained while his son looks at the trains because he is not particularly interested in trains himself.

Greg describes that his weekly excursion with his son, Brian, is their Friday afternoon trip to Wal-Mart. His son has an intense interest in the DVD section at the store. Brian enjoys taking his dad, and sometimes his sisters, to see "his" collection. Greg describes it thus:

> Greg: The first words that he ever read were "Wal-Mart". Brian loves Wal-Mart. That's his thing. Every Friday afternoon, he and I go to Wal-Mart, and we look at DVD's, because he's big into DVD's.
>
> Tracy: Is this like one of those moments of connection you described earlier that you long to have more of?
> Greg: Yea, it is, and that's why I don't mind going to Wal-Mart every Friday. Sometimes I get a little impatient, standing in the DVD section of Wal-Mart

> for 20 minutes, it's like, Brian, can we go? But he loves it, and he can keep on sharing it with me as much as he likes going.

Greg notes that it is this type of activity with his son that substiutes for what he expected when he first learned he was having a boy:

> And as a parent, as a father, I was so excited to have a son. Oh, great, we're gonna be able to do all these great things and he's gonna be a better athlete than I ever was and on and on and on, well obviously that life was flushed, at three, and all hopes of that. But we've still got these moments. Like I'd be pulling him in the wagon at the Houston Zoo, and we're going past the elephants, and he's grateful at that moment that I took him to see the elephants. And he's not crying and he's not doing anything, we're not really talking, but we've connected for two minutes. It's like taking your son to his first baseball game and you teach him how to keep score. There's none of that with us, but it's just little tiny victories like the zoo that are the great moments. (Greg)

For some parents, an opportunity for relating was simply by participating with their children in daily tasks of living. While this did not always lead to closeness, it allowed for proximity, which appeared to be an adequate substitute at times. Allen describes that this was the case for his wife, Brigitta:

> Allen: But, because life revolves around school and doing homework and going to school and doing the things we do, Brigitta continues to have just a huge amount of interaction.
>
> Brigitta: Yes, that's true. I think we're fortunate that way.
>
> Allen: So Brigitta and David have this incredibly close and intricate relationship and interaction now for years, and that continues to be the case. The lion's share goes to Brigitta in those sorts of things.

When Brigitta compares her relationship with her son to her husband's relationship, she notes:

> I think it's better for me just because of the many tasks involved in mothering and having the other dimension with school. And I'm a task oriented person. So with all of the tasks, and the sense that you're doing, giving, you sort of

> satisfy yourself with your own giving. And then, the opportunity to be in proximity to David has been satisfying in itself. We're looking at it as an overview now – there's always the challenges. But it's always been good for me to be with him, and mostly I've been satisfied with the abstraction of trying to be a good mother for him, for what he is, as different as that may be from the role of other mothers. And that has kept me busy enough and fulfilled enough. (Brigitta)

Brigitta notes that as her son gets older, and more independent, she is involved less and is beginning to experience a greater sense of loss and relational distance:

> Brigitta: But we are reaching the point, and perhaps it's the point all mothers reach, as he becomes more independent, as he needs me less, as I'm physically with him less. I'm starting to think philosophically about our relationship and this suggests to me that I'm starting to feel the gap, and so physical proximity has in many ways taken the place of the spiritual, emotional proximity. And now that we don't have that as much, I think that's why I'm starting to feel more of a gap. That's not to say there haven't been moments all along, and I expect it'll get worse as time goes on.
>
> Tracy: Does it ever feel lonely?
>
> Brigitta: Oh, ghastly lonely. Oh, yes, ghastly lonely. Without the busyness and necessity of the daily interactions, the means to connect begin to dissolve.

For a few parents in this study, particularly those with multiple children on the spectrum, participating with their children in their treatments was a way to gain a feeling of closeness and connection. This was borne of necessity because having to spend so much time with treatment left little time for other kinds of pursuits. Also, the structure of treatment allowed for relating in a way that might not have occurred in a less structured context where the child was likely to become emotionally and physically disorganized. With a child who might otherwise prefer to spend time alone in his or her room, even the time spent driving to an appointment might provide opportunities for relating. Also, with more than one child in treatment, inordinate amounts of time were dedicated to this, making opportunities for less structured interaction less available. Tammy, who has three children on the spectrum, commented,

> That's how I have fun with my kids – we do treatment (laughing)! There's not time to do anything else! Seriously, sometimes doing ABA is the best way for me to spend time with my kids. It's really structured, and I know exactly what I am supposed to do. There's much less craziness. (Tammy)

Some parents described that they felt close and connected to their children in a spiritual way. This could be defined as just feeling close and connected through some sort of invisible, energetic means, that didn't rely on any physical connection or activity. One father, James, describes the bond he feels with his son:

> I feel as close to him as any of the other kids. I think he knows how much I love him, and I feel how much he loves me. And so there's always been a bond there; there's always been, it's not a verbal thing, it's just more a feeling that you get. (James)

James's wife, Cindy, remarked, "I could just feel it. I don't know how you put that into a research paper, but I could just feel it."

Alice describes how she connects with her son's spirit:

> I can feel things from him. I feel like I can see into Brad's spirit; that I can connect to him on more of a spiritual level. I just know that he's there, that there's a being in there, that he has a purpose. He loves. I feel love back from him. (Alice)

Leann refers to her son as her soul mate, someone who melds into her, "I feel very connected. He's my little, what's the right word, he's like my little soul mate. I feel like he can meld into me, like he's part of me, almost like an extension."

For about 18% of parents (6 of 34), satisfying means to feel close to their children occurred after a period of long struggle. For these parents, the initial bond was tenuous and the early relationship, unsatisfying. But through different means, parents found ways to create closeness. Clint describes how he was not going to let his daughter's sensory issues prevent him from creating a close, affectionate relationship with his daughter:

> I get it that that may be a struggle for her, but I can't live that way. I can't have a relationship with my child when I can't show affection. So I'd say sorry, hon, you're getting a kiss anyway, and I'd give her a kiss, or I'd give her a hug or I'd give her a squeeze, and I just wouldn't back down from that, even though she'd stiff arm me, and wouldn't make eye contact with me. It was a struggle, but now she is the most loving, affectionate, touchy feely, huggy, you know, little girl you've ever met! (Clint)

Like Clint, there were other parents who set out to cultivate a physical relationship, even if it involved great difficulty in helping their children become accustomed to it due to sensory issues.

Jane narrated her journey that began as a relationship that was devoid of reciprocity and touch to one that is now rich with physical connection and affection. Jane fought for her daughter to become a co-participant in her life.

> Tracy: What were you going through? You were home alone with her…
>
> Jane: Uh huh, it was terrible. It was awful. I think I was post-partum anyway, but I'm like, how much better would it have been if I could actually interact with her? My whole life existence was to take care of this kid, who didn't care about me at all, I mean, she did. The one way we could interact with her was like chasing her. She loved, you know the really gross motor play, like throwing her on the bed, like chase around the house. Those were the only ways she would interact with us. So I would do that, but you can't do that for eight hours a day, and so we ended up starting to turn Sesame Street on, which I felt really bad about, but she loved it, and it'd actually entertain her and she wouldn't just whine at me. I'd get so frustrated, cuz I would try to

> play with her and she would walk away, and I'm like, kid, whaddya want from me?!

Jane suspected long before her pediatrician that her daughter had autism. When her daughter was finally diagnosed at around the age of 2 1/2, Jane felt relieved, even happy. She felt bad about working so hard to find a label for her daughter, but it was her first step toward understanding her child's behavior.

> I almost felt bad that I was trying to label my kid, but I just wanted to help her, I wanted to know what was going on so I could make a difference. After getting the diagnosis, it all made sense. It was almost like sunshine – I actually understood what was going on! It was the biggest relief versus feeling helpless and having no idea what is going on, at least now I understand. (Jane)

By combining early intervention services with her own efforts, Jane describes the breakthrough they have made in their relationship:

> Through lots and lots of treatment and me finally understanding how to help her, we had kind of slowly gained a relationship. But in the last six months, she's become a mommy's girl! She loves mommy. She cuddles mommy all the time. If anything's wrong now, she wants to cuddle with mom. She loves daddy, but she's a mommy's girl. (Jane)

It appears the physical closeness and her daughter seeking her for comfort and pleasure gave Jane a foundation to work from. It was from this position of closeness that she felt like there could finally be a degree of reciprocity in their relationship:

> She plays really well now! Our relationship totally changed. I think the big changing factor was being able to play because it was like we could have an interaction and actually have some kind of back and forth interaction, even if it was just putting a puzzle together. I mean, she's not great at play skills, but she can interact with people that she wants to. She actually rolled a ball back and forth last night and I was like, ahhhhhh [said with great enthusiasm], you're rolling a ball back and forth – that's amazing! Before, she would take the ball and pick it up and toss it to the side, and she wouldn't roll it back.

> She actually rolled something back like twice and I was like, you're rolling it back, this is amazing! (Jane)

At the time of our interview, Raine had just turned 3. Jane had waited a long time for this simple expression of reciprocal interaction. She acknowledges that feeling close and connected by no means requires verbal communication.

> The biggest way we connect now is through the cuddling. She just loves to cuddle and have time with mom. The talking part we don't have. But we don't need to talk to feel connected. She is very physically attached. She likes it when I give her kisses and sometimes she'll give me her hand to give me kisses and one of the ways she shows affection is she'll either put her hand on me or put her spoon on me. She doesn't actually kiss me, though. I think that's way too personal for her, too "in her face". (Jane)

Despite the fact that Jane's daughter cannot kiss her, and might never be able to, Jane still lit up with delight when she described the closeness she experiences with Raine now that her daughter is able to accept and reciprocate some affection.

For another mom, Selena, creating connection with her son began when he was an infant, actively rejecting her overtures by hitting her and pushing her away. His rejection was eroding her identity as a mother. She describes that she persisted until she felt like she had "broken through" the barriers between them. Selena comments,

> When my second child was born, Yurik was even more terrified of me touching him. He would cry like he was in horrible pain. He wouldn't sleep. His grandfather would stay up with him all night. He lived in his own world and would hit his head against the wall. Whenever I could, I would talk to him. When I was changing his diaper or changing his clothes, I would take his head between my hands and say, "Look at me. I'm your mom. We'll work this out. I love you." I did that over and over and over again. (Selena)

Selena describes how over time, and with other treatments, her son became "more calm, more relaxed" and able to smile. At 15, she describes her relationship with him as very close and very strong, "He has a lot of empathy now, and he knows he can trust me, that I'm his mom."

Some parents defined their physical relationships with their children lasting well beyond the expected developmental stage. It was important to them, however, to give their children flexibility and latitude in expressing their affection in more child-like ways, because it was to some degree a substitute for the types of interaction a parent could anticipate with a more typically maturing child.

Leann, who describes her 12-year-old son above as her "sunshine" and "joy" relays that she is sustained by her delight in her son's "goofy" behaviors and his child-like innocence. She describes her son's self proclaimed plans for his future, "He's Peter Pan forever. And he tells me all the time; I never wanna grow up, mom, never, nope, never growing up, never getting married, never leaving you. He tells me that all the time."

Leann's husband, Scott, in a separate interview, narrates a similar story:

> I mean he's 12 years old and he crawls in our bed, every morning. He still wants to cuddle. He still wants you to read him bedtime stories. He still wants you to hold him. He still wants to feel secure. Everyone wants to feel secure, but he really wants to feel secure. He hates insecurity. It's like the kid that's never grown up. And that's what we love about him. (Scott)

Neither of these parents intimated in any way during our interviews that they would try to hold their son back, or work to restrict the development of his individuation and independence seeking. But this does not mean that they cannot feel fulfilled by the child-like love and affection that he offers them on a daily basis. If it is there, they will take advantage of it as a means for relating.

About one third of the parents (29%; 10 of 34) described that they had not found a way to bridge the relational divide between themselves and their child in any kind of consistent, reliable or satisfying way. For these parents, living their relationships through "snatches" of feeling interconnected did not sustain them. Some parents, like Ted, were still very angry about their children's autism:

> I'm pretty disappointed in the whole situation. This is not a blessing. This is a hard, disappointing, sad outcome. There's no like "it's just as good, it's just different." It's not just as good. It's bad. He doesn't want to interact. I mean occasionally he does, but 80% of the time, he's self-sufficient. I mean, he's five and a half. He doesn't tell you about his day. He can't explain what he did, he can't tell you where he was, he doesn't converse. He's not special. He's delayed and handicapped and underdeveloped in a million different areas. I mean, we like him for who he is. But he's not anywhere close to a normal kid, and he never will be. (Ted)

For Ted, there is the loss of embodied relating (Fogel, 1993). There is the physical absence of his son, who does not seek him for warmth or touch, and who is only just beginning to notice when he is absent. His son's existence is ethereal to Ted, as much as Ted's existence is ethereal to his son.

Laurel's disappointment in her relationship was expressed through frustration rather than anger. She cannot keep her son close enough or still enough to generate mutual feelings of relatedness.

> Our bond isn't so good. He's hard to bond with. Like with my other son, he'll snuggle and love me and I can read to him and we can tell each other we love each other. And I do love Braxton, but I don't really feel it the same way as with my other son. We can't sit down together like that. He's running the whole time, across the room. I wish that we could really sit down, and read stories and play a game and just have that reciprocal interaction. We don't

> have a lot of that. I wish we had that because that would feel to me more like a mother son relationship than what we have. (Laurel)

Laurel has a persistent intention to relate. I hear this repeatedly through our interview. But given her son's barriers and her own self defined limits related to poor emotional self-regulation, she finds herself in endless repetitions of loss and rejection. Here she describes the hope that builds up in her as she anticipates that her son wants to play a game with her, only to be followed by the rejection she feels when he signals she is intruding on his private world:

> I try to play games with him, but he is hard to be with. He'll get the Sega game out, and he'll act like he wants you to play it. And so I'll say something like, "Oh, you want to play that? OK, let's play together". And he'll want you to turn it to the right channel. And then he'll sit there for a minute and play with it and then he'll give it to you, and he'll want you to play it so he can run around and be excited by the pictures. He doesn't necessarily want to play it together – he wants to be excited by the pictures. And if I want to switch to a different game that I want to play, he's like, "No, no, no!" That's not OK with him, and he'll turn it off. (Laurel)

Laurel's longing to be close to Braxton and the grief she experiences due to its lack is manifested throughout the interview.

Unlike some of the parents described above who used their children's obsessive interests as points of connection, one father, Allen, felt that his son's eccentric interests interfered with relating:

> Fundamental to David are his imaginary worlds. Absolutely fundamental to him. And so, when I would try to play games with him like catch or kick the soccer ball around, it would morph into this weird sort of game that involved his imaginary world, rather than just throwing the ball back and forth. I confess, I have had a hard time relating to him in the way that I had always anticipated relating to a son. (Allen)

He continues later in the interview with frustration that his son’s creative outlet is eccentric, and not one he can really relate to:

> And now he’s discovered he likes to write stories. So if there is an academic area he’s attracted to, it really is creative. I wish it could be the humanities, because that’s what Brigitta and I do. If he got interested in literature or art, we’d be all over it. Instead, he’s creating literature and art – and that’s wonderful – but it’s an outlet that kind of reinforces his eccentricities. (Allen)

While Allen appreciates his son’s creativity, he is also worried that becoming too involved or interested in it will serve to reinforce something in his son’s life that might not be in his best interest.

In the end, Allen has not been able to develop the kind of relationship he would have liked to have had with a son and the experience is sad for him:

> There’s been nothing in my sort of secret dreams for him or anything like that, nothing, none of those are being realized. Again, like I said, it takes you back to that first moment when the person you thought he might be able to become, and it’s just not. I guess that is sort of what I meant to be saying, is that there is a kind of loneliness for me, sort of a ruptured world that he lives in from me. (Allen)

A lack of physical closeness could be particularly distancing and painful for some parents. Ruby and Susan describe the consequence of not being able to hug their children:

> That was the heartbreaking part – he didn’t like to be hugged; he didn’t like to be touched. I was just so sad. (Ruby)
>
> My relationship with Mary definitely feels different compared with my relationship to my other daughter. It’s that emotional piece – the hugging – she’s never been a very huggy, feely child. It’s very distant. (Susan)

Even though parents created bridges to connect with their children, their sense of connectedness was not necessarily stable. For many parents, they vacillated between different levels of closeness and distance. Because these moments of shared understanding were often so long awaited, most parents found them to be cause for great celebration.

Reba gives voice to the gratitude and exhilaration when connection is finally made, when the relationship “dance” feels more coherent. Here she is talking about herself in relation to her seven year old son, Matthew.

> You know, his steps are just out of sync. Well, that’s not really true. It’s not that he’s out of sync. I mean, Matthew is somewhere, and we’re trying to find where he’s at – that’s our responsibility. And I would do his dance, if I knew what it was! But it’s somewhere else, and we’re trying to find him. Some days are closer – you get closer. And, I hate to keep saying it, but you just have to savor those moments because they’re few and far between. You can’t be happy 24/7. You can’t feel fulfilled and have joy all the time. So you have to take what you have and when those moments come, you have to be ready for them and soak them up and squeeze everything out of them! You remember them. Sometimes it feels like gambling. When you hit the jackpot, it’s like WOW! It’s like, OK, keep going, keep going, this is awful, and then you hit the jackpot and you go crazy! (Reba)

In a more subdued way, Susan describes her happiness when she feels in touch with her daughter.

> The other day she said, “Let’s go to the Cheesecake Factory, just you and me.” So, in some ways she can connect, but it’s at her level, and she doesn’t use quite the right words. She does have those moments when those things happen though. It’s such a happy moment when these things happen – like wanting to go to the Cheesecake Factory. (Susan)

Summary

Parent perceptions of their ability to find the means to create close and satisfying connections with their children fell into three categories. About 53% of participants felt close and satisfied. In this group, connection came through physical closeness; shared, quiet activities; entry around a child's area of interest; activities of daily life and school; and through treatment regimens and a spiritual or energetic connection. About 18% were initially quite disappointed and distressed in their relationships, but had come to find a rewarding connection. This was mostly achieved as the relationships evolved from nonphysical to physically affectionate. The remaining 29% of parents were mostly sad and disappointed with their overall feelings of disconnection and distance. This relates to some of their children's autism features such as hyperactivity and inability to sit still and focus, eccentric interests that interfere with genuine relating, aversion to physical touch and affection, and their children's decreasing dependence on them. Especially for parents in this last category there were moments of closeness that could be satisfying and sustaining, although the level of satisfaction derived from moments of connection varied among parents.

Theme 5: Change

Finding 5: While an overwhelming majority of parents described their relationships as "growing and changing", they also recognized their enduring role as caretaker of their children

There are two time periods to consider with regard to this finding. The first is historical to present for each of the parents. The second is the parent forecasting themselves into the future to describe the relationship they believe will come. In terms of historical to present, the primary finding was that changes that occurred in the child and changes that occurred in the parent conspired to change that which occurs between them. In terms of the present to the future, because of their children's disability, they were forced to focus on their role as extended caregiver.

There were no exceptions to the fact that everyone's child had changed in significant ways over time. The time and intensity of treatment differed dramatically between families, but every parent reported that their child had made progress in areas of difficulty associated with autism, including communication, social awareness and sensory processing challenges. For parents of older children (teens and adult children) there were also maturation factors that were identified as having created differences in their children's behavior, both positive and negative. When these factors combined with parents' perceptions that they had come to a greater understanding of who their children are, what they need, and how they operate in the world, parents described that their relationships were better and more fulfilling.

For Reba, and several other mothers, perceiving their children were coming to understand the concept of love, and to be able to express it toward them to any degree, was a remarkably positive experience. Here, Reba gives an account of her son beginning to understand the concept of love, and also beginning to move through developmental stages that one might expect from a much younger child:

> In the beginning, I just remember thinking, is he ever going to know what love is? Is he ever going to talk?! Are we ever going to hear his voice?! But

> as those things started to happen I felt more comfortable that the other things would start to happen, too. I still believe he is going through the same developmental stages, just later on. Does that make sense? I remember peek-a-boo not working until he was around two and a half. And even now, he'll go up to babies and say, "Peek-a-boo!" So he's getting it now, and we get to enjoy it now. It' just, kind of, a little later, which seems to fit with what they say autism is – the nerves and synapses in the brain developing a little slower and things happening a little later. (Reba)

Marissa describes feeling overjoyed when her son was able to say "I love you" for the first time:

> I remember when he said "I love you" for the first time – that was a big thing. When he figured that out and started saying that to us, that was just the highlight of my day. That was all I ever wanted from him. I mean, that's all any parent wants from their child and so when he was able to say that to us, I just broke down and cried. It was last spring when he figured that out and I'm thinking, oh my gosh, my four year old can say "I love you, mommy." It was wonderful! It was so nice to be able to have that – to have that feeling from him. To be able to feel like, oh my gosh, my child is going to be OK. Everything is going to be OK. (Marissa)

The flipside to this is Clint, a father whose daughter has made remarkable strides in becoming physically affectionate despite tremendous sensory issues when she was younger, but has still never learned to speak more than an occasional word. Clint gives voice to his pain of feeling loved, but never having heard her vocalize this to him. The following is a dialogue between Clint and his wife, Ann:

> Clint: Look at the little girl now! I'd say she just craves it (affection), and she seeks it out. And so her and I have a pretty close relationship, as close as a non-verbal relationship is gonna be. Yea, no, she's never said," Daddy, I love you" (starts to cry)…
>
> Ann: (in gentle tones) She does say "daddy" now.
>
> Clint: Yea, she does. Just "daddy," that's everything to me.

Given how much his daughter has achieved in the past 13 years, Clint remains hopeful one day Laura will be able to tell him she loves him.

One mom, who has an 18-year-old teenager with autism, describes how she has come to understand her daughter so much better over time, and how this, combined with her daughter's improved ability to regulate her moods, has helped ease many of the difficulties in their relationship:

> For about the past three years, she's probably for the most part been the easiest kid, now that I have kinda found a, sort of made peace with the idea of her having autism and since I have sort of found how she works, how her moods are, what sets her off, what doesn't, that kind of stuff. She doesn't get moody anymore, she doesn't back talk. She's amazing. She's an amazing kid. (Joie)

Another father communicates that his teen son's evolving interests in girls as combined with his son's ability to pay more attention to the world around him, has paved the way for much more satisfying, although infrequent, interactions:

> As he's gotten into puberty and is interested in girls, he can tell that I'm going to have a relationship with him over talking about that and thinking about that, that he's not going to be able to have with Brigitta. In a very belated way, he's sort of gotten the drift of what a dad can do for him that a mom can't, and what a mom can do for him that a dad can't. It's come very, very late, but as its come, it's been very nice that he would actually seek me out on those kinds of things. (Allen)

Allen is finding increased satisfaction in his relationship with David as he is sought out in the more traditional parent role as guide and mentor about life.

There were a number of parents who described that while their children had made strides with their autism difficulties, and while they had come to better understand what makes their children "tick," there was still a quality to the relationship that reminded them of having a much younger child. This was not described as a negative, however, but rather as a quality of innocence that they believed would remain for a lifetime and that they valued tremendously. One father, Clint, speaks to how his daughter will always think “I’ve hung the moon.”

In the following dialogue between Steve and me, Steve uses his relationship with his own father to describe the quality of innocence he believes he will be able to maintain with his own son over their lifetimes:

> Steve: I remember playing with my tonka trucks with my dad. I remember hanging out with him when he was working in the garage with tools and stuff, and I remember just going places with him, thinking he was the coolest thing in the world. And I’ve got that with Billy. We do things together, and we have fun together, and, yea, if you look at the bright side, I’ll always have that with him. It’ll always be like that for Billy – he’ll always have that innocent adoration for me.
>
> Tracy: So you feel like you have that, just like in the way that you felt like your dad was the coolest?
>
> Steve: Yea, yea. I think I’ll get to hold onto that for a long time.

For 2 of the parents in the study, they did not perceive that their relationships with their children had improved or grown. One mom, Susan, described her relationship with her 7-year-old daughter as “stagnant” and is sad about this enduring quality:

> I don’t think my relationship with Mary is growing. I think it is just stagnant. I think it is the same that it was since she was in preschool. I haven’t seen the emotional part grow. Certainly Mary has more language, she’s more articulate, but I don’t see our relationship as any different. It’s that connecting on a human level that’s not growing. So it’s that core deficit of autism for me that has kept the relationship stagnant. I like to think that our relationship will grow – it’s more comforting to be hopeful. I am always hopeful I will reach some sort of peace with all this stuff. Time will tell. I haven’t reached it yet. (Susan)

Camile, mom to a teenage daughter, feels her relationship has worsened over time. While she attributes some of the change to her child entering puberty and "acting like a teenager," she also attributes the disconnect as directly related to her daughter's autism. From field notes, Deb describes how her daughter comes home from school and just goes to her room. She yearns for her child to share with her all manner of things that teenagers are experiencing, that she sees her friends' daughters sharing with them. She wants to have talk of boys, and clothes and dating, but her daughter is better satisfied with intricate drawings and making friends on the internet that she has no desire to meet in person. For Camile, the rupture has become larger and more painful. While the relationship with her daughter as a young child was difficult, she believes she now has even less opportunity for sharing and joining. More than through her words, Camile's disappointment and sadness over this situation is evident in her troubled facial expressions and tone of voice during our interview.

I ended every interview by asking parents to project themselves into the future and imagine what their relationship with their children would be like 20 years from now. All but one parent (whose grown son lives in a group home) anticipated their relationship would revolve around their continued role as caretaker. Some parents appeared to look toward this outcome with dread, while others seemed almost excited by the possibilities of a lifelong connection.

One father, Ted, was quite disturbed by the possibility of needing to provide lifelong care for his child.

> I mean we don't know how we're gonna live the next 10 years, the next 20 years. We don't know if we're ever gonna be able to go out, go on a vacation. We don't know if we're ever gonna have any of the hopes and dreams we had because of a kid who can't function in the world without us. The whole family is handicapped by the disability (Ted).

Both Ted, and his wife, Gabrielle, reflected on the idea that the best outcome for them and their son would be eventual placement in a group home.

Another mom, Susan, spoke of how having to maintain the role of caregiver for a lifetime was likely to negatively impact her marriage, and she describes feeling angry about that:

> And then there is the selfish part of me, the one who wants her to go to college, to eventually leave the house. I fear she's going to be with us for the rest of our life. How will that impact my relationship with Doug? I kind of feel angry at times – I didn't sign up for this. Why should I have to deal with this? (Susan)

Some parents believed that their children would eventually achieve a mostly independent life, but that it would happen at a much later chronological age, as the children moved late through typical developmental stages of emancipation. Nedra illustrates:

> I'm certainly worried about his transitions to adulthood. He has all those gifts but I don't know how well that will translate into the ability to find a career that will use that gift. I know he'll be able to work and support himself. He doesn't have a lot of that urge to become independent, and so we're constantly having to push, OK you need to do this by yourself and OK you need to do this by yourself, and we can't push too hard because it freaks him out, and so we're having to walk this line where we're always thinking, OK, what is he ready for, what can we push him to do and what do we still do for him because he can't do that yet. He's nineteen and he still doesn't have a driver's license. And I'm sure that's a skill he could learn. (Nedra)

Nedra anticipated that her son would not remain with her and her husband forever.

Some parents believed without a doubt that their children would remain in their care in some form or another for the remainder of their shared lives. Most parents looked toward this future with acceptance, even delight.

One father has already planned the house he is going to build for his three children with autism, on some property behind his home:

> We've got a plan, you know. We're gonna buy a piece of property and depending on the level of independence, I'd like to build just a little mother in law suite with a microwave and refrigerator, so they can feel like they're living on their own right behind the house kind of thing, and that would be ideal for me. So I wholeheartedly embraced the concept, the thought that this is a lifelong thing, you know? (Clint)

Another mom, Leann, described how she and her husband were going to buy a motor home after they retired to travel around the country, and that there would always be a "wing for Brayden." She talks poignantly about imagining herself growing old with him in a dialogue with her husband:

> Leann: I envision us traveling with him a lot. I want to get a tandem bike we can ride together because I just want to keep him active and outside and doing things. We've always said when we get a camper or a trailer we'll have a wing for him.
>
> Scott: We'll have a bunk bed for Brayden.
>
> Leann: There's always a wing for Brayden. We expect he is always going to be with us. I'd like to travel more and I see us taking him with us and going places and I'd like to see him be able to work and have a job he gets some satisfaction out of but if he doesn't, I don't care. I see us taking care of him, and I always tell the other two kids they'll get him for a month every summer [laughing]. I just see us all growing old together.

Summary

All parents reported that their children had changed in a few or many ways, and that their understanding of their children had increased. These factors appeared to be associated with higher levels of satisfaction with their relationships over time. While almost all parents expected their children would require some level of lifelong care and dependence, parents had much different reactions to this possibility. For some parents, a lifelong dependence felt like a sentence. For others, it appeared to be another way for them to enjoy their life's journey together.

Summary

Five major themes emerged from during this study. First, parents differed greatly in their early relationships with their children. Descriptions ranged from feeling very close and typically bonded to feeling as if they were invisible to their son or daughter. Second, parents overwhelmingly agreed that their relationships lacked reciprocity. There was little sense of mutuality or give and take, although there were some areas where parents found their children were more skilled in this than other areas. Third, almost all parents described significant barriers to creating relationships. These ranged from the social and communication impairments related to autism to parent expectations about their children. Fourth, many parents found ways to make connections to their children that felt satisfying to them. They reported feeling close to their children, even though raising a child with autism was associated with great difficulty. Other parents were generally dissatisfied with their relationships, feeling distant and alienated. Many parents experienced feelings of closeness only intermittently, rather than in a constant or sustained way. Finally, almost all parents perceived their relationships were growing and changing over time in a more positive direction, although most parents were aware they would remain in a caretaker role.

In the next chapter I will discuss how these findings fit with the current literature and how they move beyond the literature to extend the conversation about parents relating to their children with autism.

CHAPTER V

DISCUSSION

Overview

The purpose of this study was to explore the relationships of parents and their children with autism. The hope for this work is that the findings will (1) provide a context for parents to understand their relationship with their children, (2) improve practice for professionals supporting families affected by autism, and (3) contribute to theory about the nature of autism and development in the context of social relationships. In this research I used interview-based inquiry to collect data and interpretative phenomenological analysis to develop findings. Participants in the study were primary caregivers to children with autism, and included 24 mothers and 9 fathers. One grandmother also participated, although she was not the primary caregiver for her grandson. (For ease of analysis and discussion, all participants are referred to as "parents.")

This study was framed around the following three research questions:

1. How do parents perceive and experience the nature and quality of their relationship with their children?
2. What are parents' perceptions of how they develop and sustain relationships with their children?

3. What are parents' perceptions of how their relationships with their children grow and change over time?

The findings presented in Chapter IV satisfied these three research questions. A large majority of parents experienced significant barriers that prevented them from successfully engaging their children. Some of these barriers were the social and communication challenges associated with the core deficits of autism. This finding is well documented in the literature (Baron-Cohen et al., 1996; Wimpory, Hobson, Williams & Nash, 2000). Parents were concerned that their children would not notice or respond to them if they needed help. Bacon et al. (1998) reported that children with autism have difficulty discerning when other people are in distress. Many parents perceived that their attempts to soothe and comfort their children were ignored or rejected. In other studies, parents have similarly reported that their infants and children with autism avoid contact, soothing and comfort (Cullen & Barlow, 2002; Gutstein et al., 2007; Williams, Kendell-Scott & Costall, 2005).

Most parents also agreed that their relationships felt one-sided and lacked mutuality and feelings of reciprocity. This finding resonates with other literature in which parents report their relationships are nonreciprocal (Cashin, 2004; Gutstein, 2007; Williams, Kendell-Scott, & Costall, 2005).

Parent descriptions of their early bonding and attachment experiences mirror the literature which is inconclusive. Ozonoff and South (2001), for example, reported no impairment in attachment in children with autism when compared to typically developing children. In other research, when behavioral responses at separation and reunion were compared for children with autism and their parents to typically developing children and their parents, no significant differences were found (Dissanayake & Crossley, 1997; Sigman et al., 1986). These studies conflict with findings from the qualitative literature in which most parents report they do not feel close to their children. They report feeling unacknowledged, rejected, and universally state the desire to increase feelings of closeness and connection, both physically and emotionally (Cashin, 2004; Cullen & Barlow, 2002; Cullen-Powell, Barlow & Cushway, 2005; Escalona, Field, Singer-Strunk, Cullen & Hartshorne, 2001; Field et al., 1996). The differences in these findings may relate to how attachment is being measured. It may also relate to the difference between the quantified measurement of attachment behaviors of children and how those behaviors are experienced by parents.

A factor that may be relevant to parents' perception of attachment is the idea of an extended timeframe for attachment processes to take place. There were parents in this study who felt that their children had become attached, but that the process took years rather than months. Accurately measuring attachment in children with autism may require researchers to examine children later in their development.

Parents in this study commented on the difficulties in creating relationships when their children spent significant time away from them in treatment. There is some evidence in the literature that this is a problem for parents. Hastings and

Johnson (2001) report that a parent’s time is often highly structured, and limited to driving to appointments, obtaining assessments and services, and managing the myriad of treatment providers who are involved in their child’s treatment (Hastings & Johnson, 2001). These activities may interfere with relationship building.

Some parents in this study described feeling close to their children intermittently, in “moments” or “snatches.” Multiple researchers describe similar findings. Cashin (2004) and others report that amidst the sadness of feeling distant, parents do report moments of joy and triumph when they are able to connect with their children. These moments are often so infrequent as to be noteworthy (Cullen & Barlow, 2002; Cullen-Powell, Barlow & Cushway, 2005; Trigonaki, 2002). There were many parents in this study, however, who described sustained, satisfying, close relationships. There is not a body of literature that addresses this finding.

In other research, parents have described how they turn away from themselves and toward others to find answers about their children’s atypical behaviors which are difficult to interpret (Cullen & Barlow, 2002; Cullen-Powell, Barlow & Cushway, 2005; Epstein et al., 2008; Olsson, 2004; Williams, Kendall-Scott & Costall, 2005). Parents report feeling out of control, and often seek advice and help outside of themselves rather than relying on parental instincts (Bursnall et al., 2009). Several parents in this study recounted taking a similar path to “decode” their children. These were the parents who described their children as “alien,” who turned toward autobiographies of adults with autism and science to help them interpret and understand their circumstances.

Almost every parent in this study realized they would remain in a caretaker role to varying degrees for their lifetime. Similar to Bursnall et al. (2009) and Gray (1994/2006), they found themselves involved in ongoing toileting and feeding issues, and recognized their children would need extra vigilance and care even into adulthood. A new finding to emerge from this study was that a number of parents accepted and even looked forward to that role, a more positive perspective than has been reported in the literature.

Like the parents described by Chu and Richdale (2009), parents in this study spoke of the emotional, mental and financial toll that raising children with autism has had on themselves and their families. One mother remarked, “Autism is 24/7. I don’t think other parents realize that.” In Bursnall et al. (2009) other parents described the work associated with having a child with autism as “relentless” and “the never ending story.” This can lead to exhaustion and a “wear and tear” effect on parents.

Carter et al. (2009) noted that some parents appeared to be better able to adapt to their circumstances by decreasing their expectations of their children which was associated with reductions in stress and anxiety. A number of parents in this study reported a very similar experience when they spoke of “letting go” of their expectations around their children’s eventual independence. Parents who identified themselves as having “accepted” their children’s diagnosis and being “happy” with their children for “who they are,” reported less anxiety and depression. They described having a shift in their world view, similar to the findings of King et al. (2006).

For some parents, their religious views shaped how they came to understand and accept their childrens’ disabilities. A majority of parents in this study endorsed either a Latter Day Saints or Catholic religious affiliation. Not all of the parents who fell in this category felt close to their children and content in their relationships, but many of them did. This resonates with researchers who suggest that spiritual and religious views may help parents come to terms with their circumstances. (McCubbin, McCubbin, Thompson & Thompson, 1998; Shaked & Bilu, 2006). Some parents in this study spontaneously remarked they were given their children by God; that God would not have given them this child if he did not think that they could handle it; and that there was a greater purpose to their children’s life than they would ever be able to discern. This is similar to research findings on young Latino mothers, for whom coping was enhanced in mothers who accepted that their child as a gift from God, given to them because they have been found to be worthy and that raising the child will help them become better persons (Skinner, Bailey, Correa & Rodriguez, 1999).

A new finding that emerged in this study was a belief by parents that they did not have the right to interfere with their children’s autism because the disability was part of God’s plan for the child and the parents. One father remarked, “If the Good Lord wanted my daughter to talk, she’d be talking!”

There were parents in this study who denied a religious affiliation by endorsing "none" or "not applicable." In this category, there were also parents who had come to accept their children's disability and reported their acceptance had "nothing to do with" a perspective that there is a greater meaning in life for them or for their children, or that they expected their circumstances would improve in an after life. Other parents did not disclose what might have been a nontraditional spiritual orientation that helped them come to terms with their circumstances. Spiritual orientation and religious affiliation as related to parents with autism is an area that warrants significant additional investigation.

As described above, it is evident that many of the parent stories in this study resonate with findings in the existing literature, particularly as related to negative experiences for parents. About one third of parents in this study felt alienated from their children and dissatisfied with their relationships. But for the remaining two thirds of the parents, something unexpected and surprising was happening – they were reporting *positive* experiences. These parents described feeling close and connected to their children. They told stories of relationships that were fulfilling and sustaining; relationships in which they felt loved and valued by their children. They imagined a future of lifelong companionship and caretaking with acceptance, even delight. All of these parents were involved with some kind of treatment for their children, but an overarching theme was that they were not pursuing treatments with vigor in pursuit of "fixing" a "broken" child.

To help the reader understand the richness and complexity of these two emergent groups, I have created two meta-narratives. In the first, I combine the voices of the one third of my participants who described feeling generally distant from their children with intermittent experiences of connection. In the second, I combine the voices of the two thirds of my participants who mostly described feeling close. It is important to note that for about one third of the parents in the second group, it took many years of struggle to arrive at that place. Had I interviewed them earlier in their experiences, they would likely have fallen into the first group. Thus it is likely that parents from the first group will move toward greater feelings of closeness over time. It is also important to note that even with this meta narrative, there are nuances to every individual's story that may be over- or understated in this kind of presentation. Despite its limitations, it should serve to help the reader hear and feel the parent experience.

To represent both fathers and mothers, I use masculine pronouns in the first narrative, and feminine pronouns in the second. This in no way implies that more fathers felt distant, or that more mothers felt close. I write the narratives in first-person so the reader can “hear” the story as it was told through my re-construction. I am paraphrasing quotes from participants in these narratives, but I do not identify them individually as that would interrupt the flow. Many of the quotes have already been used in Chapter IV.

Metanarrative 1

In the first narrative, I write about a fictional father, Richard, who is describing his daughter, Mary, who was diagnosed with high functioning autism at the age of 3. Richard reported that his primary concerns about his daughter before the diagnosis was made were her remarkable sleep problems and obsession with swinging.

Richard talking about his daughter, Mary, age 7.

> This is what our relationship is like. It's like we are two balls being tossed into the air that are supposed to be hitting, but we keep missing each other. Sometimes they hit, and I think that is happening more and more, but I don't know. I try to do stuff with her, but it's not that pure enjoyment, that feeling close. It feels distant, like she always wants to be doing something else. She doesn't stay with me the way her brother does. Sometimes she just wanders off while we're in the middle of something and I'm like, what the heck am I supposed to do with that?
>
> I don't really know what she's thinking. Sometimes I wonder what kind of pain she experiences during the day. Not pain, really, but what's it like in her world? I can't understand her the way I understand my son. I can't really get into her world. I don't usually know what she is thinking and feeling.
>
> I don't think she really understands feelings. I worry about that. Does she know what love is? Will she ever be able to tell me she loves me? She says it sometimes, but does she feel it? Does she know what it means?
>
> I wouldn't describe her as neglectful; it's more like she's indifferent. Neglectful sounds more like she is ignoring me on purpose. I don't think that's the case. It's more like she just doesn't notice me. I don't enter into her consciousness.
>
> I don't think she knows what to do when I am hurt. I don't know if she realizes that other people have feelings. Sometimes I joke that if I fell down the stairs she would just walk right over me and keep doing what she was doing. I joke about it, but underneath it's a scary thought. Actually, it terrifies me.
>
> If she could be interested in something I was interested in that might draw us together. But she is always in her imaginary worlds which are fundamental to her way of being. Sometimes I try to get involved, but she wants me to do this or that – she wants to direct me – and I'm usually not going in the direction she wants me to go. Everything always morphs into this kind of weird game that I don't want to be part of. I guess it's gotten

> better in some ways. Now that she is older and has some better fine motor skills, she likes to do some craft projects together. She seeks me out more around stuff like that. It's been a long time coming, but it is very nice to me that she would seek me out.
>
> Sometimes I get so frustrated I can't stand it. I feel crazy. I don't even want to visit her at school because she just ignores me. Does that sound terrible? Should a father ever feel that way? I want to be able to just sit and cuddle and read with her like I do with my son, but she is always racing around. She can't sit still. I know she tries, but…
>
> Sometimes I think the problem in our relationship is that I focus too much on what is wrong with her, rather than looking for the good things. I'm always worried about the future – will she ever get a job? Will she live on her own? Will I have to brush her teeth forever? These thoughts haunt me and I think they keep me from feeling close, from enjoying her in the moment, just for who she is. Sometimes I think I should just let her be, and let our relationship flourish the way it is supposed to.
>
> I wouldn't say we are "close" per se. Sometimes I feel close to her, but I am not sure she feels close to me. She's always slightly out of reach – kind of at arm's length. Maybe that's just her definition of closeness. Maybe she's perfectly happy the way things are. Maybe that's the way it is for autistic kids.
>
> She doesn't really count on me for any kind of parenting or emotional connection, I know that. It's almost like I am invisible, irrelevant. I think people are just ghosts in her world. When she was little, I felt so disconnected I didn't feel like I would even be part of her life. How could that be?! I am her father, and I felt like I would never be part of my two year olds' life!
>
> I don't always feel disconnected. Sometimes, there are these snatches, these moments of connection that I just try to savor. The other day we were at Village Inn. We were just sitting there. We weren't talking. We weren't doing anything, but she looked up at me and smiled and I was just like, you know what, that's the best feeling in the world. We were sharing a look over burgers and fries and that made my day. Those are the small victories, the moments I live for.

Richard's narrative is intended to demonstrate the confusion and heartache parents in the first group feel trying to understand their children, and the obstacles that arise in their attempts to seek closeness. These relationships are unlike the normative parent child relationships in which both partners appear to have inherent desire to contribute to shared feelings of closeness and pleasure

(MacDonald & Carroll, 1992). It is a story that has been well developed in the literature.

Metanarrative 2

In contrast, the following passage is a meta-narrative trying to capture the core experience of the parents who feel connected and satisfied. In this narrative, Marilyn is a fictional, 39-year-old mother to a son, Preston, age 14, who was diagnosed with low functioning autism at the age of 3 1/2. Marilyn reported that she felt that her bond with Preston was “normal” and that she has always felt close.

Marilyn talking about her 14-year-old son, Preston.

> We’re very close! He’s my sunshine, my joy! He’s never learned to speak but he’s the cuddliest, snuggliest 14 year old around! He’s a teenager, and he still loves to snuggle! I love how goofy he is, and I hope he never loses that. He loves trains so I’m always taking him to the train exhibits that come through town.
>
> We can’t talk together, so we do a lot of stuff. He loves to hike. Sometimes we go on long bike rides. He’ll just hang out with me when I do the things I like to do. When he was little, I’d scoop him up and put him in the stroller and stroll him around the neighborhood under the moonlight. That would chill him out and then I could get him ready for bed. We’d laugh when the ducks were quacking. That always cracked him up!
>
> I don’t really know how to explain it, but I have always felt like I could see into his spirit. I feel bad for some parents who have kids with autism who feel like their kid just isn’t there. Like there’s nobody inside. I have never felt that with him. I have always felt connected, like he wants a relationship with me. I was never worried about his development except he didn’t seem like he was learning to talk, so we finally took him to a specialist. I was sad, of course, like every parent is when they get that autism diagnosis, but I mostly just focused on what we needed to do next. He calls me his “best mom, Marilyn”. He called my husband “John” for about eight years, but I think he finally understands that John’s his dad!
>
> I don’t think of him as that little alien baby anymore. He seems pretty normal now. When he was little, he didn’t seem to care if I left the house. He

> wouldn't cry or anything! I can't tell you how happy I was when he cried for first time. I know that sounds crazy, like a mom shouldn't be happy when their child cries, but he never used to cry when I left. The first time he cried I called my husband and said, "He loves me! My child is four years old, and he loves me!"
>
> He doesn't really give me that same kind of emotional feedback like my other kids; I don't really get that from him. He spends a lot of time in his room. There's not a lot of give and take. In some ways, our relationship is really one sided. But I don't expect that from him because he has autism. I can't change it. I can't fix it. That's just the way he is.
>
> I think when I finally gave up thinking he was going to grow up and be independent just like his sister, I think that's when things started to get better, when I stopped worrying so much. Instead of seeing him down the road in the future as this grown up with all kinds of problems, and when I got off the roller coaster of running around trying to fix him every minute, I just accepted that he would get as far as he could, and I would support him the best I could. I figure when I'm 70 I'll still be talking to his employers, just like I talk to his teachers now!
>
> I picture us growing old together. My husband and I want to travel around in a motor home after we retire, so we'll put in a bunk bed for him and he can travel with us. My husband and I like to say, we'll always have a wing for Preston.

These groups are not as dichotomous as they are represented here, but these narratives give a flavor of the dramatic differences in parent experiences in their relationships. While there was ample literature relating to Richard's experience, there is little literature to rely on to understand Marilyn's.

A major contribution of this study is to begin the conversation about how and why these positive experiences are possible. Based on a synthesized understanding of the themes, it appears that parents who had a way to *share* something with their children – no matter how brief or insignificant – felt closer to their children than parents who did not have this. The expectation of children's response seemed dramatically reduced. As long as the experience was perceived as being *shared*, that was good enough. Often, what was shared was space and time. It was as if the expectation of typical relational mutuality, reciprocity and intimacy was altered to match the children's capacities. While the system was still co-regulated, the subtlety of the signals and the perceived value of those signals were adjusted. There is some literature that suggests that this model is a useful way for understanding relationships when a child has a disability that may impair communication, whether through physical, cognitive or social challenges (Olsson, 2004). What may be unique here, however, is that while other literature suggested that the disabled partner may make mutual adjustments for interaction, that may not be the case here. It may be that the parent makes almost all of the accommodations to create relationship. Parents in this study spoke to this idea. Parents narrated multiple avenues to create shared spaces, even if interaction was mostly absent.

There did appear to be qualifying criteria for a connection to be associated with parental satisfaction – it had to be a connection that felt *meaningful* to parents. If parents associate physical touch with closeness and their children rejected hugs, they told stories of great unhappiness and despair. If their avenue for intimacy was discussing current events and they could do this with their children, they told stories of feeling content and close. The means to connect had to match their definition of what constitutes closeness. If they could choreograph the experience to fit their definition of meaningful, they seemed satisfied, most of the time.

For this to be interpreted that some parents were better at creating connections than others, however, would be a misinterpretation of the data. In the dynamic system of parent child relationships, no single factor can account for these differences. In the remainder of this section, I discuss possible interacting elements that make this outcome more or less likely.

As a researcher, I read and reread narratives trying to tease out child, parent and contextual factors that might account for the differences between satisfied and dissatisfied parents. While I can draw no simple conclusion, I was able to identify multiple frameworks to study the question. Based on the dominant approach of the autism literature, the most logical place to start appeared to be by differentiating children by severity of diagnosis. Perhaps there was some relationship between severity of diagnosis and feelings of connection. I turned to the psychiatric and medical literature to explore this idea.

The Current Science of Autism

Research on the neurobiology of autism has advanced considerably, even since the inception of this study. It is now generally accepted that autism is a genomic disorder that is expressed in neurologically complex and varied ways (Betancur, 2011). How children express the disorder in one family can be different from how a child expresses it in another family. This may contribute to social and emotional characteristics that impact the parent child relationship and parent perception of closeness and satisfaction.

It has long been suggested that the differences in the expression of relationship behaviors is strongly associated with the heterogeneity of the disorder. Scientists no longer refer to “autism,” but rather to “autisms,” suggesting diverse etiology, expression, treatment courses and prognosis (William McMahon, presentation, 2011). While it has been common to refer to the heterogeneity of autism for a number of years, that idea has referred to *behavioral* expression of the disorder and mostly as related to severity of symptoms -- ranging from minor to severe -- and associated with functioning, from low to high. The idea of heterogeneity here is being used differently. This now refers to *qualitatively* different categories within the disorder, much like cancer is currently conceptualized. One does not view cancer as residing on a “spectrum” from “low to high” because that would imply only differences in amount, not quality. Because our understanding of cancer as a disease process is so much more literate than our understanding of autism, we can identify and categorize cancer into different types. We are just in the beginning stages of having a similar ability to categorize autism based on different phenotypes.

In a comprehensive review of the clinical and research genetics literature, Betancur (2011) asserts that autism is a “behavioral manifestation of tens or perhaps hundreds of genetic and genomic disorders” (p. 42). The range in severity of the core neurological impairments combined with a multitude of associated symptoms blend to create a disorder with highly diverse expression (Pelphrey, Shultz, Hudac & Vander Wyk, 2011). The core deficit has been suggested to be a failure in the anatomical development of the “social brain” primarily affecting an individual’s capacity to participate in social interaction (Pelphrey et al., 2011). The variation in the degree of impairment in the social brain, however, will differentially influence the social characteristics and capacities that a child with autism brings to the parent child relationship. It is therefore not hard to imagine that parents would have very different experiences in their relationships based on the “type” of autism and the array of co-morbid conditions.

Despite the evolution in our scientific understanding of autism phenotypes, the idea of autism as residing on a spectrum continues to dominate the literature, and with it the embedded assumption that as children move from lower to higher functioning (autism to Aspergers, for example) and presumably from a greater to a fewer number of autism characteristics, relationships for parents would become relatively easier. This association was not borne out in this study. There are examples of parents, Clint and Rose, for example, who have children who have never learned to speak and who are labeled “low functioning.” Both of these parents placed themselves in the group of parents who feel close and satisfied in their relationships. Contrast this to Tammy and Allen, parents to children with Aspergers who are labeled “high functioning,” whose children are highly verbally skilled, who were much less positive about how they experience their sons. Verbal capacity alone was not enough to bridge the relational gap. In fact, verbal fluency can interfere with relating, as is attested to by many parents with Aspergers children who do not enjoy their children's frequent monologues.

Turning away from the idea that severity of diagnosis would be associated with decreased feelings of connection, perhaps co-occurring challenges account for differences. In this study, some of the children with autism had severe sensory processing challenges such as an aversion to touch, separate and apart from where they were diagnosed along the spectrum. This "tactile defensiveness" is not a defining characteristic of autism, but it can be a co-occurring impairment. When children were not able to be physically affectionate, however, parent perception of relationship closeness and satisfaction was usually very low. In fact, the inability to be physically connected created a perception for many parents of a ruptured relationship. For many parents, being able to hold and soothe their babies was the *definition* of relationship.

This would suggest that perhaps one of the differences for parents who feel more or less satisfied is the receptivity of their children to being held and touched. There is literature that suggests this. In several qualitative works, parents almost universally concur they do not feel close to their children with autism. They describe feeling distant, constrained, limited, "shut out" and unacknowledged (Cashin, 2004; Cullen & Barlow, 2002; Cullen-Powell, Barlow & Cushway, 2005). They report feeling actively rejected, pushed away, ignored and avoided (Escalona, Field, Singer-Strunk, Cullen & Hartshorne, 2001). They almost universally state the desire to increase feelings of closeness and connection, both physically and emotionally (Field et al., 1996). In two qualitative works in which touch interventions were conducted (Cullen & Barlow, 2002; Cullen-Powell, Barlow & Cushway, 2005), the researchers found that by teaching parents particular ways of touching and giving massage, their children responded quite positively. Dramatically, *all* participants in both studies report feelings of increased closeness and intimacy with their children following the touch-based interventions. They report increased satisfaction with their relationships and increased ability to relax with their children. Interestingly, they still report that the relationship feels one-sided, with the child being "in charge" of when and how the touch interventions take place.

This finding resonates with the parents in this study who felt alienated and distant from their children until their children were able to overcome touch aversion. It does not resonate, however, with the parents in this study who felt close to their children, despite their children being reluctant to make physical contact. Again, this may speak to qualitatively different types of autism and the complexity of co-occurring conditions. It is possible that the type of parent who would self-select to participate in a "massage intervention" would be the parent of a child with a particular type of autism and/or sensory processing impairment. The recommendation of massage as a means to increase feelings of closeness would be helpful to parents with this kind of autism, but not necessarily needed or useful for parents with children with different kinds of autism. Treatments need to be specific to phenotype.

A child characteristic that has not been well studied is relational orientation. I am using this to describe whether a child is more or less open to relating. This could be defined as a willingness to approach a parent (proximity seeking), the frequent use of social referencing, and the use of a communication style that projects warmth.

There is some suggestion in this study that the parents who were satisfied in their relationships also had children who had a more open relational orientation. These were the children who sought out their parents for interaction, even if the interaction was described as nonreciprocal. Leann is a good example of this. Leann's son, Brayden, who is 11, seeks her out often throughout the day. He has lists that he brings to her with the names of cartoon characters on them. He wants her to repeat the lists. If she makes a mistake, he insists she repeat the list again, starting from the beginning. An observational analysis of this dyad might produce the finding that the interaction lacked mutuality and reciprocity, a core deficit of autism. But this finding would miss the context of the interaction, which is the number of times her son approaches her throughout the day and how Leann *feels* about the interaction.

During my interview with Leann, Brayden was watching television in the other room. Over the course of our 2 hour interview, he entered the kitchen four or more times to interact with his mother. He brought her his lists as Leann had described, and he also smiled, frequently referencing her face and giving off an overall air of happiness and satisfaction with his mother.

Compare this to Ted, whose son was described by his parents as remote and distant. Like Brayden, he was diagnosed with high functioning autism (HFA) as a toddler. Ted's son, Dylan, age 5, was also present during our interview. He spent most of his time in a nearby room, talking to himself, walking up and down the stairs, and fiddling with the blinds. He is classified as having HFA because he can speak and attend preschool. He only came over when directly requested by his parents. His father explained they had taught him to be "very compliant" which was his explanation for Dylan coming over to us so promptly. Because of his promptness in responding to commands such as "come over here," Ted described that his son was almost like a "pet" that comes when he is called. Ted has very low levels of satisfaction in the relationship. He is disappointed, angry and feels like his entire family is now "handicapped." He does not see himself as having a useful function as a father to Dylan, and nor does he believe that Dylan relies on him as a parent. Dylan could have come from Kanner's original sample of boys he examined and from whom he first identified the "autistic affective disorder." Dylan appears disinterested in people and is described by his parents as having odd preoccupations, much like the boys in that sample. Is it possible that some of the difference between Leann and Ted's feelings of closeness can be accounted for by the differences in the approach/avoid orientation of their children? And can this be accounted for by differences in phenotype?

A complicating factor in this example is how the children approached their parents, once the approach was made. In my interview with Leann, when

Brayden entered the kitchen, he ignored me, the stranger, but he would always look and smile at his mother. She appeared to be special to him. In my interview with Ted and his wife, when Dylan came into the room where we were talking, his affect remained unchanged. Like Brayden, he ignored me. He did not approach his parents with smiles or conventionally accepted behavioral configurations that would imply warmth. He came over to his father as requested, and answered a question about his school day. His gaze toward his father was fleeting. When his father appeared to have nothing else for him to do, he left the room and continued with his previous activities. There was no sense that he did not *like* me or his parents. There was the feeling that he had no *interest* in us.

Now we have to consider that there is a confound between how often a parent is approached, combined with the quality of the approach. Multiple approaches from an annoying or emotionally distant child are not the same as multiple approaches from a child whose approaches are desirable. Consider the cases of Allen and Laurel.

Both parents described their children as “approaching.” But the approach was not desirable. Allen describes it as his son, “Coming at me. I couldn’t get a break.” His son’s approaches and bids for interaction were considered eccentric and unwelcome. Laurel describes her son as “looking like he wants to interact, but then being totally aggravating because he wants total control and I end up yelling at him.” These children were not described as “remote” and “distant.” In fact they sought out interaction with their parents frequently, but the overall quality of the relationship was still perceived as unsatisfying most of the time.

Relational orientation alone is not enough to understand differences in feelings of closeness and satisfaction. There were also children who were described as remote, who ate dinner away from the family, whose interactions were mostly one-sided, and yet still the parent described satisfaction and closeness. It is difficult to understand how child characteristics alone could account for differences. It becomes apparent that other frameworks are needed.

Parent Expectations

One factor that helps bring some clarity to the conversation is differences in parental expectations of what relating with a child is “supposed” to be like. One of the most intriguing cases is that of Jodi. It is highly possible that Jodi’s son could have been diagnosed with autism before the age of two based on our current understanding of how autism is expressed at very young ages. These characteristics correspond to the description that Jodi gave of Adam as an infant – tactile defensive, perseverative, nonresponsive in social interaction and delayed in communication development. We might predict that Jodi would have felt distant from her infant son, but this was not the case. Jodi did struggle, but it was a struggle around nonrelational elements such as sleep disturbances, pottying, tantrums and eating difficulties. Jodi had explanations for her son’s behavior. She was not surprised, for example, that her son did not want to be held, because she was often reminded by her mother that she was “the same way” when she was an infant. She attributed this characteristic to his genetically determined temperament and worked around it. She was not concerned or deterred from what might be described by an outsider as unusual play. She explains that the fact that all he wanted to do was “line up” cars was not a deterrent to interaction. In fact, it was an entry point. Jodi narrates all of this in the following:

> Jodi: He didn’t like to play peek-a-boo, things like that, but I figured that was just his personality, the games that you play with babies and the songs you sing and patty-cake, he just wasn’t interested. He wouldn’t respond to you. My mom is always reminding me that when I was a baby I didn’t like to be held, and that she had to hold me facing out and that I would flail my arms and kick and scream. I realize now I had a lot of sensory issues, that’s my contribution to Adam!
>
> T: Did you feel a mutual connection, even though he didn’t like to play those typical baby games and could be unresponsive?
>
> J: Yea, because we would do other things. He liked lining up cars, and I’m a huge auto racing fan, so I thought he was lining them up like in the start of a car race, so I thought that was great. So we would do that together.
>
> T: Was there a sense of mutual give and take?
>
> J: I think it was more like he was allowing me to be in his space with him, it wasn’t more of an interactive thing.

For Jodi, for whatever set of complex reasons associated with her own upbringing, her expectations for parent infant relationships, and her predilection for auto racing, she did not characterize her relationship with Adam as unfulfilling or difficult. She describes it as close and satisfying in the present, but more importantly, in their early history together, before he had treatment.

Jane, who had a daughter very similar to Adam in terms of ASD characteristics -- social unresponsiveness, tantrums, lack of play skills and the rejection of being held and cuddled – had a very different experience than Jodi in her early relationship. Trained in early child development and a social worker, Jane brought very different expectations to her relationship with Raine. Jane knew that her child had autism long before anyone else would agree to give her a diagnosis. That is how sensitive her antenna was to relational dimensions such as reciprocity and how important those dimensions were for her to feel connected. Jane talks about what she expected having a child would be like as compared to the reality of her experience with her baby daughter:

> We didn't have the emotional connection when she was a baby. I just didn't understand it; you're just supposed to be connected; you're just supposed to love them and they love you. But the emotional connection, I mean, it was so frustrating that it wasn't there; I just found her so frustrating; I couldn't connect with her; I couldn't teach her anything, I couldn't do anything with her; it just made me crazy like I loved her and I would have been hit by a bus for her, but emotionally it just wasn't there. (Jane)

The emotional intensity she seeks did not seem to be present in Jodi's early interactions with Adam either, but Jodi did not require the emotional intensity to feel connected. For her, lining up cars with her son sufficed. They brought different expectations, explanations and understanding to their relationships, and these ways of thinking about their children seemed to be associated with their levels of satisfaction and feelings of closeness.

While some aspects of child characteristics combined with parental expectations explained a greater number of the parent experiences, these two areas alone could not account for some of the stories that were told. Some parents needed to construct new meaning.

Parent / Cognitive Construction

In Piaget's model of cognitive constructivism, knowledge is created from what one knows and what one is experiencing (Piaget, 2000). Experiences either confirm or challenge existing cognitive schema. Over time, individuals make changes in how they understand the world. This process was evident in some of the stories of the parents in this study. Through their experiences, they changed their internal schemas they had about their children. This freed them to appreciate their children in different ways. James describes how they looked at their son differently after they accepted his autism:

> James: A lot of those treatments seemed more like torture rather than therapy. And so we set our goal. Our primary goal for Josh is for him to be happy. We're not gonna go to these extremes to try and "fix" him, because, you know what? He's not broken. We're loving him. We're teaching him to deal with life and to live with life. We're just not trying to make him be like everyone else.
>
> Cindy: After we decided that, everything became a celebration again! There's those stories of the people who come out of autism, the one in a billion that gets over it, and you hope for that, you hope that one day they'll wake up and they won't be autistic anymore, but it you're hoping for that and working towards that and that's all, you're missing out.

Allen, during the participant feedback process, emphasizes the hazards of the future orientation which can cause parents to "miss" the child in the present:

> The bigger problem for us has been finding ourselves sometimes focusing anxiously on the problems and uncertainties of the future rather than the incremental progress of the present. When we projected the little person of the present, deficits and all on an imagined person of 10, 20 years later, this

> produced a great deal of anxiety and interference in our ability to notice whatever abilities he did have. We found ourselves more irritated with him, and even treating him differently, paradoxically having higher expectations of him precisely because we were in our minds dealing with the 17 year-old we feared he would become, rather than the 7 year-old he was, who indeed had lots of deficits, but who also was making very small, but significant progress in important ways, and who was for all of his deficits very loveable in so many ways that we were sometimes missing. (Allen)

Allen's experience is supported in the literature. For most parents, feelings of loss and grief are common reactions to a diagnosis of autism in their child (Chu & Richdale, 2009; Dumas et al., 1991; Estes et al., 2009). The child they thought they had is transformed into a child who is likely to have lifelong, severe disabilities. Dreams for their child vanish, replaced by confusion, anxiety and fear about the future (Bursnall, Kennedy, Senior & Violet, 2009; Cashin, 2004; Kanner, 1943; Trigonaki, 2002; Williams, Kendell-Scott & Costall, 2005). But if they can construct new lenses for viewing their children, this can contribute to greater peace of mind and more fulfilling interactions.

Summary

These three elements – child characteristics (including autism phenotype), parent expectations around the meaning of "relating," and parent cognitive constructions of their world may all simultaneously interact to support more or less satisfying relationships. What is missing from this discussion, however, is an examination of how social factors also impact parent relationships. I review some of those elements in the next section.

Social Constructions and Understandings

Cognitive constructs and meanings do not simply arise within individuals. How we think about the world is socially influenced. The cognitive maps in parents' heads are influenced by social constructs around religion, disability, economics, politics, culture and gender.

Religion

The social construction of religion played an interesting role in parent narratives. Ted said to me during our interview, "You can use me as your one non-LDS example of someone who thinks all of this is really bad!" He described that he did not have a religious framework to "explain" his son's disability. He remarked, "I don't think that we are all going to die and all live happily ever after in a happy place. I don't believe that. What I have to deal with is what is here and now, and it's not good!"

Compare this to a number of parents who spontaneously remarked they were given their children by God; that God would not have given them this child if he did not think that they could handle it; and that there was a greater purpose to their children's lives than they would ever be able to discern. If we believe we were chosen to shoulder a hardship and that there is meaning (and reward) in doing that the best we can, is it not likely to create a different experience than if we believe we randomly gave birth to a child with a severe handicap that is going to impact us negatively for the rest of our lives? One father took this idea a step further and suggests that it is not his purview to change his child: “If the Good Lord wanted my daughter to talk, she’d be talking!”

Conceptualizations of Disability

Disability theory suggests that the concept of disability itself is a social construction. Someone is only disabled to the extent that they cannot participate in a particular environment. Limitations in the environment, not impairments that reside within them, cause them to be dis-abled. Altering environments will reduce disability. As parents, we internalize social constructions of disability and may view our child, and ourselves, differently as a result. This may explain parents who describe their children as “alien.” The concept of “alien” implies comparison to “other,” to be different from someone else. Where are parents’ understandings of “difference” coming from? Is this a societal projection?

There is support for this in the literature related to how disabilities are perceived across cultures. In some Native American communities, a child’s functional abilities are valued over their disabilities, and there are often no labels in these cultures for disabilities such as autism (Connors & Donnellan, 1998). Instead, the child is often referred to by a descriptive label (e.g., “she runs away” or “he gets excited”) rather than a classification denoting pathology (Connors & Donnellan, 1998).

In a culture in which he is labeled, “can’t sit still and concentrate in class,” he will probably require a diagnosis and environmentally based “accommodations.” Whether a child seems “alien” to his parents is in part a function of how the parent has been culturally conditioned to view that child. This social construction becomes a factor in how they relate to their child.

Socioeconomic Factors

How much of what parents want for their children with autism is socially and culturally influenced? How much is the drive to help their child achieve independence a function of social expectation, particularly in market economies where productivity is so highly valued? Understanding this is essential because the social pressure to “fix” one’s child appears to be related to a parent’s satisfaction in their relationship.

There are also socioeconomic issues that impact parent relationships. The only evidence based treatment for autism, Applied Behavioral Analysis, is notoriously expensive. If done as originally intended (40 hours per week, most weeks of the year) it can cost between $50k and $70k per year. Pressure on a parent to want to treat their child and to not be able to afford it can directly influence their relationship. Jane, during the participant feedback process, described how this negatively affects her play with Raine:

> I feel grief that comes with feeling helpless to “fix” her or to get all the services she needs. I get so sad that I can’t make it all right or even afford the services that would make a difference that playing with her can be overwhelming for me. (Jane)

There are a number of studies that may relate to these findings, and expand them as well. There is some literature that suggests that parents of children with autism interact with their children with autism for shorter periods of time than parents of children with other types of disabilities and parents of typically developing children (Crawley, & Spiker, 1983; Konstantareas, 1991; Konstantareas & Homatidis, 1988/1992). An assumption of the current study was that this may be due to the tendency of a child with autism to actively reject, ignore or negatively respond to parental bids for interaction. The finding from this study may add to that conclusion that perhaps part of the reluctance to engage is to avoid being confronted with either behavior one does not believe they can fix or behavior which creates anxiety about the future.

One mother describes her great reluctance about visiting her child in his school which may be explained by this finding:

> I hate going to his school and spending time with him. It should be the opposite. I should want to spend time with my son. But I don't want to go there, because it makes me think about my future, and how he's going to be like this forever, and how I can't control him and how upsetting that is to me. It puts me in a depressive mode for like a day and a half. Seriously, sometimes I just want to pay the extra money so that I don't have to go to the school. And I think, what mother wants that? Shouldn't I want to have a relationship with my child? I do want a relationship with him, but it's so aggravating. And I don't like that, and I'm really bothered by that, but I don't know how to change it. (Laurel)

In either case, the avoidance now relates not just to the child's behavior, but to the unique significance a parent attaches to that behavior and the emotional response that results from that. Rounding out this finding in this way creates a more relational and perhaps realistic perspective about how both parent and child might contribute to reduced interaction.

Cultural Factors

I had intended to investigate parent relationships from at least two cultural perspectives: non-Latino and Latino. This goal has been thwarted by my slow entry into the Latino community. Only 4 of my participants self-identified as Latino.

Based on this small and self-selected sample, however, no cultural differences were identified in how individuals experienced their relationships. There was a difference, however, between the parents in Utah and the mothers in Mexico around assigning blame for their children's condition. None of the mothers who live in Utah reported that they were blamed by their spouses or pediatricians for their children's condition. Both mothers from Mexico, however, reported that their doctors told them they were "bad mothers" and "doing things wrong" and therefore it was their "fault" that they were struggling with their babies. When one of the mothers was asked why she thought her doctor was blaming her, she replied, "Because in Mexico everything is behind the times. People don't know enough about autism here." Part of her motivation for participating in the study was the hope that her story would increase awareness in the United States about the struggles of mothers like her living in Mexico. The literature on qualitative experiences of parents in relationships with their children with autism is scant and given the very small number of participants from Mexico, it is not prudent to over interpret this finding. Additional investigation in this area is warranted.

Gender Differences

A serendipitous finding in this area was a gender difference in perception of the cause of problems in the early relationship. Given the small sample and the self-selection of participants, interpreting this difference is not meant to imply statistical significance. But based on the parent stories, there was a meaningful difference in how mothers and fathers explained their children's early difficulties to themselves.

Among mothers who described their attachment as disrupted, about 40% blamed themselves for difficulties in bonding and attachment. None of the fathers expressed self-blame. Of the mothers who blamed themselves, 8% were also blamed by their spouses and pediatricians. No fathers reported being blamed by their spouses or pediatricians. The 2 women who were blamed by their spouses and doctors both live in Mexico, one in a small, rural community, and one in a large, economically important city.

Historically, parents in general, and mothers in particular, were blamed by for their children's autism. Kysar (1968) describes Eisenberg and Kanner's characterizations of parents with children with autism:

> Eisenberg and Kanner depicted parents in their series of autistic children as characterized by qualities of 'emotional frigidity', 'mechanization of care and almost total absence of emotional warmth'. Bettelheim has written that the mother's pathology is often severe … He asserts that the initial cause of withdrawal is the child's correct interpretation of the negative emotions with which the most significant figures in his environment approach him. (p. 564)

By the 1950s, this constellation of characteristics and pathology became known as the "refrigerator mother."

Although the mothers in the study were not familiar with this term, they nonetheless turned first to themselves to explain their children's unusual attachment behaviors. There is little in literature specifically about mothers blaming themselves for their children's autism, but there is discussion of mother-blaming in the general medical literature. Kuhn and Carter (2006), for example, found that it is not uncommon for mothers to blame themselves for their children's health problems. With regard to why no fathers blamed themselves, Jackson and Mannix (2004) found that women are more likely to seek healthcare for their children and therefore withstand greater scrutiny, perhaps suggesting why mothers are more likely to blame themselves than fathers. An avenue for future research would be investigating possible gender differences between men and women in how they make attributions about blame.

It should not be overlooked, however, that because a father did not comment on feeling responsible in some way, that he did not feel responsible. Men may be acculturated to disclose less if they think they will be perceived as weak. This may have been particularly present being interviewed by a female researcher. Ascribing self-blame might have felt undesirable and uncomfortable. Men might have responded differently on an anonymous survey. This speaks to a need for further research on the differences between what men and women may reveal during one-on-one interviews, particularly as related to holding oneself accountable for what is perceived as a negative outcome.

Summary

The number of elements that contribute to why parents may experience their relationships so differently are dizzying. The individual and social elements described above are not an exhaustive list. But the idea that there is an interaction among child, parent and contextual characteristics that contributes to feelings of closeness and satisfaction is important and warrants much additional study. The model in Figure 3 may be a starting point for discussing our understanding of the complex variables that interact to produce meaningful differences in how parents experience their children.

Factors Contributing to Perceptions of Closeness and Connection
between Parents and their Children with Autism

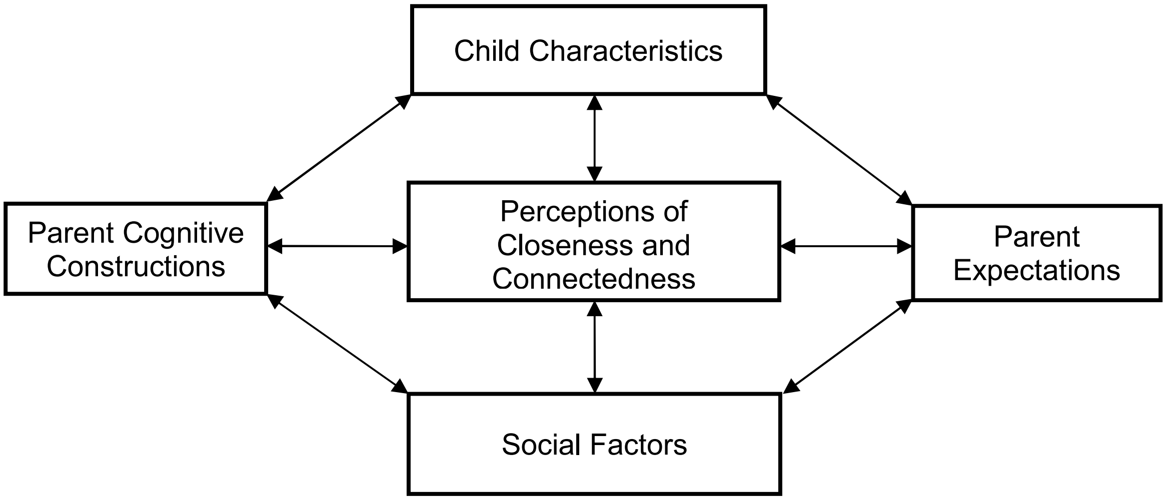


Figure 3. A Multivariable Model for Understanding Perceived Connectedness between Parents and their Children with Autism

Significant additional research is warranted in this area to expand and test this model.

Assumptions Revisited

The primary assumption in the beginning of this study was that parents would experience their relationships as alienating, painful and confusing. The secondary assumption was that these feelings would create distance and longing for closeness. The third assumption was that these problems would be associated with the social relatedness impairments that children bring to relationships. These assumptions matched the experiences of about one third of the parents in this study. For the remaining two thirds, these assumptions were not met. The model described above is an attempt to explain this outcome.

Methodological Considerations

It may be an artifact of the nonrandom sample that two thirds of the parents in this study were unexpectedly positive about their relationships. Parents were invited via online announcements to participate in a study exploring their relationships with their children. Parents with positive relationships may have been more likely to want to discuss this topic, and may have self-selected at a higher rate to participate. There was some indication of this in the way that some parents responded to the request for participation. One parent remarked in an email: “I’d love to be part of your study. My daughter and I have a really good relationship.” The mother to one of the fathers in the study made a similar comment, “I really think you should talk to my son. He’s done amazing things with his three kids who all have autism. He has spent so much time developing relationships with them.”

Social desirability may also have played a role. Parents may have wanted to impress the researcher by describing positive relationships that could be attributed to their effective parenting and good treatment choices They may also have been embarrassed to reveal negative thoughts about their children and parenting. There is some autism literature that a parent’s guilt or denial contribute to overstating feelings of closeness (Hoffman et al., 2009).

The impact of religious affiliation on parent conceptualizations of their relationships is also worth considering. It may be that the religion a participant endorses influences how they perceive their relationship and whether they describe it to an outsider as more or less satisfying. There was some indication that for some of the parents, their religious beliefs contributed to putting a more positive perspective on their circumstances. In both the LDS and Catholic faiths there is a strong emphasis on family relationships, and since the combined percent of participants from these two faiths was 71%, this may have influenced the findings. The useful aspect of qualitative work, however, is that as a researcher I have access to individual cases, and I know that there were parents who were either LDS or Catholic who did not describe their relationships in positive terms, and there were parents who denied having a strong faith background who were quite satisfied with their relationships.

It is possible that open-ended, semistructured interviews provided parents with the opportunity to describe the complexities of their relationships that may have revealed more examples of idiosyncratic positive methods for feeling close and satisfied in one's relationships that may not have been found on survey-type instruments and scales with predetermined categories.

While it is not typical to critique the sample procedures in a purely phenomenological study, there are elements of this interpretation that move toward positivist science. As was stated in Chapter III, this requires some ability to move between constructivist and positivist paradigms without having to reject one or the other as more useful. Regardless of whether "greater" or "fewer" parents experience feelings of closeness and connection, however, the contribution of all of the parent experiences to better understand the phenomenon can stand on their own as important and meaningful.

Conclusions

Parents with children with autism can experience great satisfaction, joy and closeness in their relationships. Parents can also feel alienated and distant, and long for connection. Most parents move between the two ends of this connectedness continuum – as is typical in all human relationships – because relating is a dynamic process, not a static state. Many parents experience that their relationships improve and they feel closer to their children and more satisfied over time, especially as they have been able to develop a better and clearer understanding of their children's unique patterns of relating.

The elements that influence how and whether parents experience connection are innumerable. They include individual factors and social factors. The partial list of individual factors include the type of autism a child has, co-occurring conditions, child temperament, child and parent relational orientation, parent expectations, parent gender and parent constructed cognitions. The partial list of social factors includes the influence of social constructs of religion and disability, socioeconomic and political influences and cultural contributions. All of these factors are influenced by time.

A useful way of organizing these multiple influences is to revisit the original theoretical framework set forth in this thesis, the concept of the parent child relationship as a dynamic system that is ever changing. Even using qualitative methods, I reduce the system in order to discuss it. To try to capture the parent child relationship in the frame of a study like this is to try to capture the essence of a dance in a still photograph. It can be done, but it is not completely satisfying or completely whole.

Understood with its limitations, this study adds to the literature by refocusing the conversation about parents and children and autism onto (1) the positive relationship possibilities, and (2) the vital need for parents to feel connected to their children.

Recommendations

There are a number of ways this research can be useful. As was my original intent, I hope these findings make the lives of parents better, the lives of professionals more effective, and our conceptualization of autism more useful. In order to do this effectively, researchers, professionals and educators need to unite their knowledge and resources to support parents, educate professionals, and further investigate relationship models in diverse circumstances. The following suggestions could be implemented through the development of self-help materials, curriculum for support groups, and integration into social work education, and other venues for continued education for other, relevant professionals.

Supporting Parents

As researchers, professionals and educators, we need to unite our knowledge and resources to more effectively support parents who live in families affected by autism. I believe we can accomplish this in the following ways:

1. We need to help parents find ways to connect to their children that are meaningful to parents.
2. We need to consider that parents need more from professionals than information about how to help their children. They need strategies for feeling closer to their children.
3. We need to give parents access to other parent stories. One idea is to create a parent story corps for parents to both participate in and listen to.
4. We need to teach parents about the dynamic systems perspective to expand their understanding of their circumstances to lessen self-blame.

5. We need to provide parents with materials that are based on both qualitative and quantitative research. Parents need both generalizations and case studies to find themselves represented.
6. We need to provide greater support to Latino families and to work more effectively and consistently to get them involved in research.

Supporting Professionals

1. We need to train practitioners in dynamic systems so they can carry complex models with them in their interactions with families
2. We need to train practitioners using findings from both quantitative and qualitative research. They need to understand the general and the particular to be best prepared to help individual parents.
3. We need to train professionals to consider the impact of positive parent child relationships on the entire treatment endeavor.
4. We need to train professionals to understand that a parent child relationship can be satisfying and sustaining, even if it looks different from normative parent child relationships.
5. We need to train professionals to understand how social influences and constructions, especially as related to disabilities, impact parents.

Extending Theory

We need to start a conversation about how we talk about autism. We may find it more useful to move away from the idea of autism as a spectrum disorder to autism as a multiform or “manifold” disorder.

We need to broaden the conversation about parent child relationships to include atypical expressions of those relationships between parents and their children with disabilities.

Areas for Future Research

I think it is critical to continue to investigate relationships between parents and their children with autism. I think both qualitative and quantitative research is needed. The movement from constructing meta-stories to focusing on a set of discreet variables and back again enriches our overall understanding of the phenomenon and moves knowledge development forward. Almost every element identified in Chapter V would be a potential area for research. One intriguing area would be to study relational style of children with autism. Another fruitful area of research might be gender differences related to feelings of closeness and satisfaction. Attention needs to be paid to cultural differences and similarities in parent experience. Other areas would be how parents use religion and other meaning of life constructions to understand their experiences.

Investigating the association between parent perceptions of connection with their children and parent variables such as depression and anxiety would also be fruitful. It may be that one of the factors that contributes to greater distress for parents raising children with autism versus parents raising children with other types of disabilities is the mediating variable of relationship connectedness.

Although my intent at the beginning of this study was to increase participation of Latino families in autism research, the number of Latino parents I interviewed fell short of what I had hoped. I urge future researchers to continue efforts to expand autism research beyond non-Latino Caucasian families.

Researcher Reflections

As I come to the close of this study I am both joyful and sad. The satisfaction of taking a vague idea and constructing it into a scholarly study is unsurpassable. The satisfaction of being “done” is also unsurpassable! But with being done comes a bittersweet feeling of losing touch with all the parents I spent mornings and evenings with, sharing our joys and our sorrows around our children. One of the fathers in the study told me many months after our interview that he felt “kinda awkward” being able to feel so *free* to talk about his relationship with his son. He thanked me for “letting him talk that night.” I can say to that father and to all the parents in this study, thank you for letting me listen. The stories I heard changed me, changed how I look at my son, and changed how I participate in my relationship with both of my sons. I started out from a position of helplessness, and finished with a sense of great hope. There was a quality of intimacy and connection during interviews that I did not anticipate that I will miss. I feel impassioned to find a way for this work to give back to the parents who helped me, and to other parents like us. May we all find our way home to our children.

APPENDIX A

GUIDELINES FOR REFLEXIVITY JOURNAL

(Based on recommendations by Ahern, 1999)

1. Identify personal reasons for undertaking the research.
2. Clarify personal value system and acknowledge areas in which you know you are subjective.
3. Consider how personal feelings influence whom you choose to approach and how you approach them in terms of selecting respondents.
4. Become attuned for signals that indicate a need to be reflective during data collection phases
5. Recognize feelings that could indicate a lack of neutrality.
6. Notice whether anything new or surprising is arising in the data. If not, reflect on whether this is a cause for concern or an indication of saturation.
7. Consider additional forms of data collection that might provide greater breadth, depth and insight
8. Reflect on how you write up your summary account of individual interviews, including whether you have tended to draw on the quotes/conclusions of a particular individual or subset of respondents who may confirm prejudgments.
9. Note whether the evidence in the literature is supporting the analysis or if it might be bound by the same intellectual/cultural biases that may be present in you.
10. Be willing to reanalyze data if you conclude bias has been operating.

APPENDIX B

SEMISTRUCTURED INTERVIEW GUIDE

I had worked and reworked several semistructured guides that I presented during my proposal in December of 2011. After discussion with committee members, we decided that the best approach would be the simplest, which was to just ask one very broad question. This was the initial directive:

Tell me about your relationship with your child.

I found after the first few interviews that this question was too constraining. Many parents didn’t want to start here, they wanted to start with their story, which started with their child’s birth, and sometimes before. When I was so focused on trying to gather data “just on relationships” for fear I would not get enough information on my focus area, I was more anxious and more directive during interviews. I had to keep pulling people away from their story to fit into my frame. Over time, I began interviews differently. I would still explain the purpose of the study and emphasize my relational focus, but then I would say:

Tell me your story about you and your child.

Related or not I do not know, but interviews gradually got longer and longer. I had anticipated that interviews would run from 60 to 90 minutes. Once I started feeling more relaxed and open, interviews naturally began to lengthen. They moved closer to 2 hours or beyond, with the longest interview going about 3 ½ hours. By giving parents the opportunity to tell the story they wanted to tell, I was still able to gather data related to my focus, but the atmosphere was more relaxed and enjoyable.

APPENDIX C

PARTICIPANT KEY (QUICK GUIDE)

Parent Pseudonym	Parent Age*	Family Structure	Child Pseudonym	Child Age*	Child Diagnosis (ASD)
Nedra	48	Partnered	Kevin	19	Aspergers
Joie	42	Partnered	Tess	18	PDD NOS**
Liliana	34	Partnered	Miguel	4	PDD NOS
Cindy & James***	42/46	Partnered	Josh	8	Autism
Dawn	37	Partnered	Nelson	6	Aspergers
			Danny	4.5	PDD NOS
Camile & Tom	34/33	Partnered	Anna	14	PDD NOS
Louise	41	Partnered	Benton	15	Aspergers
			Keeton	13	Autism
Greg	46	Partnered	Brian	10	Autism
Mercedes	33	Partnered	Arden	7	PDD NOS
			Neil	5	PDD NOS
			Benny	3	PDD NOS
Ted & Gabrielle	29/26	Partnered	Dylan	5	Autism
Jodi	38	Partnered	Adam	14	Autism
Ruby	55	Partnered	Caleb	8	Autism
Marissa	34	Partnered	Miles	4	Autism
Leann & Scott	43/44	Partnered	Brayden	12	Autism
Jenna	31	Partnered	Lucy	8	PDD NOS
Tammy	39	Partnered	Hayley	14	Autism
			John Michael	11	Aspergers
			Sean	6	PDD NOS
Selena	35	Single	Yurik	15	Autism
Laurel	30	Partnered	Braxton	7	PDD NOS
Clint & Ann	43/33	Partnered	Payton	15	Aspergers
			Laura	13	Autism
			Wyatt	12	PDD NOS
Brigitta & Allen	55/50	Partnered	David	16	Aspergers
Jane	26	Partnered	Raine	3	Autism
Steve	38	Partnered	Billy	6	Autism
Alice	36	Partnered	Brad	11	Autism
Susan	44	Partnered	Mary	7	Autism
Rose	50	Partnered	William	23	Autism
John & Reba	43/42	Partnered	Matthew	7	Autism
Ellen	46	Partnered	Luke	9	PDD NOS

NOTES: *Ages are in years; child age refers to age at time of interview
**PDD NOS = Pervasive Developmental Disorder, Not Otherwise Specified
***Two names appearing on the same line indicate a couple

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