# PARENTS OF CHILDREN WITH HIGH-FUNCTIONING AUTISM: EXPERIENCES IN CHILD-PARENT RELATIONSHIP THERAPY (CPRT)

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This qualitative study attempted to capture the experiences of parents of children with high-functioning autistic spectrum disorders participating in child-parent relationship therapy (CPRT). Parents of children with high-functioning autistic spectrum disorders (HFASD) are prone to experiencing stress in the parent-child relationship due to difficulty in social understanding and rigid behavioral patterns often found among children with HFASD. Moreover, parents of children with HFASD may feel challenged to find suitable interventions that are time-limited, affordable, and appropriate for parents and children with HFASD. Because no research currently investigates the perceived acceptability of CPRT for parents of children with HFASD, it was decided that a qualitative study would best capture the experiences of parents of children with HFASD participating in CPRT to understand more fully whether CPRT is an appropriate intervention for these parents. Four parents and one grandparent were interviewed prior to and following their participation in 10 sessions of CPRT. Thematic analysis of the pre- and post-intervention interviews as well as the 10 CPRT sessions revealed eight themes related to the parents overall experience of CPRT and change in the parent, child, and parent-child relationship: understanding of CPRT concepts, reactions to CPRT, group dynamic, child characteristics, parent characteristics, knowledge and experiences with HFASD, family context, and parent-child relationship. The emerging themes indicated that the five participants found CPRT to be a useful intervention for developing skills to deal with child-behavior concerns related to HFASD. The participants also reported developing a better understanding of their children with HFASD and four parents reported increased closeness in the parent-child

relationship. The implications for this research are that CPRT may offer parents of children with HFASD a time-limited intervention that meets their needs as parents, as well as possibly helping parents and children with HFASD develop increased closeness in the parent-child relationship.

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# PARENTS OF CHILDREN WITH HIGH-FUNCTIONING AUTISM: EXPERIENCES IN CHILD-PARENT RELATIONSHIP THERAPY (CPRT)

The Centers for Disease Control (CDC; 2009) estimates that approximately one in 110 children in the United States qualify as having autism or a related disorder, an increase from one in 125 five years ago and one in 10,000 ten years ago. Features associated with autistic spectrum disorders (ASD) include delays in social skills, communication deficits, and rigid and repetitive behaviors (American Psychiatric Association; APA, 2000). Children demonstrating higher functioning on the autistic spectrum typically present with higher cognitive functioning and verbal ability, however, delays in social understanding and rigid behaviors and interests still create significant concern for parents (Rao & Beidel, 2009). Delays in social understanding and rigid behaviors for children with high-functioning autistic spectrum disorders (HFASD) also have a significant impact on the development of the child. Children with HFASD are frequently aware they experience the social world differently from typically developing peers and may feel considerable isolation and loneliness stemming from struggles to form friendships and close relationships (Myles, 2003; Tantam, 2003).

Although parents of children with classic autism tend to experience more severe cognitive and behavioral challenges than parents of children with HFASD, the higher intellectual functioning of children with HFASD does not lessen the stress associated with parenting children with HFASD (Rao & Beidel 2009). Although many parents of children with HFASD report feeling emotionally close to their children (Dissanayake & Crossley 1997), they also report experiencing particular distance in the relationship between parent and child (IJzendoorn et al. 2007). One challenge to the parent-child relationship stems from the unpredictable and difficult to understand social interactions typically associated with HFASD. Parents may perceive their

children as disinterested, uncaring, and distant. The lack of reciprocal emotional engagement may cause parents to pull away, creating further distance in the parent-child relationship. Also, children with HFASD frequently are inconsistent in their responses across people, settings, and time (Marcus et al., 2005), which may further strain parent-child relationships. Additionally, disruptions in emotional relations among family members often present a central challenge to parents' attempts to provide a typical family life (Gray, 1997).

Currently, many of the most popular parenting interventions teach parents of children with HFASD behavioral strategies for identifying maladaptive behaviors, extinguishing those behaviors, and shaping new, more adaptive behaviors through successive approximated trials (e.g., Anderson et al., 1987; Lovaas, 1987; Mceachin, et al. 1993; Smith, 1999). The behaviors selected for change are often those perceived as maladaptive and detrimental to the development of the child. As such, the behaviors of the child with HFASD are seen as deficient rather than different as parents and therapists spend considerable energy to shape behaviors in children that more closely resemble what is considered to be socially acceptable. The lack of understanding for the experiences of the child with HFASD may lead to considerable stress in the parent-child relationship, as parents may focus on correcting a child's behavior rather than understanding it. Children with HFASD may feel isolated and misunderstood as those who provide love, shelter, and protection cannot understand their world experiences.

While the efficacy of behavioral interventions is well documented (see Foxx, 2008; Ross, 2007), the published results typically focus only upon child outcomes. Moreover, few published studies (e.g. Grindle et al., 2009) address the parents' involvement, such as how parents change and how the parents' perceptions of their children change as a result of participating in

behavioral interventions. Furthermore, such interventions do little to specifically address the quality of the parent-child relationship.

Over the last two decades, humanistic, play-based interventions for children with HFASD have emerged to provide child-centered interactions between the parent and child and facilitate the development of stronger parent-child relationships by increasing understanding of the child's experience (Beckloff, 1999; Greenspan & Wieder, 2006). Because children with HFASD demonstrate similar attachment behaviors with parents as typically developing children (Dissanayake & Crossley, 1997; Rogers, Ozonoff, & Maslin-Cole, 1993), considerable potential exists for using humanistic interventions to teach parents strategies to enhance the relationship between parent and child and strengthen relational bonds between children with HFASD and their parents (e.g., Greenspan & Wieder, 2006; Miller & Miller, 1989; Wolfberg & Schuler, 1993). Child-parent relationship therapy (CPRT; Landreth & Bratton, 2006), which teaches parents of children with HFASD child-centered skills to provide a non-directive play environment for their child, is a potentially viable, yet unexplored intervention to enhance the parent-child relationship for children with HFASD and their parents.

CPRT is a relationship-focused 10-session filial therapy treatment model designed to address the needs of both parents and children. CPRT empowers parents to be therapeutic agents in their children's life. CPRT training is presented in a small group format that teaches parents attitudes and skills used in child-centered play therapy (CCPT). Parents integrate these skills during weekly 30-minute play sessions with their child (Ginsberg, 1989; Landreth, 2002; Landreth & Bratton, 2006; Van Fleet, 1994). These sessions promote feelings of safety, acceptance, and understanding between parent and child as well as teaching skills in areas of choice giving and limit setting.

CPRT also builds upon parents understanding and empathy for their children to enhance understanding and communication in the parent-child relationship Research on CPRT supports its effectiveness with a variety of presenting issues and populations (Bratton, Ray, Rhine, & Jones, 2005; L. Guerney, 2000; Landreth & Bratton, 2006; VanFleet, 2003, 2006) and results of research on CPRT indicate its effectiveness in enhancing parent-child relationships (Costas & Landreth, 1999; Kale & Landreth, 1999; Landreth & Lobaugh, 1998; Tew, Landreth, Joiner, & Solt, 2002; Smith & Landreth, 2003). The scope of CPRT suggests its viability as an intervention to enhance the parent-child relationship while decreasing the stress associated with raising a child with HFASD.

To date, no research currently investigates the experiences of parents of children with HFASD participating in CPRT. However, Josefi and Ryan (2004) presented a case study of a six-year old boy with severe autism participating in CCPT. Through qualitative and quantitative analysis, the authors determined that the client was able to enter into the therapeutic relationship and show improvement in autonomy and pretend play. Though research of CPRT with children with HFASD is limited, this case study suggests that it may provide a viable way for relating to children with HFASD. In addition, research on DIR/Floortime (Greenspan & Weider, 2006) further suggests that children with HFASD and their children can benefit in their relationship through parents providing a non-directive play environment.

The purpose of the current study was to investigate the experiences of parents of children with high-functioning autistic spectrum disorders (HFASD) before, during, and after their participation in CPRT using a phenomenological method of qualitative inquiry (Creswell, 2007, Moustakas, 1994, Patton, 2002; Van Manen, 2001). Specifically, the primary researcher investigated the perception of parents of children with HFASD concerning the structure and

content of CPRT. The researcher also examined the perceived impact of CPRT on the parent, the child, and the parent-child relationship. A detailed description of the instrumentation, participant selection, data collection, and qualitative analysis used for this study follows.

#### Methodology

This qualitative study followed a phenomenological approach to qualitative analysis to understand experiences of the participants' experiences before, during, and after their participation in Child-Parent Relationship Therapy (CPRT; Landreth & Bratton, 2006). Specifically, the primary researcher investigated the perception of parents with children with HFASD concerning the structure and content of CPRT. The researcher also examined the perceived impact of CPRT on the parent, the child, and the parent-child relationship. The study included five parents (N=5) of children diagnosed with HFASD who participated in ten sessions of CRPT as well as pre- and post- intervention interviews.

# **Participants**

A purposeful criterion sampling method was used to select participants. Using a flier distributed through local elementary schools, the researcher sought parents or caregivers with children between the ages of four and eight who were previously diagnosed with high-functioning autism (HFA), Asperger's Disorder, or Pervasive Developmental Disorder Not Otherwise Specified (PDD NOS). Parents would participate with this child as their child-of-focus during Child-Parent Relationship Therapy (CPRT). The children-of-focus selected for this study were not currently participating in play therapy or interventions for HFASD.

Creswell (2007) recommended between 3-10 cases for a phenomenological design. Eight parents completed screening interviews and all met the criteria for inclusion, but only five were able to meet at the same time each week. Table 1 presents the demographics for the five

participants. Participants were assigned pseudonyms for the purposes of publication.

Table 1

Participant Demographics

Parent	Age	Gender	Family	Ethnicity	Child-of-	HFASD	Relationship to
			Status		focus	Diagnosis	Child-of-Focus
Carly	48	Female	Married	Caucasian	Eric (8)	HFA	Maternal
							Grandmother
Mary*	35	Female	Married	Caucasian	Aaron (8)	Asperger's	Biological Mother
Dave*	43	Male	Married	Caucasian	Aaron (8)	Asperger's	Biological Father
Hannah	40	Female	Married	Caucasian	Jack (5)	PDD NOS	<b>Biological Mother</b>
Madeline	38	Female	Married	Caucasian	Zane (5)	HFA	Biological Mother

<sup>\*</sup>Married Couple participating in CPRT Group

## Screening Instrument

Qualifying parents also completed the Social Communication Questionnaire (SCQ) as a screening instrument to validate the diagnosis previously received by the child. The SCQ is a 40-item, parent/caregiver screening measure that identifies the symptomatology associated with disorders on the autism spectrum and is appropriate for individuals above the chronological age of four. The SCQ has been found to have good discriminant validity (Charman et al. 2007; Corsello et al. 2007). A recent study of the properties of the SCQ in a cohort of children with ASD confirmed the utility of the SCQ as an efficient screener for at-risk groups of school-age children (Chandler et al. 2007). A total score of  $\geq 15$  is recommended to minimize the risk of false negatives and indicate the need for a comprehensive evaluation. This score was used as the cutoff for screening purposes for this study. All of the children of parents selected to participate met or exceeded the recommended cutoff of  $\geq 15$ .

## Recruiting Procedures

During the initial meeting with participants, we provided the parents a written informed consent, read it aloud, and answered their questions. The informed consent explained the

potential benefits and risks involved and highlighted the voluntary nature of the research. The parent participants signed the informed consent document verifying that they received the information and agreed to participate in the study. The participants received \$100 cash upon conclusion of their participation in this study. Because the parents participating in this study committed approximately 25 hours of their time, this compensation was given to help compensate for mileage incurred by the participants and was given unconditionally to avoid coercion.

#### Child-Parent Relationship Therapy (CPRT)

Consistent with CPRT methodology, the five parents met weekly in a 2-hour group format to facilitate small-group interactions. The curriculum content and procedures used during treatment followed the CPRT 10-session treatment protocol (Bratton et al., 2006. The ten sessions took place over nine weeks to accommodate the parents' schedules. Building upon the empathy and understanding the parents already possessed for their children, the parents learned developmentally appropriate strategies for communicating acceptance of their children. The parents learned to use reflective responses with their children that conveyed understanding of their children's thoughts, feelings, and motivations. The parents learned to communicate choicegiving to return responsibility to their children and limit setting strategies to set appropriate limits when needed. The parents also demonstrated application of CPRT skills by completing a skills checklist when observing the video recorded play sessions of other group members. The purpose of the skills checklist was for parents to identify and discuss CPRT skills they noticed other participants using in their sessions. In order to ensure adherence to the CPRT protocol, the primary researcher received supervision from an expert in CPRT.

According to the CPRT protocol, parents participated in and video-recorded five 30-minute

play sessions with their children-of-focus, during which they practiced the attitudes and skills learned during CPRT and received direct supervision from other participants and the group leader during CPRT sessions. The parents in this study conducted and video-recorded their play sessions in play therapy rooms located in the same counseling clinic where the CPRT group sessions were held.

#### Data Collection

Table 2 outlines the steps of data collection. Each participant's interview transcripts, field notes, and personal information were assigned an anonymous code to maintain confidentiality. Electronic files and video-recordings were kept under double lock that included a password-protected computer kept in a locked room.

Table 2 *Qualitative Data Collection* 

Data Source	Procedures
1. Pre-Intervention Individual Interviews	The pre-intervention individual interviews occurred before parents began CPRT and lasted between 30-minutes and 1-hour. The interview was video-recorded and facilitated by the primary researcher. The primary researcher inquired as to the parents' experiences being a parent to a child with HFASD, current family dynamics, and expectations of CPRT.
2. Transcriptions of 10- week CPRT Sessions	The 10 CPRT sessions were video-recorded and transcribed by the primary researcher. Each transcript began at the time the group began and concluded upon completion of each group.
3. Post-Intervention Individual Interview	The post-intervention individual interviews were audio- recorded and occurred upon completion of the scheduled 10 CPRT sessions. Information provided by parents during the pre-intervention interview and 10 CPRT sessions informed the content of the post-interview questions. Content included the parents' experiences of CPRT regarding the usefulness and acceptability of the intervention and the perceived impact on the parent, child, and parent-child relationship.

#### Research Team

A research team trained in qualitative methodology coded and analyzed the data. The research team, which included the lead author and two doctoral counseling students, had experience leading or co-leading at least one CPRT group and received specialized training in child counseling and play therapy. The lead author is a licensed professional counselor and has worked extensively with children diagnosed with autistic spectrum disorders (ASD) and their parents. The second member has experience working in private practice as a licensed professional counselor with children with ASD and their parents. The third member is a Caucasian female who has worked with children and parents using play therapy and CPRT and has practiced child-centered play therapy with children diagnosed with autism.

Prior to beginning data analysis, we bracketed our biases, assumptions, and experiences (Moustakas, 1994). The purpose of bracketing was to openly discuss our thoughts, feelings, and values regarding the research study to prevent potential bias from interfering with the process of analysis. We discussed our views of CPRT, HFASD, families of children with HFASD, other interventions used for HFASD, and the usefulness of qualitative research. We revisited the bracketing process throughout data analysis when potential biases emerged.

#### Data Analysis

We analyzed the three data sources individually in the following order (1) preintervention interviews (2) CPRT sessions (3) post-intervention interviews. Interim analysis
began immediately following the completion of the pre-intervention interviews and continued
throughout the rest of the data collection (Huberman & Miles, 1994). For each data source, we
randomly selected a subset of the data for initial analysis. We first individually read through each
transcript comprising the data subset to grasp an overall feeling for the content (Creswell, 2007).

During the second read through, we made margin notes about main topics and patterns (Huberman and Miles, 1994; Patton, 2002). We clustered these statements into common themes or meaning units, which we collapsed into meaningful categories. Over a period of weeks, we drafted a preliminary coding manual based upon the meaningful categories. We then tested the intercoder reliability of our preliminary coding manual by individually analyzing the data subset, and then as a team we revised and clarified the coding manual when discrepancies emerged.

We continued this process until an intercoder agreement of at least 80% (Huberman & Miles, 1994) was established for the data subset. We then applied the coding manual to the remaining transcripts of the data source. To ensure continued intercoder reliability, each member of the research team independently coded a minimum of 66% of the total dataset, We continued to hold meetings to account for discrepant coding and coder drift (Marques & McCall, 2005).

At this point, we began data analysis for the next data source. When analyzing the second and third data sources (CPRT transcripts and post-intervention interviews), themes emerging from analysis of the previous data source were considered in the development of the new coding manual. Because all data sources concerned the same participants across a related experience, themes from the previous analysis carried over as meaningful and relevant. Carrying themes across each analysis promoted the development of a single coding manual to apply across all data sources. We continued data analysis until all data sources were coded in their entirety. After analyzing approximately 11,980 lines of transcription data across three data sources, we reached a mean intercoder reliability of 87% for the final coding manual, which fell within the accepted range of 85-93% recommended by Bakeman and Gottman (1997).

#### **Trustworthiness**

Qualitative researchers seek trustworthiness to ensure that the findings are worthy of

attention by others (Lincoln and Guba, 1985). The researchers used several verification procedures to ensure trustworthiness in this study. Triangulation of multiple sources and multiple methods of data collection increased the rigor of the study, confirmed results, and highlighted inconsistencies (Patton, 2002). We made use of reflexive journals and peer debriefers to reflect on the process and reveal bias (Lincoln & Guba, 1985). An audit trail, which included raw data, process notes, and drafts of code manuals and protocols was created and maintained throughout the study. The use of multiple coders with no contact with the research participants contributed to increased objectivity during analysis (Patton, 2002). The results were written with thick description with specific details, context, and quotations.

#### Results

The results are divided into two sections. In the first section, parents are introduced along with their child-of-focus. The textual descriptions provide a clearer understanding of the participants in the study and a context for their experiences in CPRT (Moustakas, 1994). The textual descriptions also provide a thick description, which is the "foundation for qualitative analysis and reporting" (Patton, 2002, p. 437). In the second section, identified themes are presented to provide a structural description of the experience of the participants (Moustakas, 1994), which will be explained and supported through representative quotes from participants. *Parent Experiences* 

Prior to receiving a diagnosis of HFASD for their children, all of the parents reported feeling stressed knowing that something with their children was creating difficulty for both the children and parents. Mary stated that, "not knowing was extremely anxiety producing" while Carly stated, "when he's in these tantrums or wants his way or won't stop talking, people think you're just a bad parent." All of the parents reported feeling disheartened upon receiving their

children's diagnoses of HFASD. Hannah described feeling "sad," when she received the diagnosis. Dave described his reaction as "unhappy" while Madeline stated that the diagnosis was "devastating" and "it felt like I had received a death sentence."

Despite negative reactions to the news, the parents also reported feeling relieved upon receiving the diagnosis and agreed that when they received a diagnosis, they felt they could move forward to help their child more effectively. Hannah described her and her husband's reaction: "I think we were just happy to have a diagnosis so we could move forward with a plan for him." Mary stated that, "I was overjoyed because I was, like, I know. At least I know what's going on and now I know. I can focus on what I need to do to help him." Madeline said of her reaction, "I guess it helps to have a name for it." Dave summarized his reaction to the diagnosis by stating, "We didn't need the doctors to tell us. We kind of knew."

Dave described his goals for participating in CPRT as wanting "better tools, and not only better tools for Aaron, but also for Mary and I." For Aaron, Dave said that he wanted "a way to make it so that he can have better days, maybe a better future." Mary described wanting to get "any additional tools I can have in my little toolbox that will help me help him." She went on to say that she wanted to meet other parents who share her experience as a parent to a child with HFASD. Hannah stated that her overall goal for participating in CPRT was for her and her husband to have an "improved relationship and communication" with Jack. Carly stated wanting to participate in CPRT for, "learning ways to help him," and remarked, "it will be nice to be with some other people that maybe understand some things that we've gone through in social settings, sometimes being the outcast, yeah, and how they've dealt with that." Madeline said she wanted "to add more skills to her repertoire," and stated that anything she can learn to help Zane "that is

a natural approach" would be beneficial. She also stated that from her participation, "maybe I'd get to understand him better."

# **Emerging Themes**

The research team determined that eight distinct themes best represented the phenomenological experience of the five participants. The first cluster of themes concerned the parents' experiences of CPRT and included: understanding of CRPT concepts, reactions to CPRT, and group dynamic. The second cluster of themes concerned changes in the parent, the child, and the parent-child relationship and included: child characteristics, parent characteristics, knowledge and experiences with HFASD, family context, and parent-child relationship. Each of the eight themes is defined in the context of the participants' experiences and supported by participant quotes.

Understanding of CPRT concepts. This theme was coded when participants questioned CPRT concepts, expressed understanding of CPRT concepts, or displayed a lack of understanding of CPRT concepts. When learning how to make reflective statements, Dave remarked, "You're talking about learning a different language." As the sessions progressed, the participants demonstrated an increased grasp of CPRT ideas. One CPRT homework assignment was for participants to practice giving a short burst of attention to their children-of-focus. Carly described her experience, "So it was unusual. I could tell that it meant something to him, I think, that I stopped. And that I told him I'm stopping what I'm doing and I'm going to listen to you. I thought that was interesting."

Views of CPRT. All of the participants expressed reactions to CPRT throughout the training. Madeline said of CPRT, "It's different," and "I'll be interested to try it and see if it gets a different response." Hannah stated, "I'm looking forward to these play sessions because I think

it will just be really interesting to see him outside of his element." Dave reported, "The choice giving has really been a pretty big, it's been a big thing in our house. It hasn't been terribly successful at times, but there's been a lot of choice giving," to which Mary replied, "I can tell you that since we started I've used it five or six times at least and every time it has worked."

Group dynamic. The participants displayed emerging group dynamics during the CPRT sessions, such as linking shared experiences, seeking and sharing perceptions related to raising a child with HFASD, and seeking clarification from group members when understanding was lacking. All of the participants reported positive experiences with the group dynamic they experienced. Dave stated, "I think it helped that we each kind of discussed the other kids' situations, because we were seeing what that they weren't seeing and then you see it and you hear it from somebody else and you go 'oh, I missed that." Madeline shared of her experience of the group dynamic, "I didn't feel nervous or threatening to share something like that in a group." Carly said, "as the sessions went along, it got a lot easier to talk about things and that made it easier. And they made it easier, the group did."

Child characteristics. All of the participants described various aspects of their child-offocus during the study. Madeline shared of Zane, "My son doesn't outwardly invite me in to
play." Carly described Eric and shared, "He will only wear Spider-Man clothes." At the end of
CPRT, Hannah reported that she was unsure if CPRT had affected Jack's behavior yet. When
asked what changes she noticed, Hannah stated, "I don't think I can tell yet. You know, the
choice-giving has worked a couple of times." However, Madeline reported of Zane that "I think
he's aware that I'm watching him more or in a different way." Mary reported changes she had
seen in Aaron, "he's not so hard to deal with," and "he's been me hugging more." Dave

confirmed Mary's report, "After this he's been a lot more connected to her. She's gotten hugs.

That's a big thing, that's a big thing for her."

Parent characteristics. All of the parents described their parenting practices, stressors, strengths, and areas for growth. Hannah stated, "I think that sometimes I'm not challenging him (child-of-focus) to get outside of the box and grow." Dave shared, "As far as our situation goes, I tend to be awake more so when he has issues I'm usually there." The participants also described changes that they noticed in themselves as parents as a result of going through CPRT. For example, Carly shared, "I think I'm a lot calmer, I really do," and went on to say that, "Probably it's made me a nicer person, maybe a little bit." Mary shared, "I feel more confident," which was echoed by Dave, who said, "I feel a lot more confident in dealing with him."

Parent knowledge and experiences with HFASD. The participants also shared how HFASD had affected their lives. For example, participants described experiences of other people's perceptions of them and their child with HFASD. Dave described what the group dubbed the Wal-Mart look:"

We've all had it. You go to the store and they insist you've got to go over to the toy section, so you've got to go to the toy section and then try to do the rest of your shopping and everything else. And he starts kinda melting down. And then you're actually hearing the comments behind your back or you hear them in the aisle as your walk by, or you're going down another aisle later and they say, "Oh, there they are again." Or you see them go the other direction. That's the Wal-Mart look. And there's no better place to get it.

Family context. All of the participants shared how their home life influenced their roles as parents to their children-of-focus. Dave described his and Mary's home environment as "A circus, really a circus." Carly, the only grandparent in the group, described how Eric's mom struggles with depression, "She has some depression problems, and she has said herself she thinks that affects him." Hannah, who was the most reserved of the group members, did not

share much about her family context, but that she and her husband both work full-time and "do a fair amount of travel."

Parent-child relationship. Throughout CPRT, participants described various aspects of their relationships with their children-of-focus. Mary said of her relationship with Aaron, "I play with Aaron a lot, actually," but then clarified, "Well, he likes to do things by himself, but he wants you to be near him." The participants also described changes they noticed in the parent-child relationship since beginning CPRT. Hannah noted, "I don't know if I can pinpoint something from a relationship standpoint that's changed. I mean, it's hard because I felt that I couldn't be any closer to him before the class." Carly stated, "I think we have a much closer relationship." Mary shared of her relationship with Aaron, "We always considered us to be pretty close in our own way, but it feels like that he's connecting a little more with me." Dave echoed the changes that Mary noticed, "I think it has helped with his relationship with both of us, but more so with Mary."

## Discussion

This study used a phenomenological research design to explore the perceptions of four parents and one grandparent raising children diagnosed with high-functioning autistic spectrum disorders (HFASD) participating in child-parent relationship therapy (CPRT). CPRT teaches parents child-centered play therapy skills in a group setting and is designed to enhance the parent-child relationship and increase parents' knowledge and confidence when dealing with child-behavior problems (Landreth & Bratton, 2006). To explore the parents' experience of CPRT and to better understand the extent to which the experience of CPRT addresses the needs of these parents, the researcher examined the parents' responses during individual semi-

structured pre- and post-intervention interview sessions and analyzed the content of the ten CPRT sessions.

The first aim of this study was to explore how parents of children with HFASD experience the usefulness of CPRT. CPRT teaches that the parent-child relationship is the primary agent of change (Landreth & Bratton, 2006), but because children with HFASD typically display atypical engagement in interpersonal relationships (Greenspan & Weider, 2006), the appropriateness of CPRT for parents of children with HFASD was uncertain. All of the parents began the study knowing very little about CPRT and play therapy, but stated that they were interested in receiving an intervention of some kind that would help their children. This finding is consistent with past literature, which has found that the inability to locate and arrange appropriate services is a primary source of stress for parents of children on the autistic spectrum (Hastings & Johnson, 2002; Weiss, 1991).

Qualitative analysis of parent comments during the training sessions and interviews demonstrated the acceptability and perceived usefulness of CPRT for this group. All of the parents were able to identify specific skills they learned through CPRT and demonstrate application of these skills through interactions with their child-of-focus as well as through group discussion. The finding of acceptability of CPRT is consistent with previous qualitative studies demonstrating the acceptability of CPRT (e.g. Edwards, Sullivan, Meany-Wallen, & Kantor, 2010; Foley, Higdon, & White, 2006). However, this study represented the first study demonstrating the acceptability and usefulness of CPRT for parents of children with HFASD.

The perceived acceptability and perceived usefulness of CPRT by the parents in this study is consistent with emerging literature demonstrating the benefits of developmentally based interventions for children with HFASD. In contrast to behavioral models, which approach play

and interpersonal interactions as a skill (Sturmey & Fitzer, 2008), developmentally based interventions incorporate experience-based, playful, and enjoyable interactions to enhance attention, pretend play, and communication for children with autistic spectrum disorders (Bernard-Opitz et al., 2004). Developmental interventions often incorporate play as a developmental expression that facilitates individual experiences and social interactions, which contribute to further development (Greenspan & Weider, 2006; Mastrangelo, 2009).

CPRT shares aspects of these developmental interventions, such as teaching parents to interact with their children during 30-minute play sessions in an unstructured environment that allows the child to be in the lead. This approach is seen as developmentally appropriate because parents are seeking to understand their child from the developmental perspective of the child rather than coaching the child to behave at a level of development they have not yet reached. The parents in this group reported appreciating the opportunity to understand how their children experience the world without feeling the pressure to direct or steer their children. They reported noticing that their children possessed dimensions to their communication and social interaction that they had not noticed previously. Without feeling it necessary to hone in on and correct specific behaviors, the parents said they recognized their children's desire to engage with them, but in a way that they had not recognized previously. This experience fits with emerging ideas about HFASD as being not a deficit in social communication, but a different kind of social communication (Baron-Cohen, 2002; Greenspan & Weider 2005), one which the parents in this study were able to recognize perhaps due to the emphasis in CPRT on understanding the needs and intentions of the children-of-focus.

The parents reported that the skills they found most beneficial were choice-giving and limit-setting. All of the parents initially stated believing that they carried the responsibility for

controlling their children. In addition, because of their children's frequently rigid, unpredictable, and reactive behaviors, they stated they often felt isolated from family and friends. They also expressed feeling stressed when taking their children to public places, such as stores and restaurants, because their children could have meltdowns at any moment. With choice-giving and limit-setting, the parents expressed that they felt more confident dealing with child-behavior problems because they possessed a specific strategy they could follow. They also stated that they trusted their children more to solve problems independently and bring themselves under control, a finding consistent with other CPRT studies indicating that participation in CPRT increases parents' understanding of their children (e.g. Edwards et al., 2010; Carnes-Holt, 2010; West, 2010).

Despite reporting generally positive reactions to CPRT, most parents reported feeling concerned about giving their children too much freedom and worried about not being as directive as they felt was necessary. A large part of this concern seemed to stem from previous training received by the parents that focused on structuring most routines for their children. Some of this concern also originated from previous experiences with their children not being able to handle responsibility offered to them. Considerable session time was spent addressing whether children with HFASD can handle the responsibility that parents were asked to provide during the special play times and how to return levels of responsibility that are developmentally appropriate for their children.

This concern regarding child responsibility may highlight a potential limitation of CPRT with this population. Ten sessions may be insufficient for parents of children with HFASD to feel confident allowing their children more freedom and responsibility. While all of the parents reported understanding the benefits of allowing their children increased freedom and

responsibility, they did not fully embrace the concept through their play sessions. Parents appeared unsure and hesitant to return responsibility to their children during all of their sessions. For instance, parents were quick to set limits and when limit-setting was unsuccessful they tended to intervene directly to correct their children's behavior. However, because the parents in this study understood the benefit of allowing more freedom and responsibility, an accommodation for CPRT might be extending the sessions beyond the ten and focusing more extensively on the experience of giving their child freedom and responsibility to allow parents time to increase their comfort with this practice.

Moreover, while all parents expressed an understanding and appreciation for the concepts of CPRT, they struggled to apply the approaches consistently. Again, this struggle may concern the inherent structure of CPRT, specifically that it extends only over ten weeks and asks that parents only engage in 30-minute play sessions once per week. Considering the extensive interactions that these parents have with their children, the dearth of opportunities to practice the CPRT approach under supervision may interfere with the development of these approaches. For instance, all of the parents reported using choice-giving and limit-setting at home, but when they described in detail the procedures they followed, they tended to leave out important steps, such as reflecting their children's intentions or feelings before setting the limit. This trend was also observed while the parents conducted their 30-minute play sessions in the counseling clinic. Consequently, while the parents interactions with their children changed as they progressed through CPRT, their specific application of CPRT techniques only approximated the actual techniques. Again, increasing the frequency and duration of CPRT may address this limitation.

Finally, before beginning the group, all of the parents expressed a desire both to meet other parents and develop new skills. All of the parents acknowledged the group structure of

CPRT was a positive part of their experiences and expressed gaining considerably from the support offered by the group. Because CPRT is offered in a group format, it is difficult to determine to what extent the parents benefited from the being with parents in a similar situation as opposed to learning new skills. The increased confidence that the parents in this study expressed may be due to their decreased sense of isolation and the encouragement they received from other parents during the group sessions. However, it is also possible that both elements contributed synergistically to the parents' experience and that removing one element would decrease the quality of the other. Another important area for research might be to compare individual and group experiences of CPRT to determine the extent to which the group influences perceptions of success.

## *Implications*

The findings of this study have several implications for influencing interventions offered to parents of children with HFASD. The first is that all of the parents reported desiring an intervention that would help them feel more capable meeting the needs of a child with HFASD. From their participation in CPRT, the parents reported that they had found such an intervention. Many behavioral interventions are one-on-one, time intensive (up to 40-hours per week), and often extend over several years. Studies have found that participation in these types of programs can increase caregiver stress resulting from having to recruit and maintain a suitable team of therapists, assume considerable financial burden on the family, and accommodate disruption in family routine (Johnson & Hastings 2002; Maurice et al. 2001). Although this research study did not evaluate whether parents believed CPRT to be more effective than other interventions, all parents found CPRT acceptable and useful. Therefore, CPRT might serve as a viable option for

parents of children with HFASD and one that is considerably less time-intensive than many leading behavioral interventions.

In addition, the majority of parents reported experiencing increased closeness in the parent-child relationship. While this was not a stated goal parents prior to beginning CPRT (most stated they wanted better tools to manage difficult behaviors), the majority reported feeling pleased with the increased closeness they felt with their children. Some parents reported learning that what they originally perceived as asocial behavior in their children might be their children's attempt to connect and engage, but in a way that is atypical by conventional standards. For instance, one parent stated now recognizing that her son's repetitive behavior of writing numbers and letters was not a way of tuning out the world, but his way of connecting with her. While viewing recordings of her special play times during CPRT group sessions, she said that the other group members helped her to understand that he would look at her as he wrote and communicate to her what he was writing, and that seeing this helped her to feel emotionally closer to her son. Structuring future interventions to help parents of children with HFASD understand that their children's social behaviors are different, not necessarily deficient, and to recognize the intention behind the behavior, may help address potential distance that both parents and children with HFASD experience in the parent-child relationship.

Finally, prior to beginning CPRT, parents in this study reported feeling isolated from other parents and wanting an intervention that connected them with others raising children with HFASD. All of the parents expressed that the sharing of experiences during CPRT helped their understanding not only of CPRT, but also of autism and of their children. One important element that CPRT offered the parents was the chance to establish this connection, which may have been a large source of the positive reaction the parents expressed about CPRT. For future

interventions designed to help parents of children with HFASD, incorporating this group support component may increase parent confidence and contribute to greater success experienced by the parent resulting from the intervention.

#### Limitations

The potential for researcher bias represents a possible limitation to the current study. Although data analysis revealed positive outcomes related to treatment acceptability and perceived effectiveness, the primary researcher's dual role as both researcher and trainer may have negatively affected data collection and analysis. However, the other two researchers had no contact with the participants and therefore provided an objective perspective. In addition, the researchers ensured trustworthiness through triangulation, audit trail, and persistent observation (Patton, 2002).

Another limitation of the study is that all parents participating in the study identified as Caucasian, indicating a lack of multiethnic diversity for this study. In addition, all of the children of focus participating with the parents were male. However, diversity was present in that the study consisted of one grandparent as well as one married couple.

In addition, this research study lacked follow-up with the parents to determine the maintenance of the approach to parenting learned during CPRT. The post-intervention interviews were conducted only one week following the conclusion of CPRT. No information was collecting regarding whether the parents were generalizing the attitudes and skills or continuing to use these tools upon completion of CPRT. Moreover, an important part of CPRT is for parents to continue having 30-minute playtimes with their children-of-focus to continue incorporating the CPRT approach to further enhance parent-child relationships. Although all of the parents reported that they planned to continue using the approach they learned through CPRT, they may

have felt obliged to answer a particular way because the group leader also conducted the post-intervention interviews. Because information regarding the maintenance and generalization of CPRT skills was not included in this study, one cannot determine whether the parents continued to use what they learned beyond the duration of the ten weeks of CPRT training.

Recommendations for Future Research

In addition to examining the acceptability of CPRT for parents of children with HFASD, another purpose of this study was to provide a foundation for future research investigating the effectiveness of CPRT with this population. Although this study demonstrated that these parents benefited from the content and structure of CPRT, future studies should focus on isolating particular variables common to parents of children with HFASD. For instance, parents in this study frequently described the stress they feel as parents to a child with HFASD. This stress is supported by the literature, which demonstrates that parents of children on the spectrum experience elevated levels of stress (Dabrowska & Pisula, 2010; Epstein, et al, 2007). Examining whether CPRT is effective at reducing stress for parents of children with HFASD would support its use as an intervention for this population.

In addition, although the parents' comments demonstrated the acceptability and usefulness of CPRT, it is difficult to determine whether the specific strategies put into practice by the parents changed the perceived quality of the parent-child relationship or whether CPRT changed how the parents perceived their child. However, most parents in this study reported that changes in the parent-child relationships were an important outcome of CPRT. An important area for future research could be to interview children to better understand their experiences of CPRT and what changes they are seeing in their parents. Another potential area for study could be

examining how the relationship changes during and after the parents' participation in CPRT to determine if identified changes in the relationship maintain after CPRT is over.

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# APPENDIX A EXTENDED LITERATURE REVIEW

Definition and Diagnosis of Autism and Autistic Spectrum Disorders

Autistic disorder, or classic autism, is a neurodevelopmental disability that typically appears in the first three years of life, persists throughout the lifespan, and has serious effects on a person's cognitive, communicative, and social development (American Psychiatric Association; APA, 2000). Autism is characterized by deficits in communication, socialization, and play skills (Centers for Disease Control; CDC, 2009). Specifically, children with autism lack social awareness, struggle with verbal and nonverbal communication, avoid eye contact, are unaware of social cues, and display rigid, ritualistic behaviors. Autism varies in terms of symptom severity, age of onset, and the presence of various features (APA, 2000). Symptom manifestation can differ considerably between children, as there is no single behavior consistently associated with a diagnosis of autism (Greenspan & Weider, 2005). While children with autism may demonstrate growth and development to some degree, they will most likely always have delays and deficits (APA, 2000; CDC, 2009).

The development of autism as a diagnosable mental health condition has evolved considerably over the past half-century. Leo Kanner (1943), an Austrian born physician and researcher at Johns Hopkins University in Baltimore, Maryland, originally labeled this condition "early infantile autism" when describing eleven children he observed as markedly withdrawn, socially aloof, and lacking in communicative speech (Wing, 1997). Kanner, whose work was grounded in child development, particularly the work of Gesell, observed that children with early infantile autism were unresponsive to the environment, lacked appropriate social engagement and play, and insisted on sameness in their environments and routines (Volkmar & Klin, 2005). Kanner distinguished early infantile autism from similar disorders, such as childhood schizophrenia, based upon the developmental onset of symptoms. Whereas children diagnosed

with childhood schizophrenia developed symptoms following several years of normal development, children with early infantile autism presented with symptoms within the first few months of life, sometimes even at birth, and presented with symptoms throughout development. Kanner speculated that autism was an inborn quality not related to other medical conditions. Thus, for Kanner, the developmental nature of early infantile autism warranted its unique classification as a developmental disorder (Volkmar & Klin, 2005).

Kanner deliberately chose the label "autism," which is Latin for *self*, to convey the self-contained quality he observed in his eleven original case studies (Volkmar & Klin, 2005).

Kanner borrowed this term from Swiss psychiatrist Eugen Bleuler, who used the term in the early 1900s to describe a quality of schizophrenic patients that included idiosyncratic, self-centered thinking (Wing, 1997). The label "autism" suggested that children with this condition lived in their own world and lacked the biological preconditions to psychologically metabolize the social world (Volkmar & Klin, 2005).

Though Kanner's work received considerable attention, early infantile autism remained closely associated with childhood schizophrenia for many years as researchers and practitioners debated over appropriate diagnostic criteria. As a developmental disorder, the broad range of symptom expression and evolution of symptoms throughout development made establishing a clear diagnosis extremely difficult. In addition, communication deficits common among those with autism meant that an affirmative diagnosis often relied solely upon caregiver report, creating problems in terms of reliability and validity of diagnosis (Wing, 1997).

By the 1970s, researchers began to propose more categorical conceptualizations of this condition. At the same time, multiaxial and multidimensional approaches to mental health diagnosis in general were gaining increasing recognition and favor in the psychiatric field. In

1978, while seeking a clear differential diagnosis of early infantile autism, Michael Rutter synthesized Kanner's original report to generate a highly influential definition of autism that consisted of four distinct features: (1) early onset by age 22, (2) impaired social development, (3) impaired communication, and (4) unusual ritualistic and rigid behaviors. In addition, Rutter specified that impairments in social interaction and communication were distinct from intellectual impairment (Volkmar & Klin, 2005). Rutter's contribution to the identification and diagnosis of autism gained considerable traction in the mental health field and greatly influenced the eventual distinction between autism and childhood schizophrenia in the mental health community.

Just a few years following Rutter's proposed definition of autism, autistic disorder received official recognition as a distinct developmental disorder in the *Diagnostic and Statistical Manual of Mental Disorders-III (DSM-III)*, published by the American Psychiatric Association (APA, 1980). The *DSM-III* drew heavily from Rutter's work and classified autism using a multiaxial criterion based upon Rutter's identified features of autism. Moreover, the *DSM-III* placed autism under the newly created heading of pervasive developmental disorders (PDD), a category meant to convey impairment in the "development and unfolding of multiple areas of functioning" (Volkmar & Klin, 2005). However, the highly categorical nature of diagnosis in the *DSM-III* created several complications regarding conceptualization of individuals with autism. For instance, the developmental onset of autism, as well as the variation in severity of symptoms often seen in individuals with autism, went largely unaddressed in the *DSM-III*.

An attempt to address such issues was made through revisions in the *DSM-III-R* (APA, 1987). However, these changes came at the expense of loosening the diagnostic criteria for

autism considerably. According to the *DSM-III-R*, individuals could receive a diagnosis of autism by displaying higher levels of functioning than originally delineated in the *DSM-III*. The *DSM-III-R* also removed the criteria for age of onset as a central diagnostic feature, meaning that individuals developing symptoms late in childhood could still meet the criteria for autism. Moreover, the *DSM-III-R* created a new diagnostic category, pervasive developmental disordernot otherwise specified (PDD-NOS), which allowed individuals who previously failed to qualify for a diagnosis of autism, to carry a diagnosis of PDD-NOS if they displayed autistic symptoms. Loosening the diagnostic criteria for autism and autistic related disorders dramatically increased the number of false-positive cases diagnosed to nearly 40% (Rutter & Schopler, 1992; Spitzer & Siegel, 1990), and led to an increasingly blurred distinction between autism and intellectually disabled individuals (Volkmar & Klin, 2005). Thus, while the *DSM-III-R* sought to clarify the diagnostic criteria for autism, the amended criteria rendered a diagnosis of autism in more question than before its publication.

The *DSM-IV* (APA, 1994), and the *DSM-IV-TR* (APA, 2000), which followed the *DSM-III-R*, built upon extensive research and field trials using diagnostic criteria contained in previous versions of the *DSM*. Based upon these field tests, these latest versions of the *Diagnostic and Statistical Manual* reinstituted the age-of-onset criteria for a diagnosis of autism and made the diagnostic criteria more specific to decrease the potential for false-positive cases and preserve the developmental nature of the diagnosis. To qualify for a diagnosis of autistic disorder in the *DSM-IV* and *DSM-IV-TR*, an individual needed to display at least two criteria related to social abnormalities (Group 1), one criterion related to impairment in communication (Group 2), and one criterion range of interests and activities (Group 3). Together, these three groups constitute what is commonly termed the "triad of impairment" and are central criteria in the diagnosis of

autistic disorder as well as all autistic spectrum disorders (Cashin & Barker, 2009; Wing & Potter, 2002). In addition, the age of onset of autism now must occur prior to age 3 years, as evidenced by delay or abnormal functioning in social interests, language as used in social interaction, and symbolic/imaginative play. Table 3 presents the specific *DSM-IV-TR* diagnostic criteria for autistic disorder.

Table 3

DSM-IV-TR Criteria for Autistic Disorder (299.0)

- A. A total of at least six items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):
  - (1) Qualitative impairment in social interaction, as manifested by at least two of the following:
    - (a) marked impairments in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body posture, and gestures to regulate social interaction
    - (b) failure to develop peer relationships appropriate to developmental level
    - (c) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g, by a lack of showing, bringing, or pointing out objects, of interest)
    - (d) lack of social or emotional reciprocity.
  - (2) qualitative impairments in communication, as manifested by at least one of the following:
    - (a) delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gestures or mime)
    - (b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
    - (c) stereotyped and repetitive use of language or idiosyncratic language
    - (d) a lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level.
  - (3) restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
    - (a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
    - (b) apparently inflexible adherence to specific, nonfunctional routines or rituals
    - (c) stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
    - (d) persistent preoccupation with parts or objects

- B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.
- C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

The "triad of impairment" for autism includes qualitative impairments in the following areas of functioning: social interaction, communication, and rigid patterns of behavior, interests, and activities. Since Kanner first described autism, deficits in social behavior have been recognized as essential features of the disorder. Children with autism often fail to establish peer relationships, lack normal relatedness with familiar people, display a preference for aloneness, demonstrate poor eye contact and gestures, and lack initiative to engage in communication with others (Rutter, 1978; Wing & Gould, 1979). In fact, deficits in social interaction are often the first concerns of parents of children with autism, leading them to seek medical or professional evaluation. Parents may notice that their child is failing to form close relationships with family members or peers, and that their child is not engaging in social contact like other similarly aged children. Consequently, parents often first notice symptoms of autism when the child begins social interactions, such as play-dates, daycare, or preschool.

The extent of social skill deficits often indicates the severity of autism. Among more severe cases of autism, children tend to treat others as if they are objects. They tend to be unresponsive and fail to initiate interactions with children or adults (Loveland & Landry, 1986; Trad, Bernstien, Shapiro, & Hertzig, 1993). They often do not play with others, preferring to be by themselves, and demonstrate little interest in developing relationships (Rutter, 1974). They may experience failures to communicate based on deficits in their ability to use gestures or eye contact (Buitelaar, can Engeland, do Kogel, & de Vries, 1991; Kasari, Sigman, Mundy, &

Yirmiya, 1990). Among children with less severe deficits in social understanding, the preference for social isolation is not as pronounced. They may not actively avoid social contact, but their interactions often lack spontaneity or an intuitive grasp of social interactions shared by typically developing children (Wing & Attwood, 1987; Wing & Gould, 1979). For those that actively seek out social contact, the quality of the relationships is often qualitatively different than that of typically developing children. They may display behaviors such as repetitive questioning, inappropriate touching, narrowly focused conversation, and odd postures, gestures, and facial expressions (Loveland & Tunali-Kotoski, 2005).

Despite deficits in social understanding, research suggests that children with autism may display signs of attachment to parents and caregivers (Ozonoff & South, 2001; Shapiro, Sherman, Calamari, & Koch, 1987). Such studies indicate that a basic capacity for attachment exists in children with autism not unlike children with other developmental delays or younger typically developing children. Thus, according to Loveland and Tunali-Kotoski (2005), some of the foundations for normal social behavior may be present among children with autism. Still, deficits in social understanding have implications for more complex social interactions.

Another common characteristic of individuals with classic autism are deficits related to language and communication. According to Rimland (1964), approximately 50% of children with autism never develop speech or master only rudimentary forms of communication, such as crying or whining. For those children who acquire speech, they may display rigid speech patterns, such as inaccurate rhythm, inflection, pitch, and articulation (Schreibman, Kohlenberg, & Britten, 1986; Targer-Flusberg, Calkins, Nolin, Baumberger, Anderson, & Chadwich-Dias, 1990). Children with autism may also struggle to consistently produce spontaneous speech and instead focus on minute details of conversation. This tendency may manifest through

perseveration, the persistent repetition of specific words or phrases of interest in an almost hyperactive manner.

Up to 75% of children with autism may at some point display echolalia, the repeating or echoing of words said by self or others with no apparent regard for meaning (Prizant, 1983).

While echolalia may appear devoid of functional purpose, some studies have suggested that echolalia may serve an important communicative function among children with autism by allowing them to remain involved in social-communicative exchanges (Prizant, & Durchan, 1981). Rydall & Mirenda (1994) also suggested that echolalia may aid in the process of language acquisition by sustaining the social-interactional context in which conversations take place. However, a study by Tager-Flusberg et al (1990) suggested that while echolalia may facilitate conversational skills, it does not necessarily facilitate grammatical development, meaning that it may not necessarily be facilitative to further developing skills in conversation. According to Loveland and Tunali-Kotoski (2005), echolalia may be best viewed as a communicative strategy used by children with ASD who cannot consistently produce speech. Webber and Scheuermann (2008) also suggested that echolalia may represent ways of expressing anxiety or desires, and thus be a meaningful and purposeful method of communication for children with autism.

Children with autism may also display pronomial reversal, commonly manifested as a reversal of the pronouns 'I' and 'you.' While typically developing children commonly display pronominal reversal until around the age of two (Loveland, 1984), individuals with autism make pronoun reversals commonly and frequently (Lee, Hobson, & Chiat, 1994; Loveland & Landry, 1986). Moreover, children with autism also engage in conversation with very literal meaning, ascribing only one meaning to a word and displaying a lack of ability to generalize meaning to different contexts (APA, 2000).

Stereotyped, repetitive, or ritualistic behaviors are another feature commonly associated with ASD and include behaviors such as rocking, flapping hands, pacing, clapping, scratching, and walking on toes (Weber & Schuermann, 2008). More severe forms of these behaviors, such as head-banging, may be more serious and lead to self-injury or injury to others. However, such behaviors are not unique to autism and present among typically developing children as well. For instance, Gesell (1928) described these behaviors as rigid likes and dislikes and routine-seeking behavior. Gesell originally theorized that children's rigid behavior might function as a mechanism for organizing and accommodating to the environment. Moreover, Kopp (1982, 1989) hypothesized that ritualistic behaviors might give children a sense of self-control and help them regulate emotional states. However, such insistence on sameness often inhibits daily functioning for children with autism.

Rutter (1978) categorized rigid or ritualized behaviors into four categories. The first category involves rigid patterns of play, such as the persistent lining up and rearranging of toys. A second common rigid behavior involves intense preoccupation or attachment to a particular object. For children with autism, this may manifest as obsessive attachments to seemingly insignificant objects, such as a paperclip or particular rock. These children may insist that they always have the toy with them and grow upset if denied access to the object. A third form of rigid behavior involves developing preoccupations with certain ideas, objects, or sounds, or places. Finally, children with autism may insist on routine-seeking or rule-governed behavior. For example, a child going to the grocery with her parents may insist on going through the same door and walking through the aisles the same way each time. When children are prevented from engaging in rituals, they may exhibit maladaptive behaviors to cope with the change in routine, such as aggression or tantrums (Charlop-Christie, Malmberg, Rocha, & Schreibman, 2008).

One commonly associated feature of autism, abnormalities in the development of cognitive skills, is not specifically mentioned among the differential diagnosis of the *DSM-IV-TR*. However, the *DSM-IV-TR* states in the text description of Autistic Disorder, under the heading "Associated descriptive features and mental disorders," that in most cases, "there is an associated diagnosis of Mental Retardation, which can range from mile to profound" (APA, 2000, p. 71). Moreover, the *DSM-IV-TR* further states that, "the profile of cognitive skills is usually uneven, regardless of the general level of intelligence, with verbal skills typically weaker than nonverbal skills" (p. 71-72).

Etiology of Autistm. A diagnosis of ASD is based on descriptions and observations of behavior (Lord & Bishop, 2010). While significant evidence suggests that ASD is a neurodevelopmental disorder, there is not yet a valid biological marker or biological test (Abrahams & Geschwind, 2008). Thus, the etiology of autism is currently unknown. However, a number of theories have emerged ranging from early ideas about "refrigerator mothers" who withheld love and affection (Wing, 1997) to various prenatal experiences, such as viral infections, exposure to environmental toxins, and prenatal, perinatal, and neonatal trauma (Lathe, 2006). Maternal health, such as hypothyroidism and other medical conditions have also been postulated as potential causes. Current theories range from environmental factors to genetic predispositions, including a wide range of possible interactions between these two factors.

The most convincing research concerning the cause of autism concerns genetic research (Lathe, 2006). Results of twin studies and family studies demonstrate a strong genetic component to autism. These studies indicated an increased risk for siblings being 60-fold when one sibling has autism, while the increase risk for monozygotic twins being 600-fold if one twin has autism (Bailey, Le Counteur, Gottesman, Bolton, Simonoff, Yuzda, & Rutter, 1995).

However, these studies may not adequately address the possibility of prenatal or neonatal trauma, as children in these studies share the same mother. However, such research has led to a recent focus on identifying the genetic predisposition that may contribute to autism among individuals. For instance, Vorsanova, Voinova, Yorov, Kurinnaya, Demidova, and Yurov (2010), used "state of the art" cryogenic and molecular-cryogenetic methods to study chromosome anomalies and variants among mothers of children with autistic disorders. The results showed that mothers of children with autism, when compared to the control group, showed increases in the frequencies of anomalies, suggesting a possible genetic predisposition for autism. At present, however, research is inconclusive regarding the exact etiology of autism.

Though the diagnosis of *Autistic Disorder* has evolved considerably since Kanner's initial publication on early infantile autism, it remains a condition that is difficult to classify. While publication of the *DSM-IV* in 1994 enhanced the specificity of *Autistic Disorder* compared to previous editions, it also retained the diagnosis of PDD-NOS while adding *Asperger's Disorder* as another diagnosable condition under the PDD umbrella. Moreover, another commonly employed label, *high-functioning autism* (HFA), which refers to individuals meeting the criteria for Autistic Disorder but also possessing an average or greater I.Q., has further compounded the labels used to address variations of autistic spectrum diagnoses. Because individuals with Asperger's Condition, PDD-NOS, and high-functioning autism are the focus of this research, a more thorough discussion of each condition follows.

### High-Functioning Autism

The uneven profile of cognitive development and verbal ability is important in the diagnosis of Autistic Disorder, as these criteria typically differentiate *Autistic Disorder* from other disorders within the spectrum. The descriptive label, *high-functioning autism*, often refers

to individuals meeting the criteria for Autistic Disorder, but lacking impairment to cognitive functioning. High-functioning autism (HFA) is not officially recognized as a diagnosis according to the APA, but is a term commonly employed to describe individuals meeting the diagnostic criteria for Autism, but who are of average IQ and possibly possessing higher verbal ability than is typically associated with Autistic Disorder (Volkmar, State, & Klin, 2009). The HFA label is often used in autism research literature to denote individuals on the higher end of the autistic spectrum of functioning. However, use of this label may cause confusion regarding the exact presentation of autistic symptoms being described. First, as stated previously, HFA is not an official diagnostic category, but a descriptive label. Thus, use of the label lacks specificity. Second, HFA often is meant to subsume Asperger's disorder and PDD-NOS, which are also included in the spectrum of autistic disorders, yet commonly perceived as high-functioning variants of autistic disorder, or high-functioning autistic spectrum disorders (HFASD). HFASD is differentiated from HFA due to HFA specifically referring to individuals meeting the criteria for autistic disorder (APA, 2000), but with average or above average cognitive ability, while HFASD subsumes HFA, Asperger's disorder, and PDD-NOS.

#### Asperger's Disorder

Around the time Kanner was exploring early infantile autism in the United States,

Austrian pediatrician Hans Asperger (1906-1980) was independently exploring a similar cluster
of symptoms. Asperger possessed a strong interest in special education and, in 1944, described
children between the ages of 6-11 who had difficulty socially integrating into groups despite
seemingly normal cognitive and verbal development (Klin, McPartland, & Volkmar, 2005).

Specifically, Asperger observed that these particular children possessed extreme egocentrism and
limited social drive. However, Asperger noted that some patients were able to develop

relationships over time, unlike many children diagnosed with childhood schizophrenia. Like Kanner, Asperger borrowed the term *autistic* from the then current medical description of schizophrenia to describe the cluster of symptoms he observed. Asperger termed the condition autistic personality disorder in childhood and, like Kanner, differentiated the cluster of symptoms he observed from childhood schizophrenia by emphasizing the enduring developmental nature of the condition.

Asperger's work remained largely unexplored until Lorna Wing (1981) presented an influential review of Asperger's work which included detailed case studies of children presenting with symptoms consistent with Asperger's conceptualization. However, unlike Asperger's original conceptualization, Wing proposed that the associated difficulties were observable in the first few years of life, including lack of normal interest in and pleasure in other people, communication difficulties, reduced sharing of interests and activities, absence of a drive to communicate, and failure to fully develop symbolic play (Wing, 1981). Wing proposed the name Asperger's syndrome (AS) for the condition and conceptualized AS in a way consistent with the "triad of impairment." Consequently, Wing's conceptualization brought Asperger's disorder into the autistic spectrum and eventually into the spectrum of diagnoses contained within the DSM-IV-TR (Klin, McPartand, & Volkmar, 2005).

Wing's paper received considerable attention and subsequent studies addressing AS increased steadily (Klin, Volkmar, & Sparrow, 2000). Of particular issue was whether AS was distinct from high-functioning autism (autism with lack of significant cognitive impairment). Continued exploration into the distinctions between AS and autism eventually led to marginal recognition that the two conditions differ qualitatively. In 1994, the APA included Asperger's

disorder as a distinct diagnosable condition under the heading of pervasive developmental disorders. Table 4 presents the current *DSM-IV-TR* criteria for Asperger's disorder (2004).

Table 4

DSM-IV-TR Criteria for Asperger's Disorder (299.80)

- A. Qualitative impairment in social interaction, as manifested by at least two of the following:
  - (1) Marked impairment in the use of multiple nonverbal behaviors such as eyeto-eye gaze, facial expression, body postures, and gestures to regulate social interaction
  - (2) Failure to develop peer relationships appropriate to developmental level
  - (3) A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people)
  - (4) Lack of social or emotional reciprocity
- B. Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
  - (1) Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
  - (2) Apparently inflexible adherence to specific, nonfunctional routines or rituals
  - (3) Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
  - (4) Persistent preoccupation with parts of objects
  - (5) The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning
- C. There is no clinically significant impairment in social, occupational, or other important areas of functioning
- D. There is no clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years).
- E. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than in social interaction), and curiosity about the environment in childhood.
- F. Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia.

The cluster of symptoms originally recorded by Asperger continues to be incorporated into the current diagnostic criteria included in the *DSM-IV-TR* (2004) including: impairment in nonverbal communication, idiosyncrasies in verbal communication, areas of special interests,

intellectualization of affect, clumsiness and poor body awareness, conduct problems, and later age of onset. (Klin, McPartland, & Volkmar, 2005). However, because Asperger's Disorder shares a similar diagnostic criterion as Autistic Disorder (APA, 2000), such as difficulty in social interaction and rigid behaviors, particular symptoms differ fundamentally from Autistic Disorder.

Regarding age of onset, unlike individuals with autism, individuals with AS display no significant delays in self-help skills or cognitive development prior to age 3, as manifested by expressing normal curiosity about the environment and the acquisition of age-appropriate learning skills and adaptive behaviors. In addition, individuals with AS lack early onset impairments to communication associated with autism (APA, 2000). Individuals with AS typically are able to use single, non-echoed words communicatively by age 2 years and spontaneous communicative phrases by age 3 years, and some parents report that their child may begin to talk before learning to walk. (Klin, et al, 2005). Vocabulary acquisition, however, may be unusual as child may learn complex and adult like words not typically associated with very young children. Moreover, their vocabulary acquisition may reflect a specialized, narrowly focused interest rather than the childlike vocabulary commonly associated with social play and typical child experiences. Parents may also report that once their child begins to talk, the speech takes on a pedantic "teaching" quality in terms of tone and phrasing that often appears overly formal. Hence, young children with AS may struggle with typical give-and-take when engaging in conversation with peers, family members, and other adults.

As children with AS transition to preschool, they may develop intense and highly localized interests about which they are able to learn a tremendous amount, such as dinosaurs, particular movies and video games, and specific areas of science (e.g. geography, weather,

etc...). As they develop a wealth of information about such topics, they are often eager to share their knowledge with peers and others, who may subsequently distance themselves due to lack of sharing such intense interest, leading to a sense of isolation from the social world. For instance, a child with AS may engage another person in a one-sided conversation that is characterized by a long-winded pedantic speech about a favorite topic, which is often narrowly focused. Consequently, children with AS may find themselves socially isolated, but not from a motivation to distance from social situations. Rather, children with AS may actively seek the company of others, but do so in a way that is perceived as inappropriate or eccentric. They may express interest in friendships and forming relationships, but struggle socially due to awkward approaches and perceived insensitivity to the feelings and intentions of others. In these situations, the child with AS may approach other children awkwardly, such as by speaking loudly when in close proximity or becoming highly agitated when other children do not follow their agenda, which may involve a game restricted to a narrow or developmentally atypical interest. Parents often do not notice early social struggles until the child is outside of the home environment and interacting with peers and new adults in novel settings. Thus, it is typical for parents to first develop concern for their child at the time of transition to school or school-like settings.

Children with AS also develop particular patterns of speech that, although not as severe as with autism, may differ from what is considered typically developed. First, children with AS may have speech patterns characterized by poor inflection and intonation. They may exhibit a constricted range of intonation patterns that seem mismatched to their communicative intent. Their rate of speech may be either too fast or too slow, or lack fluency. Their voices may also lack appropriate modulation and they may be seen as speaking too loudly considering the

physical proximity of the listener. Second, children with AS may have speech that is tangential and circumstantial, which conveys a sense of looseness of associations and incoherence. Third, children with AS are often characterized by marked verbosity. The child may talk persistently about a favorite subject with seemingly total disregard for the interest or level of engagement of the listener. Moreover, attempts by the listener to interject or change topics are often unsuccessful.

Children with AS may also develop highly circumscribed interests and amass large amounts of factual information about a topic in a very intense fashion. Often, children with AS will amass incredible amounts of factual knowledge about a topic without a genuine understanding of the broader phenomena involved. For instance, a child may memorize the names and information of all the members of Congress, but lack a real understanding for the purpose of Congress or the role that members of Congress play in government. This quality of AS may not be as observable in early childhood, as many typically developing children express strong interest in favorite topics, such as sports, toys, comics, and TV shows. However, the intensity of special interest often seen in children with AS may negatively interfere with reciprocal social interaction and the interest often dominates conversation with others. Children with AS may also demonstrate poor or awkward motor coordination. They may struggle with skills, such as peddling a bicycle, opening a jar, climbing outdoor play equipment, or catching a ball. They may also exhibit unusual gait patterns, odd posture, poor fine motor skills, and deficits in visual-motor skills (Gillberg, 1990).

Finally, children with AS tend to gravitate towards routine to the extent that experiences detracting from established routines may result in heightened anxiety and uncertainty. Thus, a child with AS may insist on maintaining familiar routines, follow rigid schedules governing

prescribed routines, and ask repeated questions to adults when making sense of changes in routine. Some have speculated that the insistence on routine and concrete, predictable phenomena contribute to the anxiety and lack of fluidity frequently demonstrated when faced with social interaction, which itself is inherently implicit and subjective. The strong preference for routine have led some to speculate that this is what draws children with AS to a fascination with facts and patterns within letters and numbers, which may serve to ground the child in what would otherwise be a fluid, unpredictable, and perplexing social environment (Klin et al, 2005).

The similarity of features between AS and autism indicates that the disorders may be related and perhaps represent varying levels of severity along the continuum of autistic spectrum disorders (ASDs). As such, the validity of AS as a condition that is distinct from autism remains controversial (Klin et al, 2005; Ozonoff & Griffith 2000; Volkmar & Klin, 2000). AS also has been referred to as high-functioning autism (HFA), yet this label is also somewhat enigmatic. HFA is not a formal diagnosis, but rather a descriptive term referring to autism without significant impairment to cognitive functioning. Some argue, however, that HFA does not accurately capture the qualities of AS, such as circumscribed intellectual interests and a desire to engage the social world, despite difficulties in doing so. Baron-Cohen (2002), who proposed that AS may fall more in line with a personality disorder rather than an acute mental disorder, has offered an alternative perspective. This view captures the notion that individuals with AS are capable of living independently, but present with particular personality tendencies that are atypical from the general population.

Pervasive Developmental Disorder-Not Otherwise Specified

Pervasive Developmental Disorder Not Otherwise Specified (PDD NOS), sometimes referred to as *atypical autism*, also shares similar diagnostic criteria with autism and AS, but the

severity of impairments does not warrant a diagnosis of Autistic Disorder or Asperger's Disorder (APA, 2000). According to the APA, this category should only be used when there is severe impairment in the development of reciprocal social interaction associated with impairment in either verbal or nonverbal communication or with the presence of stereotyped behaviors, interests, and activities, but the criteria are not met for a specific pervasive developmental disorder. The APA further states that when late age of onset, atypical symptomology, or subthreshhold symptomology precludes the diagnosis of autistic disorder, a diagnosis of PDD-NOS may be applied.

By definition, individuals with PDD-NOS present with fewer or less severe symptoms than individuals with autism or AS. The DSM-IV-TR (2000) states that PDD-NOS is a disorder of reciprocal social interaction that is associated with impairments in either verbal or non-verbal communication or with repetitive behaviors or restricted interests. Moreover, individuals with PDD-NOS may possess a dedication to routines, limited imaginative or symbolic play, and stereotyped behaviors. However, unlike individuals with autism or AS, in individuals with PDD-NOS these features may be mild or absent. Moreover, individuals with PDD-NOS may or may not display deficits in expressive or receptive language.

Towbin (2005) suggested that the PDD-NOS label serves several purposes depending upon the circumstance. First, the PDD-NOS label can be used as a default diagnosis when background or diagnostic information is insufficient to render a diagnosis of autism or AS. Second, the PDD-NOS label can indicate the presence of behavioral features related to autism and AS, and although the features fail to meet the diagnostic criteria for the former, the PDD-NOS label indicates that these features are causing impairment in functioning for the individual in question (Allen et al, 2001). In this way, PDD-NOS represents a diagnosis of "mild" autism

and indicates a difference in severity rather than a difference in type. Third, PDD-NOS can be used for individuals presenting with the three core features of autism, but with onset later than three years of age. Finally, PDD-NOS can represent a diagnosis that is qualitatively distinct from autism or AS, suggesting that while features of PDD-NOS relate to autism and AS, such as difficulty in social functioning, they manifest in such a way that is distinct from, rather than a "milder" form of the previous two conditions.

#### Summary

Autism was once considered a rare childhood disorder. In his original report, Kanner narrowly defined autism and later expressed concern at the sudden trend to diagnose children displaying only isolated symptoms as "autistic" (Kanner, 1973). In terms of recent prevalence, from 2002 to 2006, the Autism Developmental Disabilities Monitoring Network (ADDM), a division of the Centers for Disease Control, reported a 57% percent increase in prevalence of children diagnosed with autism. In 2006, the ADDM estimated that approximately 1 in 110 children were affected by autism based upon a survey of 308,038 8-year olds across 11 states. The cause of such a dramatic rise in diagnosed cases remains in question. However, when considering the increase in prevalence, the number of increased cases includes all Autistic Spectrum Disorders (ASDs), which include Autistic Disorder, Asperger's Disorder, and PDD-NOS. Thus, one plausible explanation for the recent increase in prevalence is due to broader diagnostic criteria, as well as increased awareness of ASDs among professionals and the public in general.

Based upon the similar diagnostic criteria of Autistic Disorder, Asperger's Disorder, and PDD NOS, the PDD umbrella has garnered some controversy (Volkmar & Klin, 2005). The qualitative similarities of Autistic Disorder, Asperger's Disorder, and PDD NOS have led some

in the field to question whether distinguishing between the three disorders is necessary (Rosenberg, Daniels, Law, & Kaufmann, 2009). Although each disorder possesses a separate diagnostic category in the *DSM-IV-TR*, much debate centers on whether Asperger's and PDD NOS are qualitatively different from Autistic Disorder, or merely represent varying levels of autistic severity.

Currently, the Centers for Disease Control (CDC; 2009) define ASDs as qualitatively similar disorders ranging in severity from mild to severe. While the CDC acknowledges autistic disorder, Asperger's disorder, and PDD-NOS as distinct diagnoses, they also classify all three diagnoses together as ASDs, describing them as "a group of developmental disabilities that cause significant social, communication, and behavioral challenges." However, when seen as a group of disabilities along a spectrum, categorical diagnostic criteria such as the differential diagnosis used by the *DSM-IV-TR* is limiting. It is difficult to judge the severity of symptoms when the diagnostic criteria call for indicating whether a particular symptom is present or not.

Greenspan and Wieder (2006) proposed that for diagnostic purposes, professionals examine three core areas of functioning, which relate to the "triad of impairment" followed by the APA in the *DSM-IV-TR* (2000). First, to what extent is the child able to establish closeness with family members? Second, to what extent does the child exchange emotional gestures and is this done in a way that is continuous? Third, when the child begins using words, are they used meaningfully and with emotional intent? If the child demonstrates functioning in the three above areas at a level below what is age appropriate, then a diagnosis of ASD may be indicated. An important implication of perceiving ASD along a spectrum of developmental disorders is that under the right conditions, development can be stimulated, even if delayed by the presence of ASD symptoms (Greenspan & Wieder, 2006). What constitutes the proper conditions to spur

development depends greatly upon the theory one uses to conceptualize the developmental onset and course of ASD.

#### Theories of Autistic Spectrum Disorders

Several theories regarding the psychology of ASDs have been postulated concerning how ASD influences the trajectory of development and how individuals with ASD change throughout their development. Theory is important to understanding ASD as how one conceptualizes ASD will influence which interventions are most suitable and guide expectations of particular interventions. Three particular theories regarding the nature of ASD, the mindblindedness theory, the executive dysfunction theory, and the weak coherence theory are considered most relevant in current literature when describing the behavior and psychological profile of individuals with ASDs (Rajendran & Mitchell, 2007).

Mindblindedness Theory.

The mindblindedness theory (Baron-Cohen, 1995) proposes that children with ASD are delayed in developing *theory of mind* (ToM), which is the ability to take the perspective of another person, imagine another person's thoughts and feelings, and make sense of and predict another person's behavior (Baron-Cohen, 2008). Essentially, a person uses ToM to develop a working theory about what another person is thinking, feeling, and planning. The individual develops this theory based upon inferences regarding the mental state of another person, which often are not explicitly communicated. Children with ASD seem to lack the ability to pick up such skills naturally. Because people with ASD may not be able to use ToM to interpret or anticipate what others are doing or going to do, they may be puzzled by other people's actions or anxious because other people's behavior seems unpredictable. They may find other people's behavior confusing, unpredictable, or even frightening.

ToM is strongly related to the notion of joint-attention, in which an individual not only looks at another's face and eyes, but also pays attention to what that person is noticing. Joint attention is typically observed by noting how a child follows another person's gaze. In typically developing children, joint attention emerges around 14 months of age (Butterworth, 1991; Scaife & Bruner, 1975), but children with ASD show reduced frequency of joint attention in toddlerhood (Baron-Cohen, 1989). They point less, look up at faces less, and do not turn to follow another person's gaze as much as typically developing children. The inability to engage in joint attention is indicative of a delay in taking the perspective of another person, as joint attention requires that one infer that people are looking at something of interest to them.

Moreover, the second part of joint attention, the act of paying attention to the object of another person's attention, represents the ability to not only detect but to respond, which is an important foundational skill in social communication.

Another dimension of ToM relates to the intuitive understanding for how other people's minds work. Children are not formally taught these principles, but rather they emerge through interactions in social environments. For instance, the typical 3-year-old can pass the *seeing leads to knowing* test in which children observe a picture of one girl touching a box and another girl looking in the box (Pratt & Bryant, 1990). Children pass this test by observing that the girl looking in the box is the one who knows what is inside, yet children with ASD often struggle making this inference (Baron-Cohen & Goodhart, 1994).

Moreover, the typical 4-year-old can pass the *false-belief test* (Perner & Wimmer, 1985). This test, called the unexpected transfer test, describes a girl with the marble who places the marble in a box and then leaves the room. The girl staying in the room then moves the marble from the box to a nearby basket without the knowledge of the other girl outside of the room.

Children in the study were asked where the girl who owns the marble would look for it when she returns to the room. Typically developing 4-year-olds commonly state that she will look for the marble where she left it, in the original box, suggesting they understand that the girl will look in the box even though the children know the marble was moved. This response indicates ToM, meaning that typically developing children understand that the girl looking for the marble knows less about its location than they do. However, 80% of children with ASD in this study stated that she will look in the basket because that is where it is, indicating that children with ASD were unable to understand the girl with the marble's *false belief* about the location of the marble (Baron-Cohen, Leslie, & Frith, 1985).

Deception is another dimension of ToM, and children with ASD often present with delays in understanding the concept of deception (Baron-Cohen, 2008). Deception is easily understood by the typically developing 4 year old because they understand that deception is simply making someone believe that something is true when it is actually false. Deception is essentially the process of manipulating someone else's mind. However, children with ASD are slow to understand deception and are actually more at risk for being exploited for their gullibility, as they tend to assume that everyone is telling the truth.

The strength of the *mindblindedness* theory is that it accounts for the social and communication difficulties observed in children with ASD. However, it may not be universal in applying to all individuals on the spectrum. For instance, Baron-Cohen et al (1985) found that only 80 percent of children with ASD failed the false belief test, meaning that 20 percent passed, suggesting that mindblindedness may not be a universal trait among individuals with ASD. Thus, mindblindedness may explain some patterns of cognitive functioning in autism, but not all, and be better conceived as a common delay among children with ASD rather than a universal quality.

In addition, while *mindblindedness* accounts for social and communication struggles, the theory cannot account for non-social features of ASD, such as the uncertainty often observed in children with ASD regarding emotion recognition and responding. For instance, individuals with ASD often report that they are puzzled by how to respond to another person's emotions. Consequently, Baron-Cohen has expanded the ToM theory to include the greater concept of empathizing, suggesting that individuals with ASD experience delays in intuiting both the cognitive and emotional states of other individuals, which subsumes ToM and emotional responding under one theory.

Executive Dysfunction Theory. The executive dysfunction theory states that children with ASD lack developmentally appropriate ability to control actions such as creating plans, executing plans, staying on topic, and shifting attention. Executive function (EF) is the cognitive construct used to define goal-directed and future-oriented behaviors (Duncan, 1986; Jurado & Rosselli, 2007). As such, EF is the ability to control one's actions, such as motoric actions, attention, and thought processes (Baron-Cohen, 2008). EF also influences one's flexibility, organized search, and use of working memory (Pennington, 1994). Recent neuroimaging studies have shown that executive functions are associated with particular regions of the frontal cortex of the brain (Monshi, Petrides, Strafela, Worsley, & Doyon, 2006, Stuss & Alexander, 2000), suggesting that EF dysfunction in individuals with ASD may be neurological in nature. EF dysfunction has been linked to individuals with ASD, who share behavioral similarities with patients with frontal lobe lesions (Ozonoff, Pennington, & Rogers, 1991). These behaviors include a need for sameness, strong liking for repetitive behavior, lack of impulse control, difficulty initiating new tasks, and changing between tasks (Hill, 2004; Rajendran & Mitchell, 2007).

This theory has utility in explaining repetitive behaviors often seen in autism, such as a lack of ability to plan actions or shift attention (Baron-Cohen, 2008). Children with ASDs may struggle transitioning to a new plan or course of action. Consequently, children with ASD may struggle with changing conversation topics, adapting to a new social situation, or understanding ideas or linguistic phrases outside of familiar contexts. The lack of adaptability in executive functioning causes children with ASD to become stuck and repeat, or perseverate, particular nuances of experience, such as certain phrases, ideas, or concepts.

Numerous studies examining deficits in EF among children with ASD have been conducted in the past twenty years. In the first study looking at EF in children with autism, Prior and Hoffman (1990) administered the Wisconsin Card Sorting Test (WCST), a test of cognitive flexibility, to a sample of children meeting the criteria for autism and a typically developing control group. Prior and Hoffman found that the children with autism made significantly more perseverative errors than matched controls. The authors noted that the children with autism made the same mistakes repeatedly and seemed unable to develop a suitable strategy to overcome their difficulties. A number of studies followed Prior and Hoffman's initial study, and Pennington and Ozonoff (1996) reviewed 14 studies of dysfunction in EF among children with ASD. They found that children in 13 of those studies demonstrated impairment in at least one EF task. According to Pennington and Ozonoff, the group differences demonstrated a large effect size (Cohen's d = .98). In addition, Hill (2004) conducted a similar review of ASD literature and found difficulties among multiple dimensions associated with EF, including planning, mental flexibility, inhibition, and self-monitoring. Robinson, Goddard, Dritschel, Wisley, and Howlin (2009) also found that children with Asperger's Disorder and high-functioning autism differed at a statistically significant level from typically developing children in a number of EF domains, including

inhibition, planning, and self-monitoring. According to Robinson et al, this study suggested that deficits in EF among children with ASD may not be related to cognitive level, but represent a core quality of ASD.

The particular strength of the EF dysfunction theory is that it captures the difficulty individuals with ASD may have shifting attention. Because EF dysfunction represents a deficit in cognitive functioning, cognitive remediation is seen as a viable intervention in conjunction with other forms of therapy, such as psychotherapy and organized social activities. Targets of cognitive remediation include developing skills in memory, attention, motivation, and language. Such treatments may be cognitive, behavioral, or a combination of both (Ozonoff, South, & Provencal, 2005) and aim to improve skills within specific cognitive domains, including expressive/receptive language and visual/spatial skills by breaking down complex behaviors into basic components through a component process task analysis. Necessary skill components are then taught in a hierarchal manner and through repeated practice.

Despite evidence indicating the presence of EF dysfunction among children with ASD, the theory is not without limitations. Although the theory is helpful in explaining rigid and repetitive behaviors, such behaviors are conceptualized as occurring at random and without context rather than being purposefully chosen and followed. It dismisses the content of the behavior in question, which may have particular value or interest to the individual with ASD. Baron-Cohen (2008) suggested that the term "executive dysfunction" be revised to reflect that individuals with ASD may be remarkably adept at inhibiting stimuli outside of their narrow spotlight of attention rather than randomly focusing on stimuli to cope with a fluid environment.

Weak Central Coherence Theory. According to the Weak Central Coherence Theory (WCC), individuals with ASD experience problems integrating information to create a coherent

and global picture. Instead, individuals with ASD focus on the minutia – the small, local details of a scene (Baron-Cohen, 2008). Thus, the difference between the typically developing child and the child with ASD concerns the ability to see the big picture (Happé, 2005). Frith (2003) suggested that the ability to organize details of information into a larger picture might be disturbed in individuals with ASD, noting that children and adults with ASD often show a preoccupation with details and parts. According to Frith, individuals with ASD demonstrate detail-focused processing at the expense of attending to global configuration and higher-level meaning. This conceptualization is consistent with Kanner's (1943) initial observation that children with ASD displayed fragmentary processing and struggled to experience wholes without full attention to the corresponding parts.

There is considerable evidence for WCC in the research literature. Among the earliest studies, Shah & Frith (1983) used the *Children's Embedded Figures Text* (CEFT, Witkin, Oltman, Raskin, & Karp, 1971), in which participants were asked to locate a small target shape in a drawing of a larger everyday object. Results indicated that children with autism scored above average and did better than typically developing children of the same mental and chronological age. Shah and Frith also found that participants with autism were faster at reproducing 40 different block designs included in the Block Design subtest of the *Wechsler Intelligence Scales* than learning disabled and neurotypical controls. In this test, participants were asked to assemble as fast as possible a three-dimensional construction using painted blocks that is identical to a two-dimensional picture. The key feature of the Block Design Test and the Embedded Figures Test is that a figure can be segmented or include smaller components, yet in the neurotypical population, the salience of the smaller components is not as great as the global figure (Rajendran & Mitchell, 2007). Frith (2003) suggested that individuals with ASD show

better performance on these tasks because they lack the cognitive drive to attend to the global form and can more easily focus on the details.

WCC theory also extends to higher-level conceptual abilities, such as language (Rajendran & Mitchell, 2007). Numerous studies using homographs (words with one spelling but two or more pronunciations and meanings) have found that individuals with autism failed to use the correct pronunciation of a word given its context and either struggled to or simply did not use the preceding sentence to determine correct pronunciation (Frith & Snowling, 1983; Happé, 1997; Jolliffe & Baron-Cohen, 1999; López & Leekam, 2003; Snowling & Frith, 1986). Results of these studies suggest that individuals with autism may be reading prose as a series of unrelated word lists and failing to make appropriate contextual associations. However, such skills are needed for understanding the implicit intent of communication beyond the surface structure of language, which may explain some of the social difficulties seen in autism and ASD (Rajendran & Mitchell, 2007).

A particular strength of WCC is that it conceives what could be considered a deficit among children with ASD as a potential asset. Children with ASD may show excellent attention to detail, memory for detail, and skills in a narrow topic (Baron-Cohen, 2008). Thus, rather than being seen as a deficit in global processing, WCC instead represents superior local processing. Moreover, the theory explains patterns of excellent and poor performance with one cognitive postulate (Happé, 2005). WCC predicts strong performance in areas requiring attention to details and parts, but poor performance on tasks requiring the recognition of global meaning or integration of stimuli in context. According to Happé (2005), WCC conceptualizes individuals with ASD in terms of cognitive *style* rather than cognitive deficit.

Still, WCC theory has experienced challenges as a unifying theory of ASD. Norbury (2005) found that individuals with autism as a group did not perform differently than typically developing individuals when comprehending lexical ambiguity, suggesting that WCC is not a universal feature of ASD. Moreover, Mann and Walker (2003) found that struggles in WCC may be better accounted for by deficits in broadening the span of visual attention, meaning that the cognitive style attributed to WCC may actually be visual rather than cognitive in nature.

Currently, WCC theory no longer seeks to explain all aspects of ASD, but rather represents one part of cognition in autism (Happé & Frith, 2006).

Summary. Together these three theories of ASD, mindblindedness, EF dysfunction, and WCC, offer explanations for the psychology and behaviors commonly associated with ASD. However, there is lack of consensus regarding which theory is correct, as each theory has research that offers support and evidence against. Moreover, neither theory fully accounts for the full range of behaviors observed in ASD. Thus far, a unifying construct that might tie the three theories together has yet to emerge. However, Best et al (2008) studied the extent to which measures of these three theoretical explanations predict ASD among children. They found support for each theory contributing to a cognitive phenotype for ASD, and stated that the extent of ASD impairment can be reflected in severity of mindblindedness, WCC, and EF dysfunction.

## Play and Autistic Spectrum Disorders

Play is a complex developmental process often seen lacking in children with ASD. Due to deficits in social understanding, language and communication, and ritualistic and rigid behaviors, children with ASD often display play behaviors that appear out of sync or delayed when compared to typically developing children. As such, deficits in play behavior are considered a common feature of children with ASD and considered among the diagnostic criteria

for the three ASDs in the DSM-IV-TR, including Autistic Disorder, Asperger's Disorder, and PDD-NOS (APA, 2000). Mindblindedness suggests that symbolic play fails to emerge due to an inability to represent ideas outside of one's self, while EF dysfunction suggests that children lack the cognitive flexibility to engage in the abstract thought needed for representation of symbolic play. Moreover, WCC, states that abstract thought requires seeing the global picture and that children with ASD become hyper-focused on details and particulars.

Piaget (1962) considered play to be an intrinsically motivated activity in which the result is pleasurable. Piaget categorized play into two distinct categories: sensorimotor and symbolic play. Sensorimotor play, or functional play, involves the manipulation of objects as a way to acquire competency and mastery of actions and object schemas. Sensorimotor play allows children to gain knowledge about their own body and helps in developing a frame of reference about the world. Through sensorimotor play, the child learns to differentiate self from others.

Typically developing children move from sensorimotor play into symbolic play around the age of 18 months, and such play becomes increasingly elaborate as the child moves into school age. Symbolic play emerges from the child's growing ability for mental representation and provides a means for understanding and engaging the social world. According to Greenspan & Wieder (1998), the transition to symbolic play is one of the most important leaps a child will make. Symbolic play represents the child taking initiative and building a symbolic world that increases the child's ability to use and understand words and ideas. Symbolic play is also important in the development of empathy. Empathy is the understanding of another's emotional and cognitive perspective and represents a movement from the child's egocentric perspective to a view that multiple perspectives exist regarding a particular experience. Symbolic play facilitates this process by involving the child in using imagination and creativity to let particular play

experiences represent something other than their literal and concrete function. For children with ASD, however, the process of creative or symbolic play often fails to emerge as expected (Hobson, Lee, & Hobson, 2009; Mastrangelo, 2009).

Young children with ASD are often observed not to engage in reciprocal or pretend play at the age and developmental levels when these play behaviors would be expected. Play among children with ASD often remains obsessional, mechanical, and repetitive with a marked absence of cooperative or symbolic play (Wolfberg & Schuler, 1993). Children with ASD play repetitively with objects by repeatedly lining up objects, spinning them, or putting them in their mouths, which suggests a predominance of sensorimotor play at a time when symbolic play is expected to emerge. For children with ASD, symbolic play might develop over time (McDonough, Stahmer, Schreibman, & Thompson, 1997; Williams, Reddy, & Costall, 2001) and some children with ASD develop varying levels of functional play and, to some extent, symbolic play, but the level of their play is frequently lagging behind the level of their peers.

Consequently, children with ASD often fail to engage in peer-related play due to lack of a developmental match.

Lack of peer play for children with ASD may further inhibit the development of symbolic play. According to Piaget (1954), when children play together they learn to adapt their imagination to meet the needs of the environment and of each other, indicating that shared symbolic play is an important piece in developing social understanding and communication. Thus, children with ASD, who struggle to engage in social play that involves mutual understanding and some level of symbolic representation, may also fail to benefit from the give-and-take of normal social interactions and further compounding their difficulty deciphering social and emotional cues in others' behavior (Wolfberg & Schuler, 1993). The leading theories

of ASD, mindblindedness, executive functioning dysfunction, and weak central coherence, each offer different conceptualizations for the paucity of symbolic play among children with ASD (Hobson, Lee, & Hobson, 2009; Mastrangelo, 2009).

The mindblindedness theory suggests that children with ASD are delayed in their ability to develop ToM, which would allow them to perceive or understand the thoughts, feelings, or intentions of others. Because of this gap, children with ASD struggle with metarepresentation, which is the process of detaching a representation from its seemingly fixed form and allowing it to stand for something else. For example, children with ASD will find it confusing when a banana is used as a telephone during play (National Research Council, 2001). Research on mindblindedness has demonstrated that children with ASD have difficulty understanding knowledge, empathy, deception, humor and teasing, language, and false belief (Brown & Whiten, 2000). Consequently, such difficulties inhibit further development of fundamental skills needed for peer interactive play, such as joint attention, social understanding, and reciprocal communication (Mastrangelo, 2009). In support of the mindblindedness theory, Leslie (1987) conducted a study demonstrating that pretend play requires the child's mind to decouple representations of the world from what is actually represented, which allows the child to engage in "metarepresentation," and apply symbolic meanings when objects are either absent or typically represent something else. Leslie found that children with autism could not represent the pretend world alongside the real world. Leslie suggested that children with autism lack the innate ability to decouple representations of objects or ideas from their usual meaning. Moreover, Baron-Cohen (1987) found that children with autism produced much less symbolic play than comparison groups, but found no significant differences in levels of functional play.

Pretend play provides early evidence of a developing theory of mind based on the child's ability to create metarepresentations (Mastrangelo, 2009). The mindblindedness theory asserts that because ToM is either absent or delayed in development, that children with ASD display pretend play that is either lacking or unusual. According to Rutherford and Rogers (2003), children with higher capacities of ToM tend to have more expressive levels of symbolic play and are more likely to create imaginary friends. However, the mindblindedness theory only explains the social aspects of atypical development of symbolic play among children with ASD. A missing component is that children with ASD also tend to perseverate on small details and this tendency may also detract from typical development of symbolic play, which is the focus of the theory of executive functioning (EF) dysfunction.

The theory of EF dysfunction asserts that children with ASD fail to develop symbolic play in a timely or typically developing manner due to their inability to coordinate multiple stimuli or experiences into a single coherent representation. Hughes and Russell (1993) described executive function as the mental coordination of attention, planning, inhibition of inappropriate behaviors, and changes in response. According to the EF dysfunction theory, children with ASD possesses a neurological predisposition that makes such coordination either difficult or not possible, causing them to perseverate on details and otherwise miss the larger picture.

Evidence for the EF dysfunction theory emerged from a study conducted by Lewis and Boucher (1988), who designed an experiment looking at performance versus competence in symbolic play among children with autism. Results of this study indicated that children with autism did not struggle with representational aspects of play, but struggled with the generation of play ideas. The children with autism in this study demonstrated the ability to substitute meanings

and follow imaginary themes, but did so when another individual suggested the symbol. When the symbol originated from another person, the children with autism could represent absent objects in play, assign new identities to existing objects, and ignore the understood meaning of an object with simultaneously holding a symbolic meaning. Findings from this study provided a challenge to Leslie's (1987) assertion that children with ASD cannot hold symbolic representations due to lack of sufficiently developed ToM. If children could hold symbolic representation and engage in symbolic play when the symbols were suggested, this indicates that children with autism possess the ability for symbolic representation, but may lack the intrinsic drive or cognitive resources to do so independently. There may be improved ability for children with autism or ASD to engage in symbolic play when scaffolding is provided by another adult or peer (Mastrangelo, 2009).

Proponents of the EF dysfunction theory assert that the deficit of symbolic play in children with ASD primarily concerns a deficit in *spontaneous* symbolic play rather than symbolic play in general. Thus, the deficit in symbolic play is not indicative of a global inability to pretend, but a lack of motivation to do so (Jarrold, Smith, Boucher, & Harris, 1994).

Rutherford and Rogers (2003) noted that symbolic play requires shifting attention from one interpretation of an object to another and that gaps in pretend play seen in children with ASD could be related to an inability or a difficulty in shifting attention, which is a feature of executive control. However, when the symbolic representation is provided by an outside source, children with ASD are free of the responsibility to generate symbols and shift attention intrinsically, which allows them to engage in symbolic play more freely. However, an important criticism of this explanation concerns whether children who are engaged in such adult- or peer-led play are engaging in symbolic play or merely following the modeling of the person leading the play. For

instance, does the child really understand the prescribed symbolic representation or are they following instructions? The third theory, the weak central coherence (WCC) theory, addresses this question to some extent by suggesting that children with ASD present with cognitive processing that is implicit and automatic, which enables the rapid interpretation of information that may interfere with the ability to engage in symbolic play.

The theory of WCC suggests that difficulties in symbolic play emerge from a basic cognitive predisposition in observing global meanings in larger contexts (Mastrangelo, 2009). In typically developing children, central coherence refers to the interpretation of parts or details into a larger whole. Thus, typically developing children will synthesize parts of experiences and integrate them to develop a larger meaning that embodies the experience as a whole. This ability is also important in symbolic play, which requires that children take meaning from parts to create meaning for the whole. For instance, in children's play, a banana might represent a telephone, but they must integrate aspects of the telephone into their play with the banana even if those aspects are only mental representations. Thus, the child is creating a larger whole from only a partial representation. However, children with ASD demonstrate a lack of understanding for how a banana could represent a telephone, despite a similar shape and way of extending from the ear to the mouth, just as a real telephone might. With regard to symbolic play, WCC manifests as the child's inability to focus, or preference for not focusing on the gestalt of the experience.

Though several different theories account for the lack of emergence of developmentally appropriate symbolic play among children with ASD, none of these theories accounts fully for this delay. Another potential explanation for the delay of symbolic play among children with ASD has to do with the type of symbolizing that children with ASD may struggle to grasp. Hobson, Lee, & Hobson (2009) conducted a study using a sample of children with autism (n =

16) and compared various forms of symbolic representation with a group of developmentally delayed children who did not meet the criteria for autism (n = 16). According to the researchers, both groups displayed similar ability for metarepresentation, meaning that both groups possessed the ability to engage in symbolic play. However, the children with autism displayed a lack of generative/creative symbolizing that involves investment and fun on the part of the child. In other words, children with autism may not derive as much pleasure from engaging in creative, spontaneous play, suggesting they may not be intrinsically drawn to such play. Such a finding might also help explain that much of the symbolic play seen among children with autism involves object substitutions (Libby, Powell, Messer, & Jordan, 1998), where children with autism have learned that a certain object can represent something else rather than enjoying the spontaneous pleasure of saying, "This can be whatever I want it to be" (Hobson, Lee, & Hobson, 2009).

In summary, although children with ASD certainly do engage in play, the nature and quality of their play may differ considerably from that observed in typically developing children. Rather than moving into the area of symbolic, imaginative play, children with ASD may appear to remain fixed in the realm of functional and adaptive play. The study by Hobson et al (2009) raises the question of whether symbolic play among children with ASD can be coaxed to emerge by a peer or an adult who provides symbols for the child to use. A more behaviorally orientated view may say that symbolic play does emerge under such conditions, though critics of this view assert that children are merely following the rules established by the play partner. However, the results of Hobson et al indicated that children with ASD are capable of metarepresentation, which provides the foundation for symbolic play, but they may lack the intrinsic motivation to engage in such play. Moreover, Hobson et al (2009) suggested that symbolic play with another

individual, which includes identifying with their playfulness and pretending, may add another important dimension to the development of symbolic play. Therefore, when provided with an environment conducive to symbolic play, which includes play with another individual as well as the opportunity for the child to lead, a child with ASD may subsequently experience the intrinsic motivation to engage in symbolic play that includes creativity and spontaneity (Greenspan & Wieder, 2006).

The School-Age Child with High Functioning Autistic Spectrum Disorder
As previously described, the spectrum of autistic disorders is broad and displays
considerable heterogeneity (Gillberg & Coleman, 1992; Klin, Schultz, Volkmar, & Cohen,
2002). ASD may present with subtypes that differ widely in severity, clinical presentation, and
developmental course, as well as in level of cognitive, social, and language ability. Although
classic autism, referred to as Autistic Disorder in the current *DSM-IV-TR* (APA, 2000), displays
the most severe impairments to functioning, the remaining conditions (high-functioning autism,
Asperger's Disorder, and PDD-NOS), considered together as HFASD, present particular
challenges for the child as they enter school age and increase their level of social interaction.

For children with ASD, social deficits often become obvious during the preschool years, when they struggle to establish peer relationships and struggle along multiple dimensions of interpersonal communication. Although social deficits may decrease in severity throughout the school years as children with HFASD gain familiarity with particular people and settings, they are likely to retain socioemotional differences (Bailey, 2001). School-age children with HFASD often appear *active-but-odd* (Wing & Attwood, 1987), meaning they may actively seek out social contact with others, but the form of their social contact is often usual and sometimes inappropriate (Loveland & Tunali-Kotoski, 2005). Even though they may have considerable

language skills and express a high interest in communicating with others, they may do so in a way that involves repetitive questioning, inappropriate touching, and conversation focused exclusively on the child's own narrow interests. These children may also display odd postures, gestures, and facial expressions.

One struggle for children with HFASD is that because they often appear to exhibit levels of functioning similar to typically developing peers, they are often placed in situations in which they are expected to exhibit age-appropriate social judgment and social behavior (Loveland & Tunali-Kotoski, 2005). These expectations may come from significant adults in the child's life, including parents and teachers. However, such expectations may create considerable difficulties for children who cannot meet the social expectations placed upon them.

For children with HFASD, their way of interacting with the world is typically literal and concrete, and they show a limited range of awareness of the emotions, thoughts, and motivations of others. In addition, these children tend to prefer rigid and predictable routines in their daily life, so that unexpected events, new people, and unfamiliar surroundings can elicit significant stress. Moreover, when stressed, they may regress to behaviors displayed at earlier ages, such as tantruming and self-stimulatory behaviors, including rocking or perseverating (Wing & Attwood, 1987).

Because of the higher cognitive ability of children with HFASD, they may be aware that they are different from and not always accepted by others around them (Attwood, 1998). Despite their average to above average abilities in intellectual, language, adaptive, and academic areas, children with HFASD experience chronic struggles in relating to others and feeling accepted, and due to their higher level of functioning, are often very aware of their social isolation (Bauminger & Kasari, 2000). The social deficits experienced by children with ASD, especially those

involving interactions with same-age peers, may become more difficult as the child develops. As social complexity and social demands rise, a child may become very aware of the underlying social challenges, which in turn may contribute to the development of secondary mood and anxiety problems (Myles, 2003; Tantam, 2003), especially for higher functioning individuals with ASD.

Anxiety is a condition also associated with children with ASD. Children with ASD, particularly those with HFASD, are reported to have higher rates of anxiety problems when compared to children without ASD (Gillott, Furniss, & Walter, 2001). A child with ASD who experiences high levels of anxiety may display tantrums, agitation, irritability, noncompliance, and aggressive behavior. Families and teachers often report an increase in challenging behaviors during situations that induce anxiety, such as changes in familiar settings and new or unfamiliar social settings. Sukhodolsky et al (2008) examined parent-rated anxiety symptoms of 171 children aged 5-17 years meeting the criteria for ASD and not currently taking medication. According to the authors of this study, participants were free of serious medical disorders and other psychiatric disorders requiring medication. Parents completed the Child and Adolescent Screening Inventory (CASI, Gadow & Sprafkin, 1994), which contains 26 items across 8 anxiety disorders, to assess levels of anxiety of their child. Results from this sample indicated that 43 percent of the participants met the screening cut-off criteria for one or more of the six DSM-IV anxiety disorders. The number of children with PDD who met the screening symptom criteria of anxiety disorders was twice as high as the 20 estimates of pediatric anxiety disorders in the general population, suggesting that children with ASD experience higher levels of anxiety on average than what is normally expected. Moreover, results of this study indicated that higher levels of IQ were associated with forms of greater anxiety in children. This result is similar to

that of previous studies indicating that higher IQ is positively correlated with more severe anxiety among children with ASD (Lecavalier, 2006; Weisbrot, Gadow, DeVincent, & Pomeroy, 2005).

In a related study, White and Roberson-Nay (2009) explored the relationship among anxiety, loneliness, and degree of social skill deficit among a sample of children with ASD ranging in age from 7-14 years. The participants (n = 20) had low average or average intelligence (average IQ = 92) and had clinical diagnoses of autism (n = 2), PDD-NOS (n = 3), or Asperger's disorder ((n = 15). Thus, the majority of participants fell within the HFASD spectrum. Results of the study indicated that participants with higher levels of anxiety reported greater feelings of social loneliness. Moreover, individuals with average total anxiety scores reported much higher levels of loneliness than those with less anxiety. Though this study included a relatively small sample size, the results suggest a positive correlation between anxiety and loneliness among children with HFASD.

Depression is another potential struggle for children with HFASD. As previously discussed, children with HFASD are often aware of their social isolation, yet possess a hunger for social connection, which may yield feelings of loneliness and depression. Currently, the majority of studies examining depression among children with HFASD concern adolescents rather than school-age children. Yet, the results of the most recent studies indicate a positive correlation between HFASD and depression. Whitehouse, Durkin, Jaquet, and Ziatas (2009) investigated the relationship between loneliness, depression, and friendship among 35 adolescents with Asperger's disorder. The researchers compared the results with 35 typically developing adolescents matched on chronological age, school year, and gender distribution. Results of the study indicated that individuals with AS displayed higher levels of loneliness and

depressive symptoms, with loneliness being negatively correlated with the quality of their friendships. According to the authors of this study, the increased levels of negative affect may be related to the poor quality of social relationships.

In a study examining the relationship of both anxiety and depression, Lopata et al (2010) examined symptom levels of anxiety and depression in children with HFASD compared with matched control children using self-reports and parent ratings, as well as examined differences between the two condition groups. Using multivariate analysis, results indicated elevated depression and anxiety symptoms at a statistically significant level among the HFASD groups based on parent ratings, but no statistically significant difference between groups based upon child self-report. This result suggests that children with HFASD and their parents view the severity of depressive and anxiety symptoms quite differently, with parents indicating greater severity than the children. The authors suggested that parents may misinterpret social withdrawal and lack of emotional attunement on the part of their child as depression, or that the children lack the emotional insight to report depressive symptoms as fully as they experience them. The results of the study indicated, however, that parents also experience the effects of potential depression and anxiety symptoms experienced by children with HFASD.

In summary, school-age children with HFASD struggle with social interaction and peer relationships, and these struggles may intensify as the child grows older and engages in more complex social interactions and experiences. Unlike children with classic autism, children with HFASD seem to express a desire for relationship and social connection, yet possess delays in social functioning that may prohibit such relationships from forming successfully. Consequently, children with HFASD may experience depression and anxiety symptoms due to an awareness of isolation and feelings of loneliness. The study by Loperta et al (2010) indicated that parents of

children with HFASD are also attuned to the depression and anxiety symptoms experienced by their child. The following section turns to a discussion of parents' experiences when caring for a child with ASD and reviews select interventions used to address the needs of parents and children with ASD.

## Review of Parent Needs

Autistic Spectrum Disorders (ASDs) present significant challenges to parents and caregivers. Parents of children with ASD experience challenges that begin prior to their child receiving a formal diagnosis of ASD, spurred by the recognition that their child is developing differently from their peers. Considering the wide range of behaviors subsumed by the spectrum of autistic disorder, parents may face particular challenges depending upon where the child lies on the spectrum. Although children with classic autism tend to experience more severe cognitive and behavioral challenges, the higher intellectual functioning of children with HFASD does not mediate the stress associated with parenting children with ASD (Rao & Beidel, 2009).

On average, parents of children with autism report having their first concerns about their child's development when the child was around 18 months of age (Howlin & Moore, 1997).

Davis and Carter (2008) found statistically significant elevated stress levels among 54 mothers and fathers raising toddlers diagnosed with autism (mean age = 26.9 months) based upon the Parenting-Stress Index (PSI; Abidin, 1995), indicating that the stress associated with raising children with autism begins very early. McConkey, Truesdale-Kennedy, and Arlene-Cassidy (2008) reported that among a sample of 72 parents of children with ASD, two-thirds reported concerns with their child's developmental progress, specifically with speech and communication difficulties, prior to the child being 18 months of age. In addition, noted behavioral concerns were repetitive in nature, such as ritualistic behaviors (i.e. rocking back and forth) and adherence

to strict schedules, from which any deviation led to strong outbursts. In all, the researchers noted a pattern in the parents' recollections that stressed specific concerns associated with behavioral features of autism, indicating that a primary source of stress for parents are behavioral problems associated with autism, and that these concerns begin early in the child's life.

Moreover, Keenan, Dillenburger, Doherty, Byrne, and Gallagher (2010), using a mixed methods approach, reported that diagnostic and planning processes experienced by 97 parents of children with ASD were stressful for parents and that the diagnostic process took considerable time. Keenan et al reported that for parents, the process of diagnosis was distressing, unclear, difficult to understand, and did not lead to clear advice on how to proceed with treatment planning. Keenan et al indicated that the mean age for diagnosis for the children represented in this study was just over 4 years of age and that diagnoses took place on an average of 16 months.

Osborne and Reed (2008) examined 15 focus groups of parents raising children with ASD. Children represented in this sample included preschool, primary school, and secondary school-age children. At the time of diagnosis, most parents reported wishing for a quicker and easier process of diagnosis. In addition, Goin-Kochel, Mackintosh, & Myers (2006) reported that among a sample of 494 parents of children with ASD, forty percent were not satisfied with the process. Among the children with ASD represented in this sample, 59.9% had a diagnosis of autism, 23.5% had a diagnosis of Asperger's syndrome, and 16.6% had a diagnosis of PDD-NOS. Among this sample, children with Asperger's received a later diagnosis than children with autism or PDD-NOS, which the researchers attributed to the child with Asperger's primarily displaying problems in social communication that often emerge at the time the child enters school settings. This finding is consistent with findings by Howlin & Asgharian (1999) who

found that the diagnostic process tends to be drawn out for children with Asperger's syndrome, resulting in potentially greater frustration for these parents.

Osborne, McHugh, Saunders, and Reed (2008a) further found that among parents of 85 children with ASD, parents who received an earlier diagnosis reported less stress than parents whose children received a later diagnosis. However, the researchers also described a crystallizing effect of stress once a diagnosis was made, meaning that the stress level the parents reported at the time of diagnosis tended to remain constant after the diagnosis. This finding suggests that stress does not decrease for parents once a diagnosis of ASD is made for their child. Instead, the level of parent stress indicated at the time of diagnosis is stable for a time. The authors cited a lack of resources and the stress of taking on new responsibilities as possible sources of parent stress.

For parents of children with HFASD, the uneven and unusual course of development can create further challenges. There is no predictable developmental roadmap characteristic for all children with HFASD, meaning that the child's uneven profile of development may make gauging appropriate expectations difficult and predicting future development challenging (Schuntermann, 2002). For example, when parents notice their young child able to solve complex puzzles or math problems, or remember in detail a route to a favorite restaurant, they may focus upon these strengths and fail to notice developmental lapses in social or communicative skills. Basing expectations for development on strong skills in one area can result in considerable parental frustration when their child experiences developmental delays in other areas (Marcus, Kunce, & Schopler, 2005).

Another stressor for parents of children with HFASD concerns delays in social communication. Although children with HFASD typically have intact basic language skills,

disruptions in emotional relations among family members appear to be a central challenge to the parent's attempt to provide a typical family life (Gray, 1997). Impairments in typically developing emotional and social reciprocity may mean that family members do not receive expected verbal or social feedback from their children. Moreover, children with HFASD frequently are inconsistent in their responses across people, settings, and time (Marcus et al, 2005). For instance, if a child with HFASD responds to a request from one parent to come to dinner, but ignores a request from another parent, the parents may assume the child is being oppositional. However, the child may be responding to contextual cues rather than the language of the parent. Such distinctions can be difficult for parents to grasp and understand. If parents assume that the child is being oppositional, their discipline techniques tend to be confrontational and negatively charged (Dix, 1993). Marcus et al suggested that appropriate intervention can help parents recognize which behaviors result from a lack of understanding or lack of ability and which behaviors are potentially oppositional.

Considerable research further suggests that parents raising children with ASD experience elevated stress associated with parenting. According to Dabrowska and Pisula (2010), who surveyed 162 parents of children with developmental disabilities, parents raising children with autism indicated higher stress at a statistically significant level than those with other developmental disabilities. In addition, mothers scored higher than fathers in terms of parental stress in families raising children with autism. Parents raising children with autism tended to use less effective coping strategies than parents raising typically developing children and thus experienced greater levels of reported stress.

Moreover, as Quintero and McIntyre (2010) observed, the stress associated with raising a child with autism is not limited to the parents. In a study of 20 families with a preschooler with

ASD and 23 families with a normally developing preschooler, Quintero and McIntyre found that mothers of a child with ASD reported more daily hassles, life stress, and depression.

Interestingly, sibling behavioral adjustment was predicted by maternal stress, with siblings of children with ASD displaying more problems related to behavior adjustment than normally developing siblings. The researchers stated that the relationship between maternal well-being and sibling adjustment is valuable in that it suggests the pervasiveness of maternal stress on the family system.

Osborne, McHugh, Saunders, and Reed (2008c) identified a relationship between maternal stress and decreased effectiveness of teaching interventions for young children with autism. Osborne et al. divided a sample of 65 children into four groups based upon reports of maternal stress, which ranged from low stress to high. Children participating in the group with high stressed mothers reported fewer gains from teacher interventions than the other groups, suggesting that high levels of parenting stress may counteract the effectiveness of early teaching interventions.

Osborne and Reed (2009) further observed that high levels of maternal stress predicted the severity of child behavior problems. In a study of 137 mothers raising children with autism, Osborne and Reed found that behavior problems of children with autism positively correlated with the stress levels exhibited by their mother. However, maternal stress tended to increase as child behavior problems increased, suggesting a self-perpetuating cycle of maternal stress and child behavior problems. Phetrasuwan and Miles (2009) found a similar relationship between maternal parenting stress and behavior problems of children with autism. This study included 108 mothers of children with autism and found that mothers reported at a statistically significant

level a strong connection between elevated levels of parent stress and child behavior problems, as well as elevated levels of depression and lower overall levels of well-being.

Despite the stress that parents and families with children with HFASD may experience, research also suggests that children with HFASD exhibit attachment behaviors similar in function and style to those of children without ASD (Dissanayake & Crossley, 1997; Rogers, Ozonoff, & Maslin-Cole, 1993). Rutgers, Bakermans-Kranenburg, van IJzendoorn, and van Berckelaer-Onnes (2004) conducted a meta-analysis that included 10 studies with data on observed attachment security (N = 287) between parents and children with ASD. Despite impairments of children with ASD in reciprocal social interaction, the majority of studies found evidence for attachment behaviors in these children and that the average percentage of secure attachments amounted to 53 percent across studies that used the Strange Situation Procedure (N = 72). However, the researchers indicated that the meta-analysis revealed that children with autistic disorder or PDD-NOS are less often securely attached to their parents than children without autistic disorder, and the effect size was "rather substantial" (p. 1131) (r = .24). Moreover, the researchers reported that children with ASD possessing higher mental development indicated no statistical difference in terms of attachment from comparison groups. Dissanayake and Sigman (2001) suggested that impairment in emotional understanding and responsiveness may be overcome by cognitive strategies, but that these strategies may not fully compensate for the observed deficits. Results of this meta-analysis indicated that children with HFASD display attachment behaviors with their parents, and that these attachments may be secure in nature.

Another study by IJzendoorn et al (2007) compared the attachment behaviors of parents of children with ASD with parents of children with mental retardation, language delay, and

typical development. Results indicated that parents of children with ASD were equally sensitive as parents of children without ASD, but that their children showed more attachment disorganization and less child involvement. Moreover, less severe autistic symptoms in the social domain predicted more attachment security. Thus, the results of this study are somewhat contradictory to the meta-analysis conducted by Rutgers et al. However, the importance of both studies indicates the presence of attachment between parents and children with ASD, though the quality of that attachment may vary depending upon social functioning. The presence of attachment behaviors between parent and child suggests that children with HFASD form relationships and that the relationship between parent and child is among the most valuable. According to Greenspan and Wieder (2006), although the rapid exchange of emotional signals is harder for children with ASD, the ability to love is present, whether or not it can be easily expressed.

Finally, Bauminger et al. (2008) ran study comparing peer interactions of a group of children with ASD (n = 44) and a group of typically developing children (n=38) to investigate children's deficits in social interaction. In this study, they measured quality of interactions from individuals in each group as they interacted with a close friend. The results suggested that while child with ASD displayed limit positive emotional engagements, they also formed very strong peer attachments that the researchers referred to as "best friends." In this respect, the child with ASD were very typical in their interest in maintaining peer connections, but were less reluctant to seek out new interactions and expressed less emotional engagement in relationships they formed. In addition, children from the ASD group tended to struggle more in overall social interactions. However, this study offers some hope to parents who worry that they will never form a close connection with their child. The researchers note that the best way to practice social

skills for a child with ASD may be in the context of a close, safe relationship with a familiar individual that is one-on-one and ongoing. Thus, structuring interventions to strengthen the parent-child relationship may benefit greatly from incorporating some of the elements suggested from the findings in this study.

Though the delays experienced by children with HFASD most typically concern social communication, narrow range of interests, and rigid and routine behaviors, and lack the delays in verbal communication and cognitive ability associated with classic autism, parents of these children still experience considerable challenges and stress associated with parenting. Parents were once viewed as the cause of their child's problems with symptoms related to autism, such as Kanner's notion that "refrigerator mothers" withheld love and affection from their child, causing them lose the ability to form close relationships with others (Wing, 1989). Currently, parents and caregivers are recognized as playing an integral role in the effective treatment of their child. In the past ten years, the pragmatic and philosophical stance that parents can and should collaborate in the design and implementation of if services for their child has received broad acceptance in the mental health community (Schopler & Mesibov, 2000). Hence, many of the most widely used and recommended interventions for children with HFASD now bring parents closely into the therapeutic process.

## Interventions for Autistic Spectrum Disorders

There is a large and increasing body of research documenting the effectiveness of specific intervention strategies with ASD that address deficits in language, non-verbal communication, social skills, and improve challenging behaviors (Brock, Jimerson, Hansen, 2006). Among these interventions, play-based interventions represent one aspect of emerging treatments designed to help children with ASD overcome developmental deficits (Mastrangelo,

2009). According to Thomas & Smith (2004), the nature of play often exhibited by children with ASD does not set them up to be a preferred playmate with their peers, hence their initial play limitations may further limit their exposure to the play skills of others as well as increasing a sense of isolations from peers. Therefore, one view is that interventions that teach children with ASD appropriate play skills may help increase their ability to play and increase their sense of belonging. With extensive opportunities for play, the child's awareness of other people's mental states and intentions may be enhanced through the symbolic representation and social interaction that play often includes (Mastrangelo, 2009). According to Mastrangelo, structured play-based approaches for children with ASD typically fall into two categories, behavioral interventions and developmental-play interventions.

Behavioral interventions rely upon structured approaches stemming from behavioral principles for learning. For many behavioral approaches, play is seen as impaired due to deficits in symbolic representation, joint-attention, and social communication and understanding.

Behavioral interventions build upon the behavioral conditioning approaches developed by Skinner (1969) and later adapted for children with autism by O. Ivar Lovaas (1977). In behavioral interventions, the adult plays a pivotal role in ensuring that skills are being developed during play, such as imitation, vocabulary, and compliance (Mastrangelo, 2009). Interventions using behavioral approaches are applied behavior analysis and discrete trial training.

Applied Behavior Analysis (ABA) is a scientific discipline that is interested in the application of behavior principles to socially important problems (Strain & Schwartz, 2001). The roots of behavior analysis lie in techniques of behavioral modification, which attempts to extinguish behaviors deemed detrimental to the well-being of the child with ASD (Maurice, 1993). The approach builds upon Lovaas' (1977) model of structured teaching that assumes all

interpersonal difficulties experienced by children with ASD stem from impairments in cognitive and language ability (Mastrangelo, 2009) and developed from work with children generally functioning on the lower range of the autistic spectrum, such as children with classic autism also displaying severe cognitive impairments. Treatment focuses on the acquisition of discrete cognitive and language skills in highly organized and structured environments with precise instructional styles (Quill, 1995). While behavioral interventions emphasizing play have roots in ABA, the ABA approach did not originally emphasize play, but rather the development of social and communication skills that serve as key qualities for symbolic play to occur, such as social communication and language acquisition.

ABA is an approach that is particularly well suited to experimental and quantitative research designs. Researchers typically target very specific behaviors for change, such as increasing the correct verbal response of a child when presented with a particular stimulus. For instance, a researcher shows a child a card with a picture of a telephone and the child responds by saying, "telephone." This occurrence would count as a successful trial. In terms of social behavior, if a child in a social group initiates a verbal interaction with a peer, this too is seen as a successful trial and the child typically receives a reward in the form of something meaningful, such as a piece of candy. This form of stimulus-response training allows researchers to target specific behaviors and measure the effectiveness of an intervention based upon the increase or decrease of behavior following a specific trial. As such, there is considerable quantitative research demonstrating the efficacy of ABA approaches for children with ASD to increase, decrease, or modify behavior (Simpson, 2005). The empirical support for ABA techniques in the ASD literature is substantial and has resulted in skill acquisition in the areas of communication

and socialization as well as attenuation of associated challenging behaviors (Bregman et al., 2005; Horner, Carr, Strain, Todd, & Reed, 2002; Koegel & Koegel, 1995; Schreibman, 2000).

Regarding the applicability of ABA principles to parent-implemented interventions, single-subject studies indicate that parents can learn ABA techniques to help in reducing problem behaviors and increasing compliance, as well as in increasing communication and other adaptive skills (Charlop & Trasowech, 1991; Ducharme & Drain, 2004; Kaiser, A, Hancock, T., & Nietfeld, J, 2000; Lerman, C., Swiezy, N., Perkins-Parks, S, & Roane, H, 2000; Moes & Frea, 2002; Smith, Buch, Gamby, 2000; Symon, 2005). There have been a small group of randomized control trials (RCT) of parent-implemented interventions using ABA principles for children with ASD (e.g., Drew et al., 2002; Schreibman & Koegel, 2005; Smith, Groen, Wynn, 2000; Sofronoff, Leslie, & Brown, 2004; Tonge et al., 2006). However, these RCTs have been conducted at single sites, did not test the replicability of effects across sites, and have involved too few participants to draw firm conclusions about how effective the intervention is and for whom (Johnson et al., 2007).

A behavioral approach similar to ABA is discrete trial training (DTT), which was developed in the 1960s and targets a set of skills anticipated to increase the range of behavioral repertoires needed to play with objects. In DTT, complex behaviors are broken down into component pieces, or chunks, that are taught through numerous teaching trials. The environment for DTT is highly structured and teaching is regimented and scripted. The therapist controls the session by preselecting materials and providing extensive modeling for the desired response. DTT differs from ABA approaches in its use of shaping to achieve more complex behaviors. While ABA focuses on specific behavioral responses, DTT takes this approach as a foundation that building to more complex, interrelated skill sets. Regarding play behaviors, the DTT

therapist will break down the integral components of play, such as rolling a ball or squeezing a pop-out toy, and focus on these parts first. Once these parts are mastered, the therapist will work with the child to integrate the parts into a greater whole that resembles typical play. DTT has demonstrated good efficacy in the research literature as an intervention effective in shaping behaviors of children with ASD (Simpson, 2005; Stahmer, Ingersoll, & Carter, 2003).

Parent-interventions using DTT skills, in which parents are taught how to work with their children using DTT, have received attention in the research literature (Sarokoff & Sturmey, 2004; Dib & Sturmey, 2007; Ward-Horner & Sturmey, 2008; Lafasakis & Sturmey, 2007). In a representative study of current research of teaching DTT skills to parents, Ward-Horner and Sturmey (2008) used a multiple-baseline-across-participants-experimental design to examine the effectiveness of teaching parents DTT skills for use with their children with autism. The children included in the study were ages 4, 4, and 5 and each met the diagnostic criteria for autism. The parents had little or no exposure to the principles of DTT. Data was collected through independent observations by three raters of the parents using DTT techniques to shape their child's behaviors in a desired way. The raters observed videotapes of training sessions, interventions, and follow up sessions to establish inter-rater reliability. Overall inter-rater reliability was over 90%. Results of the study indicated that parents were able to learn the principled of DTT and apply them when working with their children. However, results also indicated that parents were only marginally successful in shaping the behaviors of their children. The researchers suggested that that the behaviors chosen for modification may have lacked adequate foundation among the children to demonstrate successful change in the time allotted for this study. In addition, the researchers suggested that the method the parents were taught to correct incorrect responses might not have been sophisticated enough to sufficiently shape

behaviors in frame that the study was conducted. Ward-Horner & Sturmey noted that findings from their study reflect previous findings that parents are able to successfully learn and implement DTT skills. However, research is inconclusive as to whether the children from the study demonstrate expected levels of change as a result of parent-implemented DTT intervention.

Criticism of ABA and DTT approaches concern the nature of what skills children with ASD are developing as a result of behavioral treatments. Although Strain & Schwartz (2002) acknowledge the impressive research indicating the efficacy of such approaches in reducing maladaptive behaviors and increasing adaptive behaviors, particularly social behavior, they caution that social behavior is a complicated, dynamic, culturally influenced, and contextually based phenomena, rather than a set of discrete skills. Consequently, though behavioral approaches have been effective in producing changes in children's social behavior, the narrow focus of these approaches have not been successful in building repertoires of social behaviors that result in meaningful lifestyle changes for children. Moreover, many behavioral approaches rely upon rewards for particular behaviors. However, many social contexts beyond the experimental condition will fail to provide such rewards for the child. Hence, according to behavioral principles, when the reward is removed from the equation, the behavior extinguishes. Consequently, if entering a peer group is not a skill valued by the child with ASD, time spent on the intervention will be for naught as the behavior has a high likelihood of extinguishing in time (Strain & Schwartz, 2001) due to the child lacking the intrinsic motivation to experience the positive association of engaging in peer or social activities.

In contrast to behavioral interventions, developmentally based interventions for children with ASD incorporate experience-based, playful, and enjoyable interactions with the hope of

enhancing attention, pretend play, initiations and responses, and communication (Bernard-Opitz, Ing, & Kong, 2004). An important distinction between developmental play models and behavioral based models concerns the nature of play assumed. Behavioral interventions tend to associate play with being a skill to be acquired, whereas developmental interventions see play as part of development and an expression that includes individual experience and social interaction that contributes to further development. Among the leading interventions using a developmental model is the Developmental, Individual-Difference, Relationship-Basel Model (DIR), developed by Greenspan and Wieder (2003, 2006).

The DIR model is a developmental, individual-difference, relationship-based model for examining the functional developmental capacities of children in the context of their biological make-up, family relationships, and interactive patterns (Mastrangelo, 2009). For many children on the autistic spectrum, Wieder and Greenspan (2003) believed that an emotional milestone is being mastered during play. Such mastery could include acquiring the ability to feel calm and focused. Within the DIR model, *D* represents the developmental capacities that emerge during the child's early years and include shared attention and engagement, back and forth interactions, problem solving, creating play ideas, and abstract thinking. The *I* represents individual differences in sensory motor processing and regulation that need to be taken into account and treated to support development. The *R* represents the relationship and environment necessary to provide the interactions through which the development of emotional, social, and cognitive capacities are nurtured, practiced, and enhanced (Greenspan & Wieder, 2006; Mastrangelo, 2009; Wieder & Greenspan, 2003).

During spontaneous floor-time play sessions, facilitators follow the child's lead by using affectively toned interactions, gestures, and words coupled with exaggerated affect to facilitate

the child's development towards more symbolic play and representation. According to Greenspan and Wieder, it is important that facilitators establish a foundation of shared attention, engagement, simple and complex gestures, and problem solving to bring the child into the world of ideas and abstract thinking (Wieder & Greenspan, 2006; Mastrangelo, 2009; Wieder & Greenspan, 2003). In addition, Greenspan and Wieder emphasize that staying calm and relaxed while also empathizing with the child's emotional tone are important elements to the DIR approach, which also includes the facilitator having awareness of personal feelings in the moment, monitoring tone of voice and gestures, following the child's lead, interacting, and tuning into the child's developmental levels. Another important dimension of the DIR approach involves the facilitator being purposeful in creating opportunities for two-way communication, which involves looking for opportunities to transform many of the child's actions during play into interactions. Through early intervention and daily opportunities for symbolic play, Greenspan and Wieder report that the child begins to learn that symbols stand for things, which help the child move up the developmental ladder (Greenspan & Wieder, 2006). Because of the importance of daily, frequent opportunities for symbolic play and interactive experiences, Greenspan and Wieder (2006) stress the value of parents learning and applying DIR concepts and applying them with their own children. Thus, a significant portion of the DIR approach involves a parent-implemented intervention.

Research using the DIR approach has yielded mixed results. Greenspan and Wieder (2006) reported results of a study of 200 hundred children receiving DIR/Floortime treatment for diagnoses of ASD over a period of 8 years. Results of the study indicated that 83 percent of children, including children from high-and low-levels of functioning, showed initial improvement in the range and depth of the engagement and expression of emotions, particularly

pleasure. Moreover, Greenspan and Wieder noted that once engaged, the many of the children moved from simple to complex emotional and motor gestures, which led to the development of functional symbolic capacities. Greenspan and Wieder also noted that once the children displayed increased capacity for symbolic representation, they began talking incessantly, as if they were excited to use their new abilities. While verbally expressed ideas were seemingly illogical and confused initially, over half of the children began using symbols creatively and logically. However, most of the children learned to express their ideas more quickly than they understood the ideas of others. Still, if their caretakers and therapists focused on rapid, two-way symbolic communication, which challenged the children to process incoming information in extended back-and-forth exchanges, children learned to comprehend the ideas of others and express abstract ideas reflecting causal reasoning (Greenspan & Wieder, 2006). Limitations to this study include the lack of a control group, lack of randomization, and the inclusion of parents who were highly motivated to facilitate the treatment of their children with ASD. However, the results of the study indicated that DIR/Floortime, which emphasizes empathic attunement between facilitator and child, as well as interactions stemming from child-led play in natural settings, is a promising treatment for children with ASD in terms of established efficacy (Simpson, 2005).

A recent study by Hilton & Seal (2007) used trial interventions in DIR and ABA with twin brothers with autism were offered to help the parents choose one of the programs for their sons. Pre- and post-test assessments were conducted using the *Communication and Symbolic Behavior Scales* (CSBS; Wetherby & Prizant, 1999), which measures seven communication clusters: communicative function, communication means (gestural, vocal, and verbal), reciprocity, social-affective signaling, and symbolic behaviors. Each of the boys participated in

16 sessions and received speech therapy during the intervention period. The ABA participant reported gains in gestural communication, vocal communicative means, and social-affective signaling. The DIR participant showed increases in reciprocity as indicated by increased eye contact, as well as increases in object play, representing a gain in symbolic behavior. The child participating in ABA showed a loss in symbolic play, as demonstrated by a decrease in the number and complexity of demonstrated action schemes. However, the DIR participant's losses included a drop in vocal communicative means and a drop in social-affective signaling. According to the researchers, the drop in social-affective signaling was an interesting finding considering that the focus of DIR is enhancing social-affective functioning. Neither the ABA nor DIR child showed changes in verbal communicative means in spite of verbal gains recorded as clinical data. The DIR child had a larger percentage gain than the ABA child in the use of words while the ABA child showed a higher use of signs. While the findings of this study indicate that DIR and ABA approaches may enhance functioning in different areas, the authors of the study caution that the results have very limited generalizability. Though the study included monozygotic twins as participants, individual differences and differing treatment conditions may confound results, and without a control group or larger sample with which to compare results, the explanatory power of the results of this study are limited. However, the authors concluded that both interventions may serve important areas of development for children with ASD, but that further research is needed before conclusions can be made as to which is more efficacious.

Two additional interventions stressing developmental play, the integrated play groups model (Wolfberg & Schuler, 1993) and the Miller Method (Miller & Miller, 1989) offer slightly different approaches to developing symbolic play among children with ASD. The integrated play groups model provides a support system for peer play in which play development is fostered by

physically arranging the environment to bring about the most competent forms of play and by guiding participation within these environments to maximize child initiations (Mastrangelo, 2009). With the integrated play groups model, experienced social partners guide play participation to maximize the developmental potential of the child with ASD. The Miller Method presents a cognitive developmental approach toward play for children with ASD. This approach is similar to child-centered play, yet provides increased structure for the play session. According to Miller and Miller, social play must be carefully structured for the child on the autistic spectrum before the child can learn to initiate activity independently. With the Miller method, play sessions are structured initially by a facilitator until the play is picked up and independently displayed. At that point, the facilitator turns over control of the play to the children. To date, both the Miller Method and integrated play groups model lack empirical research support demonstrating their efficacy. However, these approaches represent a move from strict behavioral approaches to working with children with ASD in a developmentally appropriate manner to create environments that encourage the development of intrinsically motivated expressions rather that extrinsically instilled behaviors.

In an important analysis of different types of play interventions, Bernard-Opitz, Ing, and Kong (2004) reported results of a pilot study comparing traditional approaches and natural play interventions for young children (28-44 months) with autism over a 10-week period. They reported that the children met the criteria for autism by meeting the criteria for diagnosis in the following areas: social interaction, communication, and interests and behaviors. The researchers used two matched groups with four children in each group and implemented a crossover design, meaning that both groups received natural play and behavioral treatments, but in different orders. The researchers did not report on the cognitive functioning of the participants, except noting that

two participants had lower levels of cognitive functioning, indicating that other participants may have qualified for HFASD if their cognitive levels were within two standard deviations of the mean. The behavioral group received treatment consisting of behavior modification techniques, such as table-type activities, prescriptive interventions, and adult direction, while the natural-play group received sessions in free play that included toys and games, flexible structure, and child-centered direction. Bernard-Opitz et al reported that while improvements in attending and compliance were higher following the behavioral treatment compared to natural play, both groups showed positive gains in compliance, attending, amount of play, and communication with their therapists. Parents of the children reported that compliance dropped when the behavioral condition preceded the natural-play condition, but improved when the behavioral condition followed the natural-play condition. Though the study demonstrates that behavioral and natural play interventions can be effective when used together, it is difficult to attribute gains from treatment over the other due to the crossover design. However, results suggest that natural play interventions can be effective in part with children with ASD.

Another study examining the effectiveness of non-directive play with young children with ASD involved a 16-session case study involving a 6-year-old boy with severe autism (Josefi & Ryan, 2004). Josefi and Ryan concluded that through a non-directive play intervention, the child was able to enter into a therapeutic relationship and demonstrate attachment behaviors towards the therapist. They noted that key areas of improvement were in the child's development of autonomy and pretend play, while ritualistic behaviors revealed only mild improvement.

Moreover, improvements in therapy occurred concurrently with changes reported by the client's mother at home of increased independence and empathy. Josefi and Ryan state that this preliminary study suggests that non-directive play therapy may enhance and accelerate the

emotional/social development of children with severe autism. They further suggested that for children with severe autism, behavioral techniques and non-directive play therapy may complement one another to provide an overall comprehensive treatment plan. Though results of this study pertain to a child with severe autism, considering the gains indicated in the areas of social and emotional development, two areas that children with HFASD often experience delays, non-directive play therapy might be a viable treatment for children with HFASD.

## Parent-Implemented Interventions for Children with ASD

Parent-implemented interventions, with parents learning new skills and ways of relating to their child, have demonstrated efficacy in the research literature. Two meta-analyses compared research of parent-implemented interventions for children with ASD with encouraging results (McConachie & Diggle, 2006; Meadan, Ostrosky, Zaghlawan, & Yu, 2009). McConchie & Diggle found that very few of the twelve studies meeting their inclusion criteria utilized an adequate research design from which to draw conclusions about effectiveness. However, of the studies that used randomized and control designs, which the researchers considered an important criteria from which to determine efficacy, results tended to suggest that parent training leads to improved child communicative behavior, increased maternal knowledge of autism, enhanced maternal communication style and parent child interaction, and reduced maternal depression. Of the interventions that included randomization and control designs, most were behavioral in nature and involved training parents to provide structure care and skill development for their child, such as social communication (Aldred, Green, & Adams, 2004) and joint attention (Drew et al, 2002).

The meta-analysis by Meadan et al (2009) was more specific in nature and focused on parent-implemented interventions aimed at promoting and enhancing social and communicative

behavior of young children with ASD. They reviewed twelve parent-implemented intervention studies conducted in part in the home environment. The included studies were published between 1997 and 2007. According to Meadan et al, all 12 studies reported positive outcomes for parents and children, yet they reported that closer examination of the research methods used in each study indicated considerable variability in intervention and data collection strategies. Based upon the variability of design, dependent variables, methodologies, and research questions, as well as the uniform small sample size used in each study, Meadan et al indicated that generalization of findings from these twelve studies is limited. Moreover, Meadan et al stated that most of the reviewed studies did not include other treatments that participants may have received during the research intervention, suggesting that it was unknown what variables may have accounted for gains observed in parents and children. However, according to Meadan et al, the studies reviewed in this meta-analysis indicated that parents were able to learn and implement new strategies with their children in a natural environment. The studies also indicated that parents' positive behavior change resulted in positive change in children's target behaviors, which were social and communicative in nature.

## Child-Parent Relationship Therapy

Considering the increasingly recognized efficacy of parent-implemented intervention, as well as the potential of non-directive and natural play interventions to promote enhanced social and emotional functioning among children with ASD, an intervention that offers both of these elements seems of great potential for children with HFASD. One such intervention, Child-Parent Relationship Therapy (CPRT, Landreth & Bratton, 2006) offers a structured 10-week intervention that teaches parents the principles of non-directive play so they can provide this environment at home and in other non-clinical settings. Moreover, CPRT teaches parents how to

generalize principles of non-directive play to experiences in order to enhance the overall quality of relationship with their child.

The focus of Child-Parent Relationship Therapy is on the importance of the relationship between the parent and child and on the inner person of the child (Landreth & Bratton, 2006). With CPRT, the parent-child relationship is the catalyst for change. Hence, the objective of CPRT is to help the parent relate to the child in ways that "will release the child's inner directional, constructive, forward-moving, creative, self-healing power" (p. 11). CPRT builds upon the principles of child-centered play therapy and is structured to enhance the relationship between parent and child with the parent serving as the therapeutic agent of change (Landreth & Bratton, 2006).

According to Landreth (2002), the philosophical underpinning of child-centered play therapy is that play is the child's natural language and toys are the child's words. Moustakas (1959) explained play as "a form of letting go, merging freely into experience, immersing oneself totally in the moment so that there is no distinction between self and object or self and other. Energy, life spirit, surprise, fusion, awakening, renewal are all qualities of play" (p. 2). Through play, children learn to make sense of the environment and experiences while developing a deeper understanding of self (Landreth, 2002). Children learn to control and mastery of their world, express empathy, and develop problem-solving skills (Schaefer, 1993). To harness the therapeutic potential of play, the play therapy environment provides children with facilitative toys to help children express a wide range of feelings in their natural language without judgment or evaluation. Through play therapy, children discover their own ability to make decisions and think for themselves (Axline, 1974).

Child-centered play therapy builds upon the therapeutic work of Carl Rogers and his vision for person-centered therapy. According to Rogers (Kirschenbaum & Henderson, 1989), clients know best about what they need and already possess within them everything they need to persevere and thrive. The role of the therapist is to provide a safe environment by conveying warmth, genuineness, and unconditional positive regard, and to reflect back to the client their experience in the moment as to increase their awareness of self. Within these therapeutic conditions and with increased awareness of self, the client is free to move towards self-directed growth.

Similarly, child-centered play therapy frees the child to pursue therapeutic growth in a non-judgmental environment (Landreth, 2002). The therapist does not strive for verbal conversations or control over the child during child-centered sessions. Rather, the child leads the sessions while the therapist facilitates and reflects to the child the child's experiences as they occur in the immediate moment. By allowing the child to play freely without external expectations, the child experiences the feeling of being in control and the responsibility that comes from making choices. The therapist provides this environment by relating to the child in a way that is consistently accepting of the child's thoughts and feelings. This form of responding and being-with-the-child develops within the child increased self-awareness, self-confidence, and self-control. In child-centered play therapy, the therapist removes the focus from the child's behaviors and symptoms to a focus upon the emotional intent motivating the child's actions. As such, the therapist accepts the child fully and trusts in the child's innate ability for growth.

Virginia Axline, a student of Carl Rogers and a pioneer of child-centered play therapy, outlined ten basic principles for establishing the therapeutic relationship with the child (Axline,

1974). Landreth (2002) later revised and condensed Axline's original list to the following eight principles:

- 1. The therapist is genuinely interested in the child and develops a warm, caring relationship.
- 2. The therapist experiences unqualified acceptance of the child and does not wish that the child were different in some way.
- 3. The therapist creates a feeling of safety and permissiveness in the relationship so the child feels free to explore and express self completely.
- 4. The therapist is always sensitive to the child's feelings and gently reflects those feelings in such a manner that the child develops self-understanding.
- 5. The therapist believes deeply in the child's capacity to act responsibly, unwaveringly respects the child's ability to solve personal problems, and allows the child to do so.
- 6. The therapist trusts the child's inner direction, allows the child to lead in all areas of the relationship and resists any urge to direct the child's play or conversation.
- 7. The therapist appreciates the gradual nature of the therapeutic process and does not attempt to hurry the process.
- 8. The therapist establishes only those therapeutic limits which help the child accept personal and appropriate relationship responsibility (pp. 84-85).

By adhering to these principles, the child-centered play therapist provides a therapeutic environment in which the child feels heard, cared about, and understood (Landreth, 2002). Landreth suggests that children experience a sense of mastery and self-control, an increase in self-acceptance, direction, and responsibility, and enhanced confidence in following their own

locus of evaluation. With child-centered play therapy, the focus is upon the growth of the child and the intrinsic motivation of the child to develop and move towards actualization,

While the cornerstone of child-centered play therapy is acceptance of the child by the therapist, the relationship is not fully permissive. The therapist sets limits when appropriate on behaviors that may endanger the child, the therapist, the play therapy room, or the relationship between the child and therapist (Landreth, 2002). When setting limits, the therapist focuses upon acceptance of the child's motivation behind the action and sets the limit only on the behavior. Following setting the limit, the therapist provides the child choices to redirect their motivation in a way consistent with the play therapy environment. Thus, the therapist maintains acceptance of the child while helping the child experience responsibility and self-direction.

In contrast to child-centered play therapy, filial therapy directly involves parents in the therapeutic process with their children. Developed in the 1960's by Bernard and Louise Guerney, filial therapy facilitates change in the perspective of parents of their child and their child's experiences. The Guerney's suggested that that parents have significant emotional significance in their child's life, but that children's problems often result from a lack of parental knowledge and skill (Guerney, B, 1969; Guerney, L., 2000). Through the development of filial therapy, the Guerney's sought to align the parent and therapist for the benefit of the child.

Rise Van Fleet, a former student of the Guerney's, defined filial therapy as "involving parents as partners in the therapeutic process. Parents learn to conduct special play sessions with their own children, harnessing the therapeutic belief of play for their children and their family relationships (1998). According to Van Fleet, filial therapy has the potential to reduce or eliminate presenting problems and may help prevent future problems (2003).

The Van Fleet model of filial therapy (1994) divides the process into three distinct phases. The first phase involves assessment of social developmental history, family play observations, and pre-treatment assessments. During the first phase, the parents receive a description and rationale of filial therapy. Parents may also observe a therapist-facilitated session demonstrating the child-centered play skills taught in filial therapy. The second phase involves the actual training, practicing of play sessions, and implementing the play sessions at home. The therapist begins supervision of the parents to help them hone their skills and build their confidence to increase their resolve to continue practicing the play times with their child. During supervision, the therapist addresses concerns, questions, and general issues that may arise for the parent. The third phase helps parents generalize the skills used in the special playtimes to everyday interactions with their child. Upon conclusion of filial therapy, the therapist and parent collaborate to make a plan for treatment termination and the parent completes post-treatment assessments.

Landreth and Bratton (2006) developed Child-Parent Relationship Therapy as a structured therapy, time-limited intervention that retained the core filial concepts developed by the Guerneys and Van Fleet. Despite differences in structure and time-frame, the objectives of filial therapy and CPRT are consistent: to help parents better understand and accept their child, gain insight into their own experience as parents, and improve overall parenting skills. Core to achieving these objectives is stressing the parents' involvement in the lives of their child. Landreth and Bratton defined CPRT as:

A unique approach used by professionals trained in play therapy to train parents to be therapeutic agents with their own children through a format of didactic instruction, demonstration play sessions, and supervision in a supportive atmosphere. Parents are taught basic child-centered play therapy principles and skills including reflective listening, recognizing and responding to children's feelings, therapeutic limit setting, building children's self esteem, and structuring weekly play sessions with their children using a special play kit of selected toys. Parents learn how to create a nonjudgmental, understanding, and accepting environment that enhances the parent-child relationship, thus facilitating personal growth and change for child and parent. (p. 11)

Landreth and Bratton (2006) designed CPRT as a combination of group process and didactic education, with groups typically involving six to eight caregivers meeting weekly for 2-hour groups sessions over 10 weeks. Therapists with experience in group therapy, child-centered play therapy, and child development lead or co-lead the CPRT groups.

The CPRT therapist uses the first three sessions to develop group cohesion and safety, educate the group members about the goals of CPRT, and teach child-centered play skills.

Therapists stress the importance of the play materials, review the different toys required for CPRT home play sessions, and instruct on how to structure the home play sessions. Beginning with session four, the group members begin having weekly play times with their child-of-focus, which they video-record to show during the group for the purpose of supervision. All parents participating in the CPRT group are expected to show at least one session during the 10-weeks of CPRT. For parents who may struggle to conduct play sessions at home, play sessions may be held at other locations, such as mental health clinics, churches, or other settings free of distractions. As the CPRT sessions progress, parents learn and practice new skills each week, such as modeling, reflecting, esteem building, limit setting and how to use encouragement instead of praise. In the final three sessions, parents prepare for termination and discuss procedures and concerns regarding generalizing CPRT skills to everyday situations.

Regarding the play sessions, Landreth and Bratton (2006) stress educating parents about the difference between joining the child's play and being involved in the child's play. In normal parent-child play, playing with the child typically involves a mutual interaction in which both parent and child contribute to the direction of play. While this type of play is certainly valuable and should be encouraged, CPRT teaches parents how to be involved in their child's play while allowing the child to stay in the lead. The child takes responsibility for deciding what direction the play will go, what toys might represent, and how play ends. In CPRT, parents learn to communicate involvement by using appropriate posture and responses that communicate to the child, "I'm here, I hear you, I understand, I care" (Landreth & Bratton, 2006).

Parents also learn to join the child's play when the child invites the parent into the play. However, when joining play, the parent must be cautious not to control or take over the child's play. The parent's role is similar to the role of a child-centered play therapist:

The child-centered play therapist avoids interfering with the child's play, does not offer solutions or suggestions, and above all does not allow himself or herself to be manipulated into becoming the child's teacher or doing things *for* the child. Assistance is provided only in rare circumstances when the child has tried and truly cannot do something by himself or herself. (Sweeney & Landreth, 2009, p. 23)

Landreth and Sweeney highlighted the importance of maintaining a certain role with the child. Doing things for the child without the child's invitation communicates that the parent believes the child to be incompetent. It is important that the parent maintain good boundaries when entering the child's play, remaining non-evaluative and nonjudgmental, and maintaining the relationship.

Outcome research with various populations suggests that CPRT is an effective treatment intervention. Several studies have used CPRT as an intervention to strengthen parent-child relationships, decrease parent stress, and reduce concern over child behavior problems. Landreth and Bratton (2006) reported that of the 34 studies using CPRT, 27 were controlled outcome studies. For instance, Landreth and Bratton (2006) examined the effectiveness of CPRT with 43 single parents with children of ages 3 through 7. When compared to a control group, results indicated that the treatment group consisting made statistically significantly gains in increasing levels of empathy during interactions with their children, as demonstrated by blind rater evaluations using the Measurement of Empathy in Adult Child Interactions (MAECI).

Costas and Landreth (1999) conducted a study with non-offending parents of children who had been sexually abused to determine the effectiveness of CPRT in reducing child behavior problems and anxiety. The study consisted of 23 participants, with 14 in the treatment group and 12 in the control group. Results indicated a statistically significant decrease in problematic behavior and anxiety with children who had been sexually abused. In addition, significant reductions in parent stress levels and parents in the experimental group reported statistically significant increases in acceptance of the child.

In another study, Landreth and Lobaugh used the CPRT model with 32 incarcerated fathers with children ages 4 through 9. The results of this study showed that the fathers participating in the treatment group rated statistically significantly higher after training than before training on attitude, acceptance, and empathic behavior towards their children when compared to incarcerated fathers in the control group based upon results of the Porter Parental Acceptance Scale. Additionally, children of fathers in the treatment group reported a statistically significant increase in self-esteem based upon the Joseph Preschool and Primary Self-Concept

Scale. Moreover, fathers in the treatment group reported statistically significant decreases in behavior problems in their children and decreases in stress related to parenting than incarcerated fathers in the control group.

Tew, Landreth, Joiner, and Solt (2002) used CPRT with parents of chronically ill children to determine what effects CPRT participation had upon parent stress and reports of child disruptive behavior. Using a pre-post-randomized control group design, Tew et al. included 23 total parents in this study, with 12 in the experimental group and 11 in the control group. Parents participating in the experimental group reported statistically significant decreases in parent stress and in their child's disruptive behavior. Kale and Landreth (1999) reported statistically significant increases in parent acceptance of the parents' children in a study of 22 randomly assigned parents of children with learning disabilities participating in CPRT.

#### CPRT and Parents of Children with HFASD

Although CPRT seems a viable intervention for parents of children with HFASD, little research has been done to establish the acceptability or impact of CPRT with this population. *Acceptability* refers to participants' views of an intervention's usefulness and alignment with values (Nastasi, Moore, & Varjas, 2004). Acceptability also reflects the degree to which participants see a treatment as feasible and nonintrusive (Kazdin, 1980; Kazdin, 2000). There is a direct connection between treatment acceptability, use, impact, and sustainability (Eckert & Hintze, 2000; Reimers, Wacker, & Koeppl, 1987). This connection highlights the importance of taking steps to examine those factors that possess the potential to influence acceptability before taking the steps necessary to maximize overall treatment quality.

Treatment acceptability may also be influenced by participant understanding and environmental disruption (Reimers, Wacker, Koeppl, 1987). Chafouleas, Briesch, Riley-Tillman,

and McCoach (2009) described two factors which contribute to optimal treatment acceptability:

(a) participants' understanding of the intervention and how to carry it out, and (b) an absence of environmental impediments, such as administrative, political, and financial constraints. This concern about environmental impediments was also raised by Eckert and Hintze (2000), who recommended that researchers consider various environmental factors, including interference with routine and the amount of energy and resources required to complete the treatment, when assessing acceptability.

One previous study has examined the impact of filial therapy with children with pervasive developmental disorders. Beckloff (1998) investigated the effectiveness of filial therapy in increasing the parents' empathic behavior and acceptance with their children, reducing the number of problems experienced by the parents with their children, decreasing sociability difficulties in the child, and reducing the parents' stress related to parenting. The experimental group consisted of 12 volunteer parents who received 10 weekly 2-hour filial therapy sessions and participated in weekly 30-minute play sessions with one of their children. The control group consisted of 11 volunteer parents and received no treatment during the ten weeks. Analysis of Covariance (ANCOVA) revealed that parents in the experimental group increased at a statistically significant level in recognizing their child's need for autonomy for autonomy and independence on the Porter Parental Acceptance Scale (PPAS; Porter, 1954). However, no other variables indicated statistical significance between the experimental and control group, suggesting that filial as an intervention had no effect on other variables of interest. Beckloff suggested that short length of the study period was a possible reason for the lack of significance in the overall reduction of problems.

Schopler (1995) asserted that one factor of unproven therapies for ASD is that a given

technique or approach appears to be helpful for a certain condition and is now assumed to be generalizable to individuals on the autistic spectrum. One question that emerges from the Beckloff study is the extent to which CRPT is acceptable and useful for parents of children with autism. For instance, the variables selected for measurement in this study may not be relevant to this population or, if they were relevant, there may have been insufficient information regarding the needs of the population to accurately measure the variables. Moreover, filial therapy has evolved and emerged with a formal treatment protocol in the form of CPRT, meaning that application of CPRT to this population may now have different results. However, although CPRT has demonstrated effectiveness with several different populations, this effectiveness may not translate to parents of children with HFASD.

#### Qualitative Research Methods

The past 10 years have witnessed qualitative research emerge as a more accepted and legitimate form of research in the social, behavioral, and health sciences (Creswell, 2007). However, according to Creswell (2007), qualitative research has become increasingly difficult to define in recent years. The struggle to provide a concise definition is due in part to the complex, interconnected network of concepts, terms, and assumptions surrounding the term *qualitative* research (Denzin & Lincoln, 2008). According to Denzin and Lincoln (2008), the term *qualitative* implies, "an emphasis on the qualities of entities and on processes and meanings that are not experimentally examined or measured (if measured at all) in terms of quantity, amount, intensity, or frequency" (p. 14). Thus, qualitative research represents a set of methods designed to investigate concepts or topics of interest that often lie beyond quantitative measurement.

Denzin and Lincoln (2005) provide a definition of qualitative research that conveys the complex nature of this form of methodological inquiry:

Qualitative research is a situated activity that locates the observer in the world. It consists of a set if interpretive, material practices that make the world visible. These practices transform the world. They turn the world into a series of representations, including fieldnotes, interviews, conversations, photographs, recordings, and memos to the self. At this level, qualitative research involves an interpretive, naturalistic approach to the world. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them (p. 3).

Corbin and Strauss (2008) asserted that qualitative data is rich in substance and full of possibilities. They further stated that qualitative analysis potentially discovers themes underneath the surface material, stating that qualitative analysis, "presents description that embodies well-constructed themes/categories, development of context, and explanation of process or change over time" (p. 51). Miles and Huberman (1994) reported that qualitative data provides source of well-grounded, rich description, and explanation of processes occurring in local contexts. Miles and Huberman also stated that qualitative researchers are interested "in the idiosyncratic meanings people (including ourselves) develop, and we believe in the existence of lawful yet historically evolving relationships to be discovered in the social world" (p. 23). According to Lincoln and Guba (1985), qualitative research designs allow for a detailed exploration of a topic in which participants can be studied in their natural environment.

Qualitative research has several important qualities which distinguish it from quantitative research that warrant discussion (Creswell, 2007). First, qualitative research occurs in a natural setting, which means that data is collected by actually talking directly with people and seeing

them behave and act within their context. Second, the researcher is a key instrument. Rather than relying on questionnaires or assessments developed by other researchers, the researchers themselves examine documents, observe behavior, and interview the participants. The perceptions, values, and biases of the researcher are considered an integral part of the qualitative research process. Therefore, researchers must exercise *reflexivity*, or self-awareness, to prevent personal perceptions from skewing the process of data analysis, which Patton (2002) describes as demonstrating "empathic neutrality" (p. 52). Third, in the entire qualitative process, the researchers focus on learning the meaning that the participants hold about the problem or issue, not the meaning that the researchers bring to the researcher or writers to the literature. Finally, the purpose of qualitative research is to provide a holistic account by developing a complex picture of the problem under study. Qualitative researchers strive to identify the complex interactions of any situation.

According to Leedy and Ormrod (2005), when little information exists on a topic or when variables are unknown, qualitative research can help define the parameters of a given phenomenon. Creswell (2007) echoes this rationale by stating that qualitative research is used when quantitative measures and statistical analysis do not fit the problem or research question. Thus, in areas of study in which insufficient research information exists to isolate or identify key variables for quantitative measurement, qualitative analysis can provide useful information regarding specific areas for future study. As such, qualitative research designs can assist in developing evidence-based interventions, which has become an increasingly important movement in mental health, by exploring the participant experience of a phenomenon prior to assigning and measuring variables that may or may not have particular relevance. The prevalence of qualitative research in *The Journal of Counseling and Development* (JCD) reflects the

increasing applicability of qualitative research to the counseling field. For instance, between the years 2005 and 2010, an average of 2 qualitative articles have been published per issue in JCD, with some issues containing as many as four research articles using qualitative methodologies. The number of qualitative articles represented in *The Journal of Counseling and Development* indicates that qualitative research is an acceptable approach to areas of inquiry relevant to counseling and counselor education.

To ensure reliability and validity of qualitative research, researchers employ various methods to enhance the trustworthiness of the findings. Trustworthiness relates to the soundness of a particular study and points to its quality, strength, and integrity (Patton, 2002). Lincoln and Guba (1985) assert that certain criteria are fundamental to ensuring trustworthiness. These criteria include credibility, transferability, dependability, and confirmability, which parallel characteristics commonly found in quantitative studies, namely: internal validity, external validity, reliability, and objectivity, respectively. Several important methods for increasing the trustworthiness of a qualitative study include triangulation, audit-trail, and thick description. Triangulation refers to using several kinds of methods or data, such as several different researchers or evaluators, several different sources of data, or multiple perspectives to interpret the data (Patton, 2002). Audit trails encompass a detailed account of the raw data, data reduction and analysis, informed consent documents, development of interview protocols, and the coding manual (Lincoln & Guba, 1985). Finally, thick description depicts training and research procedures, along with context and participants, with enough detail so that persons not connected to the study could assess the potential for application in similar settings (Patton, 2002).

A number of qualitative methods have been developed to explore various phenomena.

The choice of design depends largely upon the nature of the research question, the phenomena to

be explored, and the relationship of the researcher to the phenomena in question (Patton, 2002). Creswell (2007) states that:

Qualitative research begins with assumptions, a worldview, the possible use of a theoretical lens, and the study of research problems inquiring into the meaning individuals or groups ascribe to a social or human problem. To study this problem, qualitative researchers use an emerging qualitative approach to inquiry, the collection of data in a natural setting sensitive to the people and places under study, and data analysis that is inductive and establishes patterns and themes. The final written report or presentation includes the voices of the participants, the reflexivity of the researcher, and a complex description and interpretation of the problem, and it extends to the literature or signals a call for action (p. 37).

Despite the number of approaches to qualitative research that exist in literature, Creswell defines nine characteristics common to "good" qualitative study (p. 45-47):

- The researcher employs rigorous data collection procedures, meaning that the researcher
  collects data from multiple sources and in multiple forms and accurately summarizes the
  data in a form that is clear and understandable.
- 2. The researcher frames the study within the assumptions and characteristics of the qualitative approach to research.
- 3. The researcher uses a recognized approach to qualitative inquiry to enhance the rigor and sophistication of the research design.
- 4. The researcher begins with a single focus that represents understanding a single concept or idea.

- 5. The study includes detailed methods, a rigorous approach to data collection, data analysis, and report writing, including multiple levels of analysis from narrow codes or themes to broader interrelated themes or abstract ideas.
- 6. The researcher analyzes data using multiple levels of abstraction.
- 7. The researcher writes persuasively so that the reader experiences a sense of "being there" by using clear and engaging style accurately reflecting the complexities that exist in real life.
- 8. The study reflects the history, culture, and personal experience of the researcher.
- 9. The study is ethical.

Within the recognized approaches to qualitative research, phenomenology (Moustakas, 1994) represents a design that focuses on what all participants share when they experience a common phenomenon. According to Creswell (2007), "the basic purpose of phenomenology is to reduce individual experiences with a phenomenon to a description of the universal essence. Van Manen (1990) states that phenomenology "aims at gaining deeper understanding of the nature or meaning of our everyday experiences" (p. 9). However, Van Manen continues by stating that, "a person cannot reflect on lived experience while living through the experience" (p. 10). Therefore, phenomenology represents a retrospective rather than introspective process, and is a "reflection on experience that is already passed or lived through" (p. 10). The inquirer collects data from individuals who have experienced a particular phenomenon of interest and develops a composite description of the essence of the experience for all individuals (Creswell, 2007). The description consists of "what" they experienced and "how" they experienced it (Moustakas, 1994).

Moustakas (1994) provides an approach to phenomenology that includes systematic steps in the data analysis procedure and guidelines for assembling the descriptions of analyzed data.

Creswell (2007) summarized Moustakas' approach to include the following elements. First, the researcher identifies a problem that represents a phenomenon shared by several different people as to develop a better understanding of the features of the phenomenon and common experiences of the participants. Second, the researcher recognizes and specifies the broad philosophical assumptions of phenomenology, which includes the interaction between shared reality and individual experience, as well as understanding how the personal experiences of the researchers influence the phenomenon being studied, which the researchers must account for as much as possible. Third, the data are collected from individuals who have experienced the phenomenon, which consists of multiple in-depth interviews with approximately 5-25 participants, as well as other sources, such as journals, video or audio recordings, or direct observations.

Next, in addition to any other questions, two broad questions are asked of the participants: "What have you experienced in terms of the phenomenon?" and "What contexts or situations have typically influenced or affected your experiences of the phenomenon?" Fifth, data analysis consists of highlighting significant statements that provide an understanding of how the participants experienced the phenomenon. Sixth, the significant statements and themes are used to write a description of what the participants experienced. Also in this step, the researchers write about their own lived experiences and the context and situations that have influenced their experiences, which Creswell (2007) suggested could also be done throughout the research process in the form of a reflective journal. Finally, from the descriptions of themes and emerging experiences, the researcher writes a composite description that presents the essence of the phenomenon, which focuses on the common experiences of the participants. From this analysis, Polkinghorne (1989) writes that the reader should come away from the phenomenology feeling that, "I understand better what it is like for someone to have experienced that" (p. 46).

Phenomenology provides a deep understanding of a phenomenon experienced by several individuals (Creswell, 2007). Knowledge of common experiences can also be of great value for groups such as teachers, counselors, and health professionals. While Moustakas' (1994) approach provides structure for the research design, phenomenology requires some understanding of the broader philosophical assumptions inherent in the approach (Creswell, 2007). For instance, the researcher's values and biases may easily be injected into the data collection and data analysis should the research lack appropriate self-awareness. Bracketing, the process of working through and acknowledging personal values, biases, and beliefs, is one recommended process to limit researcher bias. Moreover, the researcher must carefully choose participants who have all experienced the phenomenon in question in order to uncover a common understanding. Despite these limitations, one can employ phenomenology to forge an understanding for how people transform experience to generate both individual and shared meaning (Patton, 2002).

Rationale for Using a Qualitative Approach with Play Therapy Studies

Snow, Wolff, Hudspeth, and Etheridge (2009) reported that qualitative research increases awareness of particular issues, provides a lens for viewing the researcher and participants in depth, and provides more understanding. Snow et al. (2009) discussed the relevance of qualitative research in play therapy and provided critical considerations for case studies in play therapy. Glazer and Stein (2010) argued qualitative research is a natural extension of the therapeutic process and the basic conditions of genuineness, empathy, and positive regard. The authors reported the qualitative approach to research is particularly important to play therapists and how practitioners approach patients and the dialogue they have with them. The *International Journal of Play Therapy* has published numerous qualitative studies increasing the population of

this method of research in play therapy (Edwards, Ladner, & White, 2007; Edwards, Sullivan, Meany-Wallen, & Kantor, 2010; Glazer, 1998).

Foley, Higdon, and White (2006) interviewed and collected data on six parents who completed a modified CPRT model in 9 weeks with their preschool aged child. The authors used a qualitative design to understand parents' evaluation of CPRT and emphasize specific components of the training. Foley et al. (2006) reported a decrease in parenting stress, an increase in stress due to increased personal awareness and sustained efforts to apply new skills appropriately, and an increase in intimacy in the relationship with their child.

In addition, Edwards, Ladner, and White (2007) completed a qualitative study on the usefulness of CPRT with a Jamaican mother. The mother reported that CPRT training helped her to increase parental empathy and awareness while also strengthening the parent-child relationship (Edwards et al., 2007). Though the authors noted that the implications cannot be generalized to all Jamaican mothers without further research, results of qualitative inquiry indicated that CPRT was helpful in increasing parental empathy, decreasing stress, and increasing the parent-child relationship.

Garza, Kinsworthy, and Watts (2009) used a phenomenology approach to study CPRT with three Hispanic parents. The authors asked eight questions as part of the interview process to examine the changes in the perceptions of parents upon completing CPRT. Garza et al. reported that all parents revealed changes in the child's behavior, changes in their views towards their child, and changes in child-parent relationship, including increased communication and warmth. The authors suggested that CPRT resonates with the Hispanic culture in several respects: 1) value for children to show respect to their parents or *respecto*; 2) importance of a close-knit family system; and 3) the investment of time and shared stories with other Hispanic parents.

Garza et al. concluded that the Hispanic parents in their study appeared to experience a warmer and more cohesive relationship with their children, as well as increased open communication. However, the authors cautioned that findings might have been influenced by researcher bias due to the co-leaders of the CPRT group also conducting the group interview.

Finally, Edwards et al (2010) used a qualitative design to examine the acceptability and perceived effectiveness of CPRT when administered in a school setting. Edwards et al defined acceptability as the participants' views of an intervention's usefulness and alignment with values, stating that acceptability is directly related in influencing overall treatment benefit. Parent comments from the research study, which included the training sessions and post intervention interviews, provided evidence of the acceptability and perceived effectiveness of CPRT. Edwards et al cited possible researcher bias as potential limitations to the study, as the lead investigator served as both a researcher and facilitator of the CPRT group. However, the two additional participating researchers had no contact with the participants and provided an objective perspective. In addition, the researchers ensured trustworthiness through prolonged engagement, triangulation, audit train, and persistent observation. Based upon the findings, Edwards et al recommended that future research continue to explore the acceptability and usefulness of CPRT, as well as explore the potential role of the school counseling in facilitating CPRT and in overall capacity building.

# APPENDIX B COMPLETE METHODOLOGY

#### Introduction

The purpose of this study was to investigate the experiences of parents of children with

High-Functioning Autistic Spectrum Disorders (HFASD) before, during, and after their participation in Child-Parent Relationship Therapy (CPRT; Landreth & Bratton, 2006) using a phenomenological method of qualitative inquiry (Creswell, 2007; Moustakas, 1994). Specifically, the primary researcher investigated the perception of parents with children with HFASD concerning the structure and content of CPRT. The researcher also examined the perceived impact of CPRT on the parent, the child, and the parent-child relationship. A detailed description of the research questions, instrumentation, participant selection, data collection, and qualitative analysis used for this study follows.

#### **Research Question**

What are the experiences of parents of children with High-Functioning Autistic Spectrum Disorders (HFASD) before, during, and after their participation in CPRT? Specifically, what are the perceptions of parents with children with HFASD concerning the structure and content of CPRT and the perceived impact of CPRT on the parent, the child, and the parent-child relationship?

#### Definition of Terms

*Parents:* For the purpose of this study, the term 'parents' refers to the primary caregivers of children with HFASD participating in this study.

Child-parent Relationship Therapy (CPRT). Landreth and Bratton (2006) define CPRT as the following:

a unique approach used by professionals trained in play therapy to train parents to be unique therapeutic agents with their own children through a format of didactic instruction, demonstration of play sessions, required at-home laboratory sessions, and supervision in a supportive atmosphere. Parents are taught basic child-centered play therapy principles and skills including reflective listening, recognizing and responding to children's feelings, therapeutic limit setting, building children's self-esteem, and structuring required weekly play sessions with their children using a special kit of selected toys. Parents learn how to create a nonjudgemental, understanding, and accepting environment that enhances the parent-child relationship, thus facilitating personal growth and change for the child and parent. (p. 11)

Bratton, Landreth, Kellam, & Blackard (2006) published a structured protocol entitled Child Parent Relationship Therapy (CPRT) Treatment Manual: A 10 Session Filial Therapy Model for Training Parents, which was followed for this research study.

Child-of-Focus: The child of focus refers to the child selected by the parent for participation in play sessions. For the purpose of this study, the child of focus selected by parents had received a diagnosis of High-Functioning Autism, Asperger's Disorder, or PDD-NOS, collectively referred to as *High-Functioning Autistic Spectrum Disorders (HFASD)*.

High-Functioning Autistic Spectrum Disorder (HFASD). HFASD was operationalized as a diagnosis of high-functioning autism (HFA), Asperger's Disorder, or PDD-NOS received by the child-of-focus through the local school district, mental health professional, and/or physician prior to participation in this study. HFASD was also operationalized as Total Score of at least 15 on the Social Communication Questionnaire (SCQ, Rutter, Bailey, & Lord, 2003).

#### Screening Instrument

The *Social Communication Questionnaire* (SCQ, Rutter, Bailey, & Lord, 2003) is a 40item, parent-report screening measure that assesses the symptoms associated with autistic spectrum disorder (ASD). The SCQ items are administered in a categorical *yes/no* response format and can be completed by the primary caregiver in less than 10-minutes, and then scored by the administrator in less than 5-minutes. The SCQ is available in two forms. *The SCQ Form: Lifetime* references the individual's entire developmental history, while the *SCQ: Current* is completed with reference to the individual's behavior during the past three months (Rutter et al, 2003). For the purpose of screening ASD symptoms across the lifespan, the *SCQ Form: Lifetime* will be used for this study and further reference to the SCQ will refer to the *SCQ Form: Lifetime*.

The principal caregiver most familiar with the developmental history and current behavior of the individual being assessed should complete the SCQ (Rutter et al, 2003). The SCQ is applicable to individuals whose chronological age is at least 4.0 years and whose mental age is at least 2.0 years. No professional help is required to complete the SCQ and parents may complete the instrument without direct supervision. Interpretations based upon results of the SCQ should be undertaken under the supervision of an individual who has professional training in the care and treatment of persons with ASD (Rutter et al, 2003a).

Question selection for the SCQ is based on the *Autism Diagnostic Interview-Revised* (ADI-R; Rutter, Le Couteur, & Lord, 2003), which is used to diagnose ASD based upon *ICD-10* (World Health Organization, 1992) and *DSM-IV* (APA, 1994) diagnostic criteria. The ADI-R is a 93-item structured interview that takes 1 ½ - 2 ½ hours to complete and elicits an authoritative account and an individual's developmental history relevant to ASD (Rutter et al, 2003). The SCQ question items were deliberately chosen to match the ADI-R items found to have the most discriminate validity and provide an operational diagnosis based upon three areas of behavioral functioning: Reciprocal Social Interaction; Communication; and Restricted, Repetitive, and

Stereotyped Patterns of Behavior. The content coverage of the SCQ, while briefer, is parallel to that of the longer ADI-R interview, making it suitable for use with similar populations.

The primary, validated application of the SCQ is to interpret the single Total Score with reference to the recommended cutoff score. The Total Score for the SCQ ranges from 0-40. For each item, a score of 1 (indicating *yes*) is given if a behavior is present and a score of 0 (indicating *no*) is given for its absence (Rutter et al., 2003). The cutoff score identifies individuals likely to suffer from ASD and for whom extended evaluations are recommended. The developers of the SCQ recommend a cutoff score of 15 or greater as an indication of possible ASD. According to Rutter et al., a cutoff of 15 will inevitably generate a proportion of false positives (cases when the SCQ cutoff score suggests autism, but when more complete evaluations do not support the diagnosis), such as with individuals who may suffer from profound or severe intellectual disability or individuals whose mental disorders include sociocommunicative deficits or repetitive behaviors. Thus, the recommended cutoff score of 15 represents the best compromise between false negatives and false positives.

The SCQ was developed upon a research sample consisting of 200 individuals age 4-40 years who had participated in previous studies of ASD and whose primary caregivers had received the ADI-R at some point prior to completing the SCQ (Rutter et al, 2003). From this sample, 160 individuals had been diagnosed with ASD (83 with autism, 49 with atypical autism, 16 with Asperger's syndrome, 7 with fragile X anomaly but not autism, and 5 with Rett syndrome). The remaining 40 individuals possessed non-ASD diagnoses (10 with conduct disorder, 7 with specific developmental language disorder, 15 with mental retardation, and 8 with other psychiatric diagnoses).

Four steps were taken to assess the diagnostic validity of the SCQ based upon the sample. The factor structure was explored for SCQ items using principal component factoring with varimax rotation, which yielded four factors that accounted for 42.4% of the total variation in the SCQ data (Rutter et al, 2003). The alpha reliability coefficient for the total scale was .90. Receiver-Operating Characteristics (ROC) analyses demonstrated that the SCQ is high in differentiating ASD (including autism) from non-ASD conditions and differentiates effectively between autism and mental retardation and autism and non-autism diagnoses other than mental retardation, but is less able to differentiate between autism and other ASDs (Rutter et al, 2003). Using 15 as the cutoff score for autism and non-autism, the sensitivity was .85, specificity was .75, positive predictive value was .93, and negative predictive value was .55. Using a cutoff of 15 or more gave a sensitivity of .96 and a specificity of .80 for autism versus other diagnoses (excluding mental retardation) and a sensitivity of .96 and a specificity of .67 for autism versus mental retardation. Examination of the ROCs for the Total Score suggested 15 or more as the standard optimal cutoff for differentiating ASDs (including autism) from other diagnoses.

At the time of the publication of the SCQ manual (Rutter et al, 2003), 214 cases comprised of 177 males and 37 females, ranging in age from 2-18 years, had been analyzed to determine psychometric properties of the SCQ. Group 1 contained individuals with diagnoses of autism. Group 2 had individuals diagnosed with Asperger's Syndrome and PDD-NOS. Group 3 had individuals with non-ASD diagnoses, including language impairment, mental retardation, and ADHD. The groups consisted of roughly the same number of males and females across the full age range of the sample (Rutter et al, 2003). The alpha index of internal consistency of SCQ scores was fairly uniform across groups, ranging from .84 to .93 with increasing age, with

standard error measurement (SEM) very uniformly across age groups. According to Rutter et al, the results suggest that individual children are reliably measured by the SCQ Total Score.

Since the development of the SCQ, it has received significant scrutiny, with 10 additional studies examining its diagnostic validity over many ages (seventeen months through forty years) and samples (Norris & Lecavalier, 2010). Among these studies, Corsello et al. (2007) examined the SCQ with children aged two to sixteen years (n = 590). Diagnoses were confirmed via consensus by two experienced clinicians using DSM-IV criteria following a clinical evaluation, which included the ADI-R and ADOS. Sensitivity and specificity were examined across ages and between ASD and non-ASD, autism and non-ASD, and autism and non-autism (i.e., those with PDD-NOS and non-ASD) groups. Values for these three groups were similar to each other, but lower than reported in the development sample. Sensitivity for the final group was very low (.45). Overall, Corsello et al. found that the SCQ may be better at identifying children over seven years of age than younger ones.

Eaves, Wingert, and Ho (2006) examined discriminant validity of the SCQ in children aged four to six years (N = 94). DSM-IV diagnoses were determined by a multidisciplinary team evaluation using data from the Childhood Autism Rating Scales (CARS). They found that sensitivity approached an acceptable value (.74), but specificity was low (.54). Chandler et al. (2007) found high sensitivity and specificity values when differentiating ASD vs. non-ASD children (.88 and.72, respectively) and autism vs. those with other ASDs (.90) or no spectrum diagnosis (.86) in a sample of school-aged children. For this sample, diagnosis was established by team consensus according to ICD-10 criteria and following administration of the ADI-R and ADOS. Charman et al. (2007) found similar values in a sample of nine to thirteen year olds (N = 119).

Eaves, Wingert, Ho, and Mickelson (2006) examined the diagnostic validity of the SCQ in a sample of children with a mean age of five years (n = 151) in which *DSM-IV* diagnoses were determined by a multidisciplinary team evaluation. They found that overall sensitivity was .71 in both a tertiary autism clinic and a preschool clinic, but specificity was better for the preschool (.62) than the autism clinic (.53). In this sample, Eaves et al. noted that SCQ was more effective screening lower-functioning rather than higher-functioning children.

Finally, Lee, David, Rusyniak, Landa, and Newschaffer (2007) examined the SCQ in two hundred and sixty eight children (two hundred and fourteen with non-ASD diagnoses, fifty-four with ASD) aged three to five years. Parent report, in conjunction with school classification, and ADI-R and ADOS scores (when applicable) were used to determine group membership. Sensitivity was low (.54) while specificity was high (.92). Examining values within a subsample of three year-olds (N = 78) the authors found a sensitivity of .70 and specificity of .88.

In sum, research findings validate the SCQ as a screening questionnaire that provides a reasonable index of symptom severity (Rutter et al, 2003a), while Norris and Lecavlier (2010) indicate that the SCQ has usefulness as a screening tool. Areas of further inquiry for the SCQ include the age range most appropriate for the SCQ, with four years being the recommended minimum. Thus, the minimum age for children of parents participating in this study will be set at four to be consistent with the SCQ manual. Moreover, the recommended Total Score cutoff of 15 will also be used for purposes of this study based upon the assertion by Rutter et al (2003a) that a cutoff of 15 represents the best compromise of false negatives and false positives.

#### Participant Selection

Before recruiting participants, I solicited human subject's approval from the University of North Texas Institutional Review Board (IRB). After obtaining IRB approval, I recruited participants from the community using criterion sampling (Creswell. 2007). According to Creswell (2007), "Criterion sampling works well when all individuals studied represent people who have experienced the phenomenon," (p. 128), which for this study included parents of children with HFASD participating in CPRT. I developed a flier detailing the criteria required for participation in this study and distributed it through professionals in the community. The flier specified that parents participating in the study would receive \$100 for their full participation, which included participation in the pre-interview, ten CPRT sessions, post-interview, and completion of five 30-minutes play sessions with their child of focus, during which they would practice skills learned during the CPRT group sessions.

Because illuminating the specifics of participant experience, rather than generalizing results, is the intent of phenomenological qualitative research, overall sample size tends to be small for such studies (Creswell, 2007). For phenomenological research, Dukes (1984) and Creswell (2007) recommend 3-10 participants. After undergoing recruitment and screening procedures, the CPRT group used for this study included five parent participants, two of which constituted a married couple. The participants in this study met the following requirements:

- 1. Parents had at least one child of chronological age between 4 and 8 years who they selected as their child-of-focus.
- 2. The child-of-focus was not currently receiving play therapy counseling services.
- 3. The parent of the child-of-focus consented to participate and signed the informed consent.
- 4. The parents' child-of-focus met the requirements for a diagnosis of HFASD as measured by standards set forth by their local school district, mental health professional, and/or physician. Each participant provided official documentation (i.e. assessment report from

- the school psychologist or community mental health professional) to validate the diagnosis.
- 5. The parents' child-of-focus met the requirements for a diagnosis of HFASD as measured by a pre-selected screening instrument, which included a Total Score of at least 15 on the *Social Communication Questionnaire* (SCQ, Rutter, Bailey, & Lord, 2003.

In summary, I recruited five parents of children with HFASD to participate in one CPRT group. Each parent gave consent to participate and signed the IRB-approved informed consent. I met with the parents in person on a designated day to review the purpose of the study, explain an overview of the study, answer questions, and administer and collect informed consent. The parents also had as their child-of-focus a child of chronological age between 4-8 years who was not currently receiving play therapy services. The child-of-focus met the requirements for a diagnosis of HFASD as measured by diagnostic criteria set forth by their local school district, mental health professional, and/or physician. Finally, parents who met the criteria and signed the informed consent were asked to complete a screening instrument related to their child-of-focus. To qualify for participation in the study, the child-of-focus met the requirements for a diagnosis of HFASD as measured by a Total Score of at least 15 on the *Social Communication Questionnaire* (SCQ, Rutter, Bailey, & Lord, 2003).

#### **Descriptions of Participants**

Of the five parents (N = 5) meeting the criteria for participation, which included four females and one male, all identified as Caucasian. All of the participants were married with two of the participants being a married couple (husband and wife). Four participants were the biological parent to their child-of-focus and one participant was the maternal grandmother and primary caretaker to her child-of-focus. Four of the participants worked full-time while the fifth

was not currently employed. Four participants reported having received undergraduate degrees from four-year universities while the fifth reported receiving some college from a four-year university. Although specific incomes levels were not collected for this study, all participants reported either as middle-class or upper-middle class SES. Regarding their children, four participants reported having received training in various interventions related to parenting a child with high-functioning autism which typically included behavior interventions such as applied behavioral analysis, social skills groups, and speech therapy. The fifth participant, who was the grandmother to her child of focus, reported that her grandson's diagnosis was recent and that the CPRT group was the first intervention she had attempted for her child-of-focus. All participants spoke English as their first language. All participants completed all ten session and research interviews. They received \$100 for their participation to compensate for transportation and mileage costs.

Table 5

Parent Demographics

Participant	Age	Gender	Family Status	Ethnicity	Relationship to Child-of-Focus
Carly	48	Female	Married	Caucasian	Maternal
					Grandmother
Mary*	35	Female	Married	Caucasian	Biological Mother
Dave*	43	Male	Married	Caucasian	Biological Father
Hannah	40	Female	Married	Caucasian	Biological Mother
Madeline	38	Female	Married	Caucasian	Biological Mother

<sup>\*</sup>Married Couple participating in CPRT Group

Table 6

Child-of-Focus Demographics

Participant	Child-of-Focus	Gender	Age	Diagnosis
Carly	Eric	Male	8	HFA
Mary and	Aaron	Male	8	Asperger's Disorder
Dave				
Hannah	Jack	Male	5	PDD-NOS
Madeline	Zane	Male	5	HFA

### Structure of the Study

This study was divided into three distinct phases: (1) Pre-intervention interview (2) CPRT treatment intervention (3) Post-intervention interview. A detailed description of each phase of the research study follows.

#### Pre-Intervention Interview

The pre-intervention interview occurred during the initial screening of each participant and took place only after it was determined that participants met the criteria for inclusion. The pre-intervention interview (see Appendix A) ranged in duration from approximately 30-minutes to just over one hour, depending upon the detail of the participant's answers. The pre-intervention interview questions followed a semi-structured format and covered topics such as details of the child's diagnosis, the parental needs experienced by the parents, the participant's current home life, the quality of the relationship between the participant and their child, and the participant's expectations of the CPRT group. At times, the I asked open-ended questions to encourage greater depth of answering and such questions were guided by the responses of the participant.

#### **CPRT** Treatment Intervention

The CPRT treatment intervention began after all five participants had completed pre-

intervention interviews and was facilitated by me. During CPRT training, which took place in 10-sessions over nine weeks, parents learned child-centered play therapy skills including: reflective listening, therapeutic limit setting, and self-esteem building. The curriculum content and procedures utilized during the training followed the published 10-session CPRT protocol (Bratton et al, 2006). All sessions took place at community counseling clinic appropriately equipped for group counseling. Childcare was provided for participants during each group meeting.

When facilitating CPRT sessions, I followed the protocol of the CPRT manual (Bratton et al., 2006). However, because parent participants shared the experience of raising young children with HFASD, they often expressed common concerns and questions related to this specific area of need. Thus, I remained flexible and used clinical judgment to meet the emerging needs of parents of children with HFASD while linking such concerns to CPRT content.

In addition to the group sessions, the participants were asked to conduct five play sessions with their child-of-focus during the last seven weeks of CPRT. The purpose of these play sessions was to allow the participants the opportunity to hone the skills learned during the CPRT sessions by practicing with their child during five 30-minute periods (Landreth & Bratton, 2006). Parents were given the choice of conducting play sessions in play therapy rooms located at the counseling clinic where the sessions took place or in their homes. All participating parents chose to conduct their play sessions at the counseling clinic. In explaining their decision, all participants cited chaotic home environments as their reason for conducting their play sessions at the clinic. This arrangement served to validate that all participants completed all five sessions.

Post-Intervention Interviews

The post-intervention interviews occurred during the week following the final CPRT session. The post-intervention interviews (see Appendix B) ranged in duration from approximately 30-minutes to just over one hour, depending upon the detail of the participant's answers. The post-intervention interview questions followed a semi-structured format and covered topics such as the participants' views of the structure and content of CPRT, their views on continuing and generalizing the skills learned during CPRT, and changes observed in themselves, their child, and in the parent-child relationship. At times, I asked open-ended questions to encourage greater depth of answering and such questions were guided by the responses of the participant.

#### Data Collection Procedures

The current study utilized three data sources: transcriptions of all pre-intervention individual interviews, transcriptions of the 10-week CPRT training, and transcriptions of all post-intervention interviews. Table 7 presents a description of each data source. For the interview portions of the study, the primary researcher followed the suggested interview protocol for qualitative research by beginning each interview session with rapport-building conversation (Fontana & Frey, 2005). Any statements made by the participants outside the scope of the interview were transcribed along with all responses during the interview. The primary researcher encouraged verbal comments by restating questions when necessary and probing for further explanation to increase depth of responding.

The pre-intervention interviews and CPRT sessions were video-recorded and transcribed verbatim on an Apple MacBook using the latest version of *Microsoft Word* and *Dragon Dictate* 2.0, which allows the me to speak into a microphone rather than typing on a keyboard to generate text in Microsoft Word. The post-intervention interviews were audio-recorded using a

microcassette recorder and were transcribed verbatim with the assistance of a microcassette transcription machine and typed in a word processor. Each transcription was checked for accuracy by comparing the transcription against what was said in the interview or session. Portions that could not be discerned were transcribed as "*inaudible*." Each transcription was formatted with line numbers and double-spaced.

Table 7 *Qualitative Data Collection* 

Data Source	Procedures
4. Pre-Intervention Individual Interviews	The pre-intervention individual interviews (see Appendix A) occurred before parents begin CPRT and last between 30-minutes and 1-hour. The interview was video-recorded and facilitated by the primary researcher. The primary research researcher inquired as to the parent's experiences being a parent to a child with HFASD, current family dynamics, and expectations of CPRT.
5. Transcriptions of 10- week CPRT Sessions	The 10 CPRT sessions were video-recorded and transcribed by the primary researcher. Each transcript began at the time the group began and concluded upon completion of each group.
6. Post-Intervention Individual Interview	The post-intervention individual interviews were audio-recorded (see Appendix B) and occurred upon completion of the scheduled 10 CPRT sessions. Information provided by parents during the pre-intervention interview and 10 CPRT sessions informed the content of the post-interview questions. Content included the parents' experiences of CPRT regarding the usefulness and acceptability of the intervention and the perceived impact on the parent, child, and parent-child relationship.

# Research Team

A research team trained in qualitative methodology coded and analyzed the data. The research team, which included the lead author and two doctoral counseling students, had

experience leading or co-leading at least one CPRT group and received advanced training in child counseling and play therapy. The lead author is a Licensed Professional Counselor and has worked with extensively with children diagnosed with autistic spectrum disorders (ASD) and their parents. The second member has experience working in private practice as a Licensed Professional Counselor with children with ASD and their parents. The third member is a Caucasian female who has worked with children and parents using play therapy and CPRT.

Prior to beginning data analysis, we bracketed our biases, assumptions, and experiences (Moustakas, 1994). The purpose of bracketing was to openly discuss our thoughts, feelings, and values regarding the research study to prevent potential bias from interfering with the process of analysis. We discussed our views of CPRT, HFASD, families of children with HFASD, other interventions used for HFASD, and the usefulness of qualitative research. We revisited the bracketing process throughout data analysis when potential biases emerged.

## Data Analysis

The research team met over a period of four months for theme analysis. We followed the procedures for thematic analysis recommended by Creswell (2007) and Huberman and Miles (1994). The steps used for analysis are detailed in Table 8. During analysis, the three data sources were analyzed consecutively in the following order: (1) pre-intervention interviews (2) CPRT session transcripts (3) post-intervention interviews, so that we repeated the steps for data analysis three times, once for each data source. The goal of data analysis was to develop a single coding manual with a mean intercoder agreement of 85-93% (Bakeman & Gottman, 1997) to apply to all data sources used for this study.

In the first step of analysis, the primary researcher introduced the purpose of the study and goals of qualitative analysis. We was oriented to Huberman and Miles' (1994) and

Creswell's (2007) procedures for qualitative data analysis and provided an example of the coding process. The primary researcher also introduced the research questions and facilitated discussion of potential biases that might influence the coding process. We discussed its views of CPRT, the needs of children with HFASD and the needs of their parents, views of qualitative research, and the viability of other interventions for parents of children with HFASD. When potential biases emerged, we discussed strategies for reducing such bias to maintain the integrity of the coding process. The discussion of potential bias was an ongoing process throughout the research study to preserve the integrity of the study throughout.

The second step of analysis, sketching ideas and making margin notes, consisted of we independently analyzing a portion, or subset, of the data source under consideration. The data subset of the pre-intervention interviews comprised 51.6% of the total data source, the data subset of the CPRT sessions comprised 35.4% of the total data source, and the data subset of the post-intervention interviews comprised 39.4% of the total data source. For each subset, we wrote margin notes and reflective passages on the transcripts. These margin notes were based upon ideas and reflections elicited by the material (Huberman & Miles, 1994). In order to facilitate the inductive discovery of emerging themes, members of the research team had no restrictions placed upon them when generating margin notes. When we had completed the margin notes for the data subset, they reconvened to create a comprehensive database containing the generated margin notes, which were entered into an electronic spreadsheet.

In the third step of data analysis, we discussed margin notes, including points of agreement and disagreement, to achieve consensus of what was observed. We developed a final summary representing consensual agreement of the margin notes (Huberman & Miles, 1994). This final draft summary sheet was entered into an electronic spreadsheet.

In the fourth step of analysis, we collapsed the draft summary sheet and worked with words (Creswell, 2007). In this step, we identified emerging themes in the data subset by collapsing data, developing key phrases, and discussing the meanings of these phrases. The researchers formulated key phrases based on their own interpretations and familiarity with the research questions. The researchers then compared and contrasted key phrases that emerged, which were reformulated and grouped into separate categories (Huberman & Miles, 1994). To reach the goal of identifying 6-8 meaningful themes, the researchers further reduced the information and eliminated redundancy by collapsing categories, reformulating category headings, and developing preliminary codes related to the data (Creswell, 2007; Huberman & Miles, 1994).

During the fifth step of analysis, we established intercoder reliability by independently applying the preliminary coding manual to the data subset (e.g., Marques & McCall, 2005). We coded transcripts by breaking them down the text into chunks of ten lines. For instance, when a member of the research team determined that a code appeared in a particular chunk, they coded that section with a number corresponding to the theme. The primary researcher then determined interrater reliability by assessing the percent agreement of themes coded by the team. The process of testing and revising of the preliminary coding manual continued until we reached a recommended intercoder reliability of at least 85% (Bakeman and Gottman, 1997) for each transcript in the data subset. When we hit 85% intercoder reliability for the subset, the coding manual was finalized for the data source.

In the final step of analysis, we applied the finalized coding manual to the remaining transcripts in the data source. To ensure continued intercoder reliability, we independently coded a minimum of 66% of the total dataset (Marques & McCall, 2005) and held continued coding

meetings to account for discrepant coding and coder drift. When we reached a mean agreement of at least 85%, the coding manual was finalized and temporarily set aside.

At this point, data analysis began again for the next data source. When analyzing the second and third data sources, themes emerging from analysis of the previous data source were considered in the development of the new coding manual. Because all data sources concerned the same participants across a related experience, themes from the previous analysis carried over as meaningful and relevant. Carrying themes across each analysis promoted the development of a single coding manual to apply across all data sources.

Data analysis continued until all data sources were coded in their entirety. After analyzing approximately 11,980 lines of transcription data across three data sources, we reached a mean intercoder reliability of 87% for the final coding manual, which fell within the accepted range of 85-93% recommended by Bakeman and Gottman (1997).

Table 8
Steps in Qualitative Data Analysis

Steps	Procedures
Introduction and Overall Discussion of Procedure	Introduced coders to study and oriented coders to plan for data analysis.  Oriented the research team to the research questions and facilitated a discussion of potential biases that may influence the coding process. This step was conducted only prior to the analysis of the pre-intervention interview data source.
Sketching Ideas and Making Margin Notes	The research team analyzed the initial data set by writing margin notes and reflective passages (Huberman & Miles, 1994). The research team examined the data, noting ideas and reflections elicited by the material to create a database that contained all field notes generated by the team.
Summarizing Field Notes	During weekly coding meetings, the research team compared margin notes, discussed ideas, points of agreement, and discrepancies, and developed a draft summary sheet of the initial dataset (Huberman & Miles, 1994). This summary sheet included notes that were consistent among all researchers.
Collapse Data & Working With Words	The research team used the draft summary sheet to compare and contrast key phrases, reformulate and group key phrases into separate categories, and develop preliminary codes related to the data (Huberman & Miles, 1994) to develop a preliminary coding manual.
Initial Coding	The research team used the preliminary coding manual to independently analyze the initial dataset to establish intercoder reliability (e.g., Marques & McCall, 2005). The research team discussed results and clarified discrepancies, which continued until establishing an intercoder reliability of at least 85% (Bakeman & Gottman, 1997) for each transcript of the data subset.
Final Coding	The research team applied the finalized coding manual to the remaining transcripts in the data source. To ensure continued intercoder agreement, all three members of the research team independently coded a minimum of 66% of the data (Marques & McCall, 2005). Weekly coding meetings accounted for discrepant coding and coder drift. The coding process was repeated for each data

# Trustworthiness

To facilitate rigor during analysis of the training sessions and interviews, the researcher employed specific strategies to enhance trustworthiness. To ensure trustworthiness (Lincoln & Guba, 1985; Patton, 2002), the researcher utilized the following:

- *Reflective Journal:* The purpose of the reflective journal was to elucidate potential researcher bias and provide another data source from a perspective of a person involved in the phenomena being studied (Charmaz, 2006). The researcher made journal entries upon completion of each of the ten CPRT group meetings, which contained the researcher's personal reflections of the group experience.
- *Triangulation*: The researcher compared and contrasted training session transcripts with both the interview data and in-class observations of parents' videotaped at-home play sessions.
- *Audit trail*: The researcher maintained a detailed account of the raw data, data reduction and analysis, informed consent documents, development of interview protocols, and the coding manual throughout the duration of the study.
- *Thick description*: The researcher depicted the training, research procedures, context, and participants with enough detail so that persons not connected to this study could assess the potential for application in similar settings.

# APPENDIX C

UNABRIDGED RESULTS

#### Introduction

The purpose of this study was to capture the lived experiences of parents raising children with high-functioning autistic spectrum disorders (HFASD) participating in a 10 session group training of Child-Parent Relationship Therapy (CPRT; Landreth & Bratton, 2006). The experiences of these parents were explored using qualitative methods following a phenomenological research design. At the time of this study, no research existed which examined how parents of children with HFASD might experience the content and structure unique to CPRT as a parent-education program. The research question that guided this qualitative inquiry was:

What are the experiences of parents of children with High-Functioning Autistic Spectrum Disorders (HFASD) before, during, and after their participation in CPRT? Specifically, what are the perceptions of parents with children with HFASD concerning the structure and content of CPRT and the perceived impact of CPRT on the parent, the child, and the parent-child relationship?

The results of this investigation may help inform the appropriateness of CPRT for these parents and lead to further research that explores how better to meet these needs. Moreover, the results of this research may highlight particular needs of these parents with regards to the parent, the child, and parent-child relationship, as well as inform future studies to investigate these needs as they fit within the structure and content of CPRT. In the remaining sections of this chapter, I will present an overview of the data collection and analysis, descriptions of the participants, and the themes that emerged from the data.

#### Review of Data Collection and Analysis

The three data sources comprising this study included transcriptions the pre-intervention interviews, the 10 CPRT sessions, and the post-intervention interviews. Data collection for this investigation was conducted through individual interviews and transcriptions of each of the ten CPRT sessions. During the individual interviews, parents answered questions about their experiences as a parent to child diagnosed with HFASD, including their experiences during the diagnostic process, strategies and interventions they had attempted since the diagnosis to help their child, and their identified needs related to being a parent to a child with HFASD. In addition, parents were asked to describe their child's interests and current role in the family. Finally, parents were asked to describe their expectations for the CPRT group, including what they wanted to learn from their participation. Each parent was interviewed individually before and after the CPRT intervention. The interviews were video and audio recorded and transcribed by the primary researcher. In addition to the pre- and post-intervention interviews, each of the 10-sessions were video-recorded and transcribed by the primary researcher. Interim analysis began immediately following the conclusion of the pre-intervention interviews.

The research team, consisting of the primary researcher and two counseling doctoral students, began by bracketing previous experiences and assumptions that might bias the data analysis (Moustakas, 1994). After discussing and clarifying potential biases, we began the process of analyzing the three data sets. Each data set was analyzed consecutively in the order of pre-intervention interviews, CPRT transcripts, and post-intervention interviews. For each dataset, a subset was randomly selected for initial analysis. We read and reread the subset transcripts to grasp the overall feeling (Creswell, 2007; Huberman & Miles, 1994). In subsequent readings, we made margin notes that captured initial impressions of the data (Patton, 2002).

We then compared margin notes, discussed ideas, points of agreement, and discrepancies, and developed a draft summary sheet of the initial dataset (Huberman & Miles, 1994). We next compared and contrasted key phrases, reformulated and grouped key phrases into separate categories, and developed preliminary codes related to the data to develop a preliminary coding manual (Huberman & Miles, 1994). We then used the preliminary coding manual to independently analyze the data subset to establish intercoder reliability (e.g., Marques & McCall, 2005). We discussed results and clarified discrepancies, which continued until establishing an intercoder reliability of at least 85% for each transcript of the data subset. Upon establishing 85% or greater intercoder reliability for the data subset, we applied the finalized coding manual to the remaining transcripts in the data source. To ensure continued intercoder agreement, all three members of the research team independently coded a minimum of 66% of the data (Marques & McCall, 2005). Weekly coding meetings accounted for discrepant coding and coder drift. The coding process was repeated for each data source.

When analyzing the second and third data sources, themes emerging from analysis of the previous data source were considered in the development of the subsequent coding manual. At the conclusion of analysis of the third data set, we developed a single coding manual that represented emerging themes for the three data sources. The intercoder reliability for the final coding manual was .87, within range of the recommended .85-.93 intercoder reliability recommended by Bakeman & Gottman (1997).

## Participant Demographic Profiles

The participants included five parents of children diagnosed with high-functioning autistic spectrum disorders (HFASD). Table 9 summarizes the demographics of the participants. Of the five participants, 4 were female and one was male. All of the participants were married,

and two of the participants in this group were a married husband and wife couple. The ages of the participants ranged from 35 to 48. Each of the five participants identified as Caucasian. All participants reported having some college and three reported having received degrees from four-year institutions. The length of time that each parent spent participating in the interviews and CPRT intervention was approximately 25 hours over 11 consecutive weeks.

Table 9

Participant Demographics

Parent	Age	Gender	Family	Ethnicity	Child-of-	HFASD	Relationship to
			Status		focus	Diagnosis	Child-of-Focus
Carly	48	Female	Married	Caucasian	Eric (8)	HFA	Maternal
							Grandmother
Mary*	35	Female	Married	Caucasian	Aaron (8)	Asperger's	<b>Biological Mother</b>
Dave*	43	Male	Married	Caucasian	Aaron (8)	Asperger's	Biological Father
Hannah	40	Female	Married	Caucasian	Jack (5)	PDD NOS	<b>Biological Mother</b>
Madeline	38	Female	Married	Caucasian	Zane (5)	HFA	Biological Mother

<sup>\*</sup>Married Couple participating in CPRT Group

As part of their participation in CPRT, the parents selected a child-of-focus to work with throughout the intervention, which for the purposes of this study included their child who was diagnosed with a high-functioning autistic spectrum disorder (HFASD). Four of the participants, including the participants constituting the married couple, were the biological parents to their child-of-focus, while one participant was the maternal grandmother and primary caretaker to her child-of-focus. The married couple had one child diagnosed with HFASD in their family, so they each selected the same child as their child-of-focus. Therefore, there were four children-of-focus selected by participants for this study. The children-of-focus ranged in age from five to eight.

Two of the children were diagnosed with high-functioning autism, one child was diagnosed with Asperger's Disorder, and one child was diagnosed with Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS). All of the children were enrolled in public school, with two

children in pre-kindergarten and two children in second grade. All of the children were gradeappropriate for their age. Additionally, three of the four children were receiving special services
in school because of their diagnosis, while the fourth was in general education and not receiving
special services. As part of the CPRT training, three of the children participated in five special
play times with their parent, while the child of the married couple participated in ten special play
times, five play times for each parent.

### Results

The results are divided into two sections. In the first section, parents are introduced individually, along with their child-of-focus. The textual descriptions provide a clearer understanding of the participants in the study and a context for their experiences in CPRT (Moustakas, 1994). This introduction also provides a thick description for the families, which is the "foundation for qualitative analysis and reporting" (Patton, 2002, p. 437) and promotes the trustworthiness of the study. In the second section, the identified themes are presented to provide a structural description of the essence of the experience of the participants (Moustakas, 1994) and will be explained and supported through representative quotes from participants.

*Introduction and Description of Participants* 

Each participant is detailed through a description of information shared during the initial screening and pre-intervention interview, as well as contained within the primary researcher's reflective journal. Each participant provided general demographic information and completed the pre-intervention interview during the initial meeting with the primary researcher. During the pre-intervention interviews, the participants were asked about the diagnostic process that their children-of-focus underwent when the received a diagnosis of HFASD, as well as any services or interventions the children-of-focus received. The participants were also asked about their

perceptions of the parent-child relationship and what they identify as challenges they face and their needs as parents to children with HFASD. They were asked to describe their current home life and the role of the child-of-focus in the family context. Finally, they were asked to discuss their goals and expectations of upcoming the CPRT group. Table 9 summarizes the demographics of the participants.

## Hannah and Jack.

Hannah is a 40-year old Caucasian mother of five-year old Jack. Hannah has a four-year college degree and works in a sales position for a technology company. Hannah is married to Jack's biological father, who identifies as Asian American, and also works in sales. Hannah noted that she and her husband both work full-time and travel often for business trips.

During the initial interview, Hannah presented as confident and professional. She spoke assertively and was concise in her responses. She shared that Jack was diagnosed with PDD-NOS in March of 2009, but that he tends to display only a few features associated with children on the autistic spectrum, such as speech delay, problems in social situations, and narrowly focused interests. She said that she and her husband were originally concerned about Jack's speech development, which was behind what they considered developmentally appropriate. They inquired with Jack's pediatrician about the speech delay, and while the pediatrician seemed less concerned than Jack's parents, she raised the possibility of Asperger's or autism. The pediatrician suggested that Hannah and her husband wait six months before any further testing.

Hannah shared that they followed their pediatrician's advice, but that Jack's speech development failed to improve over time. Still concerned, Hannah asked a friend, whose sister who was a psychiatrist, for some advice on how to proceed. Hannah eventually received a

referral for further assessment for Jack. Shortly after receiving the referral, Jack underwent a series of assessments and was diagnosed with PDD-NOS.

Upon receiving the diagnosis, Hannah shared that she felt "sad, but relieved." She stated that she and her husband were happy to know what was going on with Jack so that they could develop a plan to move forward with him. She mentioned that it took some time to develop a plan to help Jack and that they first tried applied-behavioral analysis (ABA). They enrolled Jack in an ABA group that met several times per week for approximately nine months. She stated that the ABA group helped Jack with his speech development and that she was pleased with the results. She shared that Jack is now in a special-needs pre-kindergarten class and that the school has focused on improving Jack's social interaction and speech.

Hannah stated that neither she nor personnel at Jack's school have experienced problems with Jack regarding hitting, violence, flapping, or other behavioral concerns often associated with autism, to which Hannah expressed considerable relief. She reported that Jack mostly likes to do his own thing in social situations, so helping Jack engage more with others has been a primary focus of intervention up to this point.

Hannah described her experience as a parent to a child with PDD-NOS as "a big learning experience." She said that she and her husband were sad initially, but "are working hard to try and turn it around, to make the best of the situation for Jack and for the family, and to give Jack the best future possible." Hannah identified as her needs as a parent to a child with PDD-NOS as "wanting to communicate with him in the best way" and "to help him grow emotionally and intellectually" as best as she can.

When describing how Jack stands out in the family, Hannah stated that he has "a great sense of humor and he's very loving and affectionate, and super smart." She mentioned that Jack

"loves to play outside, work with his hands, make little characters that he carries around, play video games, watch cartoons, and wrestle with his dad." She went on to describe Jack as "a jewel" in her life.

Hannah described her current home life as calm, but stressful at times. She stated that she and her husband both travel for work, which made it difficult to figure out how best to meet Jack's needs shortly after he received his diagnosis. She mentioned that things have stabilized recently and that they now have a nanny who is studying special education and whose brother is autistic, so they feel confident in her ability to be with Jack.

When describing what she wanted to gain from participating in the CPRT group, Hannah shared wanting "additional tools" to improve her communication and interactions with Jack. She reported that while her husband would not be participating in the group, that she wanted to share what she learns from the group with him and with those around Jack. She stated that her overall goal was for her and her husband to have an "improved relationship and communication" with Jack. Hannah also mentioned that she wanted to learn about children, autism, and parenting from the group leader. Finally, Hannah said she wanted to connect with other parents raising children with high-functioning autism.

### Madeline and Zane

Madeline is a 38-year old Caucasian mother of five-year old Zane, who was diagnosed with high-functioning autism (HFA) in June of 2009. Madeline has a college degree in elementary education and has taught elementary school, but at present she did not work and focused on raising Zane and his three-year old sister Tyesse.

When Madeline arrived for the initial meeting for the screening and pre-intervention interview, she presented as very intelligent and well spoken. She also presented as someone who

takes pride in doing things unconventionally. During the pre-intervention interview, she described her family as "earthy-crunchy," stating that they eat only organic foods, do not watch television or play video games, do not play with guns or any toys associated with violent activities, and only watch programs that have educational value. During the interview, Madeline talked at length about her and her family's background and current experiences. She appeared eager to share her perspective as a mother to a child with HFASD.

While Madeline was born and raised in the United States, she reported that she and her husband, who is Brazilian, were living in Brazil when Zane was born. She and her husband moved to the United States when Zane was very young due to the higher quality of education and resources available for children in the United States. Upon moving to the United States, Madeline's husband, who was working successfully as an engineer in Brazil, struggled to find a job, which resulted in the family moving frequently during the first years of Zane's life. She reported that her family lived in six states over four years. According to Madeline, what brought her and her family to Texas was the need for math teachers in public schools, a position for which her husband qualified. Her husband now works as a high-school math teacher.

Madeline reported that Zane received his diagnosis of HFA at 26 months of age through Early Intervention when the family was living Massachusetts. The initial concerns for Zane were delays in his speech development and lack of reciprocal communication. Madeline described that her reaction to the diagnosis as "painful," "like getting a death sentence" and "knowing that my child has something incurable." She reported never seeing the typical features associated with autism, such as head-banging, flapping, or mental retardation. She said that diagnosis did not fit her perception of him as "brilliant." She said that after she researched HFA further, many of the associated features fit with her observations of Zane. She noted that Zane received services for

HFA through the Early Intervention, but she waited to have the diagnosis placed in Zane's official school file due to her perception that autism was "over-diagnosed" in many children.

Madeline described Zane as "very affectionate." She said that Zane has always responded well to bathing, dressing, cuddling, and snuggling. She stated that he "receives attention beautifully" and gives it beautifully. She mentioned that as a family everyone sleeps together, describing her family as "very close that way." Madeline stated that when Zane is sleeping, she talks to him, thanking him for choosing her to be his mother and for teaching her about his world. Madeline stated that she believes she can "speak directly to his soul that way." In all, Madeline described her relationship to Zane as close and warm, stating that she "finds life magical with him."

She stated that Zane often passes as a typically developing child without HFA until people try to engage him in conversation, in which he struggles to engage in back and forth communication. She stated that she encourages Zane to always be around typically developing children so he has a peer role model to increase his social awareness and understanding. She stated that she takes Zane to the library to read and engages him in other cultural activities.

Madeline noted that reciprocal communication is one of Zane's goals for his school program and that he has received training on how to give appropriate responses to certain social cues. Madeline stated that she spends considerable time prompting Zane to use "socially appropriate responses." She also reported that Zane listens to stories on tape or CD, but that he tends to perseverate, or remember certain phrases and repeat them over again outside of the typical context. She described this behavior as a feature of autism by stating that when he perseverates, Zane loses contact with his surroundings, repeats the phrase in the same cadence,

and does not interject any additional words. She described this as a common behavioral feature for Zane.

Another concern Madeline reported for Zane is that he displays very rigid behaviors and interests, particularly when writing numbers or the alphabet. She stated that when Zane begins to write numbers, he will continue writing numbers in order until the sheet or board that he is writing on is completely filled. She reported that if someone were to interrupt Zane, he would start over again from "1" or "A," depending on what he was writing, and continue writing again. She stated that once he begins this behavior, he cannot stop until he feels he has reached the end.

Madeline described feeling very overwhelmed with her role as a parent. She stated that while she receives great support from her husband, he is often overwhelmed as well with his work, so that she feels much of the pressure to take care of Zane, whom she described as very challenging at times due to features associated with HFA. Regarding her needs as a mother to Zane, Madeline stated that she wanted to be more patient and observant of him and how he experiences the world.

Madeline displayed considerable enthusiasm about beginning CPRT and stated that she had been seeking an intervention focused on more humanistic aspects of parenting rather than the behaviorally focused models that she believes predominate the field of autism. When asked what she wanted to get from participating in the CPRT group, Madeline said that she wanted "to add more skills to her repertoire." She stated that anything she can learn to help Zane "that is a natural approach" would be beneficial. She also stated, "maybe I'd get to understand him better." She mentioned that her first instinct is to correct his behavior and that while she tries to show understanding she does not always know what to do after that. She also stated that she wants to have better awareness of Zane's needs and increase her ability to communicate with him.

Madeline also reported wanting to connect and share support with other parents raising children on the autistic spectrum. She stated that she often feels like she is the only one out there going through this, so "it would be nice to be with other family members who have been there." *Carly and Eric* 

Carly is a 48-year old Caucasian maternal grandmother to 8-year old Eric. Carly is married and has attended some college and works as a nurse in human resources for an assisted living facility. Carly reported that Eric's mother had struggled for some time with depression and substance abuse and that her pregnancy with Eric was unplanned. Carly and her husband agreed to take in Eric's mother during her pregnancy because she was "living on the street at the time." Since Eric was born, Carly has taken a primary role in helping to raise Eric and sought the CPRT intervention as a way to help her and her family with challenges they experience. Carly stated that Eric and his mother still live with her and her husband.

Carly presented to the initial screening and pre-intervention interview hours after Eric was diagnosed with high-functioning autism. Consequently, Carly was very emotional and shaken during the initial interview. However, Carly presented as dedicated to being a constant presence in Eric's life and wanting to help him. She stated that she had not planned to be raising another young child at this time in her life, but did not seem at all resentful of her role in Eric's life. In fact, she described her relationship with Eric as "very close," but that she has a hard time understanding Eric due to his many strange behaviors.

Carly mentioned that Eric's primary care physician had originally diagnosed him with ADHD and that he was taking medication for that. Carly stated that she first became concerned about Eric having autism when a friend who spent a lot of time with Eric, as well as worked with children on the autistic spectrum, mentioned that Eric might meet the criteria for a diagnosis.

Carly said that she disagreed at the time, arguing that Eric "was fine," but a little behind other children in his social development. However, Carly stated that when she started reading about autistic spectrum disorders, she noticed that Eric's behaviors fit with many of the associated features.

Eric was also beginning to have struggles in school with reading, writing, as well as his overall focus. Carly noticed that he was struggling to do things that her own son had done at an age much younger than Eric, such as riding a bike and throwing a ball. She also noticed that he was "obsessed with Spider-Man" and that he only wore clothes that had Spider-Man on them. She also had noticed that all of his Spider-Man figures have to be in a particular order, otherwise he becomes very agitated.

She went on to say that Eric "just doesn't seem normal like the other kids." When someone tries to talk to Eric, she stated that "he can't really converse with them." She went on to say that "he's in his own little mind talking about his own little thing and he doesn't really make eye-contact or, sometimes the things he says are kind of bizarre, but they're not, it's not funny bizarre." Carly reported that she has not tried any specific intervention to help Eric, but that she has made adaptations in her parenting style to compensate for his behaviors. She stated that she works with older people who have memory problems, and that when Eric gets stuck on a particular idea, she tries some strategies that she uses with this population that sometimes works with Eric.

Carly stated that Eric likes to play video games and spend time on the computer looking at YouTube. While on YouTube, Carly stated that Eric searches for videos that show other people displaying their Spider-Man collections. Eric then acts out what he saw on the video with

his own figures. According to Carly, Eric "likes to be like the people on YouTube." She also said that they have a dog with whom Eric frequently plays, but that he has no friends of his own.

Carly stated that Eric's relationship with his mother has been difficult. Because his mother is frequently depressed, she is often emotionally distant from Eric and sometimes snaps at him for no reason. However, Carly noted that lately Eric has become more aware of how his mom treats him, saying things to his mom thing like, "You really shouldn't yell like that" and "Don't call me a dummy." Carly said that Eric's mother is seeking services for depression, might be receiving counseling services soon, and was enrolling in a continuing education program to become a dental technician. Carly expressed considerable of relief about Eric's mother getting help soon.

Carly reported feeling a little relived at receiving a diagnosis of high-functioning autism for Eric. She described feeling like a bad grandparent because people think, "he's just a bad kid" when he "starts having tantrums or wants his way or won't stop talking." She stated, "People don't like him coming over to their house because he's probably going to throw a fit or won't share with the other kids." She went on to say that "if they understood that he can't help it and that we need help," that would be less isolating for her family. However, she stated that "he's never really been diagnosed with anything so they think he's doing it on purpose and that he's acting out, or acting that way on purpose and that he just needs to be disciplined."

Carly shared that she feels that people look at her like "you're not doing what you're supposed to do." Consequently, Carly stated, "We really don't like to take him places, to be honest. We stay home a lot." Carly went on to share that "it's tough because he's your grandkid, but like I said, people don't want you very much to come around with him, so it's been kinda tough, it's tough to take him places." When asked about the potential benefits of raising a child

with high-functioning autism, she shared, "I can't really think of a lot of rewards. I mean you love him because he's your grandchild. It's probably more difficult than rewarding most of the time."

Upon receiving the diagnosis, Carly reported feeling relieved knowing "that he's not just a bad kid or doing this on purpose." She described her current needs as "just helping him," and "to learn if it's possible for him to learn how to act in social situations or respond," while "learning ways to help him" was the main goal Carly gave for her participation in CPRT. She also stated wanting to learn ways to help Eric's mom "respond to him differently" and learn ways for her and Eric "to be able to communicate a little bit better." Carly also remarked "it will be nice to be with some other people that maybe understand some things that we've gone through in social settings, sometimes being the outcast, yeah, and how they've dealt with that." *Mary and Aaron* 

Mary is a 35-year old Caucasian mother to her 8-year old son Aaron. Mary has a college degree and works for the local school district as a teacher for homebound students, meaning students who are have sustained an illness or injury that prevents them from attending school. She is married to Aaron's father, Dave, who participated in the CPRT training with her.

Mary stated that Aaron received a diagnosis of Asperger's Disorder in December of 2009. Mary described Aaron's lack of social understanding, rigid behaviors, and narrow interests as her and her husband's initial concerns. According to Mary, she had a friend with a son diagnosed with Asperger's Disorder and that when she and her friend would talk about their sons, she noticed that many of the features her friend described resembled features she noticed in Aaron. She received a referral to a psychologist who diagnosed Aaron over the course of several interviews and assessments. She noted that she was not pushing for a diagnosis and that she

would be fine with whatever the assessments revealed, but that she wanted to know what was going on with Aaron. Mary stated that, "not knowing was extremely anxiety producing" She went on to say that "people would look at him strange" and that she would react like, "you know, I'm not raising a bad kid." She described other people's perceptions of her and Aaron as "frustrating" because "you want to defend your child, but at the same time you want them to behave."

Prior to the diagnosis, Mary described feeling stuck and unsure about what to do. Upon receiving Aaron's diagnosis, Mary described feeling "overjoyed." She reported that, "At least I know what's going on and now I know. I can focus on what I need to do to help him instead of just not knowing what to do."

Mary reported that she takes Aaron out to involve him in social interactions, and that she will "encourage him to try and play with someone." She stated that she would just try to get Aaron out and "expose him a little bit to things that were beyond his comfort level, but not to the point of having a meltdown." She also mentioned that Aaron was enrolled in a social skills group and that he has responded to the structured and organized nature of the play environment. She went on to say that Aaron often struggles in unstructured situations.

Mary described her experience as a parent to Aaron as "times of sadness, times of happiness." She described it as "an emotional roller coaster." When describing her experience with Asperger's, Mary stated that "it's not all bad, it's not a bad word. You know, there are some things that he has done that I'm really proud of." Mary noted that Aaron has multiple strengths, including being very intelligent, musical, and funny. She stated that he is extremely interested in rockets and space, and that he often dominates a conversation by sharing with others everything he knows about stars, planetary orbits, and the solar system. She mentioned that Aaron prefers to

do things by himself, but that "he also wants you to be near him." According to Mary, "it's not so much interaction one-on-one as you might think of with a child, it's kinda being there for him."

Mary also described difficulties associated with raising Aaron. She expressed that "you want him to go out and play with kids, you want him to, it's like you want him to do the things that typical kids do and he doesn't." But she said that she remembers that "he's not unhappy doing what he's doing," something she tries to remember when thinking about what he needs. She also mentioned that Aaron is prone to having meltdowns and tantrums, which she described as being difficult for her and her husband to control. She reported that these meltdowns are often exhausting and unpredictable. She stated that she often fears going into social situations with Aaron. However, even when describing challenges with Aaron, Mary's view of Aaron remained positive throughout the interview. When describing Aaron, Mary said, "I think he is a regular eight-year old. He just happens to have Asperger's."

When describing her needs as a parent to a child with HFASD, Mary said "definitely a need for a bond with other parents that are in a similar situation. Definitely not to feel isolated, not to feel alone." Mary stated that her feeling of isolation stems from having friends with typically developing children who struggle to understand what it is like to be a parent to Aaron.

From the CPRT group, Mary described wanting to get "any additional tools I can have in my little toolbox that will help me help him." She went on to say that she wanted to meet other parents who share her experience as a parent to a child with HFASD. From her participation in the group Mary said that she wanted Aaron "to be able to have things internally that he feels like he can really use," and she went on to say that she wants for Aaron "to be more independent."

Dave and Aaron

Dave is a 48 year-old father of 8-year old Aaron and the husband of Mary. Dave and Mary were interviewed separately and Dave's interview occurred after Mary's. Dave has completed some college and has worked as a telecommunications manager for an area hospital fro the past ten years. Dave lives with Mary, and his two sons, Aaron and Cameron. Dave's parents-in-law also live with Dave and his family. Dave described his current family situation as ranging from "measured chaos" to "total chaos" and that family drama is always present. Dave reported that his in-laws currently live with them because of his father-in-law's health problems, stating that he needs considerable care due to the stroke he sustained several years ago. While Dave described some benefits to the arrangement, he stated that it has created substantial stress for everyone in the home, including Mary, Aaron, and himself. The primary stressor that Dave identified is feeling undermined by his mother-in-law regarding his and Mary's parenting style.

Dave described Aaron as quiet compared to the rest of the people in the family, implying that the rest of the family is extremely loud by comparison. Dave jokingly described both of his sons as "surprisingly intelligent," but he explained this as only surprising when compared to him. He stated that Aaron does not play much with other kids because "there aren't a whole lot of kids in the family." When referring to Aaron's Asperger's tendencies, Dave stated that "there are times when it's obvious that he's definitely got a situation." Dave went on to say that Aaron "does kind of interact with the crowd, but he doesn't."

Dave stated that Aaron was originally identified as having problems by his pediatrician, but Dave reported feeling that he and Mary were originally perceived as being parents "who doesn't know how to cope." He stated that Mary first noticed possible Asperger's tendencies and when she began to worry they began seeking professional help. Shortly afterwards, Dave reported that Aaron was working with the psychologist who, in December of 2009, after a series

of assessments and interviews, made the diagnosis of Asperger's Disorder. Dave described the process of receiving a diagnosis as "pretty straightforward."

Dave shared that Aaron had undergone considerable medical procedures as a young child, saying that he was "horribly ill when he was three months old with RSV." He stated that Aaron had been in the hospital so many times that "we've lost track of how many times he's been in the hospital due to RSV or pneumonia." Dave went on to say that Aaron had undergone a vital stem treatment twice." Dave stated that Aaron "had not been allowed to have a normal childhood," and that he suspected that these treatments might have exacerbated a pre-disposition that Aaron possessed towards developing Asperger's Disorder.

Dave mentioned that Aaron struggles to make friends his own age, but gets along very well with adults and loves to spend time with babies. However, he said that Aaron wants to make friends and does spend some time with kids in the neighborhood his own age, but that these kids do not really like Aaron and only interact with him when they want something. Dave also said of Aaron's lack of friends that he wants Aaron to have friends and "to know what he is missing," but he worries that Aaron does not really understand what he is missing with regards to interpersonal relationships.

Dave mentioned that he and Mary have tried medication for Aaron to address his stress levels. Dave expressed concern about Aaron's meltdowns saying, "the less stress he seems to have in a school situation or with anybody else, the more responsive he is." When Dave described his thoughts about Aaron taking medication, Dave continued by saying, "can't say that I'm thrilled with it." Regarding therapeutic interventions, Dave said, "as far as therapy, no, we haven't done therapy."

Dave described as his goals for participating in CPRT as wanting "better tools, and not only better tools for Aaron, but also for Mary and I," and went on to say that he wants "better tools for the whole family." For Aaron, Dave said that he wants "a way to make it so that he can have better days, maybe a better future." At this point, Dave expressed his concern that Aaron will be unable to care for himself after he and Mary are no longer here, and that he fears that Aaron might end up in an institution someday. Dave mentioned that he views CPRT as a possible way to help Aaron function more independently. However, Dave also reported that he had no idea exactly what CPRT is, so he was grateful to have any intervention. Dave also mentioned that he wanted his relationship with Aaron to "not be as confrontational to get things done when we need to get things done." Dave stated that he wanted to learn how to communicate the rules clearly to Aaron so that Aaron knows who is in charge. Above all, though, Dave said that he wanted to know "what tools am I missing." In addition, because he was participating in the group with Mary, Dave stated that he wanted the two of them to be more cohesive in their parenting approach to Aaron.

# **Emerging Themes**

The research team determined that eight distinct themes best represented the phenomenological experience of the five participants. The first cluster of themes concerned the parents' experiences of CPRT and included: *Understanding of CRPT Concepts, Reactions to CPRT*, and *Group Dynamic*. Table 10 presents the three identified themes concerning the parents' experiences of CPRT. The second cluster of themes concerned changes in the parent, the child, and the parent-child relationship and included: *Child Characteristic, Parent Characteristic, Knowledge and Experiences with HFASD, Family Context*, and *Parent-Child Relationship*. Table 11 presents the themes associated with changes in the parent, child, and

parent-child relationship. Each of the eight themes will be defined in the context of the participants' experiences and supported by participant quotes.

Table 10

Emerging Themes Related Parent Experiences in CPRT

N	Theme	Definition
475	Understanding of CPRT Concepts	Included the participants' comments regarding their experience learning the concepts of CPRT. Included participant comments related to the process of learning CPRT concepts.
338	Reactions to CPRT	Included the participants' goals for CPRT, opinions and reactions to CPRT (positive or negative), and perceptions regarding generalizing CPRT beyond the scope of the training
119	CPRT Group Dynamic	Included the participants experiences of being in CPRT as a group, such as group members linking shared experiences, questioning each other for clarification, and providing encouragement and support to one another.

Table 11

Emerging Themes Related to the Parent-Child Relationship

N	Theme	Definition
473	Child Characteristics	Included the participants' descriptions of their child-of-focus' behavior and/or characteristics, such as thoughts, feelings, behaviors, and interests. This category also included descriptions of the child's HFASD characteristics, as well as awareness of their children's, emotional, social, behavioral needs.
242	Parent Characteristics	Included the participants' descriptions of themselves, such as parenting practices, stressors, strengths, and general parenting goals (did not include goals related to CPRT).
203	Knowledge and Experiences with HFASD	Included the participants' experiences specifically related to HFASD, such as sharing their knowledge of HFASD, how they experienced the diagnostic process when their child was diagnosed with HFASD, how they experienced other people's perceptions of their children with HFASD, and specific academic issues they experienced related to having children with HFASD.
156	Family Context	Included the participants' descriptions of their home life, such as family members beyond those participating in CPRT.
50	Parent-Child Relationship	Described the bond (positive or negative) between the participant and child-of-focus as described by the participant. This theme included parent-child communication, affection, and changes in the parent-child relationship noted by the participation during the CPRT training.

Understanding of CPRT Concepts. This category described how participants grasped the concepts of CPRT during the training. This theme is related largely to the process of learning CPRT and was coded when participants questioned CPRT concepts, expressed understanding of CPRT concepts, or displayed a lack of understanding of CPRT concepts. This category was also coded when participants asked for clarification of CPRT concepts.

Throughout the CPRT training, all of the participants displayed initial questions and uncertainty when a new CPRT concept was introduced. For instance, when originally faced with the challenge of making reflective statements rather than asking questions, the parents were unsure how to proceed. Madeline commented, "It's going to be so hard not to ask a question, I can feel the anxiety increase." She went on to say:

I was just thinking how bad I am at this because my first thought was, 'what are you going to show them first?' I would say, 'Show me,' maybe, 'tell me what you're going to show them.' I don't know. My first thought is always a question.

Dave echoed Madeline's comments by saying, "You're talking about learning a different language and for me it's like, I'll be honest, I'm a guy anyway, so I'm a fixer anyway, and it's hard not to come in and try and fix the situation." Even after Dave had the opportunity to practice using reflective statements as part of a homework assignment, he described his attempt use reflective statements with Aaron, "I tried, but I could never get passed the questions. It's like even when I was focusing on trying it I just couldn't keep from asking it."

As the CPRT group sessions progressed, the participants demonstrated an increasing grasp of CPRT concepts. One of the first CPRT homework assignments asked participants to practice giving a "30-second burst of attention" to their child-of-focus. The 30-second burst of attention allows the parents to experience how their child responds differently when the parents take time to notice what they are doing. In demonstrating her experience with the "30-second burst of attention," Carly commented:

I was actually peeling some apples in the kitchen to make an apple pie, and he was sitting at the bar, and he was in his own little world talking about some of his toys, but he wasn't talking to me. He was just talking to himself because he talks to himself all the time. And

I thought here's my opportunity, nobody else is around. So I said to him, 'Eric, I'm going to stop peeling these apples, because what you're talking about sounds really interesting and I want to hear about it.' So I sat down beside him and he looked at me like, 'You're crazy.' I think he was really shocked.

After her 30-second burst of attention, Carly stated, "So it was unusual. I could tell that it meant something to him, I think, that I stopped. And that I told him I'm stopping what I'm doing and I'm going to listen to you. I thought that was interesting."

The participants also expressed understanding of how CPRT concepts might apply to a child with HFASD. When reflecting on her 30-second burst of attention, Carly commented, "I learned that he could do that. He can come out of his own little thing and actually be talking to me and not just to himself about something." In addition, Madeline, Hannah, and the group leader also had the following exchange concerning how CPRT concepts might relate to children with HFASD, who often fail to demonstrate reciprocal play:

GROUP LEADER: So you're a little bit outside of the play. You're not really playing.

MADELINE: We're on the periphery.

GROUP LEADER: You're on the periphery, yeah.

MADELINE: We're learning a new way to play.

HANNAH: But you'd think that with more reciprocation, that would encourage more interactive play.

MADELINE: But I'm thinking with my own son that the reciprocity isn't there.

HANNAH: Yeah, right. No, it's true.

MADELINE: But it might bring him out if I try, that's why I'm interested to learn this. It may bring him out in a way that I haven't seen before.

When asking questions, the group also communicated an increasing understanding of CPRT concepts. When learning how to set limits, which began in session six, Hannah asked, "Like Jack will sometimes step on my feet if he's angry or I didn't do something he wanted me to do, he'll step on my feet. So do I say, 'My feet are not for stepping on?'" Embedded in Hannah's question is an appropriate CPRT response of "my feet are not for stepping on," demonstrating an understanding of this CPRT concept. Hannah also demonstrated appropriate application of another CPRT concept when making a joke. When the group leader used the example of the child-of-focus hitting his parent, Hannah responded with, "Mommy's not for hitting. Daddy's for hitting." Even though Hannah was joking, her response indicated an understanding of the CPRT concept of limit setting and offering alternatives.

Mary described a successful experience practicing reflective statements with Aaron with the following example:

What happened was he put in a DVD he hadn't seen in a long time. He started dancing, you know, he dances really funny. He had a really big smile and he was dancing. So I said, "You look really excited about that movie," and so his response to that was not to say anything, but to dance more, and more head bobbing, just more. It increased his level of excitement.

Carly also shared an example demonstrating her increasing understanding of reflective statements. She described her observation when she reflected to Eric that he was angry and confused:

With him being able to talk about it, it did seem to calm him down a little bit. Because when I first got home he was really upset about it, but letting him talk about it, he did seem to calm down a little bit and was less upset about it.

When learning about how to give alternatives to redirect the child's behavior, Dave demonstrated his increasing understanding of the underlying principles behind targeting alternatives:

He'll call me a bad name, but it's like, even though you don't want him calling you some other name, it's like, 'maybe you can just say that I'm being mean, you don't have to say that I'm being, you know.' And it's like 'I understand how you feel about me being mean,' and so you kinda give them, instead of that black-and-white, you give them some sort of medium area to go to instead of just black-and-white.

Carly also described her increasing grasp of CPRT concepts when she described her struggle using encouragement rather than praise during her special playtimes:

One thing I have insight on, and it's about the praise, is when he's doing the puppet show and he turned to me and I said, "That was a good puppet show." And after I said it I thought I'm not supposed to do that, but that's my struggle, to not tell him that something is good that I think is good."

Mary also communicated her increasing understanding of praise versus encouragement with the following summary:

This one I remember, this was a big one. Don't praise the child. It doesn't mean you that you can't say anything positive. He was saying like, you can't say, "I like way you did that." You can't make it about you. If he did something good, you can say, "you really like the way you did that."

By the end of the CPRT training, the group members each described an increased understanding of CPRT concepts. For instance, Carly expressed her understanding of CPRT concepts with an observation of her final play session:

I don't know, just I felt more relaxed. I didn't feel like I was constantly worrying about asking a question. I don't know. It seemed more natural to say, "You did it. You figured that out." Because, I don't know, it just started coming. I guess hearing it and practicing it. Because every single time, I've been thinking, 'oh please don't ask a question, what do I say, what do I say.' That I didn't feel that on the last one for some reason. I didn't ask any questions. I think it was just the practice. I think it is felt more comfortable.

Views of CPRT. This category included the participants' reactions to CPRT concepts during group sessions and play sessions, as well as plans to continue practicing or generalizing the CPRT concepts upon completion of the training. Most of the participants began CPRT with the goal of increasing their skill as parents to better meet the needs of their child-of-focus.

As the CPRT sessions commenced, the participants shared their reactions to what they were learning, which began with uncertainty and some skepticism. In the second CPRT session, Madeline said of CPRT that, "It's different." She went on to say, "I'll be interested to try it and see if it gets a different response. You're almost too passive, I guess. But I guess I could try something new. I always ask that of Zane." In the days prior to Hannah beginning her play sessions with Jack, where she would have the opportunity practice the CPRT skills, she stated, "I'm looking forward to these play sessions because I think it will just be really interesting to see him outside of his element and outside of his stuff." When Hannah shared with the group her first special playtime with Jack, she stated:

Yeah, I mean it was totally fun. Like I said, I mean, I think, you know, exploratory and discovery was neat to watch. He pretty much covered the entire space. He went all around and really got into all kinds of things and painted a little picture and loved the

sand. The sand was huge for him, so there was a lot of putting sand in the bucket, so there was a lot of, "Oh, you're filling up the bucket."

Carly had a similar reaction as Hannah and said of her first playtime, "I was surprised that he would play with the things, because at home I didn't think he would because he plays with Spider-Man and that's it."

Although the special playtimes went well for most participants, a few described struggles. While Mary described a positive experience during her initial play session, she also stated, "it was challenging too because I felt like I was being repetitive and, you know, saying the same thing." Dave also struggled with the concept of reflecting rather than participating in Aaron's play as he was preparing for his first playtime, saying, "My concern is that I won't be able to not ask questions. Yeah, and since I kinda play with him anyway, it's going to be hard not to play. It's going to be hard not to be drawn into not doing something." When describing his first play session, Dave noted:

Well it wasn't that I didn't feel like I wasn't saying enough, I felt like I was responding to everything that he was doing. And they were a couple of times where I wanted to respond but I'm trying not to say you fix the table instead of saying you fixed that. It felt like there were a bunch of dead silences.

Dave also described another moment of struggle in his initial play session. "In mine, he has that way of repeating what he's saying and to me. It was 'dad, dad, dad!' And I'm sitting there kind of going what do I say right now? However, Dave summarized his initial session by saying:

He seemed to do okay. I mean he didn't seem to be bored. I mean there's so much stuff in there, so I mean it's like you'll find something to do. Because this time he did the dollhouse and played with all those, he did some magic.

As the participants practiced and gained more experience using CPRT skills, they expressed increasingly positive reactions to CPRT. Of choice giving, Dave and Mary reported that they had been incorporating it into their daily routine at home:

DAVE: And, yeah, after just three sessions, the choice giving has really been a pretty big. It's been a big thing in our house. It hasn't been terribly successful at times, but there's been a lot of choice giving. A lot. And she's had a lot of success with the choice giving. MARY: Yeah, and I can tell you that since we started I've used it five or six times at least and every time it has worked. Every time.

DAVE: But he doesn't enjoy it!

MARY: He doesn't enjoy it, he gets mad about it, but it works. He gets really mad!

We've been giving choices all along, but it's just the tweaking of the words, yeah,

because we've always given him choices, but there's something about just using those
specific words they use on the video.

During the post-intervention interviews, all of the participants acknowledged having a positive experience with the CPRT training and positive reactions to the skills that they learned. Dave said of CPRT:

It's taken the stress off. It's taken a lot of stress out of just even the anxiety of how's he going to act in public, that's a big thing. I don't know if you got that in our final group session, but it's a big thing to have that feeling that you can actually go out somewhere, you can take your kid, somewhere, you can be happy and proud of your kid and not be nearly as concerned about what other people are doing to do, how's he going to act.

Madeline took a more general view when describing her overall reaction to CPRT:

What stands out is this is exactly what I needed at this time and, again, it was always something I looked forward to coming, and I thought 'this is something I'm getting a lot of positive things out of.' There's also too many books, there's tons of books about parenting in general and parenting a child on the spectrum. This felt much more manageable because it wasn't a class, you know, read ten chapters and show up again next week. The binder's very manageable, very accessible. The way it's even presented with the color of the cover, with places for notes. There was never too much material. It was really hands on. This is what you can do. And this is getting all the feedback. It was very helpful to have, to look at your own play sessions. That's what I remember. It was very eye opening to me. I learned about Zane and I learned about me, and that's just what I was hoping for. Actually, I wasn't even expecting to learn so much with us being apart and watching, but I learned a lot watching Zane. I learned a lot watching me too.

When Mary was reflecting on her experience of CPRT, she described specific aspects that stood out to her as being meaningful:

Watching the sessions with everyone and figuring out what we did, what we all did, that was good. Just the, you know, we had, even though we were there to learn something, we had fun, you know. It was fun. It wasn't like I dreaded going. I didn't dread going. You know, I kind of looked forward to it.

Hannah described how skills that she learned through CPRT have been helpful and also described her progress applying the CPRT skills as the training continued:

Limit setting and that whole process of choice giving after the ACT and then, you know, that whole flow. It's very helpful. And definitely I think we're getting better, that it's practice, you know, makes perfect.

When Carly was asked which skill was most useful she replied, "Probably all of them. I mean, setting the limits, giving the choices, and then knowing that once you have given the choices, there's further that you can go with it." Carly described her final perceptions of CPRT with the following statement:

I think the fact that there was another way to deal with behaviors that we had not tried before. And once we started trying it, we were seeing how it was working out. I was very skeptical at first. I thought this will never going to work. He's going to continue arguing. But they are working, and so that stands out, that I was very skeptical at first and probably I was starting to see that it was working, the techniques were working. And I was very surprised.

Madeline shared her closing thoughts about what she found important with CPRT in the group in the final session:

The very first, of the whole 10 weeks, and the very first thing is don't focus on the problem. And what's most important may not be what you do but what you do after what you did. And that's very forgiving. I haven't run into that anywhere in this autism journey as a parent of the child with autism.

Mary and Dave had a unique experience in the group as a married couple with the same child-of-focus. Mary reported on her experience going through with Dave:

Well, since Dave and I did it together, we've always been on the same page, like when it comes to how we're going to handle the boys and things like that. But I think there's even more of a sense of comradery with us, like 'we've always been in this together, but we're really in this together now.' You know, it's sort of like going from being on the same team to... I can't think of a way to put it, but we're just, obviously I'm lost for words

sometimes. But yeah, I definitely think it's brought us even closer because we do share this connection of what we've been through with the training.

Dave described his experience of going through the training with Mary:

I think it's helped with Mary and I. Again its that same thing, you know. It's not that 'I said this, you said that,' although we've had a couple of those, it's like we had one this morning, but its not the 'well, I told him he couldn't,' Actually, no, I stand corrected. We have had a few of those, but not as many. And it definitely feels better between us in the sense that we both, again, are working from the same book. And we know it works, and so we know that there are some positives on it, so we're going to continue to do it.

Group Dynamic. This category included the emerging group dynamics during the CPRT sessions, such as linking shared experiences, seeking and sharing perceptions related to raising a child with HFASD, and seeking clarification from group members when understanding was lacking.

During the pre-intervention interviews, all of the participants were asked what they wanted from the group during their participation in CPRT. All participants stated their desire to be with other parents raising children with HFASD as an important factor leading to their decision to participate in CPRT. Hannah stated that she expected:

To share experiences, which I fully expect is going to happen. A lot of sharing and I can learn from them as well, things they are doing or not, or have tried or haven't, and just kinda the whole dynamic of a parents group that has shared experiences.

In addition to wanting the support from the group, Madeline's comments echoed her desire to find new strategies from other parents who have shared her experience of raising a child with HFASD:

It's great to have other support, to know that you're not the only one out there. You wonder, "Do other families not get to go out on outings and other stuff?" All these questions or doubts you have around the school thing, just to be around other parents, other people who get it, like, 'Oh yeah, I get this,' or 'Have you tried this?' I mean, just little things. I've had a parent suggest to me once, 'Try singing to him an instruction.' That never would have occurred to me, yet he has this great musical interest, yet it never occurred to me to do that. It worked. I was like, 'Oh, I never would have thought of that.' Or other parents who've tried things and remind you to keep trying something.

Carly stated that she was looking forward to being around other parents who have experienced the same sense of isolation that she has felt:

It will be nice to be with some other people that maybe understand some things that we've gone through in social settings, sometimes being the outcast, and how they've dealt with that.

Mary stated that she was seeking:

Just the opportunity to meet other parents, more parents. I mean, the more people you know the better, that are going through this same thing, is always beneficial.

Dave also stated that he was seeking a shared experience with other parents. However, he expressed less interest than the other participants in connecting with the group:

I don't think I necessarily need anything from the rest of the group, but it does help to have the understanding that you're not alone, that everyone else faces this kind of stuff. For me, I think that's a big thing in our family is for is to just kinda come to grips with the fact that it could be much worse. It's like, yeah, this is bad, and yeah, this is stressful,

but its like it could be much worse than this. I think perspective really helps. That and just empathy.

During the post-intervention interviews, all of the participants stated they liked the group format of CPRT. When asked, "What it was like to discuss your progress with other members of the group?" all of the participants reported positive experiences with the group format of CPRT. The following quotes are from the participants' answers to the above question:

DAVE: Cathartic. It helped. It helped because you could see that yeah, you were kind of on the same track. It's like, 'Well, yeah, we saw that too.' It was like Zane did the same sort of thing or Zane did this, and then it's like, well, Aaron did that once. And then you see him doing this. I think it helped that, you know, we each kind of also discussed the other kids' situations, because we were seeing what that they weren't seeing and then you see it and you hear it from somebody else and you go 'oh, I missed that.'

MARY: It was good. It kind of validates, like 'Oh, I really did do that,' you know. It's like when you say it out loud, you know, you have somebody to share it with, it's a nice feeling, like, you know, things went really well, and the other person is like 'oh, you know, this went well for me' or 'I know what you mean,' or something like that.

MADELINE: Helpful. I have to say I think I was probably the least progressed in the group, but that might just be my perception. Well, it's good to share that. Again, to share anything in a trusting environment that reflects progress like 'this is really exciting' or 'oh, this works' or 'oh this was really challenging and I thought this isn't going to work but I'm going to do it anyway.' So it kept it positive, it kept it in perspective, so it was good. It didn't feel nervous or... I didn't feel nervous or threatening to share something like that in a group. Again, I think you were very good at creating a trusting atmosphere,

and already the group, they're in there knowing they're part of the club that is very familiar and is very unique, really, the club we belong to. But then to see what other parents go through, we could identify right away, so that was good.

CARLY: At first, I think you know, I cried the first day, but we were still kind of in need of acceptance, I guess, part of it. And I guess hearing that Eric was so much like their children, because I was still in a little bit of doubt of whether he has some issues, kind of brought it real to me that first session. But as the sessions went along, it got a lot easier to talk about things and that made it easier. And they made it easier, the group did.

HANNAH: I thought it was great. I thought it was the perfect size, because we all obviously had a lot to say, and so if you had more we probably wouldn't individually get to speak as much if you had more participants. So, I thought the numbers were good. So it was good. So, yeah, I enjoyed sharing and hearing how they had progressed as well.

So, I thought it was really open and so I enjoyed that.

Child Characteristics. All of the participants described various aspects of their child-of-focus during the pre-interviews, CPRT sessions, and post-intervention interviews. This category included the participants' descriptions of their child-of-focus' behaviors and characteristics, such as thoughts, feelings, behaviors, and interests, as well as descriptions of the child-of-focus's HFASD-specific characteristics. This category also included changes the participants observed in their children-of-focus as they went through CPRT.

All of the participants shared behavioral concerns they experienced with their children-of-focus. Mary described her struggle with Aaron's behavior by stating that, "it breaks my heart, because I send him to school knowing, okay, how crappy is he going to feel today. Because it's not like he wants to be bad." She went on to say that, "It's a horrible feeling just when you know

you have to send him to school and that you're not going to be there. He's just having a horrible, horrible time." Mary further described Aaron's struggle with school by saying that, "It's like a summer school type thing, it's only for a week, but it's academics, that's setting him up for sure for a meltdown because he doesn't have a learning disorder of any kind, but that's what he hates, school stuff, so he doesn't think he should have to do the work. And he get's frustrated." Mary also said Aaron, "I mean when he's not having a tantrum, he's just so cute."

Dave initially described Aaron by saying, "He would always be going up to his room to play by himself, even though there's other kids, and he plays with others kids, at a certain point it's either too much or he just wants to go off and do his own thing on his own." Dave went on to say, "That's actually kinda one of the first things that gave us hints about his Asperger's, is that he's always been kind of an alone kind of kid."

Madeline shared of Zane that, "My son doesn't outwardly invite me in to play," and that, "Zane is having a harder and harder time with transitions. And I'm trying things we learn here. One day it worked, the next day it didn't, but I still keep trying, but he's really having a hard time." Madeline added about Zane that, "He says bye-bye when he doesn't want to do something. 'Bye-bye school, bye-bye home, bye-bye bath,' you know, whatever he doesn't feel like doing." Madeline also said of Zane, "Zane has a flat affect."

Carly described her concerns with Eric by sharing, "He will only wear Spider-Man clothes," as well as, "that's how he expresses his anger I guess. It's not banging on a drum, it's just arguing with you on and on." Carly was also concerned about whether Eric would enjoy the special playtimes by stating, "I'm not sure he'll play for 30-minutes, because he'll play that, but then he'll want to play video games or computer." When describing how Eric struggles with change, she shared:

His mom started school this morning, and any change is not good. He was a little upset about her going off to be gone all day and he was going to be with me all day. He started thinking about all these excuses about why he shouldn't be here and he's not going to have fun and there's not going to be any kids here. And I just kept trying to reassure him that there will be kids here, but he was saying, "Well, they won't play with me. They won't like me." Just trying to find excuses, so we had a little meltdown this morning, but now he's okay.

Hannah, when sharing with the group a photo of Jack taken at his school, stated that, "He doesn't like to dress up in costumes and things like that, so I could tell he was upset because they put him in the little headband and put the tattoo on him. And generally he doesn't like his photo taken either, but he's getting much better about that." When thinking about doing the 30-minute special playtime with Jack, Hannah stated that, "Yeah, I didn't know that he would enjoy himself away from his own stuff. That's what I thought, that he was apprehensive and wouldn't hang in there for 30 minutes." However, after her first play session with Jack, Hannah shared:

I will say we went to my mom's last weekend and she's got this basement full of toys that he doesn't see often. And a few times over the weekend he would come up to me and say "mom, come and play with me," which he doesn't really normally do. And I just went down and did this, watched him do his thing and comment on it, and he loved it. I mean it seems he really likes it, this kind of play, with me watching and observing, because we did it at my mom's and we did it a couple of time. I mean he asked for it, you know? So I thought that was cool.

Dave also described what he saw from Aaron during one his initial play session:

He seemed to do okay. I mean he didn't seem to be bored. I mean there's so much stuff in there, so I mean it's like you'll find something to do. Because this time he did the dollhouse and played with all those, he did some magic.

Madeline described Zane in her play sessions by initially noting that, "Zane doesn't really play if it isn't planned play. So he started doing that are comfortable to him. So he started doing the alphabet on the chalkboard." Madeline was originally very concerned about Zane only writing letters and numbers during their play sessions together:

But that's not exploratory what he's doing. He's been able to do that since he was two because he's hyperlexic, so he's already done, we've done this. I guess I'm looking to see something a little more exploratory. I don't see that. And that's me judging his play.

Later, when Madeline was showing a video of her play session to the group, she described her changing perspective of Zane's play with the following observation:

Well, the next thing that happens is he decides to go the chalkboard and he does the letters one at a time. He's goes A, writes capital A, writes lower-case A, and turns to me, even tries to give me the chalk I think, and says, "A is for..." And that's our interactive game. I come with one. He comes up with one. He even comes over, takes my hands, and kisses me on one of these, and I kiss him back, and we go all the way from A to Z.

By the end of the CPRT sessions, Madeline stated of Zane that, "I saw his play in a different way that I hadn't seen before," and discussed how she had come to experience Zane's play differently:

I used to take it more negatively that he would do things that are very rote or very repetitive. He would have to start with 'A' and get to 'Z' and if someone interrupted towards the end, he would start over again. And I would think I going to need to help teach

him this, you don't have to do that. And so it was liberating to not jump in and correct, just to see what he does. And that is his way, that's his strength, that's his talent.

When Hannah was asked during the post-intervention interview what changes she noticed in Jack since beginning the CPRT training, Hannah stated:

I don't think I can tell yet. You know, the choice giving has worked a couple of times. But he's has always been very independent. And so I think that's something we talked about early on, that most kids in the spectrum have been independent players for their whole lives. So, I don't know.

Mary, however, had noticed changes in Aaron and described changes she had seen. She said that:

He's not so hard to deal with. And I mean, and I'm saying... I'm trying to say that like it's a compliment to him, like I think he's recognizing that something's are different and I think he's kind of stepping up and being like 'okay, well I'm given this choice and I'm going to make the choice, and I don't like it, but I'll do it.' So a little bit of maturity, maybe."

By the end of CPRT, Mary also shared that "he's been hugging me more."

During Carly's post-intervention interview, she noted that she had observed positive changes in Eric's behavior resulting from her implementing CPRT skills:

I actually heard him using the word "choices" and "policies." And so I think he is realizing that he is able to make some choices, and like I said using those words, "that's my choice." So I do think he is thinking a little bit more about it, which I think is a good thing.

Parent Characteristics. This category included the participants' descriptions of themselves as parents, such as parenting practices, stressors, strengths, and areas for growth. This

category also included changes they noticed in themselves as parents as they went through CPRT.

In the beginning of the training, all of the parents described feeling as though they were lacking sufficient skills when it came to raising a child with HFASD. Hannah stated:

And I think that sometimes I'm not challenging him to get outside of the box and grow. So sometimes I feel like I'm over accommodating to him, trying to please him, because he's really picky about some things, like what foods he'll eat. So finally I'll just feed him what he'll eat because I know if I don't, especially in social situations, it's going to go off the hook.

#### And Madeline shared:

Zane takes swipes at me when he's really upset. You know, and I can tell he's reaching to swat at me. And the only thing I've done, and I'm kind of embarrassed to admit this, is I'll say, "hitting mommy?" And he looks upset. And then I'll say, "you're upset," but then I say "it's okay to be upset, it's not okay to hit mommy."

As a married couple Dave and Mary shared many common experiences with regards to parenting Aaron. For instance they had the following exchange during group:

DAVE: Yeah, but I think I can say that because as far as our situation goes, I tend to be awake more so when he has issues I'm usually there. She (Mary) doesn't get that chance all the time, to go and be the one who he runs to and sits in your lap, but he does, he still does it.

MARY: But I'm the one who's there after school, so it's like I get it then, at least when he gets off the school bus and he's had a bad day or whatever. You know, he'll tell me, you know, but I have to ask.

During the post-intervention interviews, all of the participants described changes that they noticed in themselves as parents as a result of going through the program. Hannah stated:

I think mostly just instead of making choices for Jack, letting him make his choices. And I think more about fostering his independence and letting him guide himself through challenges. Because before, you know, it is easier to help him put their shoes on. You know, sometimes it's just easier. But I think I have changed, because I'm more mindful that it's important to let him make those decisions for his development because he has a lot of decisions to make in life by himself.

Carly said of changes she noticed in herself as a caregiver, "I think I'm a lot calmer, I think. I really do," and went on to say that, "Probably it's made me a nicer person, maybe a little bit. Maybe I'm not so grouchy when I come home from work with everything being a mess. So, I would say probably it has changed especially, maybe, me and his mother, and maybe me and my husband because I don't come home that grouchy."

#### Mary shared:

I feel more confident. Like you said, like kind of knowing what to do. Like I don't dread getting into a situation where he might have a meltdown because I won't know how or what to do, or I'll have to leave. So it's helped to reduce my anxiety, to calm me down, and feel more confident.

Dave echoed Mary's confidence and commented on changes he feels as a parent by saying:

I feel a lot more confident in dealing with him. I feel like we're both also, that helps us, I think it helps to have both parents involved because it allows both of to get the training and also work together, and we're definitely on the same plan.

Parent Knowledge and Experiences with HFASD. This theme included the participants' experiences specifically related to HFASD, such as how they experienced the diagnostic process when their child was diagnosed with HFASD. Examples include Hannah sharing, "I had never been exposed to autism or Asperger's or anything on the spectrum before, so, you know, it's been a big learning experience for us, for sure." Madeline described her reaction to Zane's diagnosis as, "it was just painful, like, 'Oh no, this can't be. He's perfect. I was stunned, like anyone would be. I feel, I think you'll hear from other parents who may say this, it felt like a death sentence. Your child has something that is incurable." However, not all of the participants had such a reaction to the diagnosis. Dave, Mary, Hannah, and Carly all used the word "relieved" to describe their feelings upon receiving a diagnosis of HFASD for their children-of-focus.

At times, the parents would share their knowledge of HFASD with the rest of the group. For instance, when explaining how Aaron's diagnosis of Asperger's Disorder may have manifested, Dave shared the following with the group:

You know they talk about how it's genetic, that it's pretty much a physiological genetic situation, there are studies that show that certain parts of autism and Asperger's can be triggered by childhood stress and what's considered posttraumatic stress for children.

Of all the members of the group, Madeline shared the most regarding her views of autism. After talking about Zane being sick, asked the group:

Have you ever noticed, speaking of fevers, have you ever noticed when your children with autism have a fever, or even high fever, that their behavior is like that of a more typically developing child? Have you ever noticed that?

Madeline also defended her view of considering Zane a "child with autism" rather than an "autistic child" by saying, "That's what I always say, that they're kids first, but kids who have

autism, not autistic kids. I'm a stickler about that." She also shared, "As they say, once you've met a kid with autism, you've met one kid with autism."

As Madeline learned more about CPRT and what her role in CPRT will be when having special play times with Zane, Madeline shared her past experiences with learning about how children on the spectrum play:

Well, there's always this thing about how to play with a kid on the spectrum, how to engage them, how to engage them lying on the floor, how to pull stuff out of them. "Oh you're doing that, oh, you've got that."

Later when describing research she had done on being a parent to a child with autism, she stated:

All the books that I've been reading about autism, in snippets, all say the same thing. In the beginning, you want to do so much to help your kid, like any parents helping their kid, and for them it's not a sprint, it's a marathon, instead of day-to-day, look over longer periods of time.

Madeline even used her knowledge of Asperger's to help Dave integrate the CPRT concepts of reflecting into his communication with Aaron to help facilitate more effective communication. She offered the following suggestion:

People with Asperger's tend to focus on a singular subject. That's all they talk about and it's not conversational. They're telling you everything they know on this subject. Here's a way that might not only curb that but might also help you to have a more dialectical conversation.

Participants also described how they experienced other people's perceptions of their children with HFASD. The following extended passage, which occurred in the first group

session, was pivotal in that all members of the group connected with it. In this passage, Dave described what the group dubbed "The Wal-Mart Look:"

Well, we've all had it, you know, you go to the store and they insist you've got to go over to the toy section, so you've got to go to the toy section and then try to do the rest of your shopping and everything else. And he starts kinda melting down, and you go, you know what? It's a Saturday, I need to get some other stuff done if I can't do this, I can get the rest of the stuff done, it's not that big a deal. You go over there and it escalates. And you get the huffs. You get the dirty looks from other people, and next thing you know they end up on the floor or screaming in the basket. And then you're actually hearing the comments behind your back or you hear them in the aisle as your walk by, or you going down another aisle later and they say, "Oh, there they are again." Or you see them go the other direction. That's the Wal-Mart look. And there's no better place to get it.

Finally, group members discussed specific academic experiences they had had related to having a child with HFASD. Mary shared the following example of working with Aaron's special education teacher:

And this is the expert, the Asperger's, autism expert in the school. It's like when the expert who deals with this all day for years, she's been doing this for a long time, tells you, "I'm at a loss," it doesn't make you feel real good.

Family Context. This category included the participants' descriptions of their home life, such as family members beyond those participating in CPRT. All of the participants shared extensively about how their home life influenced their role as parents to their child-of-focus. For instance, Mary and Dave shared a home with Mary's parents, which for them created

considerable stress for them as parents. Mary described their current living arrangement at home with the following statement:

My dad's, he's 75 now, but his health has kinda gone down, like slowly, you know, very slowly, but it's kind of a mutual thing where we figured that we could help my mom out, you know, by helping with my dad. And then, at the time, Aaron was only four and he was coming out of a lot of serious health issues himself and so it was just a really good situation. It has its pros and cons, I mean, there are days when it's really hard, you know. Can you imagine living with your mother-in-law? You know, I mean, I live with my mom, but for Dave, my husband, you know, I feel for him sometime because it is hard. But, definitely a lot more benefits than negatives, so

Mary also shared that, "There's a lot of stress at home too because my mom's got natural ability to give you a look that gives you the guilt." During his pre-intervention interview, Dave described his perception of the family context as:

As circus, really a circus. You know people talk about it. Honestly this is, there are times when it's just a normal day, you know, when nothing big happens, but there are times when it's just total freaking chaos. I mean absolute chaos!

Dave and Mary also talked a lot about Aaron's older brother Cameron and how he influences the family dynamic. Dave shared that:

Aidan is getting a lot of support that he needs, and Cameron has gotten kind of, not necessarily forgotten, but, and I wouldn't say left behind either, but it's obvious that Cameron kind of feels a little left out. And that's, for me, when we first came in, as concerned as I am about Aaron, I'm equally if not more so about Cameron.

Mary added:

Cameron is ADHD and is very excessive on the hyperactive talking, and, literally,

Cameron can talk and talk and not stop. Dinnertime is hard because no one else can talk,

so we do have to do that a lot because we do have to say, "Cameron, hold on. We need to

let Aaron talk."

Madeline also had some struggles at home when the group began, which created an additional source of stress for her. Madeline reported:

My stepdaughter, and she has come to live with us in this past year. And what we thought was originally difficulty getting used to the new country, language and family, turns out to be only the tip of the iceberg. It turns out she has some really serious mental problems that we were not told about and that her mother abandoned her. And now we have her. So we have now two very special needs children in our household.

Carly also described sources of stress in her family context when talking about how Eric's mom has struggled with depression:

I think until recently it was not very good, but I think his mom is trying to get some help. She has some depression problems, and she has said herself she thinks that affects him, but she has gone through days to where she just sleeps for days and then she's awake for several days, and she's had some problems with depression too. But she has enrolled in these classes, as she told you about. It's a dental assisting school. She's been without a job since last summer, so I think that's a lot of her depression, but she's starting a new career and she is trying to make some better choices on friends, so I think in the last few weeks it's been better, but prior to that it was not real good because she was real moody and screaming at him a lot of times and real moody.

Hannah, who was the most reserved of the group members, did not discuss much about her family context, but shared that she and her husband both work full-time and "do a fair amount of travel." Hannah shared that their work schedule had made it difficult to find the best care for Jack, but that they have worked in out recently.

Parent-Child Relationship. This theme described the bond (positive or negative) between the participant and their child-of-focus as described by the participant. This theme included parent-child communication, affection, and changes in the parent-child relationship noted by the participants during the CPRT training. Throughout CPRT, participants shared various examples of their relationship with their children-of-focus. Early in the training, Madeline shared, "He sleeps with me usually. He usually ends up with me, he starts in his own bed, but he usually ends up with me if we can't get him to sleep." During her first play session, Madeline described another aspect of her relationship with Zane:

He looked straight at me and I never want to look away or point back to what he's doing, or acknowledge that he looked at me, especially because that's something we've always worked on together to make eye contact.

However, Madeline expressed her struggle during the play sessions to experience a stronger connection with Zane. She shared, "Well, yeah, I was trying, I'm trying to see more of his face, I guess. Because I don't feel very connected to him. I'm not playing with him and it's so repetitive what he's doing."

Mary said of her relationship with Aaron, "I play with Aaron a lot, actually," but also clarified what she meant by playing with Aaron:

Well, he likes to do things by himself, but he wants you to be near him, so I'm just near him or he's got his book or his outer space things and he's holding them and he's reciting the monologue from the Discovery Channel show. You know? So, it's not as much interaction one on one as you might think of with a child, it's kinda being there for him. In a later session, when the group was asked to write to their children a short letter saying what they appreciated about their children, Mary described her reaction to Aaron's disappointment that the letter was not from one of his teachers:

It's Aaron. I don't take it personally. And he said, like I was telling him, I said "it's a letter for him," and he said, "It's not good enough." He's just saying what's in his head. He's just being honest. He's not trying to be hurtful.

During the post-intervention interviews all of the participants were asked to describe any changes they noticed in the parent-child relationship since beginning CPRT. Hannah noted:

I don't know if I can pinpoint something from a relationship standpoint that's changed. I mean, it's hard because I felt that I couldn't be any closer to him before the class, but I guess maybe the one thing that has changed is noticing different things about Jack and just kind of observing him more. That's what I'd say.

Carly stated that, "I think we have a much closer relationship, actually. He seems calmer, and I think I'm probably a little calmer," while Madeline shared that:

It makes me, just as I said when I came in the first day, it makes me what to get even closer to him. That's why I came. I thought that was great that I got to see how he feels about himself. This is what I thought, I thought he's been doing this along and I just didn't know how to understand it or see it.

Mary shared of her relationship with Aaron:

We always considered us to be pretty close in our own way, but it feels like, I don't know, and I guess it has to do with that he's connecting a little more with me. Like he's

hugging me, he doesn't usually hug me. I would say that's what we started with. I could count the number of times where I would say that he's ever hugged me. And he hugs me a lot now.

Dave also echoed the changes Mary noticed in the parent-child relationship during his postintervention interview:

I think it has helped with his relationship with both of us, but more so with Mary because although I think I was kind of tuned into his situation before, I think now that she's got a better understanding and he knows that we're both playing off the same playbook, that he knows, he knows it's not 'oh, pull on somebody else's strings.'

Dave went on to share that, "With Aaron, it helps to know what he's thinking, and I think it helps to know what he's thinking to just sit there and shut up and listen." Finally, Dave shared that "He understands that we're the parents, which I think is something that, I think I had a connection with him before, but I think I've got a better connection."

#### Summary

This chapter presented descriptions of each participant and their children-of-focus, as well as the resulting themes from the analysis of the pre-intervention interviews, CPRT sessions, and post-intervention interviews, using quotes from participants to highlight each theme. We analyzed the data using a coding manual developed through thematic analysis with a final intercoder agreement of 87%. Themes related to the first research question were *understanding* of CPRT concepts, reactions to CPRT, and group dynamic. Themes related to the second research question were child-characteristics, parent characteristics, knowledge and experiences with HFASD, family context, and parent child-relationship. For each research question, the themes were presented in order of prevalence, or the number of times we unanimously

determined that a theme was present in the data. In the following chapter, the results of these themes will be discussed.

# APPENDIX D OTHER ADDITIONAL MATERIALS

# University of North Texas Institutional Review Board Informed Consent Form

Before agreeing to participate in this research study, it is important that you read and understand the following explanation of the purpose, risks, and benefits of the study and how it will be conducted.

**Title of Study:** A Phenomenological Investigation of Parents of Children with High-Functioning Autism Participating in Child-Parent Relationship Therapy (CPRT)

**Principal Investigator:** Dee Ray, Ph.D., Associate Professor, Department of Counseling and Higher Education; Director, Child and Family Resource Clinic

#### **Key Personnel:**

Jeffrey M. Sullivan, Department of Counseling and Higher Education, University of North Texas

Haley Stulmaker, Department of Counseling and Higher Education, University of North Texas Jenifer Ware, Department of Counseling and Higher Education, University of North Texas

**Purpose of the Study:** You are being asked to participate in a research study which involves helping understand parents' experiences of their participation in a parent training model called Child Parent Relationship Training (CPRT). The goal of CPRT is to help parents build a stronger relationship with their children. A strong parent-child relationship is particularly important for families in which a child has been diagnosed with an autistic spectrum disorder. CPRT aims to support parents by helping them better understand their children's concerns and helping them learn developmentally appropriate responses that foster healthy social-emotional development. As part of this research study, you will be participating in CPRT over the course of 10 weeks.

**Study Procedures:** The entire project should take approximately twenty-six hours. You will meet weekly with a trainer for two hours in a group with other parents. During CPRT, you will also do 5-6 weekly play sessions with your child at home. Each play session will be about thirty minutes. You will also be video recorded playing with your child to help you better understand your child's needs and to help you learn responses that can help your child feel closer to you, while facilitating your child's communication with you through play. Through play, children can more comfortably communicate their world.

The ten-week training will include the following:

<u>Before</u> the ten-week training, you will be asked to complete one screening assessment. The <u>Social Communication Questionnaire</u> asks questions about the general communication and social skills of your child. In addition, you will be asked to answer some basic questions about yourselves, your child, and your relationship with your child. This will be done through an interview lasting approximately one hour conducted by either the primary investigator or key research personnel.

<u>During</u> the ten-week CPRT training, you will learn skills that are designed to strengthen your relationship with your child, understand your child's needs, help you know how to respond to your child in difficult situations, and help your child feel understood. Video and live demonstrations, live practice sessions, role-plays and group discussion will be used to help you apply CPRT skills. The weekly group sessions will be video recorded. You will also be video recorded playing with your child throughout the 10- week session to assist you in learning the CPRT skills. You have an opportunity to share a video of you and your child within the group for supervision of your skills and encouragement.

<u>After</u> the ten-week training, you will be asked to participate in a one-hour interview to answer some basic questions about yourselves, your child, and your relationship with your child.

**Compensation:** You will receive \$100 USD for your full completion of all research components, including: screening assessments, pre-training interview, 10 sessions of CPRT, seven play sessions with your child, and post-training interview. No compensation will be provided for partial participation in this study.

**Foreseeable Risks:** There are no foreseeable significant risks to participating in this study. You might feel some discomfort discussing your family's experience with autism or by hearing another parent's story or through sharing other personal information with the investigator or other parents. The investigator will attempt to minimize discomfort by ensuring that you do not feel pressured to disclose information that would cause discomfort.

**Benefits to the Subjects or Others:** Potential benefits of being in this project may include a stronger parent-child relationship, increased confidence in parenting and reduced problem behaviors of your child. You may also benefit from being with other parents who are having similar experiences with their child.

Procedures for Maintaining Confidentiality of Research Records: You will be assigned a code and only that code will be used on any stored information you provide, including pre and post video recordings. The confidentiality of your individual information will be maintained in any publications or presentations regarding this study. No one will view your group or play session recordings or look at your assessment responses other than the investigators/raters. Assessments will be kept for no more than seven years beyond the end of data collection and will be destroyed by the researcher. All recordings and assessments will be securely locked in a secure location in Matthews Annex at the University of North Texas, Denton, TX.

**Questions about the Study:** If you have any questions about the study, you may contact Dr. Dee Ray or Jeffrey M. Sullivan at (940) 565-2066.

**Review for the Protection of Participants:** This research study has been reviewed and approved by the UNT Institutional Review Board (IRB). The UNT IRB can be contacted at (940) 565-3940 with any questions regarding the rights of research subjects.

**Research Participants' Rights:** Your signature below indicates that you have read or have had read to you all of the above and that you confirm all of the following:

- The researcher, Jeffrey M. Sullivan, has explained the study to you and answered all of your questions. You have been told the possible benefits and the potential risks and/or discomforts of the study.
- You understand that you do not have to take part in this study, and your refusal to participate or your decision to withdraw will involve no penalty or loss of rights or benefits. The study personnel may choose to stop your participation at any time.
- You understand why the study is being conducted and how it will be performed.
- You understand your rights as a research participant and you voluntarily consent to participate in this study.
- You have been told you will receive a copy of this form.

Printed Name of Participant	Date
Signature of Participant	Date
For the Principal Investigator or Designee:	
•	this form with the subject signing above. I have ntial risks and/or discomforts of the study. It is my xplanation.
Signature of Principal Investigator or Design	nee Date

# DISSERTATION PRE-INTERVENTION INTERVIEW QUESTIONS

- 1. Tell me about your family.
- 2. What was the process of diagnosis like?
  - a. How much time went by between the time you first started having concerns and the time your child was diagnosed?
  - b. How did you respond to the diagnosis?
  - c. What have you done since the diagnosis to help your child?
- 3. How does your child stand out in your family?
- 4. How would you describe your current home life?
- 5. What are some of the activities that your child likes to do?
- 6. What has been your experience as a parent of a child with high-functioning autism?
- 7. What would you identify as your needs as a parent of a child with high-functioning autism?
- 8. What would you like to get from your participation in this group?
  - a. What would you like for your child to get out of it?
  - b. What would you like to get from me as the group leader or facilitator?
  - c. What would you like to get from the group?
- 9. Do you have anything you would like to add?

# DISSERTATION POST-INTERVENTION INTERVIEW QUESTIONS

What are the parents' perceptions of the process (structure and content) and outcome of CPRT?

#### **Process-Structure:**

- 1. What were your reasons for agreeing to participate in this project?
- 2. What did you think about the organization of the training?
  - a. Weekly meetings
  - b. Length of training per session
  - c. 30 minute play sessions at home
- 3. Several different kinds of instructional methods were used during the training (videos, lecture, group discussion, modeling/demonstration, and written materials). Were any of the methods more or less useful? Why?
- 4. What are your perceptions of the group format that was used during this training?
  - a. What did you like?
  - b. What did you not like?
- 5. What was it like to discuss your progress with other members of the group?
- 6. How important was the \$100 incentive to you?

#### **Process-Content:**

- 7. What do you remember about the training sessions?
- 8. Several specific skills were taught during the session.
  - a. Which of the skills did you find useful? Why?
  - b. Which of the skills did you not find useful? Why not?
- 9. What did you think of the different toys you were asked to collect for the play sessions?
- 10. What was it like to do the special play sessions?
  - a. What did you like?
  - b. What did you dislike?
  - c. To what extent do you think you conducted the play sessions the way they were taught?

d. Did you have any difficulty doing the play sessions? (If so, describe)

### **Outcome- Generalizability and Sustainability:**

- 11. Are you planning to continue using the skills taught in the training? (If so, which ones?)
- 12. Have you begun, or have you considered, using the skills taught in this training with other children?
- 13. Are you planning to continue the play sessions now that this training has finished? Why or why not? How long do you plan to continue doing the play sessions?

# What are the parents' perceptions of the impact of CPRT on the parent, child, parent-child relationship?

- 1. In what ways have you been affected by what you learned in this training? (attitudes, feelings, perceptions, behaviors)
- 2. In what ways has this training addressed your needs as a parent of a child with "high-functioning autism?"
- 3. How has participating in this training influenced your relationship with your child? Can you give an example?
- 4. In what ways, if any, is your child different as a result of you being involved in the training? What does he do differently now?
- 5. Has anyone else in your child's life commented on changes in your child?
- 6. In what ways, if any, has this training changed your other relationships? Can you give an example?

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