REMARKABLE MOMENTS: COMMUNICATING TRUST IN THE
RELATIONSHIP BETWEEN THE CHILD WITH AUTISM AND THE
PARENT/CAREGIVER

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Sandra L. Weber
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The Undersigned Faculty Committee Approves the

Thesis of Sandra L. Weber:

Remarkable Moments: Communicating Trust in the Relationship between the
Child with Autism and the Parent/Caregiver

Shulamit Ritblatt, Chair
Department of Child and Family Development

Patricia Geist-Martin
School of Communication

Sascha Mitchell-Kay
Department of Child and Family Development

3/15/11
Approval Date
DEDICATION

This thesis is dedicated in grateful admiration to one whose acceptance and trust has given me wings:

Across the tossing waters of my inner world
I see your troubled eyes, knowing not the charted course
On which my soul relies.
Be it earthbound or skyward hurled,
What proportion will prevail?
This sense of self I must define,
As on through life I sail.
Will you truly understand
The turmoil that exist,
And teach me how to fight against
Compelling tides I must resist?
Anchor me with all your strength,
Be my rock and my castle foundation.
Hold fast, lest I slip like sand
Before I have fulfilled creation.
Teach me all you know of life
That I may judge my birth,
Discovering that within myself
There dwells someone of worth.
Question you to what just end
Does all your benevolent council lead?
From the destructive depths of mind division,
My tortured soul is freed!
Ten things I want people to accept about (my) Autism without asking questions:

1. I am really smart! Don’t underestimate me.
2. “Not being able to speak is not the same as not having anything to say.”
3. I have a sense of humor!
4. Stupid people and “whiners” test my patience!
5. Two things I can’t live without are God and Nascar.
6. We do feel emotions. If we didn’t feel emotions, why would we scream?!
7. We are capable of learning consequences, even at an early age!
8. We are able to apply skill in more than one area….memorizing comedy and memorizing academics.
9. You have to find a way to connect with us first…..trust is important.
10. It is important to strive for excellence instead of settling for mediocrity. Failure is failing to try.

I believe in the power of the “Human Factor,” for which there are six dimensions: Spiritual Capital, Moral Capital, Aesthetic Capital, Human Capital, Human Abilities, Human Potential, and Undiscovered Talent (Adjibolosoo, 2005). These dimensions must be fostered and cultivated in children with Autism so that we can speak with voices “Louder than Words.”

- Erik N. Weber, MPA Candidate
  San Diego State University, 2011

Reprinted with permission from a lecture, “Living with Autism.”
Very little solid scientific research has been conducted that directly documents a specific neurobiological structure in the human brain, regulating the innate perception of “basic trust.” As an alternative, researchers are pursuing studies in analogous components of the “trust factor” to answer the question, “is there a biological basis for ‘basic trust’?” Because perceived caregiver trust is a key component in autistic behavior remediation, this study affirms, articulates, and expands on the idea that there are actual biological indicators that reflect “basic trust.” In addition to synthesizing previous applicable research regarding Autism Spectrum Disorder, this study illustrates the ways in which trust is communicated between parent/caregiver and the child with autism. To explore this topic, the study gathered both qualitative and quantitative information using a demographic survey and interview format. The participants of this phenomenological qualitative investigation consisted of twelve parent/caregivers whose children had been professionally diagnosed with autism. Collected quantitative demographic survey data and in-depth qualitative narrative information was evaluated for common themes within the respective parenting experiences. The long term benefit of illuminating the importance of trust formation in the success of therapeutic autism intervention programs outweighed the potential risk of emotional discomfort from retelling/reliving of some unpleasant memories. Anonymity was preserved through coding of the informational materials for the parent/caregiver participants. Interviews were done at a location and time selected by each volunteer to maximize personal comfort, convenience, and to promote the narrative process.

None of the current commercially-based methods for therapeutic intervention have produced consistent results in every diagnosed child. Regardless of the degree of disability, the ultimate goal for the ASD child is behavioral compliance. Without it, appropriate socialization at any level is impossible to achieve. The underpinning for behavioral compliance that leads to socialization is the ability to experience a sense of “basic trust” and to perceive the caregiver(s) as trustworthy.
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this study, and who also trusted me to understand the joys and the sorrows of their individual journeys.
CHAPTER 1

INTRODUCTION

The concept of trust formation in the normally developing child has heretofore been primarily perceived as a subjective philosophy that is theoretically founded. Contextually speaking, the definition of trust is dependent upon the academic or scientific discipline to which it is being applied. For the purposes of this paper, “basic trust” is defined from the psychosocial perspective, as is presented in established child development literature. According to developmental child psychologist, Briggs (1975), “….the cornerstone of love that nurtures is psychological safety…..the bedrock of safety is trust. Without it, later growth rests on emotional quicksand that effects all future development.” Likewise, Erikson theorized that, within the concept of “basic trust,” if the child’s physical needs (nourishment, sleep, and warmth) and his psychological needs (responsiveness, contact, affection, and play) are satisfied, he will have a sense that the world is a pleasant place. He will develop trust, which Erikson says is essential if the child is ever to become a mature personality. On the other hand, if a child’s basic needs are not met, if he becomes panicky in his sense of helplessness, or the world feels threatening or frustrating, he will develop basic mistrust (Lazerson, 1971, p.139, Smart, & Smart, 1973, p. 215). Development of “basic trust” also permits the child to respond to a wide range of emotions from which he will refine the capability of mastering reality (Lazerson, 1971, p.145). “When the child finds his or her bids for comfort are met with sensitivity, the child develops a sense of security and is more likely to open up to and trust others” (Vicary & Fraley, 2007).

STATEMENT OF THE PROBLEM

Very little solid scientific research has been conducted that directly documents a specific neurobiological structure in the human brain, regulating the innate perception of “basic trust.” As an alternative, researchers are pursuing studies in analogous components of the “trust factor” to answer the question, “Is there a biological basis for ‘basic trust’?” Assuming that there is, can it also be demonstrated through phenomenological qualitative
investigation that perceived caregiver trust is a key component in autistic behavior remediation? How is trust communicated between parent/caregiver and the individual with autism?

**PURPOSE OF THE STUDY**

This study, designed to establish both evidence base and peer-review research, fills the existing gap in the area of trust communication and relationship formation necessary for creating successful therapeutic inroads in the treatment of children with autism. The research also demonstrates a biological base for trust, using parent/caregiver interviews and narrative examples of relational behaviors that evolve as a result of perceived trustworthy interactions.

It has been widely accepted by all disciplines that the key to successful acquisition of appropriate social behavior in typically developing children, and in those diagnosed with developmental abnormalities, is a relational foundation that relies on trust formation early in infancy. With no definitively identified cause or “cure” on the foreseeable horizon, it is important to examine how individuals with autism differ from “the norm,” both behaviorally and physiologically (Mash & Wolfe, 2010, p.301; Myers & Johnson, 2007; Pardo, Vargas, & Zimmerman, 2005; Sykes & Lamb, 2007). It also becomes imperative to understand the underlying physiology of the disorder before devising a plan of compliance intervention that is crucial to any behavioral or social remediation. The advent of advanced technology has now allowed researchers to document neural pathways, both in normal subjects and in those diagnosed with ASD related disorders (Pierce & Courchesne, 2000). Doing so has created possibilities for evaluating critical developmental factors related to “basic trust.” Research in this area, indirectly generated through associated elements of the “trust factor” such as attachment behaviors (Smart & Smart, 1973, p. 215; Vicary & Fraley, 2007), facial discrimination and processing (Pierce & Courchesne, 2000; Pierce, Haist, Sedaghat, & Courchesne, 2004; Pierce, Müller, Ambrose, Allen, & Courchesne, 2001), and the function of the oxytocin hormone in social interaction (DeAngelis, 2008; Hollander et al., 2007; Kirsch et al., 2005), can ultimately demonstrate the physiological effect of caretaker trustworthiness in the ASD child. Because there is currently no direct peer-reviewed research, existing studies from parallel aspects of trust must be used to exemplify how brain
structures are capable of adaptation or modification, given appropriate time, in order to meet an altered functional need (Gaffrey et al., 2007).

By opening the research door to examine the importance of trust in the process of relationship building, improved strategies will ultimately be incorporated into care-giving and treatment that will produce an improved overall result for children with autism, formerly believed to be devoid of emotional capabilities.

**THEORETICAL BASES AND ORGANIZATION**

Thus far, the cause of Autism Spectrum Disorder (ASD) cannot be isolated to even a handful of genes, traced to a parental mutation, or definitively tied to a specific environmental toxin in every case (Gaffrey et al., 2007). Researchers are trying to identify areas of the brain that are most often affected from either the prenatal “complex” form of autism or from the postnatal “regressive” type, in an effort to understand how to help the brain adapt to its neural deficits (Pierce & Courchesne, 2000). Even though neuroscientific brain mapping efforts continue, the modifications in structure that precipitate socio-emotional and communication network dysfunctions are undetermined. Nevertheless, some studies do indicate that the introduction of external factors can stimulate motivation, interest, and increased attention which eventually cause brain region and network improvements in the deficit areas of those with higher functioning autism. In some cases, the brain activation process can appear more normalized (Courchesne et al., 2007).

The neural circuitry that is involved in the complex process of trust formation is not totally understood in humans. Some research has identified the amygdala (involved in fear or social cognition) as a participatory structure (Kirsch et al., 2005), along with the neural systems in face processing, pointing to the fusiform gyrus (Pierce & Courchesne, 2000). Other researchers are exploring the levels of the oxytocin hormone, either generated or absorbed artificially by the ASD child to determine whether or not a deficit exists (DeAngelis, 2008). It has been noted that in cases of Williams Syndrome, oxytocin binding is altered such that the brain does not cognitively monitor or override its effects on overt friendliness to strangers (Damasio, 2005; Grice et al., 2001).

None of the current commercially-based methods for therapeutic intervention have produced consistent results in every diagnosed child. Regardless of the degree of disability,
the ultimate goal for the ASD child is behavioral compliance. Without it, appropriate socialization at any level is impossible to achieve. The underpinning for behavioral compliance that leads to socialization is the ability to experience a sense of “basic trust” and to perceive the caregiver(s) as trustworthy (Lazerson, 1971, p.145).

**LIMITATIONS OF THE STUDY**

For the purposes of this writing, in an effort to answer the proposed research questions, three components of “basic trust” that have been scientifically evaluated, and that are prominent features of early infant development, are examined first – attachment behavior, facial discrimination and processing, and the effects of the oxytocin hormone on social bonding. These salient factors found in the normal child development of “basic trust” have been generally absent in the child with Autism Spectrum Disorder (ASD) (Shultz et al., 2000). A review of the literature will show that if the origins and parameters of perceived trust are understood in the Autism Spectrum Disordered child, it is possible to either retrain the brain to operate around dysfunctional structures that block normal attachment behaviors, or to synthetically/chemically alter those defective structures to promote socially acceptable levels of attachment which fit within perceived normative standards. Because the United States lacks these experimental approaches, the researcher was compelled to pursue alternate methods for identifying the bio-indicators for trust formation.

Although new research is limited, current studies indicate that persons with autism can experience some level of cognitive improvement (Kennedy & Courchesne, 2008). One of the intentions of this study is to provide deeper insights and further illumination regarding previous research findings.

Because “basic trust” is believed to be lacking in persons with Autism Spectrum Disorder, Theory of Mind and empathy studies are relatively restricted with regard to ASD responses. These two characteristic derivatives are briefly refined and reviewed in order to assist in understanding other social ramifications. In addition, the defining parameters of trust and trustworthiness are included in the literature review to add clarity and continuity. Study results will show that perceived caregiver trustworthiness can ultimately promote successful levels of compliance in the child with autism (Angell, Stoner, & Shelden, 2009).
CHAPTER 2

REVIEW OF THE LITERATURE

ATTACHMENT BEHAVIOR DEVELOPMENT

The attachment theory as cited by Vicary and Fraley (2007) was originally developed by Bowlby (1969/1982) to explain the nature of the emotional bond formation between normally developing infants and their primary caretakers. He theorized that this bond is a product of an innate motivational system, the attachment behavioral system, which acts as a means of keeping a child in close proximity to the primary caregiver (Vicary & Fraley, 2007). This component of “basic trust” has been extensively covered by behavioral theorists, child development specialists, and social psychologists for years. Technological advances have provided creative and problem-solving researchers with the means to visually document their theories on how the brain processes information, promoting better understanding of both normal and alternative neural pathways that can develop as a result of structural brain dysfunction.

In her article pertaining to nonverbal responses within attachment relationships, Bugental (2005) discusses both social cognition research and the social neuroscience aspects of the neurohormonal processes that may act as mediators between attachment security and nonverbal behavior in both parent-child and adult-adult interactions. Although some limited assumptions and allusions to the historic “refrigerator mother” theory are made (originally believed to be the causal factor in autism development), it should be noted that care is taken when exerting a “broad brush” approach to parent-child attachment in all cases of documented disability. One would have to ponder the question, “Does stress/anxiety actually surface before or after the ASD diagnosis?” Bugental, on the other hand, remarks that adults who have a history of abusive behaviors will respond to child neediness and conflict cues with increased levels of stress and physiological arousal. The same pattern has been observed in mothers who tend to be depression-prone. In both instances, the adults convey vocal signals of anxiety, disengaged communication, or negative nonverbal affect with deficits in decoding capacities.
In short, there are two routes through which maternal stress may influence child attachment. Stress may either serve as a direct source of influence on the attachment patterns shown by their children or as an indirect influence on attachment---as mediated by maladaptive changes in their coding and decoding patterns. (Bugental, 2005)

The author also states from her research that child attachment can be affected both directly and indirectly from maternal stress. Additionally, as insecurely attached children, they are more likely to demonstrate higher levels of baseline cortisol or to exhibit cortisol reactivity to stress-induced events. From her previous study in 1999, the author found that infants showed physiological stress from “still face” exposure to depressed mothers; and that young children responded to harsh/abusive parenting with nonverbal avoidance and eye aversion.

Children’s stress reactions to an insensitive, unresponsive or negative care-giving style can be understood as a route through which early experiences may carry forward to influence responses within later close relationships. (Bugental, 2005)

Considering that this article was not directly referencing children with the ASD diagnosis, the conclusions create thought provoking questions regarding the attachment capability for children with neurologically compromised brain function, either at birth or within the first four years of development. If a normally developing infant or young child is adversely impacted by the parent/caretaker response-style, and is unable to self-generate corrective rationalizations, the ASD child is definitely at an increased risk for caretaker dissociation over time.

In her publication describing the ability of parents to cope with grief vs. their episodic stress, Hewson states, “Parents cannot make an honest attachment to the real, handicapped child until they have withdrawn their affection from the normal, wished for child” (1997). She goes on to claim that parents can vacillate daily between “retreat” and “confrontation,” as they attempt to address issues of early therapeutic intervention for the disabled child, as well as recurrent levels of denial used to shield themselves from being overwhelmed by their distress. Hewson reiterates that some ongoing sadness may be incorporated in the long-term responses of parents as they try to meet the needs of a child whose abilities have been “lost.” She goes on to say that “loss will become stressful for a person only if their appraisal of the situation is that it taxes their resources or endangers their well-being” (Hewson, 1997). Interestingly, she references the findings of other researchers who claim that in comparison to fathers, “recurrent stress patterns are more apparent in mothers” (Hewson, 1997). This fact
was also noted in a literature review prepared by author, Erik Weber (2008) in preparation for the publication of his book, *Autism for Dads: The Importance of a Father’s Love*. Erik is an adult whose autism was professionally diagnosed at 3 ½ years of age.

Likewise, Feldman, Gordon, Schneiderman, Weisman and Zagoory-Sharon (2010), whose research will be referenced in the subsection of the **Role of Oxytocin**, makes the statement in her article: “Parent-infant interactions and bond formation demonstrate the important impact of early social experience on human capacity to form attachment relationships” (Feldman, et al., 2010).

Mash and Wolfe paraphrase restatements of findings in their text, *Abnormal Child Psychology*, that are taken from other researchers. These study results indicated that the quality of the mother-infant attachment can be a contributing factor in play-behavior development which ultimately leads to the quality of social skills demonstrated by the child (Mash & Wolfe, 2010, p. 305).

In an article by Harris (2003), reviewing the studies of MacLean, attention is given to neuroimaging studies in social cognition, mother-infant communication, along with other behavioral elements (such as trust), and how those elements pertain to the activation of complex neurological systems. MacLean contended that brain circuits are linked to complicated behavior patterns during development, and that subsequent disruptions generate behavioral phenotypes that manifest themselves as neurodevelopmental disorders like autism (Harris, 2003). Isolating and defining the physiological origins of moral behavior, empathy, forgiveness, and the elements that identify attachment behavior through social displays and integrated brain functioning are still among the neuroimaging studies being researched primarily through animal models, rather than human (Harris, 2003).

In her dissertation intended to explore the supportive relationships influencing the lives of academically successful subjects with autism, Robledo (2007) determined the following:

A dynamic model of supportive relationships emerged, with trust, unity, and support as three core categories of these relationships. The data suggest that the quality of the relationship between the individual with autism and the support provider can be a critical factor within effective support.

The researcher discovered through her study that persons with autism are capable of intimate, mutual, and reciprocal supportive relationships. Her findings reflect an understanding of the
autistic social world that only few intuitive individuals have perceived over the years. Needless to say, further documented research would be extremely beneficial in educating autism practitioners and parents (Robledo, 2007).

**FACE PROCESSING IN AUTISM**

Facial discrimination and processing, an integral part of attachment behavior and “basic trust” formation, have also been evaluated in an effort to scientifically define the parameters of autistic social deficits.

Recognition of individual faces is an integral part of both interpersonal interactions and successful functioning within a social group. Therefore, it is of considerable interest that individuals with autism and related conditions have selective deficits in face recognition--sparing non-face object recognition. (Schultz et al., 2000)

Using functional magnetic resonance imaging (fMRI), the authors examined fourteen ASD individuals and two separate control groups of fourteen participants each. In every instance, the group with autism used either the right or the left inferior temporal gyri (ITG) during face discrimination activities. Both of the control groups, processing their face recognition information primarily with the right fusiform gyrus, showed ITG activation in object processing instead. By their own accounting, the researchers expressed some limitation in their study, citing that three quarters of their participants with autism were also classified as mentally retarded. Although they reported no functional differences in their patient group, the researchers felt that their sampling should have been larger so that the study could be composed of either those with autism or with Asperger Syndrome, rather than both. It was also felt that neuroanatomical abnormalities within the Autism Spectrum condition would be better evaluated by performing hand-tracings of activated areas, instead of using brain-warping techniques to create composite activation maps. Size variations in the inferior-temporal cortex may have resulted in other special distortions (Schultz et al., 2000).

Numerous other peer-reviewed articles have been published by Courchesne and Pierce, separately and in combination with other researchers. In 1985 as a collaborative effort, Dr. Courchesne investigated visual and auditory stimuli elicited by event-related brain potentials (ERPs) in both non-retarded autistic and in normal age-matched individuals. It was determined that non-retarded autistic individuals could have (1) diminished capacity to
process novel information; (2) simple visual information may be less impaired in its classification than auditory material; and (3) visual and auditory ERP anomalies do not necessarily reflect maturational delay. Understanding that individuals with autism can potentially be visual learners is a key issue in designing a learning format that will be both useful and meaningful over time (Courchesne, Lincoln, Kilman, & Galambos, 1985).

Pierce, in conjunction with Courchesne, examined the neurofunctional organization of face processing in autism, as an integral part of social interchanges. Their study included both normal and autistic subjects, and evidenced that the fusiform gyrus is increasingly activated during face processing of normal participants in the study (Pierce & Courchesne, 2000).

Continuing their face processing research using functional MRI, Pierce, Courchesne, Ambrose, Allen, and Muller teamed up in 2001 to study hemodynamic responses occurring during perception tasks. For the most part, their work concurred with other researchers’ findings. However, their sample population was restricted to seven subjects with autism, and eight age-equivalent normal controls. Admittedly, in the examination of ASD subjects there were no standards for analyzing functional data from psychiatric populations that are diagnosed with multiple, developmental brain anomalies.

Furthermore, given the significant heterogeneity of biological defects in this disorder, it was predicted that individual subject data would reveal unique and non-overlapping patterns of activity between autistic patients, in contrast to the predicted consistent pattern in response to faces seen in normal subjects. (Pierce et al., 2001)

In this research, the areas of focus were the fusiform gyrus (FG), inferior temporal gyrus, middle temporal gyrus, and amygdala. Unlike their normal counterparts who processed faces with 100% consistency at maximum activation within the fusiform face area, the participants with autism processed facial features in aberrant locations---frontal cortex, primary visual cortex, cerebellum---using other neural circuitry. In some instances, the neural systems used were different for each individual. This scattered activation might lead one to theorize that the degree and extent of early neural abnormalities, along with variations in the type or intensity of environmental stimulation of each ASD child, could have a modifying/mediating effect on how that individual develops a compensation mechanism for facial recognition (Pierce et al., 2001).
Pierce et al. (2004) again studied the “fusiform face area” (FFA) using seven adults with autism and nine normal control participants. The focus of this version of their face recognition research was to examine the brain structures that are activated in response to familiar faces, rather than to strangers. Their findings showed that those with autism had a similar, though limited, network activation in response to familiar faces when compared to the normal subjects. Also, the fusiform activity was greater for the familiar faces than for the stranger faces. The amygdala inclusion in the activation implies that it is involved in “multiple socio-emotional functions, (and) can be responsive in autism in the presence of stimuli that represent high reward value, such as mother’s face.” It is likewise important to note that:

Furthermore, the presence of a distinct network to process familiar faces in autism, one that included limbic structures and was not in response to the faces of strangers, suggests socio-emotional processing in autism…The main finding of FFA activity in autism stands in contrast to most past fMRI studies of face processing in this disorder. This positive result may reflect the use of personally significant faces that enhanced attention and motivation in the autistic participants (Pierce et al., 2004).

Their research made the key point that a propensity for more positive responses was enhanced when subjects with autism were motivated by “high-interest” stimuli, such as the face of their mother or co-worker, in which case the FFA responded similarly for both groups of participants. Familiar faces increased interest and motivation, and elicited significant functional activity of the amygdala in both the normal adults and those with autism. There is now speculation that the dysfunction of the FFA may reflect defects in the systems that modulate the “fusiform face area,” rather than the area itself (Pierce, et al., 2004). As previously mentioned in Chapter 1, Courchesne et al. (2007) published a study documenting early brain mapping research. The ultimate goal is to define the areas of dysfunction so that the treatments for individuals with autism can be prescribed to suit specific needs more effectively. The article also mentions that other studies show “…if sufficient instruction, motivation, or interest is given to the participant to overcome the natural tendency to not engage these regions (fusiform area), the local and long distance networks (medial frontal cortex) can be activated” (Courchesne et al., 2007).

In a more recent study, Schumann, Carter Barnes, Lord, and Courchesne (2009) compared the brain structures of males and females with autism, finding that the enlarged
The amygdala of the female was not related to the severity of social or communication impairments. This finding was contrary to those of the male subjects. The authors remarked that their results may have been affected by the small sample size, however. Unlike the study by Pierce et al. (2004), Schumann et al., (2009) reported that their subjects responded both to familiar and unfamiliar faces, leading them to theorize that their participants with autism may have been both motivated and attentive to all stimuli.

Measuring regional cerebral blood flow (rCBF) in conjunction with an emotion recognition task using facial emotion stimuli, prosodic voices and baseline gender-recognition, Hall, Szechtman, and Nahmias (2003) examined eight high-functioning autistic men and eight non-autistic men. The researchers documented that emotional processing in autistic persons resulted in lower rCBF in the inferior frontal and fusiform areas and higher rCBF in the right anterior temporal pole, the anterior cingulate and the thalamus. Rather than engaging the limbic emotion system for emotion processing, as did the normal control group, the participants with autism seemed to rely on prototypical representations of emotions, categorical knowledge, and attention processes to interpret emotional signals. They appear to process facial stimuli through a selective analysis of features rather than holistically (Hall et al., 2003).

From a study with twelve participants, Pierno, Mari, Glover, Georgiou, and Castiello, (2005) reported that children with autism do not necessarily look directly at a face. Compared to normal children who naturally use gaze encoding to infer the motor mental states of others, the high-functioning subjects with autism demonstrated abnormalities in gaze observation. As a result, they had difficulty determining another person’s motor intentions from the direction of their eyes.

More recently, foreign researchers have attempted to combine the study of face processing with intranasal administration of oxytocin to observe brain function with and without the hormone. Domes et al. (2009) collected data from sixteen healthy adult right-handed women who had normal vision. Both fMRI data and eye tracking measurements were taken as the subjects viewed ten photographs with a neutral expression and other selected facial emotions (fear, anger, happiness). Data was gathered from the participants with and without the administration of intranasal oxytocin for comparison purposes. From the gathered information, it was determined that brain structures involved in face processing for emotions
were more activated by the presence of oxytocin. Although study consisted only of female
subjects, the researchers theorized that their results implied “significant sex differences in the
oxytocin responsiveness of brain areas which are relevant for the processing of emotional
and social information” (Domes et al., 2009). However, the article did not state how that
conclusion was determined from their results. Nevertheless, it is noteworthy that a
comparative study of face processing was conducted, thereby providing a baseline for future
research.

**The Role of Oxytocin**

In recent years, some research has been undertaken in order to examine the likelihood
that emotions could be modified chemically for the benefit of those experiencing
physiological or functional deficits. Through animal model studies, Kirsch et al. (2005), have
experimented with oxytocin administration, finding that their subjects had an increase in
trusting behaviors. They postulated that their results indicated a neural mechanism for the
effects of oxytocin in neural cognition, which could likewise be applicable to the human
brain. In children who have known developmental abnormalities, and who struggle with
issues of “basic trust,” behavioral compliance, attachment behavior, facial discrimination and
processing, this form of artificial hormonal intervention could open the door to therapeutic
strategies for an array of social dysfunctions.

Oxytocin has a multifaceted role in the body, and is linked with selective social
bonding and some regulatory behavior. Primarily produced in the hypothalamus, and
released into the blood through the pituitary gland, or to other parts of brain and spinal cord,
oxytocin binds to receptors to influence physiology and behavior. Although traditionally
affiliated with maternal bonding, and considered a female hormone, oxytocin is now
recognized as being present and important in both sexes. Some human studies have
demonstrated that early experiences, probably mediated by oxytocin, are correlated with later
social behaviors, especially in deprived circumstances. In related animal studies, those
treated with oxytocin after a long period of isolation, no longer showed signs of anxiety,
depression, or cardiac stress. This has led researchers to ponder the benefits of external
administration of oxytocin to individuals with social or emotional deficits. One study
reported by these researchers stated that autistic and ASD diagnosed adults were given
injections of oxytocin and subsequently demonstrated improvements in ability to identify emotional content on a speech comprehension task, unlike those individuals on a placebo. Since oxytocin has some effect on the autonomic nervous system, the authors have theorized that the hormone could protect the nervous system from shutting down when confronted with stressful circumstances (DeAngelis, 2008).

Because the chain of neural events triggering a release of oxytocin is not fully understood, nor how exactly the hormone stimulates “enhanced trusting behavior” in a given individual, there are possibilities for further study. In conditions where the “trust factor” is either diminished or lacking, there is an opportunity to explore the possibility of artificial augmentation (Damasio, 2005; Kirsch et al., 2005).

In 2006, Tom and Assinder of Australia looked at the relationship of oxytocin in health and disease. Their work addressed the roles of the hormone in somatic and autonomic cardiovascular systemic regulation, physical pain, gastric motility, osmoregulation, and thermoregulation, as well as oxytocin importance in social behavior and psychological stress. Oxytocin was found to have positive effects on communication, reduced stress during conflicts, and improvements in the ability to recognize limited social cues. Perceptions of trust were also noted with the chemical administration of the hormone. The researcher stated:

Recently, defects in the oxytocinergic system have been associated with autism spectrum disorders that are marked by poor social functioning and repetitive movements. (Tom & Assinder, 2006)

Plasma oxytocin levels having been found to be reduced in ASD subjects, clinical trials were conducted to record any changes following hormone administration. A significant decrease in repetitive behaviors, depression and anxiety, along with an improvement in speech comprehension and social skills were subsequently reported following oxytocin treatment (Tom & Assinder, 2006).

Hollander et al. (2007) also studied social cognition improvements in ASD subjects resulting from oxytocin administration. The researchers speculated that oxytocin most likely plays a role in the related social deficits (Hollander et al., 2007).

Carter reiterated in her 2006 research that intranasal oxytocin precipitates an increase in “trust.” In conjunction with other sited studies as support, Carter proposes the hypothesis:

…adaptive systems, including those influenced by the autonomic nervous system, are regulated by dynamic interactions between oxytocin and vasopressin.
Dysfunction in any aspect of this system could influence the features of ASD. (Carter, 2006)

As part of her research on the sex differences in Autism Spectrum Disorders with relation to oxytocin and vasopressin, Carter noted that compared to typically developing children or other developmental disabilities, children diagnosed with ASD had a higher incidence of gastrointestinal (GI) symptoms. This was supported by the autonomic nervous system role in physiological responses. The article also referenced the theoretical viewpoint held by other researchers that ASD may be the result of an assault on the immune system.

It has been hypothesized that infection or inflammation plays a role in the etiology of ASD. Neuroglial activation and neuroinflammation have been reported in brain tissue and Cerebral Spinal Fluid (CSF) from patients diagnosed with ASD…Whether the relationship between inflammatory processes and ASD is ‘cause or effect’ is not known, but the fact that neuropeptides, including oxytocin (OT) and vasopressin (VP), can influence the immune system and inflammation may be relevant to an understanding of both the direct and indirect causes and treatments for ASD. Vasopressin also has been implicated in inflammatory processes, including a central effect on body temperature. (Carter, 2006)

In her results, Carter also notes that females seem to be less sensitive to the effects of vasopressin compared to males, especially during development. This may explain the higher numbers of ASD affected males compared to females. There is speculation that the increased level of oxytocin in the females may directly or indirectly have a protective effect against vasopressin.

Experiences associate with reductions in fear and an increased sense of safety or trust would be expected to be protective in ASD and related disorders that are characterized by high levels of anxiety. (Carter, 2006)

Swiss researchers, Baumgartner, Heinriches, Volanthen, Fischbacher and Fehr, conducted a blind study in 2008 combining the administration of intranasal oxytocin with fMRI studies to visualize neural circuitry that is activated in relation to “trust behavior.” The demonstrated results of the relationship between the oxytocin neuropeptide and the increase in perceived trust lead the researchers to hypothesize that their findings could be helpful in understanding disorders such as autism, which is characterized by fear and social interaction. Documenting neural responses to trust invoking activities with brain imaging with (or without) administered oxytocin made it possible to examine the structures involved in the feedback processing/reward learning as well. Additionally, the question was raised about the
need for periodically changing behavioral rewards for behavior modification and intervention strategies so that subjects maintain participation interest in programs. The researchers stated, “Trust is indispensable in friendship, love, families, and organizations, and it is a lubricant of economic, political, and social exchange” (Baumgartner et al., 2008). They went on to say, “Oxytocin exerts its effect automatically or even unconsciously in subcortical brain structures which can be modulated without explicit awareness of the subjects” (Baumgartner et al., 2008). In their study design, the researchers found that even normal subjects tended to recognize and react more negatively to trust betrayal circumstances in the absence of oxytocin. Future studies are projected to examine dysfunctions in neuroendocrine mechanisms (oxytocinergic system) that impact social disorders such as autism (Baumgartner, et al., 2008).

More recently in Belgium, Declerck, Boone and Kiyonari (2010) conducted a research study using a combination of placebo and intranasal oxytocin to test the responses of 259 university students to specifically designed economic games that explored social behavior. According to their findings:

> Trust is apparently enhanced by the combination of oxytocin and prior contact, an interpretation which is substantiated by the significant interaction effect (oxytocin*prior contact) on cooperative expectations. (Declerck et al., 2010)

The literature review included in the article reported that plasma oxytocin administered to ASD adults tended to improve social information processing and to increase self-initiated social interactions (restated from Hollander et al., 2007). It was also suggested that increased trust, reduction of fear-related responses, and processed social stimuli all were facilitated by oxytocin production. Supposedly, oxytocin has an effect on the conceptual recognition and encoding process, but not the early perception of social cues. Conversely, when trust was not warranted in an all-or-nothing circumstance due to a lack of social information, risk aversion and cautious behavior were significantly enhanced by oxytocin (Declerck et al., 2010).

From baseline plasma and salivary oxytocin levels, Ruth Feldman et al. (2010) examined the data of fathers and mothers engaged in fifteen minute play sessions with their infants. Their findings showed the following:

> Human mothers who provided high levels of affectionate contact showed an oxytocin (OT) increase following mother-infant interaction but such increase was
not observed among mothers displaying low levels of affectionate contact. (Feldman et al., 2010)

It was noted that mothers and fathers engaged in a different play style from each other---mothers were much more affectionate and fathers demonstrated more stimulatory touch in parent-infant contact. Although the baseline plasma and salivary oxytocin findings were similar for both groups, parents who gave high levels of either affection or stimulation with their children also had higher increases in oxytocin levels. It was noted that infant physiological responses to stress were decreased by affectionate maternal contact. On the contrary, premature infants, or those whose mothers were depressed and had diminished contact, were reported to also demonstrate long-term stress regulated disruptions in the hormonal and brain systems (Feldman et al., 2010).

**THEORY OF MIND AND EMPATHY**

As an indicator of social understanding that often functions in tandem with the capacity for empathy, the ability for Theory of Mind comprehension is a characteristic which enables humans to appropriately predict and respond to the behavior of others. It is considered to be essential in making sense of the perceived mental states of oneself and of others (Colle, Baron-Cohen, & Hill, 2007). It is believed that between 15-60% of individuals diagnosed with autism who have improved verbal and communication skills may also have some underlying ability to process insightful or interactive behavior.

Ability to read the intentions, beliefs, feelings, and desires of others from their external behavior has adaptive significance in human evolution. (Mash & Wolfe, 2010, p. 311)

Although it has been believed that individuals with autism do not possess the capacity to read minds in the normal way, research is being pursued to evaluate their understanding of metaphors, irony, or other speaker emotions that include the intentions to lie or to tell jokes (Mash & Wolfe, 2010, p. 311).

In a study of sixteen children with autism, Colle et al. (2007) researched false belief understanding to determine the correlation between Theory of Mind impairment and lower language levels. It was noted that when Theory of Mind tasks are less linguistically demanding, the ability to understand could function independent of language. The findings
also suggested that both the acquisition and use of Theory of Mind were facilitated by language (Colle et al. 2007).

According to the research of Adolphs, Sears and Piven (2001), the function of the amygdala in the recognition of emotions from facial expressions (fear), and in the making of more complex facial-driven social judgments (perceived trustworthiness), was reinforced in its importance. In keeping with other studies noted in the “face processing” subdivision, it has been documented that persons with autism do not process faces holistically. However, the findings of Adolphs et al. (2001) indicated that most of the subjects responded within a normal range to facial expressions of surprise, anger, disgust, sadness, happiness, and fear. Even though research indicates that social and emotional information is not processed in the same way by persons with autism, it has still been difficult to determine the exact location of the impairment. It is possible that in higher-functioning individuals, there may be a compensatory aspect that enables them to use verbal mediation as a strategy for deciphering more demanding social judgments and emotions from facial recognition tasks.

…autism may result from an impaired ability to link perception of faces to the retrieval of social knowledge, and that this impairment may result, in part, from dysfunction involving the amygdale. (Adolphs et al., 2001)

The ability to understand the thoughts, feelings and needs of others, and to see things from another person’s perspective, has been viewed by some professional disciplines as a key element in the emotional intelligence necessary for meeting and adapting to those needs. This also includes experiencing the perspectives, frustrations, or concerns of others, whether it is in the professional arena or in personal relationships (Adjibolosoo, 2005; Howell & Costley, 2006).

In 2008, Kennedy and Courchesne published research that looked at the intrinsic functioning of the brain and its alteration as a result of autism. Commensurate with previous studies, they noted that individuals with autism generally were less interested in social-emotional relationships while having profound interest in objects, rules and regularities. They also stated that these diagnosed individuals “may lack the neural machinery to disambiguate the rather complex and subtle cues of social and emotional communication” (Kennedy & Courchesne, 2008). The researchers theorized that persons with autism may develop an
alternate approach to interaction in which they focus on their cognitive and attention strengths instead of their social-emotional weaknesses.

The writings of Greenspan and Wieder (1998) specifically address adult/child interaction and its importance to social development:

Two-way communication is essential for all human interaction. It also allows children to learn about themselves and about the world….Without these essential experiences in two-way communication, children can’t form a basic sense of intentionality, which means they can’t begin to form a true sense of who they are or see that the world is logical. (Greenspan & Wieder, 1998, p. 77)

Additionally, the authors of the sited text make the following important statements that will later be shown in the current research study as a critically important factor in the development of trust communication:

Empathizing with your child’s feelings is also helpful to you….Acknowledging his feelings can defuse this struggle….he will respond to your patient and encouraging tone of voice. (Greenspan & Wieder, 1998, p. 306)

**Trust and Trustworthiness**

The definition of trust and/or trustworthiness has been reviewed in the literature of many fields of study as the focus of healthy vs. unhealthy relationships. In examining several of them (couples, friends, parent/child, parent/teacher, employer/employee), there appears to be a consistent pattern of descriptive characteristics regardless of which relationship type is being assessed. Very little has been specifically written about parent/caregivers and children with autism, other than to address the difficulties that parents experience in coping with the special needs child (Geist-Martin, Ray, & Sharf 2003, p. 171; Hewson, 1997; McKeever & Miller, 2004; Weber, 2008, p. 64).

The writings of Cutrona, Russell, and Gardner (2005) reiterate those of Bowlby in 1969 that state: “Early experiences with caregivers lead people to develop beliefs about the availability of others in times of need and the extent to which one is worthy of love.” Cutrona et al., go on to say:

Individuals whose attachment orientations develop a secure underpinning will be more comfortable with closeness and will trust others to be available if needed. Conversely, children who develop insecure attachment behaviors may not be able to subsequently overcome their fear and mistrust of others who offer social support…The process of building trust takes time. (Cutrona et al., 2005, pp. 77, 87)
Authors DiFonzo and Bordia (2007), in a chaptered book on rumor psychology, discuss their definition of trust as being the willingness to embrace vulnerability when it is believed that another person has his/her best interest in mind (pp. 186). They go on to state that “trust acts simply to produce positive attitudes and cooperative behavior” (pp. 187), and to surmise that it also helps individuals to perceive the vague actions of others as being either less uncertain or friendly instead of hostile in intent (pp. 188, 203).

Similarly, Burke and Stets (1999) in a Social Psychology Quarterly claimed that the process of trust is activated when another person verifies the individual’s self-view. Seeing that person as being dependable and predictable enables the “self” to begin the process of developing dependence on, and trust in, that other person. Even though their reported research was a portion of another longitudinal study of recently married couples, their observations of the trust relationship are worth mentioning.

We suggest that insofar as a person’s identity is verified repeatedly in interaction with others, whether by intention, negotiation, or happenstance, that person will gain knowledge of the others’ character and will come to trust those specific others (Burke & Stets, J. 1999)

From their research with professional educators and mothers of children with disabilities, Angell et al. (2009) believed that the first step in establishing a collaborative relationship is to develop trust. However, the researchers claim that definitions of trust can vary and are actually still emerging. Reference was made to consistent terminology such as vulnerability, benevolence, reliability, competence, honesty and openness. It was their belief that all of these listed attributes should be present in a “fully trusting relationship.” Their study had sixteen who participated in a qualitative questioning about teacher performance in both general and special education environments. It is interesting to note that the mothers felt their trust of the teachers was inhibited if there was a demonstrated lack of knowledge about their children’s disabilities. They also were trust-inhibited if there was perceived teacher inflexibility in disciplinary methods, teaching methods, and failure to implement disability accommodations. Additionally, the authors’ data referenced individual parent factors that they believed had an influence on their study results: (a) the mothers’ history of trust, (b) their individual disposition to trust, and (c) the communication from their respective children about the class experience. Likewise, it is noteworthy that the authors referred to other
research as indicating the parents’ past experiences with trust (pre-bias) can influence their responses in the present.

Having sufficiently defined the characteristics of trust and/or trustworthiness in a variety of circumstances, an assumption can be drawn that there are similarities from one discipline to another, regardless of diagnostic parameters. In addition, in the context of challenging daily life circumstances, it should be mentioned that when a parent/caregiver is only able to maintain a minimal level of personal emotion-control while attempting limited behavioral management for the child with autism, it is difficult to pursue any form of incremental steps toward communicating trustworthiness. For some parent/caregivers, their struggle to cope with challenges is perceived as just too overwhelming (Hewson, 1997).
CHAPTER 3

METHODOLOGY

DESIGN OF THE INVESTIGATION

Because of the diversity in the Autism Spectrum Disorder population, selecting similar study subjects in an effort to minimize compounding variables was a formidable challenge. The intention of this phenomenological qualitative research was to isolate perceived parent/caregiver trust as an important salient component for autism remediation. In addition to purposeful interviews with parents, a structural/textual description of the perceived pivotal trust-formation event for each child (as parentally reported) was incorporated into the depiction of before and after “epiphany” behaviors. The goal was to demonstrate the need for, and the value of, the “trust factor” in autism remediation which evolves in, and emanates from, the parent/caregiver relationship.

This study was qualitative ethnographic research in which narratives, stories, and accounts of experiences are analyzed to look at content, themes and commonalities. The people who were approached as potential participants were from a specific population with whom the researcher has had a relationship, and who were willing to share personal information/insights pertaining to a child with autism. There were two parts to the interview process:

1. The Qualitative Questionnaire (See Appendix A) is a short series of questions in which the participant is asked to describe in detail a “Remarkable Moment” in time when there was a meaningful and undeniable communication between parent/caregiver and the child with autism. Events or circumstances leading up to the “Remarkable Moment” were likewise explored. Personal emotions elicited by the memories generated in the process of recollection, and how those recalled experiences pertain to the communication process were recorded as part of participant narratives. The primary focus of the questions was on the issue of trust and its formation, communication, and enhancement through the parent/caregiver relationship. The academic, professional, and experiential background of the researcher in both human psychology and autism was incorporated into the question design process. Open-ended questions that allowed for participant individuality and responsive authenticity were deliberately crafted to be potentially emotion-laden in an effort to give each participant an opportunity to tell her unique story and to share
meaningful information as she deemed appropriate. The emphasis in the question design was focused on the perceived inner feelings of the participant, rather than acquired intellectual knowledge. Likewise, the chronology of question placement could comfortably explore and verbalize a range of personal emotions throughout the interview process.

2. The Demographic Survey (See Appendix B) asked generalized quantitative information pertaining to age, cultural background, previous autism therapies and preferences, educational level, and profession of participant.

PARTICIPANTS

Study Involvement:
The individuals who volunteered for the study participated in a one hour in-depth interview using the researcher-designed Qualitative Questionnaire, along with a five to ten minute Demographic Survey. Participants could elect to divide the interview session, depending on personal time constraints due to existing family obligations. The therapy and school schedules of children with autism took precedence. The researcher (self) adapted the interview schedules of each participant accordingly.

Characteristics of the participants in this study were as follows:
- 12 Adults (over 18 years).
- Female parent/primary caregiver of a child professionally diagnosed with autism (preferably, the child is between the ages of 4 years and 8 years of age).

Selection Criteria:
The cultural background of the family, the age of the parent/caregiver, and the gender of the child whose parent/caregiver volunteered as a participant, were not restricting factors in this specific study. Likewise, the marital status of the interviewed individual was not a relevant variable. As a general rule, children between the ages of 4 and 8 years of age, who are professionally diagnosed with autism, are already enrolled in one or more autism remediation programs in the community, making formal diagnostic verification by voluntary study participants unnecessary. The parent/caregiver of a child with autism was asked by the researcher to present one of the following established documents for records review, if there is no current therapeutic program was in place for the child at the time of this study: (1) Individualized Educational Program (IEP), (2) Individualized Program Plan (IPP), (3) Pediatric Statement.
At the request of the thesis committee members, specific demographic data was collected from each of the study participants. This information was not intended to pre-empt or to supersede the importance of the qualitative responses gathered in the research. From the philosophical perspective of the professional advisors, whose interdisciplinary areas of expertise span three separate fields of study, the additional quantitative information gathered from the participants would enhance the overall results of the qualitative research (See Raw Data Table 1, Appendix C). The following list encompasses some of the results of the administered Demographic Survey Questionnaire:

1. Eleven of the twelve participants (N=12) were the parent/caregiver of a male child with autism. The remaining participant was the parent of a diagnosed female child.

2. Comparatively, the average age of the children with autism whose parent/caregivers participated was roughly five years and two months (M=5.2), while the average age of the professional diagnosis of these children was two years and seven months (M=2.6). (See Figure 1).

3. According to the compilation of demographic survey data, four (4) participants (30%) were the parent/caregiver of only one child; six (6) of the participants (50%) had two children; and the remaining two (2) participants had three and four children respectively (20%). For seven (7) of the twelve participants, the child with autism was first in the birth order. Another four (4) participants reported the child with autism as having been born second. For the remaining participant (1), the child with autism was fourth in the birth order (See Figure 2).
4. Question #7 of the survey provides two sets of data. Figure 3 shows the percent of most frequently used modalities by the participating parent/caregivers for the treatment of the child with autism. Occupational therapy (92%) and speech therapy (83%) had the highest frequency, followed by the use of videotaping/modeling (75%). According to the participants, the top five most beneficial treatment modalities are shown in Figure 4, with occupational therapy preferred by seven (7) of the twelve individuals at 58%. Parent training programs and speech therapy were the second most frequently chosen modalities by five (5) of the twelve parent/caregivers at 42% (See Raw Data Tables 2 and 3, Appendix C).

5. Survey Questions #8 through #10 demonstrate that 100% (N=12) of parent/caregivers reported the child with autism as having a trust relationship with a person other that the primary caregiver. For roughly 83% (10) of these participants, that relationship included an immediate family member; 50% (6) affirmed that the child also has a trustworthy caretaker or therapist with whom there is a special bond; while 8% (1) of the participants reported an extended family member as being in the child’s perceived
“circle of trust.” These results are based on the personal observations as reported by the parent/caretaker in response to the Demographic Survey Questionnaire, rather than by direct researcher observations of the child during any interactions with other individuals (See Figure 5; Raw Data Table 1, Appendix C).

6. In reviewing responses to both Question #15 and #16, the cultural background of seven (7) of the twelve participants (N=12) were Caucasian. Two (2) were of mixed Asian ethnicity, two (2) were African (or mixed African) American, and one (1) participant was Hispanic. Partner ethnicity had a similar distribution. Nine of the twelve (9) were Caucasian, but two (2) of those were European born. Two partners (2) were Hispanic, and one (1) was African American from the Caribbean (See Figure 6).

7. At the time of this study, the average age of the parent/caregiver was almost thirty-eight years old (M=37.9), while the average age of the partners was roughly thirty-nine and three quarter years (M=39.8), according to the data in Question #17 and #18 (See Figure 7; Raw Data Table 1, Appendix C).

8. Parent/caregiver education levels reported in Question #19 and #20 show that 33% (4) have some college experience, with one participant also having a vocational certificate; 8% (1) have an AA college degree; 42% (5) have a BA college degree; and the final 17% (2) have some type of Graduate degree. Partner education levels are as follows: 8% (1) only have a vocational certificate; 58% (7) have some college experience, with one also having a vocational certificate; 17% (2) have a BA college degree; and 17% (2) have some type of Graduate degree (See Figure 8).
Figure 5. Summary of trust relationships with others by %.

Figure 6. Subject and partner ethnicities (N=12).

Figure 7. Average age of parent/caregiver and partner in years.
INTERVIEW PROCESS

Within this specific community of autism parent advocates and activists, all supporting one another for a common cause, there are numerous families who embrace and support each other on a regular basis, incorporating newcomers continually. We communicate through a variety of mediums and frequently engage in combined family events, sharing information and resource options. Potential parent/caregiver volunteer participants were contacted briefly in person by the researcher to give a short description of the proposed study and to inquire whether or not the individual would be interested in additional preparatory information. An affirmative response from each person contacted was followed by an electronically transmitted description of the study which explained the proposed goals, the necessary time involvement, an assurance of the confidentiality of gathered data, and a request for contact information (if necessary) so that telephone Q&A would be available as needed. By sending a prepared copy of the questionnaires to the participants in advance of the scheduled interview, it was believed by the researcher that each participant would have an opportunity for personal reflection and convenient interview preparation, maximizing the probability of more thorough responses in shorter period of time during the actual face-to-face interview process. Due to the personalized nature of the data-gathering interview format, and the perceived importance of establishing a researcher/participant “trust” relationship, the researcher believes that direct contact is...
necessary in the initial phases of the consent procurement process. Coincidentally, the Southern California Special Olympics organization based in Long Beach, California, separately posted portions of their professionally generated documentary, “Special Olympics: Be A Fan,” on the internet website, Youtube (SpecialOlympicsSoCal, 2010). As part of featuring the achievements of specific special needs athletes in the original television program during the spring of 2010, the researcher was interviewed as a parent of a son with autism. Study participants were also encouraged to view the professionally prepared video in which the researcher reveals some of her own challenging experiences, as well as portions of her personal journey. The intent was to enhance the possibility of a perceived sense of kinship with participants who were preparing to reveal their own personal history, and to create an additional trusting bond from which the subjects could comfortably share intimate details of their respective lives.

Because the study has a qualitative format with an in-depth interview as the method of data collection, the ideal number of core parent/caregiver participants was determined to be not more than fifteen individuals. Originally, fourteen volunteers were approached by the researcher and subsequently agreed to participate in the study. Due to unforeseen family health emergencies, two volunteers had to withdraw prior to completion. Twelve (N=12) subjects actually completed both the Qualitative Questionnaire (See Appendix A) and the Demographic Survey (See Appendix B).

For the purposes of this study, audio-taping was used, providing a way to document conversations and to gather information pertinent to the study. Audio-tapes were transcribed by the researcher, using pseudonyms to protect all participants’ identities in data analysis. In addition to the interview questions, a set of demographic survey questions, designed to gather general quantitative information, was also developed. This adjunct questionnaire followed the qualitative interview. For this study, presentation of Informed Consent methods did not include any type of advertisement, incentives, or access to public records for recruitment of subjects.

Potential participants were either approached by the researcher at an autism family event or were contacted by telephone if that information was available. As previously stated, most of the individuals were already mutual acquaintances. Depending on responsiveness and interest, the volunteers either elected to read the prepared Informed Consent at that time,
or arranged for a subsequent date for review in their respective homes. Scheduling of participant/researcher appointments was at the discretion of the individuals and was governed by their personal time constraints, which include any therapy and school-based needs for each child with autism. Neither the Qualitative Interview nor the Demographic Survey Questionnaire process interfered with, or infringed upon, the primary responsibilities of the parent/caregiver.

Once potential participants had read and acknowledged that they fully understood the information provided by the Informed Consent letter (See Appendix D), had all questions answered, and were comfortable with every aspect of the proposed study, there was a discussion to arrange an interview location, date, and time that would accommodate their respective schedules. Each was subsequently thanked for participating as a volunteer. It should be noted by the researcher that every participant expressed gratitude for having had the opportunity to share a personal narrative from the “parent/caregiver journey” with someone who has successfully navigated many of the same challenges. Parents experiencing a perceived sense of isolation in the overall life process while caring for a child with a diagnosed learning difference (often viewed by society as a “disability”) is not uncommon in research literature or in the writings of authors who have focused on caregiver/child relationships (Cullen, Barlow, & Cushway, 2005; Geist-Martin et al., 2003; Hewson, 1997; McKeever & Miller, 2004).

For the purposes of this research study, an Olympus digital voice recorder (WS-400S) was used to audio-tape each interview session with the parent/caretaker participants. Following completion of each scheduled meeting, the recorded interviews were transferred through a USB connector to a Dell desktop computer. Using the Windows Media Player and the Windows Movie Maker for editing, interview tapes were then transferred to a blank Memorex CD-R for later transcription into a printed text. A Sony MP3 CD Walkman D-NF340, with headphones for minimizing any potential interference from external sounds, was used by the researcher to personally transcribe each interview from an audio format into printed text. Recorded participant inflections reflecting emotion-laden event descriptions; verbal variations in expressions and tone quality; narrative speed, including verbal pauses during interview discourse; and non-verbal responses that spontaneously evolved as part of the interview process, were noted in the text transcription through modifications in printing
style (i.e. emboldened lettering, word and phrase capitalization, exclamation marks, descriptive parenthetical inserts, deliberately notated pauses between phrasing, and combinations thereof). The intent was to recreate the multi-dimensional auditory verbal pattern of the participant as closely as possible, giving a more textural quality to the otherwise conventional print format.

When the transcription of all interviews was complete, the researcher began the process of examining the responses of each participant to each qualitative question, highlighting common themes. Likewise, additional coding was done to notate similar phrases or words that recurred throughout interview questioning. Because each subject had previewed a printed version of the qualitative questionnaire, the researcher was able to conduct the sessions with minimal prompts or conversational redirection. In one instance, the subject responded to every listed question without any interviewer prompts. Instead, because of her own time constraints, Mya chose to answer all questions in the form of a running narrative with time remaining for additional personal reflections added.

In most cases, participants overwhelmingly welcomed added conversation time, volunteering other personal information not on the designated study questionnaire. Although that material was retained on the CD recording, it was not necessarily transcribed into the printed format for the purposes of this study. Only responses pertinent to questions relevant to the immediate research were preserved in print. However, based on her own experience as a parent of a child with autism, the researcher recognized the potential value to participants in having an uninterrupted opportunity to share a personal narrative story, complete with deeply emotional reflections and revelations that span years of respective life experience. Therefore, each parent/caregiver was afforded that private option. In some instances, the material was sufficiently sensitive that the audio recording process was paused, allowing the participant total freedom to experience previously unexpressed feelings in a safe, accepting, and undocumented environment.

**DATA ANALYSIS PROCEDURES**

In order to efficiently manage the collected qualitative raw data for the ten study questions, one primary “Essential Theme” was identified as predominant in each specifically
designed question. Next, the responses of each participant were reviewed for common “Incidental Themes” and listed alongside the corresponding “Essential Theme.” Participant responses for every question were reviewed again, counting and recording the number of repetitions found for each “Incidental Theme” within all ten “Essential Themes” listed (See Table 4, Appendix C). Response percentages for selected qualitative and demographic survey questions were determined by a simple division—the number of total responders was divided by the number of total participants (See Raw Data Tables 6 and 8, Appendix C).

In reviewing parent/caregiver responses to Qualitative Question #5, it was noted by the researcher that all participants had included descriptions of observed post-“Remarkable Moment” behavior changes in each child with autism. To demonstrate these perceived improvements in mutual communication and bonding connection, a list was created from the seven common parent/caregiver responses. A Raw Data Table 5 (See Appendix C) was then generated to record the responses of each participant to these behavior changes. Frequency of distribution was not evaluated, however, for the purposes of this study because responses were only subjectively observed and reported. In some instances, parent/caregivers noted changes in multiple areas.

Having noted some commonality in the reported parent/caregiver childhood experiences during the interviews for Qualitative Question # 9, the researcher elected to create a Raw Data Table 6 (See Appendix C) which shows a summary of the five most commonly reported childhood circumstances with the number of participants and a percent of response frequency for each. Alongside the list of circumstances are the perceived solutions/childhood reactions of the participants, showing the frequency number and the percentage for each response. The purpose of this evaluation evolved as a result of the questionnaire responses, and was not pre-conceived until after was collected and reviewed. It was noted that each parent/caregiver had experienced significant childhood challenges in some form. Likewise, each person developed multiple individualized coping and survival strategies that have subsequently created the perceived foundation for current problem-solving skills.

In Raw Data Table 7 (See Appendix C), each individual participant response to Qualitative Question #9 was listed to show specific circumstances and solutions by
parent/caregiver pseudonym. As was previously noted, the compilation summary shown in Table 6 (See Appendix C) was developed as a more simplified form of Table 7.

The parent/caregiver responses generated by Qualitative Question #10 were first listed by individual participant pseudonym and then as an attached summary in Raw Data Table 8 (See Appendix C). The intention was to report specific as well as responses in common that evolved from the interview process.

Finally, visual bar graphs were developed from the raw data to further simplify and summarize the collected information in this research study. The illustrative Figures are dispersed accordingly throughout the Results and Discussion portions of study findings that are presented in the subsequent chapters.
CHAPTER 4

RESULTS AND DISCUSSION

To document and report the process through which the parent/caregivers in this study have established perceived trust-based communication with their respective autism-diagnosed children, the researcher conducted a phenomenological qualitative investigation with ten carefully designed open-ended questions. In some instances, these thought provoking questions had multiple parts that necessitated subjective responses relying on personal perceptions and evaluative observations. In addition, several interrogative questions were incorporated into researcher requests for narrated details throughout the interview process. Due to the lengthy responses, the researcher has selected a representative sampling from each question to illustrate the predominant Essential and Incidental Themes that emerged from the subject interviews. The original Raw Data Tables 4 through 8 can also be found in Appendix C. From the review for each numbered qualitative question, it was noted by the researcher during individual interviews that many of the participants had several responses in common. These similarities occurred regardless of cultural background, marital status, subject age, or any other demographic information gathered from the additional survey. Because each question also had multiple Incidental Themes identified, the researcher listed the number of subjects who responded accordingly to each (See Table 4, Appendix C). Within this study population, it was noted that some of these secondary themes were more frequently reported than others. The small sample size makes it difficult to access whether or not there is an ethnographic trend or if the repetitive patterns are purely coincidental. Although the original Qualitative Questionnaire is found in Appendix A, for reader convenience each interview question has been restated within the thesis text as preemptory to the individual analysis.

QUALITATIVE PARTICIPANT RESPONSES

In Question #1, the parent/caregiver was asked to recount the events surrounding the child’s differences in early development, the age when that awareness occurred, and the
resulting emotions that were experienced in the process. The most common areas of typical
development that appeared to be negatively impacted can be broadly categorized as follows:

a. Atypical behavior issues.

b. Oral and tactile defensiveness with eating disorders.

c. Communication delays and social interaction aversion.

More specifically, all participants (N=12) stated that the young child had significantly
negative responses to any type of transition from one location or activity to another. The next
most frequently reported observations (10) were “difficult eating issues” that included
spontaneous gagging, vomiting up unwanted swallowed foods, rejection of any oral texture
other than strained baby foods, etc. Lack of eye contact (10) with immediate family members
and a refusal to interact with others (9) was another reported parent/caregiver observation. In
all but one interview, the subjects (11) reported that their respective pediatricians dismissed
repeated expressions of parental concern. They were assured that lack of language and/or
other described behavioral issues were representative of a “normal delay” and not to be
concerned until the child was 3 years of age. The following interview excerpt is a typical
example of pediatric non-responsiveness to expressed parental concerns:

Ter–By 18 months, we brought it up to his pediatrician, and she told us not to
worry about it; that it will just happen one day. He will just immediately start
talking one day. And we were, like, you know, we wanted to believe the best so
we were like, ‘Well, OK, we’ll just wait on that and see!’ (nervous laugh). And,
you know, by age 2 we were, you know, alarmed! We were living in San Diego,
and we had him evaluated over at Balboa, and then by the school district. Well,
no, at age 2 we had him evaluated over at Balboa and the consensus/ feeling of
our developmental pediatrician was that, quote/unquote, ‘he didn’t do enough
WEIRD stuff to be on the autism spectrum!’ (physician’s actual spoken words to
parents).

Interestingly, of the children who were subsequently diagnosed with autism by a
professional, five (5) parent/caregivers reported that the changes in the child seemed to occur
after a high fever and/or a significant illness of some kind. Until that point in time, there
appeared to be normal development. Two of the participants (2) stated that their children
seemed to have developmental delays or differences from birth. Nevertheless, even in those
instances, the pediatricians did not acknowledge the parental concerns as being noteworthy.

Question #2 asked each person for a description of the emotional response to the
autism diagnosis and to share any grief-based experience that followed. Of the coded
Incidental Themes throughout all of the ten questions, this particular question had the greatest variety of individual responses by the participants. There were only three of the twenty different expressions that had four responses each. The others had fewer numbers. Parent/caregivers reported having a collection of mixed reactions, but did not immediately define the origins of their individual response variations. In some cases, those response origins were recognized through an unintended personal “ah-ha” revelation while answering Question #9 regarding childhood circumstances/solutions. The following three excerpts illustrate the common types of parent/caregiver responses and the coping strategies that began to emerge as a result of the diagnosis of autism:

**Sue**–I guess I said it before (Question #1) but I felt sad, scared, happy (he was going to get help) and mad….MAD that this happened to our family. It took 6 years, several miscarriages to finally have a child, and now our hopes and dreams have gone up in smoke; at least that’s what I thought at the time. He’s never going to be normal, wouldn’t play with others, have friends, play sports, go to regular school, have a job or get married. NOTHING! I thought he was going to be institutionalized, that he was going to go away; I thought that I would never have a connection with him; I thought that he was going to be a lost soul forever, and I was devastated. From that moment, I felt it was my fault! I did this to him! I didn’t take good enough care of myself, and it was because of my constant worrying during my pregnancy that caused this to happen to him. It was probably all part of my past issues, wrongs and medical problems that caused him to be autistic. ME—ME—ME!! There were times, I felt myself pulling away from my son, not wanting to love him, thinking he was better off without me. Didn’t know how I could be of help to him. I messed up by carrying him, and I completely felt at times that I should just go away, and I felt completely 120% responsible (and at times still do), GUILTY!! MY FAULT! So, I became the ‘doer’ of the house, and (partner’s name) became the bond person. I became the cooking, cleaning, play but not interactive close play. I would hold him, but I felt like he was somebody else’s child…..completely. It was SO SAD! SO SAD, IT BROKE MY HEART! I felt that because no one can say where autism comes from, it must be from ME.

**Nan**–Yeah, I have my moments; and I figure that is also a challenge to my faith. It is! It kind of brings that….what is this supposed to be teaching me at the end of the day. And I think that I already got the message loud and clear. ‘Thank you, God, for slapping me on the face! That, yeah, I can’t control everything!’ I guess not! I guess I needed this message to learn that I can’t control everything that goes on.

**Mya**–So, did I experience any sense of ‘guilt?’ I think I feel a little guilty, not so much with the diagnosis of autism…. more just the fact that I know he’s affected and what…and…..wondering in the pregnancy did I do something wrong during the pregnancy…and the realistic brain side of me says, ‘NO! He has a twin sister
who came out perfectly/typical developing.’ But the emotional side says, ‘Maybe there’s something I could have done, or should have done, or didn’t do, or whatever.’ So, um, with (son’s name) there isn’t a moment….he’s not one of the children who regressed where he moved forward and had typical development and regressed at a certain point. For him, he actually made progress slowly but surely as I was educated and as I encountered individuals who showed me how to work with him, and worked with him in a CALM AND ENCOURAGING WAY to help HIM achieve things. Because I think that a lot of his achievement occurred as he grew confident in that he could do some of these things.

The initial participant reactions to the autism diagnosis can be grouped into seven simplified areas of emotional response (See Raw Data Table 4, Appendix C). Some subjects (N=12) reported having experienced feelings from more than one category at different times:

a. **Guilt**—It’s my fault because I did something wrong during pregnancy (2), or I didn’t get a second opinion (2). It must be a gene defect (2).

b. **Sad**—because of child’s regression (3); treatment delays (4); the child’s future (4).

c. **Upset**—I failed my child (2); I had inadequate information (2); I knew something was wrong (3); the slow response of the medical community (3).

d. **Angry**—I wanted to scream and hit something (N=1); mixed with being glad that help will finally be possible (1).

e. **Doomed, overwhelmed, lost, hopeless**—(5).

f. **Denial**—Couldn’t address it (2).

g. **Acceptance**—This is fixable (5); this is God’s plan (3).

These fluctuating states of mixed emotion described by the parent/caregivers are also consistent with the findings of Hewson (1997), McKeever and Miller (2004) from articles previously referred to in the literature review.

For **Question #3**, each individual was asked to recall a period of time when the child with autism was perceived as making progress, but for no apparent reason that improvement either stopped or regressed. The parent/caregiver was also asked to evaluate what circumstances may have triggered that perceived regression. In response, all of the participants (N=12) in the study stressed that unexpected changes in home routine, school, or therapy schedule, and/or tutor substitutions by service providers, consistently trigger negative behavioral issues in the child with autism. Some parents (2) reported that specific health or environmental events have appeared to precipitate a predictable, recurrent pattern. The
observed symptoms of regressive behavior also included combinations of (a) not retaining learned skills from one day to the next (1); (b) communication changes (2), or decreased talking and eye contact along with increased screaming (2); (c) abnormal “melt-downs” during routine activities (1); and (d) intermittent tantrums (3). Two participants (2) stated that the child with autism experiences six-month cycles of feeling overwhelmed by instructions/information, while two others (2) react negatively to inconsistency, and a lack of simplicity or untrustworthiness. To illustrate this, three different representative samples have been included that demonstrate these behavioral challenges. In each instance, the individual circumstances were different. However, the parent/caregivers were able to assess the precipitating problem, create unilateral changes to alleviate the situation, and correct conditions of the child:

Sue—But then around the time we started ABA therapy, his behavior changed. He got mad, hit, biting everyone, saying ‘no,’ not wanting to follow directions. It seems like it goes through 6 month spurts. And during the time when he does a lot of the biting and stuff, it seems like he is the most unfocused and his speech gets ‘slurry.’ I can almost see in his eyes that a lot is going on; and he is trying to focus and he gets frustrated, and so I try to bring him back to center and keep his days very simple and structured, and don’t give him more than 3 tasks at a time….don’t overwhelm him with too many instructions or information at a time. I try not to overwhelm him because he misses the middle of the conversation. He hears the beginning and the end. The worst is when he is in his biting/hitting mode. I’m not sure why it happens! It’s sudden; it comes and then it goes. And then a couple weeks later it comes, and then it goes. And I don’t quite get the pattern, and I am trying to figure out the pattern.

Nan—So, recently we went on a family vacation after school got let out in June. And (child’s name) had been doing well with his in-home behavioral program and following directions, and doing his drills, and obeying the rules of sitting at the table, and asking if he could get up, and not knocking things over, and he was following the rules. But when we got back from vacation, I think that was the catalyst that got him off schedule. And then we started seeing some undesirable behaviors when we got home so we started seeing him jumping up and down when he should be sitting at the table doing his work and his drills. We started seeing him knocking things off the table….not in anger…just in… I don’t know if it was a sensory need, or what it was……just not following the rules with doing his drill. Also, a lot of scripting…a lot more scripting… and, um, not being able to focus on the task at hand, or on his drill, or on what he needed to do and work. So, that was definitely exacerbated after we came home from vacation. Once we got back on schedule, he seems to be getting back into that.
Mya–I want to say that it was a different take on the same information that we were given about the way we talk to, and verbalize, but really break it down….I think it was the first time that I realized I was probably throwing too much information too quickly at him and I simplified my speech; REALLY GOT DOWN ON HIS LEVEL; REALLY FOLLOWED HIM AROUND AND LET HIM DO THINGS THAT EVERYBODY WAS TELLING ME WAS WRONG, AND THAT THEY DIDN’T WANT HIM DOING……SPINNING THINGS CONTINUOUSLY. AND INSTEAD OF STOPPING HIM FROM DOING THAT, GETTING DOWN AND WORKING WITH HIM ON IT, AND ENGAGING HIM IN IT, AND KEEPING AT IT. THEN, HE STARTED TO MAKE EYE CONTACT, BRIEFLY, BUT HE STARTED! AND THEN HE STARTED TO…..THAT WAS WHEN HE STARTED TO DO MORE GESTURING AND COME AND GET MY HAND AND TAKE ME TO THINGS THAT HE WANTED….WHERE HE DIDN’T DO IT BEFORE BECAUSE HE DIDN’T REALLY….HE JUST EXISTED IN HIS OWN WORLD. And he didn’t view people as….maybe I was just a tool! I was still a tool as opposed to making a real connection but he realized, ‘OH, I can look outside me and get somebody to HELP me with what I need and want.’

Question #4 of the qualitative interview asked the parent/caregivers to insightfully assess their communication style, and to analyze what was done by them to improve their children’s resulting behaviors or interactions with them. This question was intended to be a preliminary precursor for Question #5, which focuses more on the “remarkable” event that may have ultimately evolved as a result of improved parental communication skills. Of those individuals interviewed, all of them (N=12) reported that the child consistently reacts more positively to a “firm yet nurturing” voice quality. Likewise, 67% of participants (8) claimed that the child with autism responded better to someone speaking slowly and calmly. About 42% of the subjects (5) have effectively used the “first do this, and then you will be allowed to…” strategy when attempting to inspire child compliance. In 33% of the cases, parent/caregivers (4) stated that playful, animated, and silly behavior from them always gets the attention of the child. The same percentage (33%) and subject number (4) was true for child responses to using small words in short sentences, and to having the adult “get down to the child’s level” to attempt communication or to establish a one-on-one relationship. Consistent interaction, relationship building over time, mirroring the child, and creating simple songs to teach tasks are other effective strategies reported by participants. As a representative sample quotation for Question #4, the researcher selected one lengthy portion from an interview. The imbedded communication strategy devised by this
parent/caregiver as an aversion technique for chronic child “melt-downs” was believed to have sufficient educational value that it warranted being quoted in its entirety as an example of effective problem-solving by the participant:

Fay—(I) definitely need to be more playful and animated in the way that I communicate with him; over the top animated and playful and silly gets his attention more, I get more of the eye contact, I get more of the participation, I get great conversation, imaginative play, all of it I get through being silly. And he tends to flock to people who are very similar….Music, I kind of default to music. If I am trying to explain something to him, I can just remember a simple song that I made up myself. I was taking a class, More Than Words. It was one of the very first therapies that we did, so they gave us these little assignments to do and one of them was make up a song to help your child learn a task. Well, at the time I was trying to teach my child that if he made a request, to wait a second so that he could get whatever it was that he wanted. Because what was happening was he would make a request, ‘I want this.’ I would say, ‘OK’ and then go to reach for the thing; but that two seconds of reaching for the ‘whatever’ he thought that since it didn’t instantly appear, that he wasn’t getting what he wanted. So, he would be upset about that. He would kind of speak these messages into the atmosphere and expect it to instantly appear in front of him. So, my task was to teach him “OK, I’m coming; it’s coming.” We made up the WAIT SONG:

‘You gotta wait, wait, wait for mommy. Gotta wait, wait, wait for mommy. Gotta wait, wait, wait for mommy till I’m ready!’

And when I had that little ‘READY’………and I would display whatever he wanted to him…. ‘READY,’ and so he understood I am ready, and if it took me more time to open the gismo—whatever he needed—if I couldn’t attend to it right that instant second, I would sing that little song, and it was enough of a fun activity, a playful way, and rewarded, that he loved that little song for a long time. And I had to do the whole song and dance sometimes.

R—Do you still do that song?

Fay—That particular song was when he was early 3. I haven’t done that song in a long time. We’ve moved on to other goals, other skills, but that’s just an example.

R—Once in a while, maybe you should throw it in there for the heck of it!

Fay—Right! But, I mean, I have moved on to several different songs. There’s a new song for each-----I default to songs. Right now, I have a ukulele, so I have made up little ditties on the ukulele, which he thinks is hilarious. I can teach anything with a ukulele, and so I’ll hear him singing those little ditties himself, and he giggles and laughs. So, I know there’s a love for music, and early on there was a connection to get those words out. The music helped him comprehend those words, not only comprehend them but to spit them back out. So, my playful attitude has really been paired up with what I love to do which is play and sing; and thankfully that has been a good fit for him.
Because the primary focus of this research study is rooted in the discovery and documentation of communicating trust between the parent/caregiver and the child with autism, the participants’ individual responses to **Question #5** are key factors in the phenomenological examination of the perceived communication “break through.” Understandably, every reported “Remarkable Moment” recorded as part of the interview process was significantly emotion-laden. For some parent/caregivers, this opportunity to share a personally momentous event was perceived by each individual as an expressly “healing” experience. For that reason, the researcher has elected to include several of these poignant stories. Hopefully, this inclusion will illuminate the underlying thought processes of both parent/caregiver and the child with autism, as well as revealing the nature of the events leading up to that “moment in time.”

In terms of the background demographics reported in her initial survey, **Fay** is of mixed African ethnicity, college educated, and has been an active home-schooling parent/caregiver. Her child was 3 years of age and totally non-verbal at the time of her “Remarkable Moment” event. His predominant mode of communication included loud, uncontrolled and unpredictable screaming. By her own admission, the spontaneous outbursts had become increasingly disruptive both to family life and to the participant’s ability to involve her child in any community activities outside the home environment. The use of the Picture Exchange Communication System (PECS) had been recommended as an alternative form of communication in lieu of the lack of understandable spoken language. The following abbreviated quote was taken from the interview with **Fay** (See Appendix E):

**Fay**—He still didn’t understand how this visual was gonna help his mother get his requests faster, easier, whatever. In the “ah-ha moment” when he understood that I knew how he felt, I went through all the little pictures that I had of him….“(BOY’S NAME) HAPPY! (BOY’S NAME) SAD! (BOY’S NAME) EXCITED! (BOY’S NAME) this and that… just different feelings. And I put them on teeny-tiny little pictures that I put on a necklace, like that teacher had these quick visuals, and so I was amazed at what he was able to do with that. We went to another outing. It was Christmas time. Someone was having a Christmas gathering and something wasn’t going the way he wanted it to go, and he would reach for my necklace and show me, ‘(boy’s name) is frustrated’…. or whatever I had named that little picture….and then you **immediately** pay attention, try to figure out what it is he wants, try to help him solve the problem, and he **did not** throw a tantrum at this particular party! So, I knew that we were gaining and making progress because he knew that I got it. SO THEN, all those pictures that I
had made ahead of time now made sense to him, and he was immediately able to use those pictures to request things. ‘I want this ball, I want this thing’ which is what the speech therapist was doing with him…this PECS Program; and this PEC, get this thing….but now it made sense to him, and we were off and running! He did great with that! But it took the collaboration of a community explaining little bits that worked for them. And it wasn’t like the one…..there’s not one thing that works for all kids. It was all these little pieces now tailored into……OK, these little components now fit (boy’s name). And the only way that I can see that you can get that is by working with the parents; because the parents are the only ones that know ‘how are you going to tweak this to fit my child?’ No one else knows that unless they have been around since Day #1.

Lex is also a college graduate, but of Caucasian ancestry. Her professional affiliation had been interrupted by the autism diagnosis of her son, who was a non-verbal child prone to tantrums and screaming as the main method of communication. Similarly, PECS had been attempted as a language alternative, but had limited success by 5 years of age. Although the circumstances of the specific event reported are somewhat different, there seems to be some striking similarities in the behavioral outcome:

Lex–At one of my son’s pediatric check-ups, (I had definitely changed physicians by then!); I expressed my concern to the doctor over my son’s unpredictably volatile behaviors. I remember him telling me that I needed to give credibility to his feelings in a way that he would realize that I understood what he was feeling. The doctor said that when my son was angry, he needed to know that I understood that, etc. The doctor’s wife was a child psychologist so I understood why he had made that suggestion. It made sense, but I also knew I was having a hard enough time just figuring out WHY my boy was screaming, and how to meet his needs! Later when we got home, I looked at the collection of pictures on my refrigerator. The magnet with the emotions was right in the middle of the door. Each face in the collection had the word under it to describe the emotion. At the very least, I figured he would learn how to recognize the words! As usual, there was an incident and he came screaming into the kitchen. I leaned down closer to his level and said something like, “Oh, you are so angry! I see that you are so angry!” I pointed to the face with the word ANGRY and repeated it again. He wrinkled up his forehead, looked at me, looked at what I was pointing to, slowed down his rapid breathing just a little, and then his eyes became wide. I remember that moment because it was the first time that I ever felt there was a real connection. I was almost afraid to breathe, or even to move, as he stood there looking at me and began to calm down! I think I was as stunned as he was! In those moments, whatever it was that had made him angry, I had time to figure out so that I could ‘fix it.’ From then on, I used those pictures and my words to express to him that I recognized what he felt, and that I understood him. After that, I gradually noticed that the screaming became less and less. Instead, he would bring me something he needed help with, or he would hand me the food
pictures, take my hand to put it on what he needed, and he looked to me to tell
others what was on his mind……… and eventually I could. In time, we became
like ET and Elliot because our minds were quietly in tune with each other.
Somewhere in the middle of his 5th year, he began to try making approximations
of sounds for foods. And I was thrilled. I knew my boy finally trusted me to
meet his needs; and I trusted myself to understand what he wanted.

This participant struggled for years to become a mom, having had multiple
pregnancies, each ending in a miscarriage. The understandable anxiousness that Sue reported
was compounded by the fact that her son, later diagnosed with autism, had also been a
fraternal triplet. When the other two fetuses did not survive, it was believed that he would
likewise not be a live birth. This parent/caregiver demographically is older than other
individuals in the study, has some college education, is employed part-time in a family
business, and is Caucasian. Her story was particularly insightful because of her willingness to
share personal revelations amidst the painful journey to parenthood:

Sue—Up until this point, I was the ‘doer’ and I would do things for my son. The
biggest challenge happening was that he was very close to (partner), and he was
listening and following directions very well. That is why I kept him still in
daycare, because the times I did have him all day by myself, he didn’t listen to
me, he didn’t respect me, and he didn’t trust me because I didn’t earn it from
him. I don’t think he ‘felt me’…..he couldn’t feel me…..I didn’t let him ‘feel’ me,
and I didn’t get that until this happened…..and so this is what happened: The
biggest change between my son and me happened about 6 months ago when he
had a high fever and was sick. He never wanted us to sleep with him; but that
night, he asked me to lay down with him. I did. While he slept burning up with
fever, I just looked at him for hours, watching him. Something changed in me. I
woke up; I saw (child’s name) for who he is ---not what I dreamed of him being
(mom is weeping while talking). From that night on, my whole energy
towards
him shifted. I became a mommy; I became a warrior, and not just the ‘doer
around the house’ mom. Something shifted in him. It was like we had this energy
bond. We both woke up that morning and we looked at each other in the eyes,
and I could feel him, and he felt me. And from that night on, I sleep with him
every night; I fall asleep with him, he puts his arm around my neck, he kisses me
and he falls asleep smelling my breath. And that was the best thing that could ever
happen between us. And it happened on accident….but not really….It was like I
needed to get to some place and all of a sudden something kicked in and I shifted
completely…….completely shifted. I am so thankful for that night. I will never
forget it. It’s as clear as day…it’s like it happened last night. And I just became
this different person, and he felt it! He woke up that next morning and from then
on, I’m IT! He wants ME, he loves ME, he listens to me more, I’m the first
person he wants to see in the morning, and the last person he wants to see at night.
He calls for me in the middle of the night and I wouldn’t change it for anything no
matter how tired I am because that bond that he and I have now is unbreakable. And I LOVE IT! I let him in, and letting him in HURTS because I am scared and happy at the same time………I am scared because I don’t want to mess it up. Sometimes I am a little hard on myself (laughing now). It was really COOL, really COOL! He wants me to read books. He wants me to sit and watch TV; he wants ME to play trains!

Cam is also a college educated Caucasian participant from an upscale neighborhood. She readily admits that her goal was not to be a stay-at-home parent; and that she had looked forward to a career in some type of business marketing prior to the autism diagnosis of her child. Mastering the art of managing what she referred to as “horrible anger issues” has been the ongoing challenge for this parent/caregiver. The triggers for his behavior elude her understanding because she claims that they have seemingly not been consistent. Nevertheless, her story reveals that she has been able to make an inroad into mutual communication that now has a more positive outcome:

Cam—So, he was an absolute tantrumer! I mean, when I am talking tantrum, I am talking 30 minutes that would end up with him throwing up, he is so upset…..that horrible, horrible tantruming! And so for the longest time that was my BIGGEST complaint and concern. It was HIDEOUS! So, one night he was getting out of the bathtub and I don’t know, I did something that upset him, something wasn’t right; and he’s very OCD; and the towel wasn’t just right and he had a fit. And he wound up falling down in his fit and cracked his tooth on the tile floor. So, I had to take him to the dentist the next day; and I knew it was going to be ugly taking him to the dentist because he was 2 years old. He hadn’t been to the dentist yet, and I had to go, and they had to look at this cracked tooth and I knew it was going to be bad. So, sure enough we get there and he actually, oddly enough, was surprisingly wonderful! He sat there in the chair, let the dentist take an x-ray, he was being fine. And I was squaring up with them, you know, filling out whatever I had to do on the way out, and I don’t know what it was that set him off, but something set him off. If it was the stress…I don’t know what it was but something set him off. And I had been talking with the therapist about different ways to approach the tantrums and this was the first time I utilized this. So, instead of what my normal instinct was, which was to get so flustered in public because he was screaming and crying and, I’m not kidding,…quite literally vomiting…because it happened and it was so disconcerting! So, instead of my resistance, which was normally what I did, I told him, ‘Ok, we’re going to step outside into the hallway, and I am going to let you roll with this. You can scream, you can shout, you can kick the wall, whatever you need to do, and I’m just going to wait. I’ll just stand right there and wait; and when you’re done, we can come back in and finish this up.’ And he did! We went outside, and it was a breakthrough because what generally would have been….it was almost like I gave him the freedom to do it and it lasted 2 minutes and it was OVER! And we
went back inside, I thought, ‘My gosh, maybe all this time my resistance of it, the tension had been the problem! And now that I gave him the freedom to scream and yell.........’

R–You understood he was angry.

Cam–He was…exactly! And I LET him be angry!

The demographic background of this participant is mixed Asian. She is a highly educated animal behavior specialist, who waited until her career was established to have children. Her pregnancy yielded fraternal twins of both genders, the male born as the smaller infant with low tone and clearly defined developmental delays. The female was not affected. Because of her background in science and in training animals, Mya was aware that her son’s sensory responses from birth were not normal. Likewise, his female sibling did not present with any of the same issues. Because of his delayed speech, the child with autism was being taught American Sign Language to aid in his communication capability. As his parent/caregiver, Mya has stated in other portions of her recorded interview that she is aggressively pursuing every option to help maximize her child’s potential. The narrative demonstrates her keen ability to utilize “windows opportunity” as they appear:

Mya–I think the first ‘ah-ha moment’ was with sign language! Because we were going through speech therapy at San Diego State and I would let him play with the doors on the way in; and then I would …I realized I could USE THAT! So, I stopped him and I made him SIGN each time, I made him SIGN. We would SIGN.....I first started him with ‘open door.’ So I would stop him, and I wouldn’t let him push the handicapped button until he signed ‘open door.’ And then one day he stopped and he signed ‘more open door.’ And I was so excited! And we started using that elsewhere! So, in that generalization, because I think he categorizes, ‘Oh, this thing is for this place, this person can do this thing.’ And he did think….everything had its place! He wouldn’t let certain people do certain things, and in certain places you can do certain things. But once we got through the ‘doors thing,’ and I would take him and say, ‘Do you want door?’….and I would take him to places to do ‘magic doors,’ he realized, ‘Hah! I can get something that I really, really want by just using my hands!’ So we really did that! So, that was our first, I think, connection. And he expected ME, more than anybody, to understand him. That is my impression. Obviously, he can’t express that. But when he would become frustrated, I was the person he lashed out at. My take on that was because he really wanted ME to get it. He thought I should get it. He didn’t expect other people to get it, but he expected ME to get it! So when I didn’t, he would scratch me, or bite me in the frustration. He never showed that kind of aggression with other people. So he would pull my hair, scratch my face. So we started doing the verbalizing, ‘I understand you’re frustrated! You’re angry!’ And I think when we took the further step of saying,
‘but we’re going to do this…’ rather than trying to get him to express it and just staying with that, and saying,….’Understand, we’re going to do something fun so you’re NOT angry and frustrated!’ We’d stop trying to fix what we thought was wrong and just redirect to something fun and he went, ‘OK!’ And gradually we just started to get more understanding and because of that I think he was more willing to be patient with ME. So, I think that the more he realized I was trying, and I was getting some things, like with everything else, he saw some success, he was M-O-T-I-V-A-T-ED to try harder. And I think the one thing that I saw, once he realized that, was he learned to have patience with me! He learned to give ME a chance to try to figure it out, where, he just didn’t before. He would just get SO FRUSTRATED AND ANGRY, and he couldn’t figure out what was wrong! At some point he just realized, ‘OK, she’s trying to figure this out so I have to give her some time.’ And obviously when he is tired, it just goes out the window! (LAUGHING). So………… (continues laughing).

In every instance, regardless of the circumstances in which the reported “moment in time” happened, 100% of the study subjects (N=12) described the following perceived changes:

a. Observable improvements in mutual communication.

b. A behavioral demonstration on the part of the child with autism that his/her needs would be met by the parent/caregiver.

c. A substantive indication that a sense of trust or perceived trustworthiness was being shown.

Commensurate with these reported improvements, 75% of the participants (9) believed that a definitive bonding connection had evolved in the post-perceived “Remarkable Moment” experience. Roughly 67% of the subjects (8) also felt that the child with autism had evolved into a parent/caregiver relationship that participants characterized as: “You see me! You understand how I feel!” Likewise, 50% of the participants (6) believed that their verbalized expectations were now understood by the child with autism (See Raw Data Table 4, Appendix C).

A summary of these parent-perceived post-“Remarkable Moment” behavioral changes are illustrated in Figure 9 (See Raw Data Table 5, Appendix C).

To further illustrate the parent/caregiver perceptions of how the “Remarkable Moment” experiences were reflected in observable improvements, to mutual communication and bonding connection with the child, behavioral changes can be grouped into three broader categories:
Figure 9. Parent-perceived post-“Remarkable Moment” behavioral changes by %.
1. Behavior modification
   a. Decrease in tantrums, frustration, or screaming (11).
   b. Increased ability to be patient with parent/caregiver (10).
   c. Increased ability to wait for gratification (9).

2. Mutual communication
   a. Perceived realization by the child that feelings/emotions are understood (12).
   b. Increase in parent/caregiver being able to act as a communicative helper (12).

3. Bonding connection
   a. Improved eye contact (10).
   b. Improved compliance with therapeutic intervention and/or therapists (9).

As in Question #5, the intent of Question #6 was to have the parent/caregiver reflect on and describe a “moment in time” that may have happened with another individual who is equally significant in the life of the child diagnosed with autism. The participants each had a story with a common theme that seemed to comparatively mirror many aspects of their own narratives. Likewise, even though the individual circumstances were different from one parent/caregiver to another, the overall experiences appeared to have shared similarities. The researcher believes that including these selected quotations will be equally valuable. They highlight perceived personality characteristics to which these children have positively responded with increased consistency. For the sake of future understanding and overall behavioral analysis, these included narratives may help to shed light on ways to design a more desirable approach to children with autism, thereby improving responsiveness and compliance:

**Fay**—In the early, early days after he was diagnosed, it’s hard to know exactly which happened first because things where happening within a 6 week time frame but I can remember an instance when I had a mom help me quite a bit. She came to my house with her son who is also on the spectrum, but has made tremendous progress. And I can recall very vividly, at the time my son was 3 and very into trains. So, he loved to play with his trains, but no one was allowed to play with his trains with him, or even come close to his trains. Those were HIS trains. I can recall in just getting support from this mom, also watching our sons play and this other young man was able to be in close proximity to the train set. And of course my son ignored what he was doing.

**R**—Was the young man talking to him?
Fay—He was making little comments. He has a very calm approach. And when he
turned on his Gameboy, it immediately caught my son’s attention. One, because
of, I think, the musical component; and also because it was not intrusive to what
my son was doing. So, it caught his attention in kind of a non-confrontational
way. It was just kind of, ‘come see if you will.’ He was down on his level, playing
on the floor, he had his Gameboy, and my son was then able to approach him. So,
I think a lot of time that’s what works for him. It’s a very subtle calm
approach, kind of ‘take it as you will,’ not an ‘in your face’ approach, ‘look
what I am doing!’ It’s a more, ‘come see on your own terms.’ And because of
that, this young man and my son STILL have a good relationship. And by the
way, that is the first time that he had met him, I am pretty sure. That’s why it
sticks out in my brain because at that time he did not warm up to strangers. It took
a long time to warm up to people. So, #1) this young man came into our home,
got down to his level, and just did a simple thing; and my son responded to it
within minutes—IT WAS AMAZING!

So, then we have been invited over to my friends house where our two boys still
play video games. My son is now able to take instruction from him and have kind
of a tutor/mentor in his life. There’s a bond there, a connection there, and it’s a
very subtle one….just a quiet nature that he responds to as well. Because I
think it’s just my son knows that he gets it and there is nothing you can do to
describe that. You can’t make that up. It just IS! And he connects to that.

R—Do you notice any commonalities in tone of voice or demeanor that he
responds to? As you think of different therapists that he has had……because he
has had some therapy now……are there any common denominators in the ones
he likes versus the ones he doesn’t like?

Fay—YES! Definitely! Not to say anything negative about any of the teachers that
we have had. They have all done an excellent job as professionals, but there’s
something about certain teachers that he picks up on very quickly. Who’s a
KID person, and who’s more clinical, task oriented. He definitely picks up on
who’s just trying to check off a check list, and who’s being casual and trying
to play. Now, the one who is trying to be casual and play is still trying to meet
goals and run programs, and what not, but they mask it a little better in that they
play first and “check-sheet” later.

Eva—Well, definitely to her dad and her grandma, the two other most important
people in her life. Where I think I was able to observe that (child’s name) trusted
someone else outside of the household was when we would go to grandma’s
house and she was, like, ‘Bye! See ya later!’

R—If you think about the personalities of the people that she responds best
to……how would you characterize………..

Eva—Oh, I’ve known that one for a long time. I have told every respite care
worker who comes to this house, ‘If you do not engage my child, if you do not
play with her you’re gone, because this kid is very high energy.’ I’m not
talking hyper, but she wants to be doing stuff. She wants to paint, she wants to
color, she wants to play with stickers, she wants to play with Play-doh, she wants to swim, she wants you to take her walking, she wants to do every possible thing that every little kid wants to do. She wants to be doing that with you and if you don’t do that then we can’t leave the house. (Personality types) I have noticed a difference between my husband’s family and my family, his family as a little more calm. **She responds better to firmness, and she picks up on fake. So, I do notice that she does respond to people that are firm, but who have a calmer voice.**

**Lex**—My son usually acted as if he was not paying attention to most people, but I would catch him ‘glancing’ briefly at them and then standing around nearby. Sometimes, with his dad, he would stand by the desk and wait for some kind of acknowledgement that he was there. On rare occasions, he would pick someone out and decide to sit by them or make eye contact. But it was usually after he had been around them for a period of time. Since his dad LOVED Thomas the Train, we bought all the tapes. Sometimes, my husband would sit and watch them while our son was standing behind the couch too. I bought the trains one at a time for our boy, and eventually they would sit together like 2 kids. That was probably the beginning of the father/son bond that later expanded to other activities together. His dad had a quiet, calm manner about him, but he also loved to entertain the kids by making funny voices that captured the attention. He used puppets and story telling to make them laugh. He **also had a firm but loving way about him that became soothing to our son’s temperament.** My goal was for our son to be as bonded to his dad as he was to me. But that was a slower process.

**Sue**—I would say that the biggest one, other than (partner’s name) is Ms. Juli from Social Communication. He never wanted to leave when we were there. Something clicked for him. He started to really trust her. He followed her. And at the end he would run to the car and as he almost got to the car she would be at the door saying goodbye, and he turned around and he would run back to her and jump in her arms and kiss her.....just love on her. **I could see that she established this base that ABA never did, that his speech therapist never did, never got to that level, because they never gave him enough room for flexibility, and they never established trust. They just went right in there, wanted him to perform and do what they wanted him to do, and then didn’t understand why he didn’t want to comply!** So it took a half an hour for Ms. Juli to “open that up” but in the next half hour, she got him to try new things! Because he was like, ‘Oh, I get you. You’re going to play with me and follow me for a little bit and then... OK, that’s good, Ms. Juli, and then I’ll follow you.’ I learned a lot from that. Even for typical kids you have to build this foundation. So, Ms. Juli, Ms. Juli......and also Mrs. Erica and Mrs. Christina at his special preschool. The connection that he has with them is really phenomenal. They do what they do because they care.

**Ter**—Um, he trusts our ABA therapist! He’s joyful and happy, and (son’s name) is not happy when he first gets here; but once he his and their playing and having fun, he is excited that Dave’s here, and he wants to play with Dave. He trusts him
to toss him around and be physical with him. He doesn’t like being restrained, though.

**Cam**—My favorite therapist, I feel like they connected so well because he treated my son like a little boy instead of like a subject, if that makes sense. Um, he spent probably a month doing **NOTHING with him** EXCEPT **hanging out with him** at the Thomas the Train table playing with trains. His tone of voice was just….he was just the **WARMEST person and constantly giving him “high fives,”** positive reinforcement but **NOT IN AN ARTIFICIAL WAY.** We have had so many therapists that where saying the right thing, but they **DIDN’T MEAN IT,** if that makes sense?…**But (male therapist’s name) MEANT IT!** He just, I could tell, (son’s name) **loved him,** and he loved (son) back! They were a little team, and he was so sweet. I **loved** that he treated him like a kid, not like a ‘check box.’ **YES, not like, I need to collect data from you.** Like, he didn’t collect data for a month. I mean, he just played with him; literally played with him! And I found, now that said, as time went on and (therapist’s name) had to get to work with him…because he was not here to be a playmate, he was here to do work with him….he started to let me know, ‘I need to draw out some of this aggression. I’ve been playing his way all this time because **we’re building a rapport,** and I just want to let you know that you may want to go downstairs for this one because I am going to start pushing some buttons, because I need to trigger the aggression. Otherwise, I can’t address it.’ So, yeah, he did! …he would just calmly address the situation and just tell him, ‘I get it! I get it! I get it little Dude. You’re just really upset!’ The progress that HE made far superseded anyone else’s progress, and I really think it was because he RESPECTED him. He treated him like a KID! He was AWESOME! Yeah! I mean it SO SINCERELY…IT MAKES ALL THE DIFFERENCE! Maybe we need to accept that not everyone is the best fit to work in this line of business.

I think that there have been perfectly nice therapists who are lovely people that are **NOT what my kid needed.** Too much of the ‘golf clap,’ the actual feeling that is behind it…**not heartfelt!** They ARE children with worth!

I think society in general, and some of the therapists too, are taught that antecedent A causes B, and that’s what they expect; and that’s what the children are…they’re the means to their paperwork. The ones that don’t feel that way make all the difference! **Gentle but firm!** Consequences don’t have to be administered condescendingly or with a lack of respect.

**The “I GET YOU. I GET WHERE YOU’RE COMING FROM!”**

**Lea**—Um, I think that the ABA therapist that we have right now….she doesn’t treat him like a student. She treats him like her friend. She gets down on his level, and he really, really, ‘digs her’ to the point that now when she comes in the door, he’s taking her bag for her, and helping her in, and walking with her to the room, and helping her set up, and he really likes her (laughing). So, now we’re trying to teach him how to say, ‘Here, let me get that bag for you!’ …because that’s exactly how he acts (laughing). He tells her, ‘Come here!’ And then she’ll bend down. She has her bag on her shoulder, and he’ll grab the bag, and he’ll drag
it into the room for her. And all the while watching to saying, ‘Come on, let’s go!’ (laughing). And all the while he’s calling her and coaxing her along, and he takes her into the room. I think he TRUSTS her because she follows through with everything she says she’s going to do. She gives him a task and she tells him, ‘Do this first; and then, we’ll do this.’ Every time that he accomplishes whatever it is that she says, then she gives him exactly what he wanted…whether it’s a toy or an activity, she gives it to him as soon as he accomplishes it; and every time she asks him to do something, it seems like he will do it for her. I mean he complies with her more than he complies with me at times.

For Question #6, clearly 83% of the participants (10) felt that the “Remarkable Moment” event which each child experienced with another “important person” in their respective lives had (a) improved mutual communication, (b) fostered a bonding connection, (c) created a sense of trust or trustworthiness, (d) had promoted a feeling of being understood, and (e) that the child likewise understood the expectations of the “important person.” In addition, 75% of parent/caregivers (9) reported the observation that the child realized his/her needs would be met by the other persons of importance (See Raw Data Table 4, Appendix C).

Question #7 asks the parent/caregiver to describe noticeable sensory changes that indicate the child with autism is “moving forward.” These observable changes are understandably subjective for each participant and are often subtle or slow in emerging:

Fay–Like I said, it’s not a quick process. I’m going to give you a word picture because I just….we’ve had a success….we’ve actually just graduated out of our Lovaas Program, or ABA program yesterday. We have said “good bye” to some teachers. So, one of the things that I told them that was important to me,…I hope that they do come back and see his life maybe years later and see how he’s doing. Because these therapies…..it’s not just a JOB, IT’S NOT JUST A JOB. IT HAS TO BE A RELATIONAL THING. YOU HAVE TO BE IN IT FOR THE RIGHT REASONS, AND IN DOING THAT YOU MAKE SUCH A HUGE DIFFERENCE IN THESE FAMILIES’ LIVES. So, I wanted them to remember that. It’s not just checking boxes. It’s not just paperwork. It’s not just run the program, do the routines. It is make that connection, make the bond, make the relationship, and it will make a difference over a lifetime. And also, TEACH THE PARENTS, because they stuck with me, and they taught me, and I could ask questions as he grew, as he changed. Like you said, you thought you were making progress and what happened! We had those surprise moments and I could say ‘what do I do next?’ ‘Well, teach him a little differently. Use these videos, video modeling, or whatever.’ Because they stuck with it and they took a ‘whole’ approach, the family as a whole and not just the child as a client, we really made success.
Of the ten parent-reported signs indicating perceived forward progress of the child (N=12), the most common expression was “tolerates being out of a comfort zone better” (6). Another frequent response was that spontaneous language increases (5). About 25% of parent/caregivers commented that the child was (a) developing a funny sense of humor (3), (b) becoming more helpful (3), (c) was demonstrating more concern for the feelings of others (3), and/or (d) was realizing that there are consequences to “unacceptable” behaviors (3). It is noteworthy that the last four mentioned characteristics are consistent with the ability for Theory of Mind comprehension and with the capacity for empathy described in Chapter 2 (Mash & Wolfe, 2010, p. 311). Additional signs were noted, but with fewer numbers of respondents (See Raw Data Table 4, Appendix C).

Parent/caregivers listed a variety of responses for Question #8 when asked how forward movement of the child with autism impacts them. Several reported feeling excited and happy, or that “there is hope!” Others used terms such as “rejoicing, celebrating, motivated and inspired.” One participant stated that the stress goes down! Yet another individual realistically described her journey as being “very exhausting because I am always on duty, trying to stay ahead of the curve, continually preparing to teach the next new thing to my child so that he can catch up in life” (See Raw Data Table 4, Appendix C).

The most personally challenging interview question for the participant, as well as for the researcher, was Question #9. The parent/caregivers were each asked to reflect on their respective childhood circumstances, and to identify challenges from which they derived coping strategies for survival. In every case, the participants not only revealed intimate childhood details that were often painful to recall, but they shared the resulting solutions. For some of these individuals, there was an additional “ah-ha” moment as it became clear that their childhood solutions are the same strategies that have been instinctively incorporated into how they manage the challenges of a child with autism (See Raw Data Table 7, Appendix C). To further illustrate this point, portions of the interviews with Sal and Sue have been included as representative samples. Although their respective life circumstances and chosen solutions were different from one another, both developed a stronger sense of self-reliance, drawing comfort from a private faith in God. Both of these parent/caregivers have been able to move past their individual childhood grief and use the coping skills from those personal challenges as effective problem-solving tools in working with their children.
Sal—My brother’s death is/was a factor in my parenting, especially in raising (son’s name) and coping with his diagnosis…..I guess I learned from them (parents) that it is OK to grieve loss, but you can also still have some triumphs; and just how important family is; and that you are stronger than you think, especially if you have good support and faith in God. My brother’s death probably has made me a bit more protective….There may have been some degree of emotional neglect because we were all depressed in the family after; and now I understand it more, because of my experiences raising (son’s name) with limited resources and dealing with his disability. I did have to fend for myself, like doing my own laundry and meals; and my parents weren’t tracking my school or other activities very much because they threw themselves into their work to cope; and because life has to go on, bills have to be paid. It caused me to be very independent, I guess, able to leave home and strike out on my own and reach personal goals ….having a fractured family and losing a member probably makes me work harder to keep my own family together.

Sue—I think that we do what we have learned. I think that not knowing before that “ah-ha moment” came between (son’s name) and I, I think that because (son’s name) was not who I had dreamed of him being, I was disappointed, and I was angry, and I felt like….but not surprised because nothing in my life ever came easy. I have always had problems. I have always had issues. I never went down the easy path. I always took the one with the rocks, the hills, the mountains, and the ditches. And it was always a challenge. Everything, everything I have done has always been a challenge. The only thing that never was a challenge was when I rode my bike. I was good at it; I was naturally good at it; and I felt the most free. I always felt like I had GOD riding with me when I rode my bike because I used to ride 100 miles at a time. So, I thought I have got to find (son’s name) what makes him feel God. What gives him that sense of “I’m good at, I’m OK!” and see where I can help him with that, because that’s priceless. You can’t read it in a book. You can only experience it. I was a PIECE OF DIRT! That’s who I thought I was! I think that was part of my fear about (son’s name) because what do I have to offer him….what do I have to offer him? I don’t even know how to calm myself down! I don’t drink anymore, I don’t smoke, I don’t binge and purge, I don’t spurt, I don’t do drugs, and I don’t starve myself so I don’t have any of my coping mechanisms with me anymore; and now I have an autistic boy! OH BOY! How am I gonna handle my stress level? And that’s when I woke up this morning and I can read you those things that….because that is why God sent me (child’s name)! That’s what He (God) is teaching me! I get to relive, I am born again, I get to relive and redo my life at 45! And WOW for me! I get to be patient with myself, I get to love myself, I get to laugh, I get to be a kid…..which I didn’t get to be a kid when I got molested at 5 ½; that was GONE; all my TRUST was GONE….I get to help, I get to re-learn TRUST, I get to see life in a magical, wonderful, fantastic life that it is instead of being so afraid of everything. So, yeah, that’s why God brought (son’s name) in my life…completely…. GUESS WHAT! WHO’S BEING TAUGHT! ME!
Although Raw Data Table 7, Appendix C has a complete compilation of individual responses to Qualitative Question #9, Table 6 (See Appendix C) provides a summary version of the parent/caregiver childhood home-life circumstances; and the perceived solutions reported by the participants. In some instances, the parent of the volunteer qualified for more than one classification. In the interest of simplicity, the experienced parental neglect/abuse was categorized into five main areas:

1. **Emotional abuse/neglect** was experienced by 67% (8) of the participants.
2. **Verbal abuse** followed with 42% (5).
3. **Physical abuse** was reported as 33% (4).
4. **Absentee parenting** was also reported as 33% (4).
5. **Substance abuse** was engaged in by one parent (1).

Similar to their parental role models, the participants adopted multiple survival strategies in order to cope with their respective levels of abuse (N=12). In the Solutions category, 83% (10) reported that they had to become independent and self-sufficient in order to cope with their circumstances. Also, 75% (9) of the volunteers claim to have become creative problem-solvers, while 58% (7) say that they learned to “self-entertain” during long periods of “alone time.” Of the participants in the study, 50% (6) had to become the caretaker for another family member(s), either a sibling or an elderly relative. Of those interviewed, 33% (4) either embraced a religious affiliation/faith, after school athletic involvement, or both as a means of offsetting any undesired emotions. Only one individual (1) temporarily sought comfort in substance abuse to mask personal pain. Interestingly, 50% (6) of the participants resolved in their early years to not repeat the parental behavior patterns that were demonstrated by their own childhood role models. **Figures 10 and 11** illustrate this summarization of parent/caregiver childhood circumstances and solutions:

![Figure 10](image-url)  
**Figure 10.** Parent/caregiver summary of childhood circumstances (N=12).
Figure 11. Parent/caregiver summary of childhood solutions (N=12).

A summary of parent/caregiver responses for Question #10 is listed as follows, with the complete compilation of individual answers listed in Raw Data Table 8 (See Appendix C):

**Most Common Response** | **Number of Participants**
--- | ---
1. Seeing forward progress/accomplishments | 8 (67%)  
   a. Inspiration | 1 (8%)  
2. Sense of humor | 4 (33%)  
3. “My child is a gift” | 2 (17%)  
   a. A gift from God | 1 (8%)  
   b. God’s miracle | 1 (8%)  
   c. Provided direction/focus | 1 (8%)  
   d. Teaches the parent | 3 (25%)  
   e. So adorable! | 2 (17%)  

For 67% (8) of the participants (N=12), the most rewarding part of being the parent/caregiver of a child with autism is seeing the forward progress and the daily accomplishments, regardless of how small and insignificant they may seem to other people. The children’s developing sense of humor was another “plus” that was reported by 33% (4) of the
participants. Many of them openly chuckled when describing the funny things that their children do to deliberately make others in the family laugh. They also have noticed that these children are easily amused by what some people would consider rather unusual or un-noteworthy…things such as funny noises, some forms of spontaneous/unexpected sounds, or odd comedic humor. Several parent/caregivers described their children as being “a gift.” Others were more specific in referring to the child as “God’s miracle” or as being “A gift from God.” For those who also have children without autism, these individuals remarked that the experience of autism-parenting has actually enabled them to “slow down and celebrate” their child’s accomplishments. They claim that they would not otherwise have taken the time to notice all of the smallest developmental milestones, and that they are grateful for not having missed those details amidst life’s busy schedule. As a result, many parent/caregivers separately shared that no “teachable” moment has been wasted, and that nothing is ever taken for granted! Improvements of any kind are liberally celebrated on a daily basis! Figure 12 illustrates the summarized version of the participant responses to Question #10:

**DISCUSSION OF FINDINGS**

It is important to remain mindful that Incidental Themes for each participant occurred in conjunction with other themes on the raw data list. It was also noted by the researcher that no set pattern of theme combinations could be found. Each parent/caregiver responded to the qualitative questions based on personal perceptions and observations that were gathered prior to the interview date. None of the participants were pre-biased by the researcher in an effort to illicit responses that were in any way disingenuous of their individual belief systems. The percentage of responses was determined by the number of responders divided by total participants for each identified Incidental Theme.

However, these reported commonalities in parent/caregiver responses throughout the respective interviews clearly reveal that the overall pattern/trend in the results transcends participant demographics. Participant/partner ages, levels of education, ethnic backgrounds, and marital status did not have any apparent impact on the perceptions of the parent/caregivers with regards to their children with autism.

This study clearly verified the need for, and the value of, the “trust factor” in autism remediation, which evolves in, and emanates from, the parent/caregiver relationship. As was
Figure 12. Question #10 – most rewarding part of being your child’s mom (N=12).
demonstrated by the collection of participant narratives, moments that foster and trigger trust between parent/caregiver and the individual with autism can be part of a progressive process that ultimately culminates in what is perceived to be one “Remarkable Moment.” In reality, this process is an evolution from much smaller events that are accumulated over time.

Having no eye contact from the child with autism does not necessarily indicate that there is no attention being paid to the surroundings! **In every case, the overarching belief, as stated by the study participants, was that the key to gaining their child’s trust, to being perceived by the child as trustworthy, and to establishing a reciprocal relationship was the direct acknowledgment to the child that his/her feelings were understood (i.e. “I see that you are happy, sad, angry, fearful, etc.”).** Once that component is accomplished, every parent/caregiver reported having experienced behavioral improvements. The underpinning for behavioral compliance that leads to socialization is the ability to experience a sense of “basic trust.” From this foundational framework, other social relationships such as the ability to experience empathy and a capacity for Theory of Mind conception can develop with proper intervention. The perceived trustworthiness of the parent/caregiver can then be extended to other individuals who demonstrate a comparable relationship-building desire.

The relationship transferability component was also addressed in the interview process. Each participant similarly described the observable demeanor of a “special” person in their child’s life (other than themselves) as being calm, firm but nurturing, speaking in slower deliberate sentences, and with genuine sincerity in their praises to the child. Those who worked most effectively, and who accomplished the most with the child, were the persons who focused on forming a relational bond before anything else. Therefore, the findings would seem to indicate that the most beneficial method of approaching autism remediation/intervention should initially focus on trust development. Once that component is solidly established, program formats can be tailored to center around, or to incorporate, what captivates the child’s interest first before expanding into the otherwise prescribed curriculum. With this format, parents expressed that their children were more inclined to be positively motivated, consistently responsive and more attentive for longer periods of time. From their viewpoint, the overall outcome was enhanced learning and social connectedness.

In addition to the previously described results, there were numerous other secondary findings that unexpectedly surfaced throughout the course of the interview process. Before
discussing any examples of clearly demonstrated empathetic behavior from children with autism, or any indications that they are actually capable of manifesting “Theory of Mind,” the researcher observationally noted patterns and trends within the parent/caregivers themselves:

1. These moms each had rather insecure attachments with their own parents. For the most part, there was an approach-avoidance relationship with the parent (not always with the mother figure). In some cases the original mother figure also had a history of insecure attachment in her childhood (Mash & Wolfe, 2010, p. 305).

2. All but one participant had a childhood history of some form of verbal or physical abuse, neglect or parental absenteeism. In some instances, the volunteer was in the caretaker role for her own mother (or other siblings and family members), maintaining a sense of calm or balance in the family environment. There were also limited instances of addiction behavior patterns in the history of the participant’s parent(s), creating the necessity for increased coping abilities. Those who had successfully addressed their own upbringing seem to be able to separate their own insecurities from the needs of the child with autism. In doing so, they have been able to view their child as an individual, rather than as an extension of themselves. Thus, they can pursue help for the child without being negatively mired in past childhood memories.

3. For those whose childhoods were cut short for one reason or another, or if “play” was not encouraged and nurtured, parent/caregivers have had to relearn “how to play.” Some participants are experiencing it for the first time through the eyes of their own child.

4. The most effective moms are ones who have come to terms with their own childhood issues and have resolved their personal inner conflicts sufficiently so that emotions are manageable or effectively contained. They have also been able to use the understanding they have gleaned in the process as a tool, rather than as a crutch in life. All of them have become active problem-solvers and “fix-it” persons as a result of their respective challenges.

5. Interviewed moms have often struggled with their new perceived identities and with how to define themselves in their individually changing rolls. There is a process of coming to terms with being a person – or with embracing the role in life – which is opposite of what was envisioned. Next is the acceptance of that new role with grace, resolve, and commitment.

6. Parent/caregivers feel rewarded by seeing slow progress in their child with autism. Experiencing the child’s sense of humor helps offset frustration from the autism challenges. Parents have learned about themselves by navigating through the child’s daily struggles.

The most efficiently effective way to describe the surprising secondary findings that surfaced several times throughout the interview process of this study is to share illustrative story samples that were narrated by the actual parent/caregivers. From these vignettes, it is
clear that some children with autism have the capacity for social qualities that were
previously believed to be neuroanatomically improbable.

The son of Sue was approaching 5 years old at the time of her story. He had already
been in a specialized pre-school setting and was receiving both speech and occupational
therapies. His “Remarkable Moment” experience with the study participant had occurred,
and the “trust factor” between them was established:

……..yesterday he had earned his marble configuration back…he had listened
really well to me. I said, ‘Would you like your marble configuration back.’ He
said, ‘Yes.’ I went to pick it up, I tripped, and I dropped it; it came apart. I started
balling. It wasn’t about the marbles! It was about everything. He looked and he
said, ‘Mommy, it’s OK! I’ll help you put it back together! It’s OK, Mommy!
Don’t be sad! It’s OK. Don’t cry Mommy! It’s alright.’ I looked at him and
said, ‘Can I have a hug?’ He said, ‘OF COURSE, MOMMY!’ He came over and
gave me a big hug and I just held onto him. He looked at me and said, ‘Mommy,
really, it’s going to be OK.’ I said, ‘Oh, you got it! You read me! You knew it
wasn’t about the marbles. You get it!’ We put the marbles back together in this
whole different configuration, and I let him do it all funky. He looked at it said,
‘This is SUPER, Mom! This is amazing!’ Through that odd situation came this
great communication and body reading that he got from me, and it was just really
cool. He read my facial expressions, but he could feel me that it was bigger than
the marbles coming apart. Maybe he didn’t know exactly what it was, but he was
really calm. He has empathy. He gets stuck on me not being happy. That’s not OK
for him and he fixates on that. After a while I just have to say, ‘OK, Mommy’s
happy.’ And then he gets all giddy and happy. He doesn’t like it if you’re not
happy. He’s reading me. His communication back to me is more direct.

In a different scenario, the 5 year old son of Nan decided to escape into the family
garage while his mom was briefly in the bathroom, and smear the contents of his diaper all
over the interior of the minivan and himself. Already late for an appointment, the participant
stated:

I have never done this before, but I got down on that kid’s level; I got in HIS
FACE. I was shaking my finger and I was at the top of my lungs saying, ‘THAT
WAS A BAD CHOICE! YOU MADE A BAD CHOICE! I AM VERY
DISAPPOINTED IN YOU!!’ And I was in that tone that I never used before with
my child and he looked at me---and my child NEVER looks at me in the
eyes….and he looked at me in the eyes and he said, ‘I’m sorry mommy! I love
you, mommy!’ This is when he had a speech delay too. And I am looking
(laughing) and I’m thinking, ‘Oh my goodness!’ Then, I gave him the biggest
hug, and I’m CRYING and I’m thinking, ‘Oh my goodness! This was how I got
through to my kid and I feel awful!’ There’s my guilt! There’s where I started
feeling guilty that that was what I did. But you know that was the first time that I
gota his face and I think that I scared the living daylights out of the kid. He had
NEVER seen me like that before! And then we proceeded to clean up the pooh and be late for whatever we were late for....see how much it matters? I don’t even remember what we were doing that day......but clearly it mattered to me at the time that we were late and that there was pooh all over the car.

In addition to demonstrating an empathetic response to the frustration and distress of his parent/caregiver, this child with autism seemed to show that he was capable of comprehending the consequences of his ill-timed behavior, and that his understanding of the concept underscoring “cause and effect” may be in tact.

Another participant, Lea, expressed very definite feelings about her son’s ability to empathize with others in a comparable situation, and to even cry with his mother if she is upset:

OK. He’s even gotten to the point now where he knows when we’re asking him to do something, and we’re serious about it, he’ll say, ‘Be happy! Be happy! Don’t be sad! Don’t be mad! Be happy!’ (laughing) He’ll tell US to feel a certain way because he KNOWS that when we’re getting stern and we’re asking him to do something, ‘Mom, Mom, don’t be sad, be happy!’ The first time that I realized ....because they kept telling me that children with autism don’t have empathy. But I kept thinking, ‘NO, but my son does!’...because he comes up to me when I’m crying and he’ll say, ‘It’s OK, Mom!’ Because I cry about everything on TV, and (laughing) so he’s like, ‘Don’t cry! Why are you crying?’... and he’ll cry with me because he sees that I’m sad and then he starts; and then I have to control myself because I’m afraid...I don’t want him to stress out because I’m crying over the All State commercial, you know? (laughing). So, when they told me he didn’t have empathy, I kept thinking, ‘Yes, he does! He’s done these things…’

Cam is likewise adamant that her son does have the capacity to empathize. She strongly expressed her viewpoint in that regard when discussing her perception of how society regards the capabilities of individuals with autism:

You know, I think that’s one of the biggest misnomers about children with autism. He doesn’t express a whole lot of emotion to strangers but the kid’s full of love. He loves his family, he loves his friends, he loves his teacher, and I think so often society as a whole looks at these kids who....you know, he doesn’t give a lot of reciprocity to strangers and they think, ‘OH, he’s NOT capable of love!’ People take the outer surface and write them off. Kids on the spectrum are so much more ‘checked in’ than people give them credit for....they are so much more ‘checked in!’ They may not be capable of caring what you did over the weekend (laughing), but they are absolutely capable of empathy! Maybe he doesn’t care what you did over the weekend, but he cares about his family; he cares about his sister if she’s unhappy so, you know, those parts do work in the brain. Not all children with autism are retarded so let’s not treat them as such! It’s NOT helpful! I did have to grieve it. That’s the best description ever of what it is! You have to quit the ‘idea kid’ that you had in mind and accept
the real one that you actually have and say, ‘We’re just gonna…’ and you know what? He is SO FUNNY! Is he a little weird? You bet! He’s so funny! I have spit water out of my nose, he’s so funny…the things that he’ll say! (laughing) So, he’s got gifts too. He really does!

It is interesting to note that having already responded to the emotional element of grief in her response to Question #2, Cam again interjects those feelings in the later part of the interview, followed by her verbalized amusement when describing her son’s funny sense of humor, what he reacts to that makes him laugh, and how she has drawn on his expressions to keep her laughing along with him in spite of the circumstances. It seems she has found a way to offset any of her perceived grief and to balance it with the joy of her child’s sense of humor.

Speaking of a sense of humor as another “secondary finding” from the study results, Mya also made reference to that near the end of her interview as well:

I would say that was at about 4 1/2. He does have a sense of humor that came when he started learning that he could exert himself; when he started realizing that he had control over some things. He started doing things because he would think it was funny and he would get a reaction. Sometimes, some of the things are a little weird! But we celebrate it anyway! I think he needs that encouragement for now.

Having been in the company of children with autism for many years, the researcher has noticed that those who evolve into a more high-functioning capacity on the spectrum have also developed an ability to grasp the Theory of Mind concept. In some instances, they have demonstrated an observable level of non-verbal understanding for others with the autism diagnosis. Fay mentioned this phenomenon in her interview when a young man with autism visited her home to interact for the first time with her young son. That interaction was described as part of the “Remarkable Moment” narratives. Also noteworthy was the story told by Sue regarding her son’s encounter with a teenage client from a local Special Day Program for persons with autism:

Just this past few weeks, my son has started to hear and get my tone and facial expressions. He’s just now getting it. Yesterday, he and I went to the park. It was a new park. A friend of mine came with her dogs and then she left. This bus came up and it was Community Coaching Center. Out come twelve autistic children. I never see autistic kids like that out in a group. They were from 8 years old to 15. Some were wearing the ear phones. Some were doing MAJOR stimming and yelling. Some were, you know, not verbal and everything. I was frozen and just kind of looking around; and all of them were REALLY loud. I just looked around and there was (son’s name), ‘HI! My name is (son’s name). Who are you?’
Would you like some chips?” And going up, ‘You want to come play with me?’ I was just like, ‘There’s my boy!’ He’s going out and he’s introducing himself, and so he made a friend, Sammie; and they played and it was absolutely beautiful! At first, Sammie was hiding underneath this table and wouldn’t come out. So, (son’s name) took his chips and went underneath the table, and said, ‘Sammie, you want a chip?’ Sammie put out his arm and grabbed a chip. ‘You want another chip?’ And Sammie shook his head, and (son’s name) got Sammie out from underneath the table, and Sammie sat and talked. It just made me so proud of him. I was so thrilled with how he was. He took Sammie all around the park, and just played with Sammie…..and Sammie was 15.

What is unique is that this little boy who was 4 ½ years old at the time of this event also used to hide under tables when he was fearful, according to his mom.

All of the participants (N=12) expressed very clear guidelines for how they believe therapy and treatment interventions should be tailored to each child. Based on their personal experiences, each parent/caregiver claims that the trust relationship has to precede anything and everything that is attempted for the child with autism. Lyn, whose son has the “complex” form of autism, rather than “regressive” stated:

He will take advantage of a person who is a ‘push-over.’ I’ve seen that when tutors come in. I tell them, ‘Oh, you’re being TOO nice! You can’t be that nice! You have to be Alpha Dog, or he will be.’ I’ll talk about the tutors because that’s the best way for me to categorize characteristics---Working and doing the same thing and getting different outcomes! We’ve had tutors that are SWEET, and right away he figured out, ‘If I throw myself on the ground and have a tantrum, or if I bite her, the lessons going to end, right? She’s gonna be like done and we’ll be like, OK, time to clean up! Or I’ll get extra break time; or we’ll take an extra long walk.’

Another parent/caregiver (Mya), whose son has had autism from birth and who has similar outbursts of frustration if attempted communication or needs are not understood (biting, scratching, punching), adamantly shared her views of what works more effectively for her child. Coincidentally, she is a professional animal behaviorist and trainer, often relying on that background to guide her perceptual understanding of her child’s struggles:

My instinct tells me that behavior can be moderated later. But I can use it to my advantage NOW to motivate him! More therapy is not better. It’s choosing the therapy that works for your family, and works for your life, and works for your child to help them make progress…….So, that’s all. He (son) is like a cat, in that if you went in a room where somebody has a cat, and somehow they (the cat) know that you’re a ‘cat person,’ well, you’re giving off ‘the vibes,’ and eventually that cat is coming over to you. The person who chases the cat will always chase that cat under a bed. It’s that way with my child. If you forced your way on him, and you were trying to do things without getting his consent, he
wasn’t gonna do it! And I think in that same respect, if you weren’t genuine, he KNEW IT! If you were going through the motions of saying, ‘GOOD JOB!’....and running him through the tests, and running him through the exercises without feeling genuinely happy for him, or genuinely excited about progress he made, he somehow didn’t want to work with that person. It might be sheer orneriness, you know, because kids can be that way. ‘I don’t really want to do this. This is getting boring for me! And you’re not excited about this so why should I be?’

R-- Just out of curiosity, and I think you alluded to it, do you see a correlation between the way you work with your son and the way you said you worked with animals. I have had two or three others all express that common mindset, but they don’t dare reveal it because people get offended.

Mya--…..just like through a ‘Mom Network’….I think it’s more prevalent now where we are really getting together and bouncing ideas. ‘Oh, this worked for my kid!’ And every kid is different, but taking bits and pieces and finding out how to make it apply to their child...... Animals like continuity. They DON’T like chaos. And I think in a world where these children have a lot of chaos, they don’t see continuity. They don’t see routine. They’re CRAVING something to be able to predict and to have some sort of sense of where their life is going….because they are getting pulled in different directions by all sorts of people. They have all sorts of people in their lives that other people don’t have. They’re being forced to go to all these strangers that other typical kids don’t have to go to. And we’re expecting them to overcome fear of all these people and to TRUST them innately when there is NO REASON to. So, you have to think of it from the terms of being an animal, because they don’t speak our language! They don’t know! And when you’re dragging them around, of course! And when you’re bringing them to places especially where they are going to do something ‘distasteful,’ OF COURSE THEY’RE GOING TO HATE TO COME BACK NEXT TIME! It just makes sense! So, in trying to build some sort of positive environment around stuff first before you can expect it. So, I really think there’s a HUGE connection. We laugh about, OK, how do you get a dog to go through a doggy door. You don’t shove them through! You don’t put a leash through and drag them through……which is what a lot of people do. You stand on the other side and go, ‘COME ON! COME ON! YOU CAN DO IT! HERE WE GO!’ And then they go through and you go, ‘YEAH!’ And then you put them on the outside AGAIN! And whether you’re using food in addition to it, it’s all building positively! So, yeah, I thought at first it was just me drawing on that because it was familiar to me. It was natural for me and it was the way I THINK. (laughing) Because REALLY, we are ANIMALS! And there is nothing offensive about saying we are the human animal because we ARE.

With the increased awareness and understanding of Autism Spectrum Disorders, and how they can manifest themselves in children at an early age, there are now more screening opportunities available for potential “at-risk” toddlers. Parental confidence/reliance on
medical professionals for early diagnostic confirmation is understandably subsiding. Parent/caregivers are becoming better informed consumers/advocates and are demanding accountability from the service providers of their children with autism. The current changes in Special Education, and the reductions in school-based services from an unfortunate economic forecast, may necessitate program modifications that focus on maximizing each child’s individual potential rather than the standard approach of “one size fits all.” Perhaps to accomplish this end result, the trend will once again be directed toward the development of working relationships that rely on “basic trust” formation. The research in this study clearly indicates that the communication of trust between parent/caregiver and the child with autism is a key component in subsequent autism remediation. Likewise, the findings point to a potential capacity for empathetic development, as well as an awareness of a Theory of Mind concept inherent in some children with autism (Adolphs et al., 2001; Colle et al., 2007; Kennedy & Courchesne, 2008). Both features are capable of being cultivated as part of the trust relationship that begins with parents. Once successfully established, the results of this study demonstrate that the social components of perceived trust and empathy can then be transferred to other trustworthy individuals, thereby opening the door to more effective and productive social interaction.
CHAPTER 5

SUMMARY, CONCLUSIONS, AND RECOMMENDATIONS

SIGNIFICANCE AND CONCLUSIONS

The purpose of this study was to qualitatively investigate perceived trustworthy relationship-formation and trust communication between a parent/caregiver and the child with diagnosed autism. By opening the research door to the examination of the “trust factor” in the establishment of a significant relationship, care-giving treatment and intervention strategies for children with autism will ultimately improve. This change will enhance the current available programs for behavior remediation through better child compliance; the quality of the service delivery to the consumer; and will benefit the overall outcome for ASD children who have previously been characterized as lacking in social skills, that include the capacity for Theory of Mind capability and the ability to empathize with others.

Without direct peer-reviewed literature pertaining to trust and trust formation in the child with autism, or without demonstrative neuroscience documentation of the physiological effect from perceived caretaker trustworthiness in the ASD child, the researcher reviewed literature pertaining to analogous aspects of trust that indirectly reflect the effects of these components on human circumstantial responses. Attachment behavior development, face recognition and processing, and the role of oxytocin hormone were studied for background information pertaining to brain structure responsiveness, along with the commensurate behavioral ramifications that have been researched by other scientists thus far. These three important elements of the natural parent/infant bonding process are generally experienced from birth and continue to develop during childhood.

In addition, two socially based dimensions of human interaction were explored in the literature by the researcher—Theory of Mind and empathy, along with the vaguely defined parameters of perceived trust and trustworthiness in the context of relationship-building.

Attachment behavior development and the boundaries of “basic trust” have literary origins dating back into the late 1960’s. Behavioral theorists, social psychologists, and child
development specialists have all contributed to the cumulative research data that has been gathered. Current technological advances now allow creative and problem-solving neuroscientists to visualize both normal and alternately developed neural pathways that have evolved from dysfunctional brain structures. These advances have illuminated variations in functionality and provided helpful data for understanding the challenges of children with autism (Bugental, 2005; Carlson, 2001; Vicary & Frayley, 2007).

Facial recognition and processing have been documented by neuroscientific research more extensively over the past ten years using adolescent and adult subjects with autism. Although findings in autism subjects have been amended and updated, the data is clear that processing in the brain can have more than one pathway depending on the familiarity of the observed face. In ASD individuals, it is possible for familiar faces to be processed normally. This finding gives hope to dedicated parent/caregivers who work diligently on daily drills with their affected children, trying to solidify any redeveloping neural pathways into increments of perceived “normalcy” (Pierce & Courchesne, 2000; Pierce et al., 2004; Courchesne et al., 2007).

The role of oxytocin hormone is still a frontier on the research horizon. Thus far, its use in the United States is not yet approved. In other global locations, research has proceeded primarily with intranasal administration of oxytocin in an effort to study how the hormone affects brain structures. Likewise, the socio-emotional implications of altered oxytocin levels were measured; and the responses were correlated with increases in participant expressions of perceived trustworthiness in response to the specific research design (Damasio, 2005; DeAngelis, 2008; Kirsch et al., 2005). Experimental populations have primarily consisted of normal individuals. However, some articles have linked the positive results to the potential benefits for those with social disorders that include autism, anxiety, and depression. Authors reiterated that the mechanism of oxytocin in humans is not yet well understood (DeAngelis, 2008).

Other social components reviewed were the ability of Theory of Mind comprehension (Colle et al., 2007) and the capacity for empathy in the child with autism (Greenspan & Wieder, 1998, p. 306) in an effort to document current findings and professional viewpoints. Trust and trustworthiness conceptual definitions were also reviewed to provide guidelines and descriptive characteristics against which to assess the findings of the current study.
With a background literature review accomplished, the researcher carefully crafted a quantitative Demographic Survey to record age, ethnicity, profession, and therapeutic intervention statistics for baseline information gathering. Next, a specifically designed Qualitative Questionnaire with ten open-ended, multi-phased interview questions was prepared. Subjects were invited to participate based on having a professionally diagnosed child with autism that was between the ages of 4 and 8 years of age. Twelve female primary parent/caregivers volunteered for the one hour in-depth interview using the researcher-designed Qualitative Questionnaire (See Appendix A), along with the five to ten minute Demographic Survey (See Appendix B). The family cultural background, the parental age, and the marital status of the caregiver were not a relevant variable for participation in the study. Eleven of the twelve subjects were a parent/caregiver of a male child with autism. The remaining participant was a parent of a female child. According to the Demographic Survey, occupational therapy was the most frequently used form of autism intervention, as well as being most preferred by the subjects. Parent training programs, along with speech therapy, ranked second on the list of preferred parenting modalities. Nine of the twelve parent/caregivers have also used videotaping/modeling as an intervention strategy (See Table 3, Appendix C). Throughout the interview and survey processes within this study, several findings surfaced that were both anticipated by the researcher and consistently reported by the participants. Likewise, there were a few surprising discoveries that were not expected by the researcher. The following is a brief summarization of those additional findings not already discussed in Chapter 4:

First, according to the Qualitative Questionnaire results (See Appendix C), a noteworthy and unexpected finding was that pediatricians for eleven of the twelve parent/caregivers insisted that the observable early language delays, or reported behavioral issues in the child, were within “normal limits” and did not need to be assessed until 3 to 3 ½ years of age. The researcher personally found this discovery to be a significantly disturbing trend, considering what is currently known about the importance of early intervention. Understanding that the parents in the study had each called attention to published “warning signs” for autism (See Appendix F), which can occur between twelve and eighteen months of age, it is unfortunate that their concerns went unaddressed by the medical professionals. During their interviews, study participants frequently reported that their children had
experienced an assortment of suspicious symptoms as toddlers that included intermittent occurrences of unexplained high fevers or unusual illnesses, a lack of eye contact, difficult eating or sleeping issues, problems with transitions from one place or activity to another, and very little interaction with others. When a professional diagnosis was finally obtained by the parents, they reported an array of responses that ranged from relief at finally having their instincts acknowledged/validated to being very upset with the delayed responsiveness of the medical community. They were also distressed by the clear inadequacy of the subsequent information provided about autism. Essentially, the parents had to search out therapeutic interventions on their own. Many expressed having endured sadness, bewilderment, a sense of hopelessness, guilt for having somehow failed the child in not getting a second opinion, and anger for not being recognized as having a valuable “voice” in the evaluation of their child’s apparent needs. A 2007 article by Myers and Johnson indicates:

Pediatricians and other primary healthcare professionals are in a position to provide important longitudinal medical care, and to support and educate families and guide them to empirically supported interventions for their children. (2007)

The consensus of this small group of study participants was that, in actuality, meaningful assistance for them was not consistently occurring beyond this hypothetical, literary representation. It just does not happen.

Second, but not totally surprising, was the discovery that all of the parent/caregivers described behavior regression triggers for the child with autism as being related to changes in daily routine, therapy, school schedules, or to tutoring personnel substitutions. Any variations would set off a child “melt-down,” including uncontrolled tantrums, screaming, physical outbursts, or other expressions of frustration. Behavior management and compliance were then said to be impossible. Immediate and extended family members reportedly have also struggled with developing workable coping mechanisms, which has strained internal relationships. Establishing consistency of parenting styles within the family unit, and creating continuity between home and learning environments was another area of expressed parent/caregiver concerns during their interviews.

Third, of the many treatment modalities now available for autism remediation, parent training programs were high on the list of beneficially ranked therapies recorded in the Demographic Survey, which was consistent with their individual interview responses. Some existing community programs do incorporate parent education to teach techniques that are
used in the classroom as a means of facilitating support at home. At the San Diego based Children’s Toddler Center, where some study participants’ children have previously attended, the Directors Aubyn Stahmer and Brooke Ingersoll, also maintain that when a variety of evidence-based teaching techniques are incorporated, and the level of structure varied, the outcome for each child can be improved. Stahmer and Ingersoll believe, as do other researchers they sited in their article, that “children may respond differently from each other to various evidence-based therapeutic techniques” (Stahmer & Ingersoll, 2004). This philosophy of “one size does not fit all” extends as far back as 1973 to a small study conducted by Gunning and Holmes for psychiatric day programs serving in-patient children diagnosed with either autism or psychosis. Their scheduled activities were adapted to suit the individual needs of the patients, as well as those in the overall population. The researchers found after eight months of child-centered treatment sessions that all of the children showed observable physical and behavioral improvements (Rice, 1980).

It was noted by Al Anbar, Dardennes, Prado-Netto, Kaye, and Contejean (2010) in a French-based journal article that when parents had a greater sense of “personal control,” they were also more likely to share information with other parents of children with autism and to talk with psychologists (Al Anbar et al., 2010). This point was reiterated by all of the participating parent/caregivers who felt that the medical community was slow to respond either with diagnostic evaluations, or descriptions of treatment options that would benefit the child. Many of them shared that they felt more comforted and informed by other mentoring parents through a type of “Mom Network” for resource information. At least four of the parent/caregivers stated that they had specifically attended the privately funded “More Than Words” parent training program to help them develop child interaction strategies that were more facilitative to better language and communication skills. The resulting reduction in parental stress levels was also believed to foster improved behavioral compliance and remediation in their child with autism (See Table 4, Appendix C). From a controlled trial of fifty-one toddler and preschool children, McConachie, Randle, Hammal and Couteur (2005) were able to affirm the effectiveness of the “More Than Words” program based on positive parental responses correlated with improved parent/child interaction:

The course content aims to teach parents to structure the child’s environment to motivate them to communicate, to create structural routines with opportunities for
their child to initiate or respond, and to use visual cues to aid the child’s comprehension. (McConachie et al., 2005)

A fourth finding consistently expressed by participants in this study was the description of the observed personality characteristics that had the most beneficial results in motivating and capturing the attention of the child with autism. In some instances, the parent/caregiver learned effective behavior management techniques from the therapist, or from the parent mentor. Other subjects had instinctive ability to draw upon their own childhood experiences as creative tools for circumstantial problem-solving, using trial and error methodology. All of the parent/caregivers clearly stated that the child with autism responded most positively to a firm, nurturing voice quality, and to a person who speaks slowly and calmly using small words in short sentences that are precise and directly to the point. For their children to maintain attention to task and to remain engaged with the individual, it was imperative for that person to “get down to the child’s level,” have consistent interaction, building a relationship over a longer period of time, and to be capable of being playfully animated—or even “silly” as needed—to capture that desired attention (See Table 4, Appendix C). As affirmed by the writings of Stanley Greenspan and Serena Wieder:

…when the child is babbling or involved in a self-stimulatory pattern of sounds, we need to pull him into an interaction. We start this process by babbling back, perhaps trying to imitate the sound the child is making. This act often gets a look of recognition (Greenspan & Wieder, 1998, pp. 342-343).

Fifth on the list of findings was the overwhelmingly positive response of each parent/caregiver when describing the details of the “Remarkable Moment” experience. Every story had a unique character in and of itself. However, the end result for all of the parent/child relationships, evolving from their newfound level of communication and trust, was profoundly life changing. The experiences became an expressed source of encouragement, enlightenment, and motivation for the participants. Likewise, no descriptive words could adequately represent the intrinsic value accrued to the parent/caregivers from having had the opportunity to share such a personally meaningful “moment in time” with someone else who also grasped the magnitude and significance of the “Remarkable Moment” experience.

The sixth finding that is noteworthy in this study appears as a set of raw data that can be found in more detail in Tables 4 and 5, Appendix C. When asked to list perceived
behavioral changes that resulted from the “Remarkable Moment” event, every parent reported having observed improvements in mutual communication and bonding connection. All of the participants felt that the child with autism had a realization that his/her needs would be met, that emotions/feelings were being understood by the parents, and that a sense of trust/trustworthiness was now perceived, even if communication was only non-verbal. Improved eye contact, the ability of the child to wait for gratification of needs, and a decrease in frustration-based tantrums or screaming, were tangible effects that also extended to improved behavioral compliance in school and therapeutic intervention settings. Parent/caregivers noted that these behavior changes helped their children to experience smoother transitions from one therapist to another. Now, the child would instinctively look to the parent to facilitate that change and to verbalize needs or feeling that the child could not otherwise express to another person (See Figure 9; Tables 4 and 5, Appendix C).

The seventh finding relates similarly to the previously described parent/child experience. Keeping in mind that the literature review discussed attachment behavior patterns and face recognition of familiar individuals vs. strangers, the child with autism understandably needs consistency, continuity, effective coping strategies, and a perception of commitment from the attending adult in order to contemplate behavioral compliance with adult-driven activities. Every participant in the study described therapists with whom their child had responded to either positively or negatively. The key factors determining the nature of the responsiveness were consistent with the characteristics previously described, but with one major addition. In Chapter 4 of the thesis, Question #6 addresses the observations of several subjects with regards to the relationship-building skills of their respective autism intervention therapists and/or teachers. Predictably, once the child with autism has determined the trustworthiness of that individual, and is comfortable with the relationship-building effort, the same mutual communication and bonding appears to be relatively transferable to the “significant other.” In the case of Kap, she first noticed that her son consistently tolerated one of his two program therapists, and not the other. Both service providers followed an identical intervention program on a daily basis. The only observable difference between the two therapists was their projected personality and their communication style with the child. However, one of the therapists was observed to have an innate stress level that was immediately detected, and reacted negatively to, by the child. His
behavior eventually became so resistant that Kap had to request a different therapist or risk losing services. As was pointed out by Hastings and Symes (2002) in their article on behavioral intervention:

Assuming that therapist performance is influential, it will only be important to consider factors that account for variation in therapist behavior or performance. At present, there is no theory of therapist performance in ABA programs for children with autism (Hastings & Symes, 2002).

The study results show that perceived caregiver trustworthiness can ultimately promote successful levels of compliance in the child with autism (Angell et al., 2009). Additionally, the findings demonstrate that social components of perceived trust and empathy can then be transferred to other trustworthy individuals, thereby opening the door to more effective and productive social interaction.

One final point that was extensively discussed in Chapter 4, illustrated with Figures 10 and 11, and reported with Raw Data Tables 6 and 7 (See Appendix C), was the revelation that eleven of the twelve participants had endured challenging childhood circumstances to which each was force to adapt in an effort to survive. The importance of this finding is in understanding how each participant was able to constructively move through the normal grieving process, develop perceived solutions to those challenges, carry the problem-solving skills forward in life, become more independent and self-sustaining, and ultimately use the knowledge gained from childhood events as tools for working with the challenges of their own child’s autism. Each of these parent/caregivers is also actively helping other moms within the “Mom Network” by sharing strategies that have been individually successful. This finding is commensurate with the article by Al Anbar et al. (2010):

Identifying parents’ beliefs about their child’s illness may be an important step in formulating family interventions to reduce distress and enhance well-being (Al Anbar et al., 2010).

It is also noteworthy that the majority of the subjects expressed how much inspiration they have derived from learning to appreciate their children’s accomplishments and forward progress. Regardless of their respective challenges in coping with frequent behavioral setbacks or their problems with finding affordable intervention services, these parent/caregivers described a new appreciation for the minutest details of the developmental process. They reiterated that nothing is taken for granted (See Appendix G).
LIMITATIONS AND WEAKNESSES

An obvious limitation and/or weakness in this thesis study were the small sample size. It should be noted that there were other parent/caregivers who expressed a desire to participate in the project. However, due to the university time constraints and externally imposed deadlines, the researcher could not interview additional subjects. A larger group of participants with data gathered over a longer period of time would have enhanced the impact of the results. Within the current study framework, there were natural constraints in the interview process that the researcher anticipated in advance. Most parent/caregivers have specific scheduling demands that are imposed by the very nature of serving the special needs of the child with autism. School and therapy appointments always took precedence over the subject interview process. Likewise, interview sessions had to be accomplished at the convenience of the participants so that their comfort and individual schedules were respected. Ultimately, the interview subject was found to be more responsive and receptive if their own needs were met as well.

Another major limitation of this study was that no other comparable research for comparison purposes has been published. Trust and trust formation are still not well understood, according to the analogous literature that was reviewed in Chapter 2. Physiological brain structures are not clearly documented for trust responsiveness, making assumptive conclusions from study data more speculative than reproducible. Quantifying trust formation in any population has not been adequately explored. Research that evaluates the roll of the oxytocin hormone in relation to trust/trustworthiness has thus far not been conducted in the United States. However, the popularity of such studies has gained momentum in foreign literature over the past three to four years. Even the social communication areas, such as Theory of Mind and the capacity for empathy, have limited references in scientific literature pertaining to autism. Funding for such projects has not yet become substantially popular to warrant its research.

FUTURE RESEARCH IMPLICATIONS

Because autism is known to be a spectrum disorder with multiple gene mutation possibilities (providing genetics is the origin), or the result of an environmental assault on the immune system that leaves behind a variety of neurologically damaged systems, no specific
treatment or intervention will adequately remediate all forms of the disorder. Regardless of how autism manifests itself in the individual, or the age of onset (“complex” vs. “regressive”), the current related literature on attachment behavior indicates that perceived “basic trust” of the caretaker(s) is a critical element in establishing necessary behavioral compliance and social appropriateness. In addition, facial discrimination/processing studies, and the limited oxytocin hormone research in social bonding, clearly demonstrate that there is a biological basis for “basic trust.” Therefore, it would seem logical that because advances in neuroscience have enabled researchers to visualize component parts of the brain during face processing studies, this same technology could be effectively pursued for identifying brain structures through functional magnetic resonance imaging (fMRI) scans that are activated during various socio-emotional functions. By observing neural pathways that respond to specifically structured tasks designed to evaluate concepts such as trust, Theory of Mind, and empathy, the resulting data would help to create a better understanding of social communication deficiencies and/or defects that generate impairments in systems that monitor or regulate social responsiveness. Knowing that persons with autism often process faces differently, and that no two affected individuals record identical neural pathways (Pierce et al., 2004; Pierce et al., 2001), the same assumption could be true for other social components yet un-researched. Future studies should continue to explore these additional components, incorporating functional magnetic resonance imaging to observe the locations of activated neural circuitry. As is done with autism face processing studies to document activated neural pathways in children and/or adults, this would provide better understanding of how to individualize intervention strategies that are designed to target the remediation of impairments or deficiencies.

Now that the time-honored developmental principle of “basic trust”–previously perceived as a subjective “feeling state”–has been scientifically shown to have valid neurological pathways vital to achieving necessary socialization and behavioral compliance in the ASD child, the most hopeful avenue for effective progress in the evolution of autism research is through continued efforts toward brain mapping. With documentation that the brain is capable of operating around dysfunctional or blocked structures, the logical assumption is that more research would further delineate physiological pathways that can be
activated with specifically focused interventions. Author Stanley Greenspan (1998) and his colleagues stated:

The only way to help each child reach his potential is to look at his individual differences and work with an individualized, developmental treatment program. (1998, p. 9)

An interesting side note to one facet of autism research was shared by Eric Courchesne in his lecture for the organization, Talk About Curing Autism (TACA), in November, 2008. He revealed that the gene mutations discovered in affected infants with diagnosed autism have not been traced to the birth parents. Whether or not these mutations will subsequently be passed on to future generations through high-functioning children with ASD is currently unknown. Eventually, there should be studies to document and follow these gene mutated individuals, just as is being done with other heritable disorders. In the interim, it is even more imperative to gather as much neurological data as possible through continued brain imaging and to map all possible functional processes. A better understanding of underlying brain changes in structure and in neurochemistry will be increasingly beneficial in assessing the functional capabilities of children with all forms of autism.

Even though it may be possible to artificially modify existing brain function through some form of intranasal administration of oxytocin, critical information about dosage, frequency of administration, the short and long term side effects have yet to be researched, refined, or medically approved. Considering that autism is a spectrum disorder of unknown origin that can affect different individuals at a variety of developmental stages with multiple co-morbid impairments (including seizure disorder), oxytocin administration should not be presumed as universally effective. Likewise, the hormone may not be equally recommended for both major forms of autism---“complex,” with noticeable impairment from birth; and “regressive,” with changes markedly apparent between 2 and 4 years of age. Providing that foreign studies of oxytocin continue, there may eventually be enough gathered data from less regulated scientific investigators to justify domestic research. In the interim, American scientists may have to remain focused on, and satisfied with, the exploration of neural circuitry through currently approved methods and technology.

Having reported in this study that eleven of the twelve parent/caregivers experienced challenging childhood circumstances -- from which they successfully adapted survival strategies later used as tools for working with their own child’s autism -- future research
could examine whether or not a correlation exists between autism behavior remediation and the caregiver’s ability and/or willingness to resolve their personal childhood issues. Are parents of children with ASD, who have not developed solutions to their respective childhood circumstances, less likely to be effective advocates for their own child’s ongoing needs? Likewise, can parents who have not been victims of unfortunate early experiences, and who were not forced to adapt for survival, be active problem-solvers when responding to the daily challenges of the disabled child? There are clearly numerous additional research questions that can be addressed from this one unexpected study finding.

**Recommendations from the Research**

Based on the multifaceted findings reported in this phenomenological qualitative research study, both the parent/caregivers and the professional service providers (school-based or therapeutic intervention) need to actively focus more attention on acquiring the type of training which fosters relationship-building between the adult and the child with autism. The reported interviews of participants are undeniably clear in their description of the personality characteristics that captivate the attention of the ASD child. Likewise, the demeanor of the individual, and the sincerity of that person’s efforts to engage the child at his/her own level, are blatantly stated as being necessary for trust formation. In every instance, these performance features are undeniably described as a blueprint for creating an atmosphere of continuity and consistency. The perceived commitment and trustworthiness of the adult (whether parent/caregiver or other therapist) by the child with autism will eventually result in a “Remarkable Moment” when mutual trust is communicated.

It has been the researcher’s intent to facilitate a better understanding of the importance of “basic trust” in fostering behavioral compliance that leads to autism remediation. Because studies have not directly addressed this key component, it is strongly recommended that other creative, problem-solving researchers begin to address not only its structural origins, but how to successfully and consistently engage the child with autism in order to improve and enhance the overall outcome of any therapeutic interventions. From the findings in this study, it is clear that ABA practitioners need to reconsider how they implement intervention programs. Therapists must focus on first developing a
relationship, and then tailor the proposed therapeutic strategy to the child. Ultimately, it is the relationship between therapist and child that is the motivation for change.

Also, by giving actively involved parent/caregivers a “meaningful voice” and by respecting their insights, this researcher sincerely hopes that the scientific and educational communities will work more effectively together to adopt strategic improvements which are both evidence-based and child-driven. Often times, the insightful opinions of informed parents can provide invaluable information that can be incorporated into the design of future studies.

Another strong recommendation is for pediatric professionals to (a) become more informed about the nuances of ASD, (b) listen more actively to the early concerns of parents, and (c) not hesitate in evaluating or screening “at risk” children who are younger than 3 years of age. According to the interview responses of the twelve participants in this study (N=12), each of their respective children with diagnosed autism demonstrated several of the symptoms prior to 2 years of age that are listed as “warning signs” by the American Academy of Pediatrics (2006) (See Appendix F). Parent/caregivers ultimately want to perceive their own relationship with the attending physician as “trustworthy.”

Based on the steadily increasing numbers of children diagnosed with Autism Spectrum Disorder (Courchesne et al., 2007; Mash & Wolfe, 2010; Myers & Johnson, 2007), instituting a mandated public policy that implements early ASD screening for infants and toddlers may not be unrealistic to envision for the future. It has been well documented in the research literature that beginning behavioral intervention to stimulate neural circuitry while the brain is still relatively malleable has a more positive and/or improved outcome for the affected child (Stahmer & Ingersoll, 2004). Furthermore when considering the potential need for long-term care, implementation of early therapeutic strategies has cost-benefit implication for both the families and the agencies which provide service to the children with autism.

Currently, there are legitimate nonprofit organizations actively in place that specialize in family mentoring, as well as preschool screening at no cost to the parents. Considering the participant-reported disparity existing in this study between the willingness of the pediatric medical community to address published ASD “warning signs” and the actual
diagnostic needs of “at risk” children, these organizations should be standardized to AAP guidelines, and given appropriate funding assistance. The valuable information and services provided to parent/caregivers of children with autism would help to offset the unaddressed deficiencies of those pediatric professionals who postpone diagnostic evaluations, denying a beneficial opportunity for early behavioral remediation.

Of additional value, would be a longitudinal investigation of individuals with professionally diagnosed autism who have evolved through many of the classic characteristics to become more high-functioning by society’s “normative standards,” comparing their early developmental deficits with adult manifestations of ASD.

Many children today are given labels that are misleading. Instead of pinpointing a child’s unique strengths and challenges, they obscure them and unwittingly demoralize and create negative expectations on the part of parents, therapists, and teachers. (Greenspan & Wieder, 1998, p. 21)

In more recent years, proponents of “Human Factor” research have applied the underlying principles to many other disciplines and fields of study that are dependent upon the effectiveness of social interactions. Within the six described dimensions of the “human factor,” three have parallel applications to the philosophical perspective of Stanley Greenspan and his colleagues. As has often been expressed by noted author and world lecturer, Dr. Senyo Adjibolosoo (2005), the fourth dimension of the “Human Factor” is called “Human Capital,” and it consists of the knowledge and skills that we acquire. The fifth dimension would be “Human Abilities,” defined as the competencies of those acquired skills. And the sixth, most important dimension is “Human Potential,” which is undiscovered talent. Those individuals who would be leaders must also assume the responsibility of recognizing, and nurturing that hidden talent in others (Adjibolosoo, 2005), especially those individuals with learning differences whose “gifts” in life are not always readily apparent.

Prior published writings of this researcher likewise reiterate a similar philosophical perspective that emphasizes the importance of valuing the potential of each person, even if the possibilities are not readily apparent:

In our family, we all knew one fact to be true. We have the ability to create life, and the power to understand the mind of the life we have created. That knowledge, coupled with prayerful perseverance and the cultivation of “basic trust,” opens windows of opportunity (Weber, 2008, p. 118).
While there is no known “cure” for autism (Mash & Wolfe, 2010; Myers & Johnson, 2007) there is accommodation, providing the child can develop a perceived sense of trust in the primary parent/caregiver. From that important relational foundation, the eventual development of behavioral compliance can lead to improvements in socialization skills, in the capacity for empathetic responsiveness, and in the ability for social understanding through Theory of Mind comprehension. Autism remediation is a process that begins with the communication of sincerity and genuine trustworthiness. As was reiterated in the descriptive sharing of actual “Remarkable Moment” experiences, trust-formation between parent/caregiver and the child with autism is a key component in that critical process.

**Acknowledging the value of the child’s feelings, and giving words to the expressed emotions, ultimately unlocks the door to a mutually meaningful connection that implies, “You see me! You understand how I feel!”**
REFERENCES


APPENDIX A

QUALITATIVE QUESTIONNAIRE
“Remarkable Moments: Communicating Trust in the Relationship between the Child with Autism and the Parent/Caregiver”

1. What caused you to notice that your child might be developing a little differently from others of the same age? When was that? Can you tell me about that day and how you felt?

2. When your child was diagnosed with autism, can you tell me how you felt? What emotions come to your mind, or did you experience any sense of “guilt” about anything related to the diagnosis?

3. Can you remember a time when you thought your child was making progress, but suddenly for no reason that improvement stopped? Can you think of anything that might have triggered the regression?

4. Can you describe a time when the way you communicated with your child made a difference in his/her behavior towards you, or in your interactions with each other?

5. If you could name a “moment in time” when you felt your child had a “break through” of some kind, what would that be? By a “break through,” I mean a moment when you knew your child with autism understood your expectations, and there was a realization that you would likewise meet his/her needs….some time when you felt that there was mutual communication and a connection between the two of you that was more “remarkable” than before?

6. Has a similar “moment in time” happened with another “important person” in your child’s life that you have observed or been told about?

7. Can you describe things you notice (hear, see, or sense) that tell you your child is moving forward?

8. In what ways do these forward movements impact you? Please be specific.

9. Do you think there is something about your own childhood that puts you in a better position to handle your child’s challenges? Please offer one or two examples.

10. What is the most rewarding part of being the mom of _____________?

Would you be willing to be interviewed again if needed?
APPENDIX B

DEMOGRAPHIC SURVEY QUESTIONS
Instructions: Please indicate or provide the answer that is most applicable.

1. What is the age of your child with autism? _________

2. What is the gender of your child with autism? _________

3. Do you have more than one child?
   - Yes How many children do you have? _________
   - No

4. What number in the birth order is your child with autism?
   - First
   - Second
   - Third
   - Fourth
   - Fifth
   - Other _________

5. At what age did you notice that something was “different” about your child? _________

6. At what age was a diagnosis of autism made by a professional? _________

7. Early Intervention (indicate ALL that apply. Rate the top 5 therapies/techniques to which you believe your child responded best, with 1 being the most beneficial and 5 being least helpful).
   - ACES _________
   - AIM _________
   - BRIDGES _________
   - CARD _________
   - CARES _________
   - COYNE _________
   - Crimson Center _________
   - DISCRETE TRIALS _________
   - FLOOR TIME _________
   - INCIDENTAL TEACHING _________
   - Inst. For Effective Ed. _________
   - LOVAAS _________
   - Mentoring programs _________
   - Music Therapy _________
   - Parent Training programs _________
   - Picture Exchange Communication _________
   - PIVOTAL RESPONSE TRAINING _________
   - Occupational Therapy _________
   - Rady Children’s Toddler School _________
   - SCERTS _________
   - School-based Intervention programs _________
   - Speech Therapy _________
   - Sports programs _________
   - TEACCH _________
   - Video taping/modeling _________
   - Other ________________________________

8. Other than yourself, does your child have another person with whom you believe he/she responds positively or with a seeming sense of trust? □ Yes □ No

9. Is this person related to your IMMEDIATE family? □ Yes □ No
10. If not, what is the person’s relationship to your child? □ Extended Family  □ Other Caregiver

11. Do you believe that your child has a favorite therapy? □ Yes  □ No

12. Do you believe that your child has a favorite activity? □ Yes  □ No

13. From your observations, is there a specific therapy, activity, or a person that your child dislikes?

□ Yes  □ No

(Optional) Please feel free to describe or characterize what you have observed:
__________________________________________________________________________________
__________________________________________________________________________________

14. Have you noticed any particular patterns or similar characteristics in what you believe your child likes or dislikes?

□ Yes  □ No

(Optional) Please feel free to be more specific:
__________________________________________________________________________________
__________________________________________________________________________________

15. What is your cultural background?
   □ Asian
   □ African-American
   □ Hispanic
   □ Caucasian
   □ Native-American
   □ Pacific-Islander
   □ Other _______________________

16. What is the cultural background of your partner?
   □ Asian
   □ African-American
   □ Hispanic
   □ Caucasian
   □ Native-American
   □ Pacific-Islander
   □ Other _______________________

17. What is your age? ___________

18. What is the age of your partner? ___________
19. Parent/caregiver’s highest level of education:
   □ High school diploma or equivalent
   □ Vocational certificate
   □ Some college attendance
   □ College degree (BA, BS)
   □ Professional degree (DC, DDS, JD, MD, Ordination)
   □ Graduate degree (MA, MS, PhD)

20. Partner’s highest level of education:
   □ High school diploma or equivalent
   □ Vocational certificate
   □ Some college attendance
   □ College degree (BA, BS)
   □ Professional degree (DC, DDS, JD, MD, Ordination)
   □ Graduate degree (MA, MS, PhD)

21. Parent/caregiver’s profession______________________________

22. Partner’s profession_______________________________________

23. Would you be willing to be interviewed again, if needed? □ Yes □ No
APPENDIX C

RAW DATA TABLE
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<th>Table 1. Demographic Survey Question Results</th>
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<td>1. Child's age</td>
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<td>6. Age of autism Dx</td>
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<td>7. Interventions - (Separate table)</td>
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<td>8. Other trusted person</td>
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<td>10. a. Extended family</td>
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<td>b. Other caregiver</td>
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<td>11. Favorite therapy</td>
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<td>b. Disliked activity</td>
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<td>c. Disliked person</td>
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<td>19. Caregiver education</td>
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<tr>
<td>Mya</td>
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<tr>
<td>Lea</td>
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</table>
Table 4. Qualitative Questionnaire Response Compilation

<table>
<thead>
<tr>
<th>Essential Themes</th>
<th># of Subjects</th>
<th>Incidental Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) Developmental Delays Observed</td>
<td></td>
<td>1. First Words delayed</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>a. Doesn’t request things</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>b. Doesn’t Respond to name</td>
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<tr>
<td></td>
<td>9</td>
<td>c. Doesn’t interact with others</td>
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<tr>
<td></td>
<td>1</td>
<td>d. Echolalia</td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>e. Constant screaming</td>
</tr>
<tr>
<td></td>
<td>11</td>
<td>2. Pediatrician insists language and/or behavior delays are normal</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>3. Lack of impulse control</td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>4. Trouble with some motor skills</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>5. Difficulty sleeping</td>
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<tr>
<td></td>
<td>12</td>
<td>6. Difficulty with transitions</td>
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<tr>
<td></td>
<td>10</td>
<td>7. Lack of eye contact</td>
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<td></td>
<td>10</td>
<td>8. Difficult eating issues</td>
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<td></td>
<td>3</td>
<td>9. Emotional anguish; mood changes</td>
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<td></td>
<td>3</td>
<td>10. Played with toys differently; looked at them sideways</td>
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<td></td>
<td>5</td>
<td>11. Changes started after high fever and significant illness</td>
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<tr>
<td>2) Initial Response – Mixed Emotions</td>
<td>2</td>
<td>1. Felt overwhelmed; helpless; bewildered; alone</td>
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<td></td>
<td>4</td>
<td>2. Felt saddened by treatment delays</td>
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<td></td>
<td>3</td>
<td>3. Felt saddened by child’s decreased progress (regression)</td>
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<tr>
<td></td>
<td>2</td>
<td>4. “Failed my child”, “It was my fault”</td>
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<td></td>
<td>2</td>
<td>5. Upset by inadequate information</td>
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<td></td>
<td>3</td>
<td>6. Upset by slow medical community response</td>
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<tr>
<td></td>
<td>1</td>
<td>7. Felt doomed</td>
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<tr>
<td></td>
<td>3</td>
<td>8. Something is NOT OK! Something is UP!</td>
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<tr>
<td></td>
<td>4</td>
<td>9. “This is fixable!” Relieved to have diagnosis</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>10. “Unsettled inside; it was not fine!”</td>
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<tr>
<td></td>
<td>11</td>
<td>11. Wondered about a defective gene</td>
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<td></td>
<td>1</td>
<td>12. Wanted to hit &amp; scream because nobody listened.</td>
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<td></td>
<td>13</td>
<td>13. Angry, but thankful there was help now</td>
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<td></td>
<td>2</td>
<td>14. Could not say the “A” word</td>
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<td></td>
<td>15</td>
<td>15. “Have to “know my end game.”</td>
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<td></td>
<td>4</td>
<td>16. Crying about my child’s future</td>
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<td>3</td>
<td>17. God has a plan/ The child was God’s plan</td>
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<td>18</td>
<td>18. Sense of hopelessness</td>
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<td></td>
<td>19</td>
<td>19. Completely lost</td>
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<tr>
<td></td>
<td>2</td>
<td>20. Felt guilty for not seeking second opinion.</td>
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<tr>
<td>3) Regression Triggers</td>
<td>1</td>
<td>1. Not retaining mastered tasks</td>
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<tr>
<td></td>
<td>2</td>
<td>2. Stopped talking or making eye contact; constant screaming</td>
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<tr>
<td></td>
<td>3</td>
<td>3. In and out of tantrums</td>
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<td></td>
<td>2</td>
<td>4. Inconsistent communication</td>
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<tr>
<td></td>
<td>1</td>
<td>5. Routine activities caused meltdowns</td>
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<td></td>
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<td>6. 6-month cycles – being overwhelmed by too many instructions/ information.</td>
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<td>7</td>
<td>7. Lack of consistency, trustworthiness, simplicity</td>
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<td></td>
<td>12</td>
<td>8. Changes in tutors, school, or therapy schedules</td>
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<td></td>
<td>2</td>
<td>9. Intestinal fungal infection or food allergies</td>
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Table 4. (continued)

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<tbody>
<tr>
<td>5) The “Remarkable Moment” in Time</td>
<td>12</td>
<td>1. Mutual communication</td>
<td>2. Bonding connection</td>
<td>3. Expectations were understood by child</td>
<td>4. Realization that needs will be met</td>
<td>5. Sense of trust/trustworthiness shown</td>
<td>6. “You see me! You understand how I feel!”</td>
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<tr>
<td>6) “Remarkable Moments” with Another Person</td>
<td>10</td>
<td>1. Mutual communication</td>
<td>2. Bonding connection</td>
<td>3. Expectations were understood by child</td>
<td>4. Realization that needs will be met</td>
<td>5. Sense of trust/trustworthiness shown</td>
<td>6. “You see me! You understand how I feel!”</td>
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<tr>
<td>9) Parent/caregiver’s Childhood Experiences as Preparation for the Autism Challenge</td>
<td>1</td>
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Table 5. Parent Perceived Post – “Remarkable Moment” Behavioral Changes

Improved mutual communication and a bonding connection observed, as demonstrated by the following reported changes:

1. Decrease in tantrums, frustration, or screaming.
2. Perceived realization by the child that feelings/emotions are understood.
3. Improved compliance with therapeutic intervention and/or therapists.
4. Increase in parent/caregiver being able to act as a communicative helper.
5. Increased ability to be patient with parent/caregiver.
6. Increased ability to wait for gratification.
7. Improved eye contact.

<table>
<thead>
<tr>
<th></th>
<th>Fay</th>
<th>Eva</th>
<th>Sal</th>
<th>Lex</th>
<th>Kap</th>
<th>Sue</th>
<th>Lyn</th>
<th>Nan</th>
<th>Ter</th>
<th>Cam</th>
<th>Mya</th>
<th>Lea</th>
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<tr>
<td>Type of Parental Neglect/Abuse</td>
<td>Resultant Childhood Reactions</td>
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<td>a). Physical-4 (33%)</td>
<td>a). Became independent/self-sufficient-10 (83%)</td>
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<td>b). Verbal-5 (42%)</td>
<td>b). Was caretaker to family member(s)-6 (50%)</td>
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<td>c). Emotional-8 (67%)</td>
<td>c). Embraced religious affiliation/faith-4 (33%)</td>
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<td>d). Absentee-4 (33%)</td>
<td>d). Became a creative problem-solver-9 (75%)</td>
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<td>e). Substance abuse-1 (8%)</td>
<td>e). Self-entertained-7 (58%)</td>
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<td>f). Athletic involvement-4 (33%)</td>
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<td>g). Self-abuse for attention-1 (8%)</td>
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<td>h). Resolved to improve upon parental role model behavior as adults-6 (50%)</td>
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Every participant described having to develop multiple coping strategies for the individual management of unpleasant childhood circumstances. Likewise, they claim that this multiplicity of solutions has been helpful as preparation for dealing with the unexpected challenges of their children with autism.

The personal observation of the researcher is that each parent/caregiver has sufficiently succeeded in resolving “childhood history” issues. This has also fostered the freedom to effectively use personal hardships as learning tools rather than as “life-crippling crutches” that are tied to unresolved childhood experiences.
Table 7. Qualitative Questionnaire Response Compilation

Individual Participant Responses to Question #9

**Question #9**: Parent/caregiver’s Childhood Experiences as Preparation for the Autism Challenge

**Fay—Circumstances:**
- a. Limited parental involvement and/or nurturing atmosphere
- b. Both parents working
- c. Caretaker for younger sibling
- d. Frequent psychological tension in the home environment

**Solutions:**
- a. Became independent, self-sufficient, a creative problem-solver to entertain self and sibling.
- b. Learned to create games and homemade toys.
- c. Became active in sports and church.
- d. Left home at an early age

**Eva—Circumstances:**
- a. Felt isolated from other family members and older siblings; had limited interaction; experienced loneliness and child neglect.
- b. Family members were involved in drugs and alcohol.

**Solutions:**
- a. Decided not to repeat family behaviors of substance abuse, etc.
- b. Wanted to marry the right person with no divorce allowed.
- c. Wanted to be a mom who was involved with her child.
- d. Decided to play with her child when requested, regardless of personal fatigue, etc.

**Sal—Circumstances:**
- a. Oldest brother died young, creating extreme long-term family trauma that precipitated some parental neglect as they worked long hours to cope with the grief.
- b. Had to fend for self, fixing meals, doing laundry, and becoming independent through the teen years.

**Solutions:**
- a. Works hard to keep current family together in spite of circumstances.
- b. Relies heavily on personal religious faith in God to cope with life’s challenges.
- c. Became more protective and determined to find answers/help for her child with autism.

*(table continues)*
Table 7. (continued)

<table>
<thead>
<tr>
<th>Lex—Circumstances:</th>
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<tbody>
<tr>
<td>a. Grew up as a “latch-key kid,” alone a lot through the early years.</td>
<td>b. Father was often gone due to his profession; but had a “difficult” personality—he was physically and verbally abusive.</td>
</tr>
<tr>
<td>c. A grandmother moved into the home after her stroke and her loss of language; S4 was her caretaker.</td>
<td>d. Tutored the daughter of a family friend who had brain damage at birth.</td>
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<tr>
<td>Solutions:</td>
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<tr>
<td>a. Learned to do pretend play, create stories, and build things for self-entertainment.</td>
<td>b. Spent time peacemaking between parents to maintain harmony in a tension-filled home.</td>
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<tr>
<td>c. Learned patience at age 10 by helping the grandmother regain language skills.</td>
<td>d. Used church affiliation and personal faith as an important refuge in dealing with family challenges.</td>
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<thead>
<tr>
<th>Kap—Circumstances:</th>
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<tbody>
<tr>
<td>a. Growing up with an aunt diagnosed with Cerebral Palsy, who needed personal care on a daily basis.</td>
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<tr>
<td>Solutions:</td>
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</tr>
<tr>
<td>a. Learned to respect and love the aunt, regardless of her disability</td>
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<thead>
<tr>
<th>Sue—Circumstances:</th>
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<tbody>
<tr>
<td>a. “Learned early on that who I was wasn’t enough.”</td>
<td>b. Always “outside looking in.”</td>
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<tr>
<td>c. Molested at 5 ½ years old. Childhood was lost.</td>
<td>d. Parentally neglected unless “acting out” or being “dramatic.”</td>
</tr>
<tr>
<td>Solutions:</td>
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</tr>
<tr>
<td>a. Substance abuses, etc., used to cope with personal pain.</td>
<td>b. Rode a bike for 100 miles at a time to feel free and accomplished; felt that “God was along for the ride.”</td>
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<thead>
<tr>
<th>Lyn—Circumstances:</th>
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<tbody>
<tr>
<td>a. A single parent family with the mother having to work 12 hour shifts to support them.</td>
<td>b. Had to cook meals, help with laundry, and take care of younger sibling from 7 years of age.</td>
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<tr>
<td>c. “Latch-key kid.”</td>
<td>d. Younger sibling frequently was in trouble at school or arguing with mom.</td>
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<tr>
<td>Solutions:</td>
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<tr>
<td>a. Became a seamstress and patternmaker, learning to “think outside the box” to create solutions; quietly “fixing the moment;” and being the caretaker personality in the home.</td>
<td>b. Later, did a lot of babysitting of other children to earn money.</td>
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### Table 7. (continued)

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<thead>
<tr>
<th>Name</th>
<th>Circumstances:</th>
<th>Solutions:</th>
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<tbody>
<tr>
<td>Nan</td>
<td>a. Came from a family where parents modeled “sticking together” regardless of challenges. b. Was mocked and ridiculed by family members for embracing a Christian faith at 9 years of age.</td>
<td>a. Developed an ability to ignore the ridicule. b. Hid the religious involvement and affiliation from the family.</td>
</tr>
<tr>
<td>Ter</td>
<td>a. Was bullied mercilessly from kindergarten through high school; never revealed the school struggles to her parents. b. Poor academic performance resulted; social awkwardness from being tall, thin, extremely shy, and wearing glasses caused her to be an easy target for peer ridicule. c. Was finally labeled as having a learning disability, creating more isolation.</td>
<td>a. Became extremely sensitive and withdrawn. b. Can relate to being different.</td>
</tr>
<tr>
<td>Cam</td>
<td>a. Had an idyllic childhood. b. Mother gave up her career to be a “Martha Stewart” stay-at-home mom.</td>
<td>a. Decided NOT be a stay-at-home mom and to have a profession in marketing.</td>
</tr>
<tr>
<td>Mya</td>
<td>a. Family was very patriarchal and had very strict behavior rules. b. Corporal punishment was heavily used. c. Mixed cultural backgrounds sometimes clashed.</td>
<td>a. Became interested in the medical field and in animal behavior training as her own way of sorting out unresolved relationship questions.</td>
</tr>
<tr>
<td>Lea</td>
<td>a. Mixed cultural background. b. Often sick as a child with multiple allergies. c. Moved frequently due to father’s profession. d. Middle child. e. Father was very strict.</td>
<td>a. Became more independent that other siblings. b. Developed high expectations for self. c. Was the “fix it” person, tutoring younger brother, and “bailing out” the older sister from her self-generated dramas.</td>
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Table 8. Qualitative Questionnaire Response Compilation

<table>
<thead>
<tr>
<th>Question #10: The Most Rewarding Part of Being Your Child’s Mom</th>
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<tbody>
<tr>
<td><strong>Fay</strong>—“Seeing him progress, knowing it doesn’t come easy; his sense of humor and ability to use his limited gifts to their full potential. He’s fun to be around.”</td>
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<tr>
<td><strong>Eva</strong>—“She makes me laugh all the time; she’s silly, and she’s always doing new things and saying new things….She amuses us all the time.”</td>
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<tr>
<td><strong>Sal</strong>—“Even when we are very tired and frustrated, we love him and are planning the next thing that might help him…I am proud of him, and I’m, in awe of his ability to keep going each day, although so many people don’t understand him…..”</td>
</tr>
<tr>
<td><strong>Lex</strong>—“Experiencing the joy of each emerging new skill…he is “God’s Miracle”…and that I have a front row seat for the most amazing life experience! He is a blessing every day, and he keeps me laughing with his funny sense of humor!”</td>
</tr>
<tr>
<td><strong>Kap</strong>—“My children have made me want to be a better person, for them and myself. I was successful in my career, successful materially, but I lacked direction and focus, just going through the motions of what was expected of me. Seeing them smile and laugh, when they come up out of the blue and hug and kiss me, I know that being a mom is the greatest gift I will ever receive in my life.”</td>
</tr>
<tr>
<td><strong>Sue</strong>—“I love watching him grow up and learn; how he sees the world and people; how I get to be a kid and enjoy the simple pleasures of life….the way he looks at me with so much love and so much appreciation, even if his actions say different. He is totally a gift…..”</td>
</tr>
<tr>
<td><strong>Lyn</strong>—“Things are just so much more preparation, so much more drills, so much more work to get to the goal, that once you get there it’s just like, ‘Oh my gosh! Yeah!’”</td>
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<tr>
<td><strong>Nan</strong>—“Just that God chose ME!....God gave him to me. He’s my gift! He’s teaching me a lot! God needed to send him to teach me a lot! And I know he will continue to teach me more.”</td>
</tr>
<tr>
<td><strong>Ter</strong>—“He’s such a sweet, adorable, kind-hearted little guy…..It’s been a long, difficult road, but I wouldn’t change a thing! He’s just an amazing little boy.”</td>
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</tbody>
</table>
| **Cam**—“I would say he’s adorable and his sense of humor amuses me. He’s so funny! That’s rewarding! You appreciate things a lot more…I feel like I know him on such an elemental and deep level; and that I probably wouldn’t ever have known him if it weren’t for this situation, as I try to make sense out of WHY God decided to give ME this child with autism. (table continues)
Mya—“I think the most rewarding part of being my son’s mom is I have to watch him work so hard at things…..I really think that it’s made me aware of how hard everybody has it and not to judge people on a single moment in time because we don’t know what they’re carrying with them…why they’re having a bad moment; and is it just a bad moment, or is it several bad moments. And to really step back and be more open and accepting: and it has really sent me on a personal journey that I didn’t think I was capable of. So that’s what I find rewarding about being my son’s mom.”

Lea—“I think just the inspiration I get from him! I think that’s the most rewarding thing……”

Summary of Responses for Question #10

<table>
<thead>
<tr>
<th>Most Common Response</th>
<th>Number of Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Seeing forward progress/accomplishments</td>
<td>8 (67%)</td>
</tr>
<tr>
<td>a. Inspiration</td>
<td>1 (8%)</td>
</tr>
<tr>
<td>2. Sense of humor</td>
<td>4 (33%)</td>
</tr>
<tr>
<td>3. “My child is a gift”</td>
<td>2 (17%)</td>
</tr>
<tr>
<td>a. A gift from God</td>
<td>1 (8%)</td>
</tr>
<tr>
<td>b. God’s miracle</td>
<td>1 (8%)</td>
</tr>
<tr>
<td>c. Provided direction/focus</td>
<td>1 (8%)</td>
</tr>
<tr>
<td>d. Teaches the parent</td>
<td>3 (25%)</td>
</tr>
<tr>
<td>e. So adorable!</td>
<td>2 (17%)</td>
</tr>
</tbody>
</table>
APPENDIX D

INFORMED CONSENT FOR EXEMPT RESEARCH
Dear ____________________,

My name is Sandy Weber, and I am a student in the Interdisciplinary Studies Department at SDSU. I am conducting a study to examine how TRUST is communicated between parent/caregiver and the individual with autism. You will be asked to respond to a series of specific questions about your child with autism; and to describe your personal feelings/observations about the relationship between the two of you. In some instances, your responses will require in-depth narrative descriptions of a specific moment in time—one in which you believe your child experienced a dramatic change, or a “remarkable moment.” The questions answered by you will be recorded using both a written and an audio taped interview format that will be transcribed into story form. The results will be reported in a thesis that I will complete as a requirement of my graduate program.

The time needed to complete the questions may vary, depending on the amount of detail that you decide to share with me, the interviewer. It could take between one to two hours, which can be divided into two sessions to accommodate your personal schedule.

**Your participation in this study is totally voluntary**, and you may elect to opt-out at any time. If you decide to participate, your responses will be recorded without any identifying information that is linked to you.

If you have any questions regarding this study, please feel free to contact me at my home number, 619-286-1144. My supervising SDSU faculty member, Dr. Shulamit Ritblatt, Department Chair, Child and Family Development, College of Education can be contacted at 619-594-5312. You may also contact the Institutional Review Board at SDSU (619-594-6622) to report problems or concerns related to this study.

Thank you,

____________________________________________                  ________________
Sandra L. Weber, Researcher                                                             Date
APPENDIX E

REPRESENTATIVE INTERVIEW SAMPLE
Fay – Interview, 30 July 2010 (9:43 PM)

1. *R—reads the question about when mom notices something was different with child’s development………..*

Fay—I started to notice that ‘my child’ was delayed in his development over time at his pediatric visits. Around about 12 months I noticed that I was waiting for those first words, and it was taking a little longer than his brother was. So, I asked the doctor and she says, ‘Well of course, because his older brother is talking for him so it is going to take him a little longer to develop speech.’ And around 18 months, the same thing, I mentioned to his doctor that, ‘You know, he’s not getting very many words that anyone understands other than myself.’

And the pediatrician said, ‘Well, we’ll worry about that at 2. He has an older brother.’ And he is also learning 2 languages in the home because my husband speaks Russian and I speak English. But my husband was speaking little bits of Russian throughout the day so that maybe that was delaying his speech. So she said, ‘We’ll worry about that at 2.’ At 2 years old when I brought him in for his check-up, I told the pediatrician, ‘Well, he only has about 12 words and I’m the only one that really understands what they are. They’re not really functional to other people.’

So my pediatrician said, ‘Well, let’s get him signed up for speech therapy.’ And there was a 6 month waiting list to get into speech therapy at Kaiser. So, that went on for another 6 months where he wasn’t developing speech at what I thought was a normal developmental stage, but then it was as if the light bulb switched and all of a sudden he was speaking full sentences, which I later learned was echolalia. That was at about 2 ½. So, the short answer is we started to notice that he was on the slow side of normal development at about 12 months, at 18 months he was still on the slow side of average for normal development, by 2 he was behind.

*R—The other question is, can you tell me about that day and how you felt, when it really sunk in that something was not right here—or did you just kind of take the doctor’s word?*

Fay—I trust my pediatrician. We have a good pediatrician. I just feel that autism was not….the warning signs were not……a lot of doctors don’t look at the early warning signs so things like the MCHAT, the early check list, was not presented to me until I finally got to that first speech therapy appointment. Had I had information early on I could have pinpointed these are early warning signs for my child, but until then I just believed OK, my doctor says ‘He’ll be fine! He’ll be fine!’ It wasn’t until that first speech appointment where I was finally given some kind of evaluation tool, and I could see how far behind he was that……but when I was finally faced with that information I always felt, well OK, there’s people here that can help us catch up. So, when I first found out that something was not developing right, I thought ‘well what do we do now? This is fixable.’

So, when he went to his first speech therapy appointment, a friend of mine actually suggested that we get evaluated to rule out autism. So, I took him to the John Richard’s
Learning Center, which is Kaiser’s special center for ruling things out; and that’s when I she finally diagnosed him with autism. And still at that point I was still in the mindset that if there is something wrong, we can fix it. So my question was ‘What do we do next?’ I was handed just a packet explaining what autism is, some of the therapies that are out there, but really not much else help. They were just going to diagnose him and come back in a year. That’s when I decided to check with some friends and find out if there was something more that I could do. And thankfully I had friends who had kids in Special Education classes that said, ‘Well contact your school and start that process’. Well, actually Kaiser did refer me to Regional Center, and another friend as well told me to call the Regional Center…….I need to back that up…….so when I found out something was wrong at about 2 1/2 with the speech appointments, I was also contacting friends that said contact the Regional Center, the school district, and the John Richards Learning Center. So, I did those 3 simultaneously. There was actually a week where John Richard’s Learning Center diagnosed him with autism on December 4th, I remember because it was my mother’s birthday, and that was a Monday; and the school district says it looks probable for autism on Wednesday; and Regional Center said ‘Yes, he has autism’ on Friday. So that’s how that went down. But all 3 of those organizations said, ‘He has autism. Now, the earliest that we can get him any kind of help or therapy or what-not’----(John Richards Learning Center)----‘come back in a year’---The school district, it was like 6 weeks till school was starting again---Regional Center, 6 months. So, it was very frustrating to say the least that we have identified a problem but there was nothing that we can do for 6 weeks. At which point I started searching for friends who would be able to guide me in the meantime.

**R—Were you panicked? What were you FEELING?**

**Fay**—Definitely overwhelmed! Saddened that I didn’t push harder and pursue more answers earlier on, because I was faced with the knowledge that had I caught this before age 3, Regional Center would have gotten him in immediately with speech therapy, other developmental therapies, but because he had hit the 3 year old mark, it was now more skewed towards a school district responsibility, which I never felt the school district needs to be fully responsible for helping a child with autism. I strongly feel that it is a medical issue as well as, you know, it needs to be an educational component, as well as there needs to be an in-home behavioral component. So, I felt like it needed to be team collaboration. This child has autism but he needs help in several areas. So, FEELINGS---I felt overwhelmed, I felt saddened that I didn’t do more, that I failed my child in that area.

2. **R—When your child was diagnosed with autism, can you tell me how you felt? What emotions come to your mind, or did you experience any sense of “guilt” about anything related to the diagnosis?**
Fay—I felt guilty that I had not done more when I had that gut instinct that he was behind, when he was not gaining his speech as rapidly, I wish I had pursued it and gotten a second opinion. But I just did not know anything. I knew nothing about autism or developmental delays. He was on the slow side of average for his physical development too. He was behind at 18 months on some things, and by 2 he was really behind, which is what finally prompted well, let’s get speech therapy at least.

R—Did you feel guilty about anything else.... Other than you just didn’t move when you felt you should have? Was there any other motivation for that (guilt) that you can identify?

Fay—Well, I guess just the unrealistic expectation that, you know, I’m the mom and I am supposed to be able to fix everything. And so I mean it’s unrealistic, but that was very hard for me to get a diagnosis, and then there’s nothing you can do...VERY HARD. You know, moms want to fix it; so if a kid is sick, you ‘tend to’ and you do all those things; but with autism, you can’t see it, you can’t touch it, you can’t figure it out, so you can’t fix it! HOWEVER, there were people during that interim time when I had to wait that 6 weeks for school to start—and I was in that overwhelming thing—

I feel that God had a plan for my life—well, He still does—but He had it all figured out before I ever knew I needed it. So, during that time He brought to my mind different people in my life that I had met earlier. And I was able to call upon those people not knowing their experience, but later finding out that they had children with special needs, and was able to get guidance through a ‘mentor mom.’ The people at my church—I explained to them that we found out he has this disability and, you know, how can we help him succeed in Sunday School. And they said, ‘No problem. We’re Special Ed. Teachers!’ I found out that there are Special Ed. teachers all over our campus at our church, and most every class that he was in had 2 or 3 Special Ed. teachers in it—like the AWANA group at our church or his Sunday School classes—which is probably why he did so well without me ever really realizing that he had autism.

3. R—Can you remember a time when you thought your child was making progress, but suddenly for no reason that improvement stopped? And then can you think of anything that would have triggered that regression?

Fay—That is a difficult question. Um, and I want to give thoughtful response to that one so can we skip that one just for now?----------Well, I will tell you a few stories and see then if that kind of correlates. I do know that we have had progressions. It is an ongoing 3 steps forward, 2 steps back….it is back and forth, back and forth, all the time. But I want to think of a specific one for that........

4. R—Can you describe a time when the way you communicated with your child made a difference in his behavior towards you, or in your interactions with each other?

Fay—but some of the stories that I have for that second question—-in the way that I interact with him—definitely need to be more playful and animated in the way that I
communicate with him; over the top animated and playful and silly gets his attention more, I get more of the eye contact, I get more of the participation, I get great conversation, imaginative play, all of it I get through being silly. And he tends to flock to people who are very similar; and so I have noticed different people out in the community—like if we do Horsemanship for the Handicapped, the people there are very silly—ADULTS—AND HE LOVES IT! So he will participate more, and speak to more people, and use those skills that we are learning more readily. We have a great babysitter who is wonderful at being silly and getting down to his level; and because he has a relationship with her (because she has been with us 2 ½ years), he has had that consistent interaction with her...he trusts her. He uses his skills more, he talks more, he plays more, he is engaged...that’s the word I want! He is much more engaged. But that also comes with...there’s several things...it’s people over long periods of time that helps him to succeed, as well as animated, but I think it’s also environmental. In his home he is a lot more comfortable and so he will be engaged more, and initiate things, and games, and show what he knows, and be more relaxed. In the community, he is a lot more cautious because it is a brand new situation, brand new people, what is expected here.......so he is a lot more cautious. But over time, because we home-school, and we go to Charter School......my older son has been going there for almost 4 years now; and my younger son who has autism has been in that environment for almost 4 years now, and we are able to succeed in that environment because he knows the ropes and has been acquainted. So, a lot of the trouble we were having in the school district is not because we don’t have excellent teachers and that they don’t do a fabulous job with what they know, its just that is too little time. We just start making progress (here’s that question!) and getting over these hurdles and meeting his IEP goals; and then surprise, we change therapist, or here’s a new OT, here’s a new speech therapist; oh, you know, it’s time for summer break; it’s time for a new routine, new schedule, a new teacher. So, a lot of times you can be very encouraged with checking off all your IEP goals. Wow! Look what he did for the year! And then over the summer, your back to setting lower goals for the next year because it is going to take him several months to get used to these people---new teachers, new faces, and he’s not going to participate or engage as much as he would have if we had just kept the continuity between people.

R—You said he responds to people who are playful and over-the-top animated. In the beginning, were you always that way?

Fay—No! No! Nope! I love to play with children. I was a kindergarten teacher in my Sunday School so I do have that element of play, and I love to use props, and silly voices, and stories and things like that when I am teaching something. But I find with my son that it needs to be a lot more just with every day life, and every day routines and not only just in game time, but anytime. It needs to just be fluid. I was accustomed to doing it when it was connected with a project. When I am less animated, he is less engaged. I don’t know…the examples that are coming up to my head and we’ll just plug them into wherever it fit in your survey…Music, I kind of default to music. If I am trying to explain something to him, I can just remember a simple song that I made up myself. I was taking a class, More Than Words. It was one of the very first therapies that we did. So, they gave us these little assignments to do, and one of them was make up a song to help your
child learn a task. Well, at the time I was trying to teach my child that if he made a request, to wait a second so that he could get whatever it was that he wanted. Because what was happening was he would make a request, ‘I want this.’ I would say, ‘OK’ and then go to reach for the thing; but that 2 seconds of reaching for the ‘whatever’ he thought that since it didn’t instantly appear, that he wasn’t getting what he wanted. So, he would be upset about that. He would kind of speak these messages into the atmosphere and expect it to instantly appear in front of him. So, my task was to teach him ‘OK, I’m coming; it’s coming.’ We made up the WAIT SONG:

‘You gotta wait, wait, wait for mommy. Gotta wait, wait, wait for mommy. Gotta wait, wait, wait for mommy till I’m ready!’

And when I had that little ‘READY’……….and I would display whatever he wanted to him…. ‘READY,’ and so he understood I am ready, and if it took me more time to open the gismo---whatever he needed---if I couldn’t attend to it right that instant second, I would sing that little song, and it was enough of a fun activity, a playful way, and rewarded, that he loved that little song for a long time. And I had to do the whole song and dance sometimes.

R—Do you still do that song?

Fay—That particular song was when he was early 3. I haven’t done that song in a long time. We’ve moved on to other goals, other skills, but that’s just an example.

R—Once in a while, maybe you should throw it in there for the heck of it.

Fay—Right. But, I mean, I have moved on to several different songs. There’s a new song for each-----I default to songs. Right now, I have a ukulele, so I have made up little diddies on the ukulele, which he thinks is hilarious. I can teach anything with a ukulele, and so I’ll hear him singing those little diddies himself, and he giggles and laughs. So, I know there’s a love for music, and early on there was a connection to get those words out. The music helped him comprehend those words, not only comprehend them but to spit them back out. So, my playful attitude has really been paired up with what I love to do which is play and sing; and thankfully that has been a good fit for him…..

R—I think the wait song would answer that…….singing silly helped you make that transition.

5. R—reads the question to S1 regarding the “moment in time; the remarkable moment” in communication.

Fay—I can remember Christmas time, early in his diagnosis because he was diagnosed Dec.4 so this was early on. Number 1, I had already been talking to friends, realizing that this was something more than just a delay and I was gleaning ideas. So, there was several key people in my life. I was going to schools and talking with teachers and what not and I remember one particular teacher had a necklace with little visuals, little PECs on it; and I asked her about that and she said that it was nice to have them readily available if the kids
had a question, or had something that they wanted to convey, or she wanted to tell them. It was quick, quick visual, and I really liked that. So, that was one idea. So, one friend/teacher told me quick, handy visuals. Another teacher told me—and this was at a Smart Start Program, I went to California’s First Five trying to get involved in a social skills group—and she told me that whenever a kid who’s having a tantrum, a fit, or whatever, all they really want to know is that you get them—they just want to understand that YOU know how they feel. OK, that was big! Then, I had my mentor mom telling me to take actual pictures of things in the child’s life, put them on magnets, and that way he could request little things, whatever...just to be able to communicate things that he was interested in, point to, get excited about. And also a feelings chart, you know, how he was feeling that day. So, I had all these little tidbits and I knew visuals, feelings, and those types of things. At the time, my son was having a LOT of trouble expressing his feelings; and he would tantrum a lot. I remember being at this Christmas festival and they had pony rides. We were waiting in line, and we got to the front of the line, and I realized that they wanted to put a helmet and a little safety harness for little kids when the rode on the horse. Well, he got on the horse; and they started to do what they do, what they did for every other child for safety, and my son was pitching a fit! Well, he was going to kick this horse so we had to take him from the pony, and he didn’t understand why, and he was just so upset. It was a sensory thing—he didn’t want this on him. So, he couldn’t ride the horse because he was going to kick the horse. So, I remember having my digital camera ready to take a nice little sweet picture of my boy riding the pony, and I remember I took a picture of him upset, and I showed him on the digital display of the camera…‘LOOK! (Boy’s name) MAD! (Boy’s name) MAD! I SEE you’re mad!’ And he INSTANTLY QUIETED DOWN! And he looked at me, and it was that light bulb moment of ‘You see me! You understand how I feel!’ And it was a HUGE moment for us. And from then on, he knew that mommy knew how he felt, OR I could SEE how he felt, and he wasn’t just out there on his own. Someone else was….could see his world….was in there with him….I made that connection! He now trusted me to be his support, to be his helper. If he had a problem, I could help him. And from then on, I think all the therapies......because of that......all the therapies could then progress because I was along side him; and he knew if he couldn’t communicate with his therapist, mom was his helper to help him communicate with the therapist. Now, I couldn’t get it right every time; I couldn’t do it perfectly. I had to guess a lot of the times what he wanted, but he trusted me enough to be patient with me and stick with it. We could then make progress.

R—There were things that led up to it.... you had schooling from your friends, little pieces of things, and you put the pieces together and.....

Fay—I’ll back up a little bit. Beforehand, I had all these friends telling me to make visuals, make visuals. Well, he didn’t want to have anything to do with it because he didn’t understand how that was going to help him communicate. He didn’t have the understanding of ‘how this tool is going to help me do anything.’ And up until that point, Mom has been guessing what he wants…If I didn’t understand, ‘OK, I want this truck,’ and I’m reaching for something else to give him and it’s incorrect, he would get frustrated. So, if I am only getting it right half the time----or how many ever percentage
of the time that I am getting it right—-he gave UP; he was frustrated. If I am trying to communicate, and he thinks he is communicating well, but he’s just screaming or BLAH; if he’s trying to communicate and I am not getting it right, then he didn’t trust me to meet his needs.

R—So, making the visuals……..

Fay—He still didn’t understand how this visual was gonna help his mother get his requests faster, easier, whatever. In the ‘ah-ha moment’ when he understood that I knew how he felt, I went through all the little pictures that I had of him…. ‘(BOY’S NAME) HAPPY! (BOY’S NAME) SAD! (BOY’S NAME) EXCITED!’ (BOY’S NAME) this and that… just different feelings. And I put them on teeny-tiny little pictures that I put on a necklace, like that teacher had these quick visuals, and so I was amazed at what he was able to do with that. We went to another outing. It was Christmas time. Someone was having a Christmas gathering and something wasn’t going the way he wanted it to go, and he would reach for my necklace and show me, ‘(boy’s name) is frustrated’… or whatever I had named that little picture….and then you immediately pay attention, try to figure out what it is he wants, try to help him solve the problem, and he did not throw a tantrum at this particular party! So, I knew that we were gaining and making progress because he knew that I got it. SO THEN, all those pictures that I had made ahead of time now made sense to him, and he was immediately able to use those pictures to request things. ‘I want this ball, I want this thing’ which is what the speech therapist was doing with him…this PECS Program; and this PEC, get this thing….but now it made sense to him, and we were off and running! He did great with that! But it took the collaboration of a community explaining little bits that worked for them. And it wasn’t like the one…..there’s not one thing that works for all kids. It was all these little pieces now tailored into……OK, these little components now fit (boy’s name). And the only way that I can see that you can get that is by working with the parents; because the parents are the only ones that know ‘how are you going to tweak this to fit my child?’ No one else knows that unless they have been around since Day #1.

6. R—reads the question about a similar “moment in time” happening with another “important person” in the child’s life……..
telling component. And because it was HER, he would let her do it, because she was a fun person to be with. He got over this.....HAS TO BE ALIGNED IN A CERTAIN WAY and IT HAS TO BE JUST SO because he LIKES her. There’s no other way to say it. He likes her, he trusts her, so it must be OK! Even though I WANT IT THIS WAY, he is willing to concede that it must be OK.

R—Do you notice any commonalities in tone of voice or demeanor that he responds to? As you think of different therapists that he has had......because he has had some therapy now......are there any common denominators in the ones he likes versus the ones he doesn’t like?

Fay—YES! Definitely! Not to say anything negative about any of the teachers that we have had. They have all done an excellent job as professionals, but there’s something about certain teachers that he picks up on very quickly. Who’s a KID person, and who’s more clinical, task oriented. He definitely picks up on who’s just trying to check off a check list, and who’s being casual and trying to play. Now, the one who is trying to be casual and play is still trying to meet goals and run programs, and what not, but they mask it a little better in that they play first and ‘check-sheet’ later.

R—In terms of an “important moment in time” with “another person,” is there one that might have come after your initial break through?

Fay—Yes. In the early, early days after he was diagnosed, it’s hard to know exactly which happened first because things where happening within a 6 week time frame but I can remember an instance when I had a mom help me quite a bit. She came to my house with her son who is also on the spectrum, but has made tremendous progress. And I can recall very vividly, at the time my son was 3 and very into trains. So, he loved to play with his trains, but no one was allowed to play with his trains with him, or even come close to his trains. Those were HIS trains. I can recall in just getting support from this mom, also watching our sons play and this other young man was able to be in close proximity to the train set. And of course my son ignored what he was doing.

R—Was the young man talking to him?

Fay—He was making little comments. He has a very calm approach. And when he turned on his Gameboy, it immediately caught my son’s attention. One, because of, I think, the musical component; and also because it was not intrusive to what my son was doing. So, it caught his attention in kind of a non-confrontational way. It was just kind of, ‘come see if you will.’ He was down on his level, playing on the floor, he had his Gameboy, and my son was then able to approach him. So, I think a lot of time that’s what works for him. It’s a very subtle calm approach, kind of ‘take it as you will,’ not an ‘in your face’ approach, ‘look what I am doing!’ It’s a more, ‘come see on your own terms.’ And because of that, this young man and my son STILL have a good relationship. And by the way, that is the first time that he had met him, I am pretty sure. That’s why it sticks out in my brain because at that time he did not warm up to strangers. It took a long time to warm up to people. So #1, this young man came into our home, got down to his level, and
just did a simple thing; and my son responded to it within minutes—**IT WAS AMAZING!**

So, then we have been invited over to my friends house where our two boys still play video games. My son is now able to take instruction from him and have kind of a tutor/mentor in his life. There’s a bond there, a connection there, and it’s a very subtle one…..just a quiet nature that he responds to as well. Because I think it’s just my son knows that he gets it and there is nothing you can do to describe that. You can’t make that up. It just IS! And he connects to that.

7. **R—Can you describe things you notice that tell you your child is moving forward? That he is progressing? Does he have a pattern?**

**Fay**—Like I said, it’s not a quick process. I’m going to give you a word picture because I just…..we’ve had a success….we’ve actually just graduated out of our Lovaas Program, or ABA program yesterday. We have said ‘good bye’ to some teachers. So, one of the things that I told them that was important to me, I gave them this ‘word picture.’ I took a plant that was given to me when my son was born so it’s significant to me.

‘If this plant represents our family, what autism did to our family…(and I cut off a piece of this plant)…it disconnected a member of our family. In trying to make this reconnection, we just couldn’t do it on our own. We could not figure it out on our own.’

And then I took a cup of water, and I took the little piece that I cut off, and I said, ‘Along came some therapies that said, well, here, try a new approach!’ I took the little stem and I put it in the water. ‘Here’s a new way of teaching and learning; here’s a new approach.’ But then I took the stem out of the water again, and I said, ‘These therapies would come, and they would teach us a little bit, and then they would be gone.’ And then I took the stem in and out of the water. ‘And then they would come and they would teach us a little bit, and then they would be gone. But it was only Lovaas (as far as therapy) that stuck with us for 2½ years.’ And I put the stem in there. ‘Over time,’ and I brought out another part of this plant that I had with the roots all down, ‘…and over time he was able to grow and develop new ways of doing things. With his disability, he was able to figure out new ways to get it done. He had these roots.’

So, I took the plant with the roots out and I stuck it next to the original plant that we had. ‘If I were to replant this next to our little family plant, he is able again to make those connections in a different way. Though it won’t be the way that it was originally intended back on the little vine as it was, the root connections were able to make deeper connections and he is now reconnected to our family in a different way….although, it was not the ideal way originally.’

So, I gave these teachers a remembrance. I gave each of them a little plant with the roots down there. At the bottom, it had little stones that said, ‘Success,’ ‘Teach,’ ‘Create,’ and ‘Inspire’….these little rocks that I had on the bottom with words on them…..I said, ‘**You watch!** These roots will actually root around these rocks, and I want you to **remember** this family and **remember** my son. Because of that teaching, and because of the **consistency** of that early intervention, he will grow and thrive. This little stem will shoot new leaves and grow, and grow, and grow.’ I also invited them; I hope that they do come back and see his life maybe years later and see how he’s doing. ‘**Because these therapies……it’s not just a JOB, IT’S NOT JUST A JOB. IT HAS TO BE A RELATIONAL THING. YOU HAVE TO BE IN IT FOR THE RIGHT REASONS,**
AND IN DOING THAT YOU MAKE SUCH A HUGE DIFFERENCE IN THESE FAMILIES’ LIVES.’ So, I wanted them to remember that. It’s not just checking boxes. It’s not just paperwork. It’s not just run the program, do the routines. It is **make that connection, make the bond, make the relationship**, and it will make a difference over a lifetime. And also, **TEACH THE PARENTS**….because they stuck with me, and they taught me, and I could ask questions as he grew, as he changed. Like you said, you thought you were making progress and what happened! We had those surprise moments, and I could say ‘what do I do next?’ ‘Well, teach him a little differently. Use these videos, video modeling, or whatever.’ Because they stuck with it and they took a ‘whole’ approach, the family as a whole and not just the child as a client, we really made success.

8. **R—In what ways do these forward movements impact you?**

**Fay**—We get so excited! I remember the early days writing an e-mail. I would e-mail my mother and explain what we were feeling, what we were going through. And I explained to her that **there is a gift of autism**. It seems so……how could you find anything that could be a gift of autism? There’s a gift in it only because I believe there’s a purpose for his life. And the gift in it is that my son is happy. He knows nothing of his disability. He’s just learning in his own way and he is developing very well. But the gift in it for the parents is that when he does succeed, and when he does learn these LITTLE things that most parents take for granted…he learned to request something; those little tiny steps…we **REJOICE**…like you see your child take his first steps. It’s a **HUGE deal**! My husband and I get **SO EXCITED** over each tiny, tiny, tiny milestone! It’s not even a milestone, but **for him it’s a big deal**. He learned to ride a Big Wheel. He never learned to peddle a tricycle. It took him forever to get the coordination, the gross-motor, crossing the midline, whatever it was that didn’t work for him. When he finally learned to peddle one foot after the other, he was 5 ½ years old! **But we had a big party celebration! Yeah! You did it!** We were so excited about it! Most kids have been peddling since they were 3, but we are excited over every little thing. There is an excitement in parenting that wouldn’t normally be there. I think I would have taken a lot of things for granted, and now I can be excited over each new little discovery!

9. **R—Do you think there is something about your own childhood that put you in a better position to handle your child’s challenges?**

**Fay**—Yes, several things. In thinking about my childhood……I think one of the things is I have good parents, they were very busy parents, they were young parents so there wasn’t a lot of spent developing our creativity, or entertainment and things like that. They just were very busy, very young, and didn’t nourish that as much. And in doing so, I think I was a creative child because I needed to figure things out to entertain myself. I spent a lot of time creating games and creating my own fun for my little brother and things like that. I did a lot of pretend play and a lot of creative stuff with my hands. People used to tell me ‘you’re going to be a little engineer when you grow up.’ I was always building little trinkets, little things, so I think that helps me with my son because I definitely think outside the box. If there’s a problem, or something I need to teach, I am going to come up with 16 different ways that we can try to approach it…games, and
modeling, and how many different ways can we look at it so that he gets lots of variations on what’s going to work for you to learn this skill. So, the creativity works. But also, my father was the spiritual leader in our family and the one thing that he instilled in me is a love for God. Because of that, early on (I didn’t become a Christian till I was 16) my father told me, ‘You do everything to the best of your ability for the Glory of God, not because you feel like it. You don’t do anything half way. You do your best for God.’ That’s one little tidbit that stuck with me; and because of it, it enriched my faith. When I was 16, I became a Christian. So, my childhood is what led me to the Lord ultimately. My faith is what got me through this very, very challenging diagnosis. I can remember in the early days when he was first diagnosed I did not know WHAT to do. They just told me WAIT 6 weeks. Well, what are you going to do while you are waiting? Well, you’re going to pray, and you’re going to pray a lot! And the other thing that I did, that I am very thankful that I did, I just opened my Bible: ‘God, what can I memorize that will encourage my heart so when I feel sad about this, what can I do?’ I just happened to be in the book of James. I memorized the entire first chapter of James…

‘James, a servant of God and the Lord Jesus Christ; to the twelve tribes scattered among the nations: Greetings…..Consider it pure joy, my brothers, when you face trials of many kinds, because you know that the testing of your faith develops perseverance. Perseverance must finish its work in you that you will be mature and complete, not lacking anything. If anyone lacks wisdom,…’ and this is the part… ‘If anyone lacks wisdom,’... which I knew NOTHING of autism… ‘If anyone lacks wisdom, he should ask God who gives abundantly to all, and without finding fault,…’ And that’s where I was. I was feeling so guilty that I missed, I messed up……..and God said ‘I will give you wisdom, and there is NO fault here.’ So, that encouraged me, and it was because of my father instilling that into me early, and I was able to look to God in the most important chapter of my life thus far. And that’s what got me through it.

10. R—What is the most rewarding part of being your son’s mom?

Fay—Hmm! There’s so many things. I think I touched on it a little bit of it just of the joys of seeing him progress. It doesn’t come as easy for him so it’s such a joy when he does reach those things. But every child has a gift. Every child has a special gift that God has given him. And both of my children have their gift that makes it special to be their mom. But if I have to answer just for (boy’s name), it is his sense of humor. But what makes it interesting about that, you say to yourself... ‘How does a child with autism display a sense of humor when his language is so limited?’ And he can use just a few words and get it done, or just an expression, just a gesture and he can pull it off in such a way to make his father, his brother, and his mother laugh. And it always amazes me! And one of them, just a simple thing, we were having cookies for a snack and my husband said, ‘Boy, you really chowed those down!’ And my son said, ‘I’m such a chowcher!’ You know, he changed the word and cracked us up…just little things that he can work to his advantage to get a smile. Yeah, that’s interesting to me only in that it made me think about his brain works. He’s working with what he has. Throw some music in there and he will make a silly song for you. I really admire that about him…he uses his
gifts to his full potential. He is a joy to those who meet him. He is a silly little guy and he can get laughs with just what he has. He’s a fun little guy to be around!
APPENDIX F

AMERICAN ACADEMY OF PEDIATRICS—ASD
“WARNING SIGNS”
What are autism spectrum disorders and what are the symptoms?

Autism spectrum disorders (ASDs) are a group of related brain-based disorders that affect a child's behavior, social, and communication skills. They include 3 of 5 disorders known as pervasive developmental disorders (PDDs). These are autistic disorder, Asperger syndrome, and PDD-not otherwise specified (PDD-NOS).

Autism spectrum disorders are lifelong conditions with no known cure. However, children with ASD can progress developmentally and learn new skills. Some children may improve so much that they no longer meet the criteria for ASD, although milder symptoms may often persist.

Symptoms

No 2 children with ASD have the exact same symptoms, but the criteria are somewhat standardized. The number of symptoms and how severe they are can vary greatly. The following are examples of how a child with ASD may act:

Social Differences

- Doesn't snuggle when picked up, but arches back instead
- Doesn't keep eye contact or makes very little eye contact
- Doesn't respond to parent's smile or other facial expressions
- Doesn't look at objects or events parents are looking at or pointing to
- Doesn't point to objects or events to get parents to look at them
- Doesn't bring objects to show to parents just to share his interest
- Doesn't often have appropriate facial expressions
- Unable to perceive what others might be thinking or feeling by looking at their facial expressions
- Doesn't show concern (empathy) for others
- Unable to make friends

Communication Differences

- Doesn't say single words by 15 months or 2-word phrases by 24 months
- Repeats exactly what others say without understanding its meaning (parroting or echolalia)
- Doesn't respond to name being called, but does respond to other sounds (like a car horn or a cat's meow)
- Refers to self as "you" and others as "I" (pronominal reversal)
- Often doesn't seem to want to communicate
- Doesn't start or can't continue a conversation
- Doesn't use toys or other objects to represent people or real life in pretend play
- May have a good rote memory, especially for numbers, songs, TV jingles, or a specific topic
- Loses language milestones, usually between the ages of 15 to 24 months in a few children (regression)

Behavioral Differences (Stereotypic, Repetitive, And Restrictive Patterns)
Rocks, spins, sways, twirls fingers, or flaps hands (stereotypic behavior)
Likes routines, order, and rituals
Obsessed with a few activities, doing them repeatedly during the day
Plays with parts of toys instead of the whole toy (for example, spinning the wheels of a toy truck)
May have splinter skills, such as the ability to read at an early age, but often without understanding what it means
Doesn't cry if in pain or seem to have any fear
May be very sensitive or not sensitive at all to smells, sounds, lights, textures, and touch
Unusual use of vision or gaze—looks at objects from unusual angles
May have unusual or intense but narrow interests

Early Signs Of Autism Spectrum Disorders
Many children with ASD may show developmental differences throughout their infancy, especially in social and language skills. Because they usually sit, crawl, and walk on time, these more subtle differences often go unnoticed.

Social Skills
A child with ASD may have

- Not smiled back to you or smiled less often or less enthusiastically than you expected.
- Not cuddled like other children.
- Not made as much eye contact with others.
- Not responded to her name being called.
- Seemed to tune others out. At other times, she may have seemed to hear environmental sounds, even very faint ones, perfectly well. This was probably confusing and may have caused you to worry about a hearing problem.

Language Delays
All children with autism show significant language delays. Those children later diagnosed with Asperger syndrome will seem to have met language milestones during the toddler years, but use of language may be abnormal.

Regression In Developmental Milestones
About 25% of children will seem to have normal development until about 18 months, after which they will gradually or suddenly

- Stop talking (if they had begun to say a few words).
- Stop waving goodbye.
- Stop turning their heads when their names are called.
- Withdraw into a shell and seem more distant and less interested in their surroundings.

Although all children with ASD will need developmental and educational services and most will need therapy and behavioral interventions, only certain children may need medicine. Medicine may be needed to control behaviors that could interfere with ASD interventions. Aggressive or disruptive behaviors can become a problem when they cause physical harm to others (or to the child himself) or when they prevent him from cooperating with therapists or teachers.

Parents are encouraged to learn as much as they can about all the different treatments available. Treatment should focus on supporting the child to succeed in the real world.
APPENDIX G

RESEARCHER REFLECTIONS
As the researcher and a participant/observer for this thesis study, I gratefully acknowledge my heartfelt thanks to the twelve “warrior moms” who generously extended to me their trust throughout the interview process. In opening their homes, sharing their personal stories, and believing that I would handle any intimate information with the dignity it deserves, I have felt privileged by having access to the details of their daily experiences and their individual struggles. All of the emotional events they shared with me during conversations—the joys, sorrows, anger—I have personally endured in my own journey with autism. Likewise, all of these moms understood that fact from the beginning of our developing relationships.

Entering into this particular thesis design, it was clear to me that I might also relive forgotten feelings when hearing participant stories, as if traveling back in time. I thought I was appropriately prepared to manage the emotional rollercoaster ride on which I was about to embark! However, having an intellectual awareness and an understanding of what I would encounter did not mitigate the internal responses that welled up inside me as I listened intently to every mother. Each description of expressed parental concerns that was dismissed by a complacent pediatrician whose denial of screening services for a child with clear indications of ASD “warning signs” has cost these families critical intervention time! I was genuinely angered by the arrogance of their “trusted” medical professionals who have, in my opinion, violated a fiduciary obligation to their patients by denying early access to established autism screening tools. It was that same type of physician arrogance that devastated my own family in the early 1990s. Fortunately, parents are no longer at risk for losing insurance coverage when there was a diagnosis of childhood autism, as was the case a few years ago. Nevertheless, nothing has improved in the area of parental ability to have legitimate ASD concerns consistently addressed by the pediatric professionals.

During some study interviews, I found myself struggling to hide my own tears when a mom described her experiences with insensitive friends and extended family members; and her overwhelming challenges with struggling to find support services, only to have access denied. Expressions of feeling isolated, and sometimes abandoned in life, brought back my own memories of those early years following my son’s diagnosis at age 3 ½. Likewise, there were times when a mom and I cried together, and then comforted each other by an empathetic hug. Fortunately, my most difficult years of coping with my son’s communication
and behavior issues are behind me, and I am reaping the benefits of my faith, courage, and perseverance as we continue to charge forward.

In response to a request from my thesis committee members for additional “researcher reflections,” I have included more descriptive details about each of my phenomenal “warrior moms.” Their individual stories are so rich with information that their personal narratives could become chapters in a book about parental survival techniques! As stated several times throughout the thesis text, the demographics of these amazing women are similar only in relation to their shared experience of having a child with autism. Furthermore, their common observation of what personality characteristics inspire, motivate, capture the attention, and create that vital trust connection with their child cannot be refuted or minimized. Therefore, here is a small sample of what I learned (or was reminded of) through time spent with each of these amazing women:

1. Fay—Her strong commitment to teaching her two children the Christian principles of her abiding faith reminded me of how important it is to celebrate the accomplishments of the moment while remembering that there is a “greater plan” in place that we cannot always see on today’s horizon. Fay, with all of her excellent teaching skills in home-schooling her children and her knowledge of creating computer graphics as visual tools, had to rediscover how to relax in her play time and to realize that those seemingly unstructured moments can also have great merit in the overall learning process for a child with autism.

2. Eva—Overcoming her own childhood challenges and her fears of being an inadequate parent has helped her blossom into an effective advocate for health-driven causes in the Hispanic community. She is becoming a wonderful mentor for autism parenting in her own arena; and her newfound inner confidence will be reflected in the beautiful daughter God has given her to shepherd into adulthood. One of my treasured gifts from Eva is a special necklace that she and her daughter created especially for me from colored beads. The medallion that hangs from the center of the necklace has a recent photo of my son and I at a Special Olympics function on one side, and a verse from Isaiah 41:10 on the back that says, “Fear not, for I am with you; be not
dismayed, for I am your God; I will strengthen you, I will help you, I will uphold you with my righteous right hand.” My joy in receiving her gift was surpassed only by seeing the pleasure in Eva’s eyes when she understood how meaningful it was to me.

3. **Sal**—As a parent of three children, she has worked very hard to find creative and effective ways to meet the challenges of her autism-affected son. Until he was born, she and her husband had been missionaries in Peru. Their limited economic resources and lack of local family support system made it difficult to access “windows of opportunity” to ease the distress from their son’s sensory issues. Still, Sal has persevered in her belief that her son has a special purpose to fulfill, and that her task is to be his adaptable support system. Recently, she and her family relocated back to the Midwest where they will again be close to supportive extended family. She has been able to resume her work as a manuscript editor on a part-time basis. I am still waiting for her son’s first book of photographic images, taken through the special lens of autism. His unique perspectives are a visual gift. I know this because I was originally trained to be an artist/teacher.

4. **Lex**—Now, here is a complex individual who specializes in being illusive and multifaceted, while still possessing the capability of intense candor. Although well-educated, she most often masks it from others, having come from a background where being “a nerd” was very unpopular. Her father was in the military, which meant periodic family relocation, attending different schools, and regularly having to find all new friends. Being accepted was not easy, nor automatic. Consequently, she has a naturally guarded side to her personality, assessing individuals carefully before allowing them into her “circle of trust.” A unique characteristic of Lex is that any casual observer would never guess she is an astutely guarded individual with the ability to blend into the circumstances of the moment.

5. **Kap**—She is a single parent of two very young ASD diagnosed children. This mom realized very early in her son’s life that something was not quite right, both with her child and with her “rocky” marriage. Her decision to return to
California from their home in the Caribbean was abruptly halted when Kap discovered her unexpected second pregnancy. She shared that she was devastated by the news, knowing her plans to make major changes in her life would have to wait. Raising her children without a male role model is difficult, but her faith in God and her determination to succeed are her strengths, as she travels the road without a reliable life partner.

6. **Sue**—What a courageous path this woman has taken in her journey with autism! I have known her for many years, and have seen her evolve through numerous personally painful stages in her life. Seeing her finally become securely grounded and self-assured through the process of reclaiming her son has been a source of joy for me. In sharing more intimated details of her life during this study, and then moving past her personal grief, Sue has become what I consider the epitome of the “warrior mom.” Her son is reaping the benefits of her “childhood solutions.” He is a gift and a “healer” on all levels for his loving parents who prayed through so many personal hardships to have him.

7. **Lyn**—She is the ultimate mother who loves being the hands-on caretaker. Admittedly, her son’s “complex” form of autism is more intense than what she envisioned. Throughout her youth, Lyn says she was a popular babysitter in the neighborhood because she knew how to play and nurture the children in her care. It did not surprise me to learn that she is a skilled pattern-maker and seamstress because she has had to use her creativity just to get a coveted hug from her son. When asked what she would want for her boy’s future development, she quickly responded with this comment, “I want *an Erik!*” That would be a reverence to my 22 year old son with autism, Erik Weber. His wit, humor, and smile are charmingly disarming; and he gives great hugs!

8. **Nan**—This mom was introduced to me by another participating parent. Once Nan realized her son with autism was comfortable with my presence in his home, his mom relaxed and began freely sharing her struggles as a working parent. Understandably, Nan initially had some reluctance to revealing her own childhood struggles. As she recognized that she could freely talk about
the importance of her faith and church affiliation, which is heavily integrated into their family life, Nan became even more comfortable with the interview process. By her own admission, Nan has realized that the course of her son’s autism is an aspect of their lives that she cannot totally control or micromanage on a consistent basis. She can only pray for wisdom and guidance as she struggles to find the most effective programs and therapists to help her son.

9. **Ter**—this mom waited for many years to start a family. She had a college degree and a profession. Her son’s diagnosis was devastating for her, and rekindled buried emotions from her own early years. Ter shared stories of being bullied by classmates all through school. Because she was tall, thin, and extremely shy, some educators unfairly labeled her as disabled. To this day, discussing those painful memories brings her to tears. Hearing others (extended family, neighbors, etc.) negatively talk about her son is equally hurtful—almost emotionally paralyzing for Ter at times! Her apprehension about her son’s future seeps through in her conversation, and she just needs the reassurance of a mentoring mom’s comforting hug. Once her husband is fully retired from the military, the family will relocate in their East Coast hometown, bringing her closer to a welcoming support team.

10. **Cam**—Her childhood was “perfect,” and she admittedly looked forward to a career in some type of marketing. Her college years were filled with art, dance, and the benefits of having what she refers to as a “Martha Stewart mother.” However, Cam was determined not to follow in those time-honored footsteps. She acknowledges that God had other plans, however! Her husband is a pilot so she says she has the luxury of staying home to work with her son with autism. During her interview process, Cam had her own “ah-ha” moment as she realized how much of her artistic nature she was tapping into just to motivate her boy through his daily challenges! She was thrilled with that revelation because it gave her a new sense of focus and re-energizing purpose!

11. **Mya**—She is such an intelligent professional animal behavior specialist, and a delight to interview. Actually, I didn’t have to say a thing initially because she
held the questions and narrated her way through everything as if she was
delivering a lecture about her life. It was amazing! She made me laugh (and
cry) with her reflections and stories. Our subsequent conversation took us to
discussions about animal training, and the similarity to working with behavior
modification in children with autism. Like two other moms, she waited to start
her family until her career was very well established. Now she says she has a
new career—her son and his non-affected twin sister.

12. Lea—This mom could easily be a physician herself, if given the opportunity.
She is very intelligent and hungry for knowledge. The complexity of her son’s
medical profile has forced her to be a constant advocate for his needs. In
addition to his care, she is trying to attend night school to finish her college
degree. With the support of her husband, who works long hours, Lea is active
in an autism parenting group on evenings when she is not in classes. She says
her son is her inspiration because he has survived so many life-threatening
events—a series of severe allergic reactions, unexplained fevers, and a seizure
disorder. She confides that it is difficult dealing with extended family
members who dismiss the importance of her son’s health status and his need
for autism therapy. Nevertheless, Lea also has endless determination to ignore
their complacency and to help her son have the best opportunities possible.

Nineteen years ago, when my own son was diagnosed with autism and mental
retardation, I was already 41 years old. It was clear that there were only two options
available:

1. Give up and find an institution to care for him, as was advised by the
   “medical professionals.”
2. Close down my own successful business, walk away from a separate
   profession in Cardiac Rehabilitation that I loved, and find a way to
   maximize my son’s unknown potential.

Obviously, I chose option 2 because if you have the faith of a grain of mustard seed, you
really can move mountains! During those years, there were no services to help parents, no
mentors, no internet information, and no insurance. In fact, if anyone revealed the diagnosis
of autism to insurance companies, medical coverage was dropped completely. Some things
have improved, but parents are still the best advocates for their children! In spite of my son’s grim prognosis, Erik is now 22 years old, has achieved his Bachelor’s Degree (3.9 GPA), and is completing his Masters Degree program. He has also written a book, and lectures in the community to prospective teachers and therapists on “living with autism.” Amazingly, he has no reservations about commenting on what is needed to help children like him. He tells his audiences that by understanding the possibilities of human potential, and focusing on the child’s individual interests as the motivation, the outcome can be more hopeful, rather than filled with sadness over the loss of the “perfect child.” Needless to say, he has been my inspiration for this study!

Although the times have changed and technology has improved, the importance of trust-formation in the process of autism behavior remediation has remained the same, from what I have observed. That fact became profoundly apparent to me throughout the interview process. We have all had the same basic struggles as parent/caregivers, regardless of our respective demographics. The experiences of the “warrior moms” were remarkably similar to my experience 19 years ago. Even with the improvements in programs and better accessibility, there is still a deep sense of emotional isolation that can surface at times, making parent-support systems even more vital. I also find it noteworthy that 8 of the 12 moms in the study revealed their strong religious affiliations, from which they draw courage and comfort. It would be fascinating to examine how their foundations in faith have impacted coping skills used in their respective daily struggles. Within that community of believers, the common mantra has been to “throw off” whatever hinders forward progress, and to “run with perseverance the race that is marked out for us.” These wonderful moms have encouraged me with their ability to do just that! I am reminded once again that the greatest tools we have as parents are within us. In our family, we all knew one fact to be true…… we have the ability to create life, and the power to understand the mind of the life we have created.

For all the times through the years when I was told by “professionals” that a trust relationship was irrelevant in the autism remediation process, I now feel vindicated in my formerly unsubstantiated belief! These twelve moms are ready and willing to carry the torch of courage, perseverance, and empowerment to the next generation of parent/caregivers so that they, too, can experience the same unbridled joy from having successfully communicated trustworthiness with their child. The ultimate goal is to illuminate the
importance of trust-formation, and to benefit children with autism everywhere by improving the quality of relationships that motivate positive change.