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Parents' and practitioners' perceptions of supports, interventions, and the home visiting process used in early intervention

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Parents’ and practitioners’ perceptions of supports, interventions, and the home visiting process used in early intervention

by

Jason Peck

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

DOCTOR OF PHILOSOPHY

Major: Human Development and Family Studies

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Abstract

Autism spectrum disorders (ASDs) have been considered an uncommon childhood disorder, but now they are estimated as one of the most prevalent types of developmental disabilities. Although people are more aware of ASDs, many questions remain. The purpose of this phenomenological study is to explore three issues: parents’ of young children diagnosed with ASDs perceptions of supports thought to be effective in addressing stress, practitioners’ views of interventions, and parents’ and interventionists’ perceptions of the structure of the home visit used in Early Intervention. Interviews and observations were used to collect data, and findings from this are presented in the context of existing research literature. Implications and recommendations for future research are provided.
Chapter 1. Introduction

Autism spectrum disorders (ASDs) are a group of developmental disabilities that can cause social, communication, and behavior challenges; they are currently one of the most prevalent types of developmental disability (Lord & Bishop, 2010). The Centers for Disease Control (CDC; 2012) estimates 1 in every 88 children in the United States have ASDs. Parents of children with ASDs consistently report high levels of stress (Abbeduto et al., 2004; DeGrace, 2004; Benson, 2006), and this stress can have a negative impact on parents, leading to anxiety, depression, and marital conflict (Weiss, 2002). Early Intervention (EI) programs provide supports to families who have a child with special needs (Bruder, 2010), and these services are being increasingly accessed to address the needs of children with ASDs and their families (Johnson & Myers, 2007).

It is clear children with disabilities and their families generally benefit from EI services (Sweet & Appelbaum, 2004), however, the field of early childhood special education has not sufficiently explored how to best match supports and services to meet the specific needs of children and families (Turnbull et al., 2007). Considering the wide range of possible interventions (Rogers & Vismara, 2008), the uniqueness of children with ASDs and their families (Guralnick, 2011), and the limited efficacy research on intervention practices for infants and toddlers with ASDs (Boyd et al., 2010) additional research is needed.

Autism Spectrum Disorders and Stress

As previously mentioned, parents of children with ASDs consistently report higher levels of stress (Woodgate, Ateah, & Secco, 2008), and lower levels of well-being compared to parents of children with other disabilities and those without disabilities (Abbeduto et al., 2004). This stress can have a negative influence on an entire family (Yamada et al., 2007).
Despite being faced with high levels of stress, many families of children with ASDs have been able to successfully adapt (Gray, 2006; Bayat, 2007). Although researchers have found support strategies associated with better family outcomes (Twoy et al., 2007), more research is needed to determine the most successful support strategies for various types of families (Kuhaneck et al., 2010).

**Early Intervention Practitioner**

Practitioners play an important role guiding parents of children with ASDs (Lord & Richler, 2006). Limited research exists on intervention efficacy (Boyd et al., 2010), and several intervention strategies could be implemented (Odom, Rogers, McDougle, Hume, & McGee, 2007). It is recommended EI practitioners consider multiple intervention possibilities along with the individual child and family characteristics before implementing an intervention (Buysse & Wesley, 2006). Despite this responsibility, there is inadequate research describing practitioners’ views of interventions used to support children with ASDs and their families (Ridge & Guerin, 2011).

**Home Visiting**

Although home visiting is the most frequent method of service delivery in EI (Klass, 2008), few studies have been conducted attempting to explore what early interventionists and caregivers do during home visits (Hebbeler & Gerlach-Downie, 2002; Roggman, Boyce, Cook, & Jump, 2001; McBride & Peterson, 1997). Therefore, it has been recommended to further explore the home visiting process in an attempt to better understand the mechanisms that make EI an effective support for families (Kormacher et al., 2008). This is particularly important for young children diagnosed with ASDs and their families because an increasing number of families are accessing EI systems (Lord & Bishop, 2010).
**Purpose Statement & Research Questions**

The purpose of these three related phenomenological studies is to explore parents’ and practitioners’ experiences in EI. Specifically, the first study examined parents’ perceptions of supports thought to be effective in managing stress. The second study explored early interventionists’ views on interventions, and the third study investigates the phenomenon of the home visit process as viewed by parents and practitioners.

Each study explores a different research question: (1) What supports do parents of children with ASDs view as being most effective in addressing stress?, (2) What are practitioners’ views of interventions used for young children with ASDs and their families?, and (3) What are parents’ of children with ASDs and interventionists’ perceptions of home visiting used in EI?

**Dissertation Organization**

This dissertation incorporates several studies, including the topics of ASDs, family stress, supports perceived as effective in addressing stress, practitioners’ views on interventions, and home visits used in EI. With respect to researcher reflexivity, I feel it is important to state my professional experience as an EI practitioner, partnering with children diagnosed with ASDs and their families, has clearly shaped my research lens. That being stated, I have incorporated several elements of rigor into this study including, triangulation, peer review and debriefing, clarification of research bias, member checking, and thick description (Glesne, 2006).

The dissertation is organized into three studies. Chapter 2 describes parents of young children diagnosed with ASDs thoughts on supports perceived as effective in addressing stress. Chapter 3 details practitioners’ perceptions of interventions, and in Chapter 4,
describes the phenomenon of the EI home visit used by professionals and families. The concluding chapter, Chapter 5, provides an overview of the study, general discussion and recommendations for future research.

References


Chapter 2. Parents of Children with Autism Spectrum Disorders: Views on Effective Supports to Manage Stress

Abstract

The purpose of this qualitative study is to examine families’ of children diagnosed with autism spectrum disorder perceptions of support perceived effective in addressing stress, in order to assist reduce parent stress. A symbolic interactionism theoretical perspective framed the phenomenological research design. Three thematic content areas emerged from interviews with six parents, whose children were enrolled in early intervention for at least six months. The findings are formal and informal supports, information on child development and strategies to help improve child behavior, and addressing communication needs parents perceive effective in managing stress. Results are discussed, implications for practitioners are presented, and directions for future research studies are provided.

Introduction

Autism spectrum disorders (ASDs) are a group of developmental disabilities characterized by impairments in social interaction, communication, and limited selection of interests (Rao & Beidel, 2009). There is growing interest in the effect of ASDs on the family. One reason may be due to the prevalence of children with ASDs. The CDC (2012) estimates 1 in every 88 children in the United States have ASDs. A second reason might be the core features (social interaction, communication and behavior issues) of ASDs have been shown to have a negative impact on family members (Hastings, Kovshoff, Ward, et al., 2005). Parents of children with ASDs experience high levels of stress (Hastings & Johnson, 2001; Duarte et al., 2005; Higgins, Bailey, & Pierce 2005), and stress can negatively influence the everyday activities of families (Hutton & Caron, 2005). Only limited intervention research
exists that addresses the needs of young children with ASDs and their families (Boyd et al., 2010). Given the estimated rate of children with ASDs, the high stress families can experience, and the limited research on intervention effectiveness for young children, in order to reduce stress it is important to explore parents’ perceptions of supports that most effectively address stress.

**Autism Spectrum Disorders and Stress**

Parents of children with ASDs report higher levels of stress and lower levels of well-being than parents of children with other disabilities (Abbeduto et al., 2004). This stress can have a negative impact on parents, leading to nervousness, depression, and conflict in marriage (Weiss, 2002). Researchers have also found negative outcomes for typically developing siblings of children with ASDs (Rivers & Stoneman, 2003). Several studies have found improvements in children’s behavior after parenting stress is reduced (Engwell & Macpherson, 2003; Bitsika & Sharpley, 2000).

Many parents of children with ASDs have been able to successfully adapt despite being faced with high levels of stress (Gray, 2006; Bayat, 2007). Families receiving informal support from their social groups, and formal support from agencies were more likely to demonstrate a positive adjustment (Chan & Sigafoos, 2001). Informal supports have been found to reduce parent stress by providing social and emotional support (Siklos & Kerns, 2006), and formal supports meeting the information needs of families helped manage stress (Whitaker, 2002).

Parents are more likely to successfully adapt to stress when they use strengths from within the family (e.g., communication), and from outside of the family (e.g., social support; Twoy et al., 2007). It is not surprising using communication strategies assisted parents to
adapt to stress. Bebko et al. (1987) found mothers and fathers reported difficulty communicating with their child as one of the most stressful aspects of parenting child with ASD. Tomanik, Harris, and Hawkins (2004) examined children with ASDs behavior and maternal stress, and found mothers reported higher levels of stress when their children were unable to communicate or interact with others. Parents using a variety of strategies experience less stress and more cohesiveness in their families (Hastings, Kovshoff, Brown, et al., 2005). Although support systems can effectively address parent stress (Mackintosh, Myers, & Goin-Kochel, 2006), access to supports are not evenly distributed across the population (Mandell & Salzer, 2007). As more young children with ASDs and their families are accessing early intervention systems (Davis & Carter, 2008), there will be an increasing need to explore the experiences of these families in order to best help parents manage stress.

**Early Intervention**

Part C of the Individuals with Disabilities Education Act (IDEA), often referred to as Early Intervention (EI), describes procedures for providing services for infants and toddlers with disabilities, and their families. EI services have been shown to effectively address stress in families who have children with ASDs (McConachie & Diggle, 2007; Wong & Kwon, 2010), but more information is needed to understand what EI services are most effective for what families (Guralnick, 2011). The EI program features that best assist to produce positive outcomes for families remain unknown (Summers et al., 2005). Therefore, more research is needed in order to identify services that will most effectively support families (Bailey, Hebbeler, Spiker, Scarborough, Mallik, & Nelson, 2005).
Theoretical Perspective

In this study, I used a symbolic interactionism (SI) framework to help build an appreciation for parents’ views of supports perceived to be useful in managing stress. SI theorists identify how social interactions are interpreted by people, and use the interpretation to generate meaning (White & Klein, 2008). The theoretical framework aligns with this study’s phenomenological design. In order to reduce parent stress, more in depth exploration is needed to understand the experiences of parents’ of children with ASDs (Phelps et al., 2009), and the supports most effective in addressing stress (Hutton & Caron, 2005; Luther, Canham, & Cureton, 2005). Therefore, the purpose of this qualitative study is to examine families’ perceptions of supports. The following research question was investigated: What supports do parents of children with ASDs view as being most effective in addressing stress?

Method

Research Design

I used SI theoretical perspective grounded in constructionist epistemology in order to construct meaning through social interaction (Crotty, 1998). A phenomenological methodology describes the lived experience of a phenomenon for several individuals, highlighting what they have in common (Creswell, 2007). Phenomenological methodology was used to better understand parents’ experiences and the meaning parents provide to their experiences (Merriam, 2002). The primary method of data collection was individual parent interviews; it allowed the opportunity to seek descriptions of the respondents’ experience of the phenomenon (Moustakas, 1994). This study received approval from the University Institutional Review Board prior to data collection.
Participants

Data were collected from 6 parents of young children diagnosed with ASDs. Purposive and referral sampling (Esterberg, 2002) was used to select participants. All family participants met three criteria: (1) participant was a primary caregiver of a child diagnosed with ASD, (2) the child received EI for at least six months, and (3) the family was either currently enrolled or had transitioned out of EI within 12 months preceding the interview. Participants were recruited through contact with their early interventionists. I provided a recruitment letter to early interventionists who gave letters to all families they worked with meeting the three research criteria presented above. Please see Appendix F for the recruitment letter. It is important to note, I had a working relationship with all of the early interventionists recruiting respondents for this study.

The family members \((n = 6)\) interviewed included 4 mothers and 2 fathers. Each parent had one male child diagnosed with ASD ranging in age from 2 to 4 years of age. The parents’ ages ranged from 26 years to 44 years of age. All of the families reported ethnicity as Caucasian for themselves and child. One of the mothers had attended 1 year of college, three parents had 4-year degrees and two had graduate degrees. All respondents were married at the time of the interviews, and all interviews took place in a location most convenient to the parent. See Table 1 for demographic information of the parents (each participant was given a pseudonym).
Table 1
*Demographic Characteristics of Parents (N=6)*

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Age</th>
<th>Race/Ethnicity</th>
<th>Marital Status</th>
<th>Employment</th>
<th>Education</th>
<th>People in Household</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sarah</td>
<td>42</td>
<td>Caucasian</td>
<td>Married</td>
<td>Information Technologist</td>
<td>4-year degree</td>
<td>7</td>
</tr>
<tr>
<td>Jennifer</td>
<td>39</td>
<td>Caucasian</td>
<td>Married</td>
<td>Communication Specialist Nutritionist</td>
<td>Graduate Degree</td>
<td>6</td>
</tr>
<tr>
<td>Tara</td>
<td>39</td>
<td>Caucasian</td>
<td>Married</td>
<td>Nutritionist</td>
<td>4-year degree</td>
<td>6</td>
</tr>
<tr>
<td>Julie</td>
<td>26</td>
<td>Caucasian</td>
<td>Married</td>
<td>Homemaker</td>
<td>Some college</td>
<td>4</td>
</tr>
<tr>
<td>Michael</td>
<td>44</td>
<td>Caucasian</td>
<td>Married</td>
<td>Police officer</td>
<td>Graduate Degree</td>
<td>6</td>
</tr>
<tr>
<td>William</td>
<td>41</td>
<td>Caucasian</td>
<td>Married</td>
<td>Finance</td>
<td>4-year degree</td>
<td>7</td>
</tr>
</tbody>
</table>

Data Collection

Semi-structured interviews were completed with each respondent, and each interview began with a social conversation in order to foster a comfortable atmosphere (Polkinghorne, 1989). Please see Appendix D for the interview protocol form. Following the social conversation, I explained the purpose, procedures, and their rights as a research participant. After responding to questions and obtaining informed consent documentation, I asked the respondents general and probing questions in order to create a comprehensive account of the phenomenon (Moustakas, 1994). Following the interview, a reflection of the interview (see Appendix C) was completed describing my general impressions. I completed all of the interviews, which were audio-recorded and later transcribed by key study personnel (all completed institutional research training).
**Data Analysis and Rigor**

Participants’ data were analyzed using a multiple step process. First the interview transcripts were read in order to acquire an initial sense of the content (Creswell, 2007), and then data were simultaneously open coded using two coding strategies: in vivo coding and descriptive coding (Saldana, 2009). After the data were initially coded, I used pattern coding (Miles & Huberman, 1994) to group initial codes into summaries providing a more meaningful and succinct unit of analysis. Refer to Table 2 for examples of initial coding and Table 3 for examples of pattern coding. Thematic findings were constructed using inductive analysis of coded data and patterns. Phenomenologists believe researchers have preconceived notions and beliefs influencing their interpretation of data (Creswell, 2007), therefore, investigator assumptions were bracketed in order to better understand the perspective of the respondent (Gearing, 2004).
Table 2
**Selected Examples of Participant Statements and Corresponding Initial Codes**

<table>
<thead>
<tr>
<th>Statement</th>
<th>In Vivo Code</th>
<th>Descriptive Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>We have become the household where all the family gatherings take place. So, Christmas and birthdays and Easter the extended family travels here. The family has been very good about understanding. My family is fantastic!</td>
<td>Extended family travels here Family understanding Family is fantastic</td>
<td>Extended family support Accommodating needs Family is understanding</td>
</tr>
<tr>
<td>Yes we even stopped going to church – even to the cry room. He [son] was just getting to rambunctious and it was hard. We started to say, okay, instead of going to the late service we will go the early service, but that didn’t work. So I felt really bad. Our friends convinced us to start back going again or we probably would have just stopped all together.</td>
<td>It was hard Didn’t work Felt really bad Friends convinced us</td>
<td>Difficulty with family routines Support from friends</td>
</tr>
</tbody>
</table>

Table 3
**Selected Examples of In Vivo/Descriptive Codes and Corresponding Pattern Coding**

<table>
<thead>
<tr>
<th>In Vivo/Descriptive Codes</th>
<th>Pattern Codes</th>
</tr>
</thead>
<tbody>
<tr>
<td>I want my family here</td>
<td>Family</td>
</tr>
<tr>
<td>Family understanding</td>
<td></td>
</tr>
<tr>
<td>Family is fantastic</td>
<td></td>
</tr>
<tr>
<td>Extended family support</td>
<td></td>
</tr>
<tr>
<td>Family lives around</td>
<td></td>
</tr>
<tr>
<td>Great friends</td>
<td>Friends</td>
</tr>
<tr>
<td>Having friends over</td>
<td></td>
</tr>
<tr>
<td>Talking</td>
<td></td>
</tr>
<tr>
<td>Friends</td>
<td></td>
</tr>
<tr>
<td>Surrounding yourself with the people who want the best for your child</td>
<td></td>
</tr>
</tbody>
</table>
Several steps were taken in order to increase trustworthiness and maintain rigor (Lincoln & Guba, 1985). Peer review and debriefing was completed through bi-monthly team meetings with key personnel. Peer reviewers examined samples of coded transcripts and preliminary thematic findings in order to ensure reliability and maintain an external perspective. Analytic memos and bracketing were used to address researcher bias. Please see Table 4 for an example of early, advanced, and self-reflective analytic memos. Early memos assist to explore qualitative codes and advanced memos refine the analysis process (Charmaz, 2006). Self-reflective memos help the researcher examine his/her thoughts throughout the research process (Polkinghorne, 2005). Member checking was completed in order to verify the completeness and accuracy of the findings. Clarifying questions were asked during the interview, samples of coded transcripts and tentative thematic findings were emailed to respondents. These approaches ensured rigor was maintained throughout the research process (Gearing, 2004).

Table 4

<table>
<thead>
<tr>
<th>Examples of Analytic Memos</th>
</tr>
</thead>
<tbody>
<tr>
<td>Early Memo</td>
</tr>
<tr>
<td>Derrick Goodmen [pseudonym] discussed a number of topics that assisted to manage stress. After looking at the initial coding, I think he has concerns for his son interacting in social settings. Initial codes emphasis difficulty for his family to go out into the community, having his son communicate effectively in a social setting, and developing friendships with peers.</td>
</tr>
</tbody>
</table>
Another element of rigor is acknowledging the researcher as the instrument of data analysis (Patton, 2002). My professional and educational background has clear influence on my perspective as a researcher. I was employed for several years in an EI program providing service to children diagnosed with ASDs and their families. At the time of this study, I worked as a research assistant on a project partnering with early interventionists. These interventionists were instrumental in recruiting participants. This study was completed as partial requirement for a doctoral program, and therefore, I benefit from its completion. At the time of this study, I have a one year old daughter. I think my training in qualitative research, professional experience, and role as a father will assist my understanding of the parents’ perceptions.

**Results**

Parents of children with ASDs are on a journey. Some events on their journey can be stressful, but having adequate supports can help ease the passage. The results from this study are presented as three thematic findings: **building bridges**, **having a map** and **open lines of communication**. The first theme is called **building bridges**, I describe the formal supports and informal supports used by the family to address stress. In the second thematic finding entitled **having a map**, parents explain having information about child development and strategies to help improve child behavior assist to deal with stress. The third thematic finding is **open lines of communication**, and parents reported addressing communication needs helped manage stress. Despite the findings being presented separately, it is recommended to consider relationships between the themes. As depicted in Figure 1, the categories formal and informal supports comprise the theme **building bridges**. Specific examples of formal supports are Area
Education Agencies (AEA) and other professional agencies, and types of informal supports are family and friends.

**Figure 1. Theme 1: Building Bridges**

![Diagram of Building Bridges]

*Note. AEA = Area Education Agency.*

**Theme 1: Building Bridges**

On their journey, parents of children with ASDs need *bridges*. A bridge is a structure that provides access over or through a barrier. Just as a bridge can help provide passage over obstacles, parents describe the *bridges* helpful managing obstacles they face. In the context of this study, *bridges* are formal and informal supports.
Formal supports are the providers from Area Education Agencies (AEAs) and other agencies such as Child Health Specialty Clinics through the University of Iowa and private practitioners. These formal supports provided access to information, and parents of children with ASDs reported having information needs addressed assisted to manage stress. As described by a mother of a three year old son with ASD, “Having a professional [from AEA] to talk with really helped [manage stress].” Although information support from AEA practitioners addressed stress, it was not always considered adequate. At times, parents supplemented the support from AEAs with support from other agencies.

“I thought it was good [support from AEA], but I didn’t think he [son] was getting everything he needed. When he was being seen by AEA and Pediatric Intervention Service [pseudonym], then I thought he is getting what he needed. So that made me feel good.”

A second mother talked about the support she received from her social worker/service coordinator at AEA, “She explained all of that [EI process]. Letting us know what to expect in his [son] disability and his age and where we should see him and what was out there. We wouldn’t have known where to start. She did a great job and that really helped me.” She described the interventionist as her “sounding board”. Adding, “It was nice to just talk. Even if we talked about her [interventionist’s] stuff - it was nice to have a conversation.”

In addition to formal agency support, informal support from family and friends helped parents manage stress. Transitioning into the community was reported to be stressful, and family and friends accommodating transition needs helped address parents’ stress. After explaining how difficult it is for her son to travel, one parent was excited to say, “We have become the household where all the family gatherings take place. So, Christmas and
birthdays and Easter the extended family travels here. The family has been very good about understanding. My family is fantastic!”

A father of a young child diagnosed with ASD described his friends as being “great”. He talked about visiting friends, “Sometimes it is just easier to not go [to a friend’s house], but everyone has been very understanding. And it helps to get out.” A second father talked about the importance of staying involved in the community, “After a while we realized, we just weren’t going out that much. Even to the church. It’s just healthy to be involved.” He continued,

“Yes we even stopped going to church – even to the cry room. He [son] was just getting to rambunctious and it was hard. We started to say, okay, instead of going to the late service we will go the early service, but that didn’t work. So I felt really bad. Our friends convinced us to start back going again or we probably would have just stopped all together.”

Having access to formal and informal types of supports helped parents bridge barriers on their journey.

**Theme 2: Having a Map**

A traveler might describe having a map as helpful in navigating a journey. Maps can provide information to the traveler about the road ahead. In this study, maps are information about child development and strategies to help improve child behavior. All of the parents interviewed described having information needs related to their sons’ special needs, and having these information needs addressed helped to manage stress. See Figure 2 for a visual representation of the thematic finding having a map, and corresponding categories child development and strategies to help improve child behavior.
A mother of 5 children mentioned being familiar with typical development, but “wasn’t sure what to expect” for her youngest son diagnosed with ASD. A second mother had difficulty describing her son’s developmental delays, and supports her son needed at childcare. She said, “the childcare program was really struggling with taking care of him while not hindering taking care of the other children.” Interventionists provided her with information regarding developmental expectations and the support he would need at childcare. Having the information helped, “saved our daycare.” She continued talking about information from interventionists, “It was really helpful because the program director was willing to give us more time. And he [son] did transition fairly well because we were all on the same page.”

Parents talked about having information about strategies to help improve child’s behavior assist to manage stress. A father said after he had information about the sensory component of eating, meal-time became less stressful,
“One of the other things we realized when it comes to food is that he wants to touch everything with his hands. He is not interested in a fork and spoon. When you think of all of the foods that are out there – when you think of touching them all. It is pretty incredible. It was frustrating for a while because he just would not try to use them [utensils], but after I thought about it [eating] from the sensory point of view. It made sense.”

A mother described her son’s behavior as “pitching a fit” when transitioning from home into the community. After being informed by an early childhood special education teacher that it is “fairly typical” for a child with ASD to “pitch fits” during transitions, she began to view “going to Target as an event.” The interventionist recommended using a “visual schedule” and “story” (scripted story) to help her son know what to expect. Scripted stories are often used to teach children with ASDs the behaviors they need to know in order to interact in a socially appropriate way (Barry & Burlew, 2004). The mother thought the intervention techniques were helpful, “The pictures and stories definitely help going to get groceries. I mean they don’t always work but they definitely help.” Parents reported having information needs met regarding how their children’s development differs from typical development, and knowing about strategies to help improve behavior assisted in alleviating stress.

**Theme 3: Open Lines of Communication**

Parents can travel on their journey more easily when *lines of communication* are *open*. *Lines of communication* refer to the interchange of thoughts and feelings from the parent to the child, interventionists, and other family members. In their journey, parents describe addressing communication needs with these groups assist to decrease stress by helping to overcome obstacles. For example, one parent reported having *open lines of*
communication with her husband made it easier for them to work on continuing to develop their relationship. See Figure 3 for a depiction of the theme, **open lines of communication** portraying the specific avenues of communication originating from the parents’ perspective.

**Figure 3. Theme 3: Open Lines of Communication.**

It is not surprising parents of children diagnosed with ASDs feel stress when communicating with their child because one of the core features of ASDs is difficulty communicating. Exposing the child to communication interventions addressed stress. One type of intervention used to facilitate communication is Picture Exchange Communication System (Bondy & Frost, 1994; PECSTM); the intervention uses pictures to foster communication development (Ganz, Simpson, & Corbin-Newsome, 2007). Although using PECSTM had not yet increased his son’s verbal language, a father said the tool still addressed his stress,

“So it [PECSTM] was not effective [increasing verbal language] for us yet. But they [interventionists] have continued to work with it because it is all over the classroom. That is the main communication device they use. I feel good knowing he is getting exposure to it.”
Communicating with their spouse helped parents to manage stress. Although no formal technique was discussed, a wife describes “taking time to talk with each other” helped to decrease stress. She talked about taking the “extra effort” to talk with her husband to make sure they stayed “connected”. She added, “I knew it was something we needed to do - no matter how busy we got.” Most spouses independently fostered lines of communication, but one wife mentioned advice she received from her social worker/service coordinator,

“She was saying to me, don’t forget to go on a date. And I thought yeah, I don’t think Jim [husband – pseudonym] and I had been out to a restaurant in months. I think you still need to do that sort of thing.”

Keeping open lines of communication with extended family helped to address stress. One mother said, “My Mom is only 10 minutes away, and she has been awesome. We talk about everything. She knows when I need to talk and when to offer advice.”

After telling extended family members about his son’s diagnosis, a father described them as being, “Very understanding with everything”.

A final line of communication perceived to address stress was having open lines of communication with interventionists. Open lines of communication adds to the theme building bridges, specifically to the category formal supports, by adding a component of effective communication to meeting information needs. A mother describes communicating with her intervention team,

“So now we all communicate on a regular basis, so that if someone finds a success of a way that works with him [son], no matter what the strategy, they communicate to each other and to all other parties so we can all do the same thing everywhere.”
Having *open lines of communication* with interventionists addressing stress is demonstrated using a negative example,

“I am wondering what additional services there are would be nice to know. Maybe occupational therapy but I am not sure how to bring it up. The focus has been on transitioning and gaining his attention. I think they are important but that [additional services] has been unanswered. Now I am not sure how to bring it up.”

Having *open lines of communication* can help parents cope with stress by providing the tools they need to overcome obstacles on their journey.

**Discussion**

In this study, parents of young children with ASDs talked about supports thought to be effective in addressing stress. Three themes emerged from data: *building bridges, having a map* and *open lines of communication*. The thematic finding *building bridges* refers to the formal supports and informal supports used by the family. Parents described having contact with formal support services, such as the AEA, addressed stress. This finding aligns with other research studies exploring the importance of formal supports (Siklos & Kerns, 2006). Informal supports, such as family and friends, also were reported to decrease stress. This finding bolsters other studies showing social support from family and friends (Crnic & Low, 2002; Benson, 2006), and support from other parents of children with ASDs (Mackintosh, Myers, & Goin-Kochel, 2006) reduces stress. It is important for interventionists to consider families’ formal and informal supports because access to a supportive social network can lead to reductions in stress, anxiety, and depression and increased life satisfaction (Dunn et al., 2001).
In the second theme called *having a map*, parents describe having information about child development and strategies to help reduce behavior assist to manage stress. This finding is related to Whitaker (2002) who found parents of children with autism have a strong desire for information to help them understand autism and their child’s needs. Specifically, one of the most common information needs in the study was for general information about ASD, and local support options available to the family. Having information about support options is particularly important because a significant amount of research suggests community support groups may reduce stress and social isolation, therefore having a positive influence on the family (Mandell & Salzer, 2007; Smith & Perry, 2005; Shu & Lung, 2005). The third thematic finding is *open lines of communication*. Trouble with communication is one of the core features children with ASDs display (Dietz et al., 2006), and in this study, parents reported addressing communication needs with their children and providing an opportunity for their children to communicate with others helped manage stress. This finding is related to McConachie and Diggle (2007) who found parent trainings lead to improved child communication and reduced maternal depression. Interventionists addressing the communication needs of children and families might also assist manage parent stress.

**Limitations**

There are several limitations to this study. Three limitations include marriage status, family ethnicity and recruitment. All of the respondents in this study were married, and support from a spouse has been shown to decrease stress (Siklos & Kerns, 2006). As a result, we do not have information about the views of single parents. Some research suggests mothers of children with ASDs have high levels of stress when also experiencing less spousal support (Bromley et al., 2004). This study did not ask about quality of support found within
the marriage. All of the respondents self-reported their ethnicity as Caucasian. Research has
found families from minority ethnicity have access to fewer formal supports and less
information (Thomas, Ellis, McLaurin, Daniels, & Morissey, 2007). Finally, recruitment is a
limitation. All of the families interviewed were recruited for this study by their
interventionists, and it is possible practitioners recruited families having a perceived positive
experience in EI. Findings from this study can not be generalized to other populations, but
hopefully will be transferred to similar contexts assisting interventionists working with families manage stress.

**Implications for Practice and Research**

Despite these limitations, results can help early interventionists in their practice.
Parents of young children with ASDs frequently report experiencing high levels of stress
(Baker-Ericzen, Brookman-Frazee, & Stahmer, 2005), and this stress has shown to have
negative impact on families (Higgins, Bailey, & Pierce, 2005). Early interventionists
typically provide service in the families’ homes (Klass, 2008), and, therefore, have direct
contact with the family. In one sense, they are on the frontline in supporting families. Despite
high levels of stress, families who receive adequate support will often positively adjust and
cope successfully (Twoy, Connolly, & Novak, 2007). Perhaps, interventionists aware of the
stress parents of children with ASDs are under, and the supports families perceive as being
most effective in managing stress, will be able to better support families. For example,
parents who report having limited informal supports might benefit from being made aware of
support groups or respite care services in their area. This is particularly important for
practitioners because high levels of parenting stress counter the effectiveness of early
teaching interventions (Osborne, McHugh, Saunders, & Reed, 2007).
Results from this study could inform future research studies. What supports do parents from minority ethnicity perceive to be effective in managing stress? What supports do families from non-traditional family structures think are effective? What is the best way to connect families of children with ASDs with the resources they need? These are three research questions that could be considered in future research studies.

References


Chapter 3. Practitioners’ Views of Interventions for Young Children with Autism Spectrum Disorders and their Families

Abstract

Many interventions are used to support children with Autism spectrum disorders and their families. A qualitative approach was used to explore practitioners’ views of interventions for infants and toddlers with ASDs and their families. Practitioners are familiar with multiple intervention strategies and often use a combination of approaches. Findings from this study describe factors influencing practitioner decision-making, perceived effectiveness of interventions, and concerns about intervention approaches. Due to the number of intervention options and variance in family characteristics, early intervention practitioners have an important role advising families on the most appropriate types of interventions. Data implies the importance of exploring practitioner perceptions of interventions due to this role guiding the family.

Introduction

Autism spectrum disorders (ASDs) are characterized by impairments in social interaction, verbal and non-verbal communication, and by a restricted array of interests, activities, and behaviors (Dietz et al., 2006). Although once considered a rare childhood disorder, recent prevalence estimates for ASDs are now estimated at about 1 in 88 children in the United States (CDC, 2012). The considerable increase in the number of children estimated with ASDs has increased pressure for effective interventions and services (Boyd et al., 2010).
Service Delivery System

Services for children with disabilities and their families are accessed through several different sources; one resource for families is service provided through Part C Early Intervention (EI) services as part of the Individuals with Disabilities Education Act (Trohanis, 2008). EI provides supports to families who have a child with a disability or are at risk for developmental delays (Bruder, 2010). According to the Division of Early Childhood (DEC, 2010), EI was established for three main reasons: to enhance the development of infants and toddlers with disabilities, to reduce educational costs by minimizing the need for special education through early intervention, and enhance the capacity of families to meet their child’s needs. EI service programs have been increasingly accessed to address the needs of children with ASDs and their families (Johnson & Myers, 2007).

Although EI services for young children with developmental delays vary greatly (Bruder, 2010), an increasing number of research studies show children with disabilities benefit from EI services (Guralnick, 2008; Trohanis 2008). Bruder (2010) suggests this is because the earlier a child is identified with a developmental delay or disability the greater the likelihood a child will benefit from interventions designed to address the child’s individual needs. Although it is clear children with disabilities benefit from EI services, the field of early childhood special education has not addressed sufficiently what supports and services should be offered to families in order to most effectively meet the needs of children with disabilities and their families (Turnbull et al. 2007).

Intervention research addressing the need of infants and toddlers with ASDs is limited (Boyd et al., 2010). Early interventionists have many approaches to consider, but the effectiveness of these strategies is unclear (Landa, 2008). Dunst (2007) stated that in order
for an intervention to be effective, strategies must evolve from the family’s priorities and routines. Therefore, practitioners must consider the service delivery system, type of intervention, and the families’ needs while choosing and implementing an intervention strategy.

**Types of Interventions**

Researchers propose three categories of interventions for people with ASDs: focused intervention, comprehensive treatments and psychopharmacological (National Autism Center, 2009). Focused interventions are specific practices intended to change a targeted behavior in a relatively brief period of time. Two examples of focused practices are early intensive behavioral interventions (Butter et al., 2003) and positive behavioral support (Buschbacher & Fox, 2003). Comprehensive treatments are a set of practices designed to have an influence on the characteristics of ASDs by incorporating a set of specific focused intervention techniques within a conceptual framework. The Early Start Denver Model (Vismara & Rogers, 2008) and Walden Toddler Program (McGee, Morrier, & Daly, 1999) are types of comprehensive treatments. Psychopharmacological interventions are drug induced changes in behavior (and are beyond the parameter of this study). Interventions can also vary according to assumptions on which they are based, such as intensity and degree of parent involvement (Krebs Seida et al., 2009). Within the three categories of interventions, a number of options exist each having a varying degree of effectiveness (Odom, et al., 2003). The ability of the EI practitioner to determine what intervention is most appropriate for a particular child with ASD and his/her family is critical, especially considering the importance of beginning intervention at the earliest possible age (Dietz et al., 2006).
**Family and Child Characteristics**

A challenge for early interventionists is to accommodate the diverse characteristics of children and families participating in EI (Guralnick, 2011). It is important for interventionists to work within diversity using families’ strengths to properly support child development (Guralnick, 2005). For example, a family using positive coping strategies is more likely to maintain family stability (Crnic & Low 2002), particularly when parents have a child diagnosed with ASD (Sivberg, 2002). Child characteristics are important to consider because severity of the disability is related to intervention approaches (Guralnick, 1998). Children diagnosed with ASDs tend to present with similar characteristics, but these characteristics differ in when they start, severity, and the exact nature of the symptoms (CDC, 2011). Considering the diversity within families, and within the autism spectrum, the demands being placed on EI program personnel are high (Odom et al., 2010). Due to variance in EI systems, the limited intervention research on infants and toddlers with ASDs, and the wide range in family and child characteristics, it is unlikely one intervention will be most appropriate for all children diagnosed with ASDs and their families (Lord et al., 2006). Therefore, the role of the practitioner in advising families on types of interventions for ASDs is essential (Charmin & Howlin, 2003).

**Role of the Early Intervention Practitioner**

Considering the wide range of possible interventions, and the uniqueness of children with ASDs their families, the role of the EI practitioner in guiding and offering advice to families about intervention options is crucial (Lord & Richler, 2006). Practitioners are presented with a difficult task of integrating complicated information from several sources (Tavakoli et al., 2000), and determining the effectiveness of an intervention (Green &
Britten, 1998). This task can become more difficult when the efficacy of intervention strategies change with context (Bregman & Gerdt, 1997). It is important to note, efficacy research on intervention strategies used with infants and toddlers with ASDs is limited and often EI practitioners adapt interventions used with preschool and school-aged children (Rogers & Vismara, 2008).

Practitioners’ experiences with interventions is important to explore because past experience with an intervention may influence future decision making more than research literature (Kam & Midgely, 2006), but there is inadequate research describing interventionists’ perceptions about the effectiveness of interventions used to help children with ASDs and their families (Ridge & Guerin, 2011). Therefore, by exploring practitioners’ views on interventions specifically for young children with ASDs and their families, we can better understand implementation of interventions.

The purpose of this study is to explore early interventionists’ views on interventions used with infants and toddlers diagnosed with ASDs and their families. The research question being addressed is: what are practitioners’ views of interventions for young children with ASDs and their families? Findings of this study can be used to inform practice and future research.

**Method**

**Research Design**

This study used a symbolic interactionism theoretical perspective (White & Klein, 2008) to inform a phenomenological research design. The purpose of this approach is to illustrate the lived experience of several individuals (Creswell, 2007). Phenomenological methods are helpful at showing the experiences and perceptions of individuals
(Polkinghorne, 1989). The phenomenon in this study is practitioners’ perceptions of interventions used with infants and toddlers diagnosed with ASDs and their families. It is appropriate to use a phenomenological design because it allows for an understanding of the attitudes towards interventions from the perspective of the practitioner.

**Researcher as Instrument**

Patton (2002) argues the qualitative researcher acts as the instrument of data collection and interpretation. Therefore, the credibility of the research is dependent upon the skill and competence of the researcher (Angen, 2000). Sandelowski (2002) states interviewing is a significant component to qualitative research, and, therefore, the researcher must be prepared through review of relevant literature and experience. A thorough review of relevant literature was completed during the research process, and as an EI practitioner, I provided interventions to children with ASDs and their families using an eclectic treatment approach, drawing from multiple focused interventions. It is possible my experiences working as an early intervention practitioner will assist me to relate to other practitioners, shape my views of existing literature, and influence my interpretation of data.

**Participants**

Convenience sampling (Esterberg, 2002) was used to select practitioners. All practitioners were working in EI, and had experience providing service to children diagnosed with ASDs and their families. Following Institutional Review Board approval of this study, initial contacts with prospective interventionist respondents began in person with a conversation about the study and informed consent process. Please see Appendix B for the informed consent document. It is important to note, practitioners in this study are a subgroup
of a larger study. I had an established working relationship with all of the respondents, and all of the interventionists discussed interest in research.

The early interventionists (n = 9) interviewed included one speech-language pathologist, one physical therapist, five early childhood special educators and two service coordinators/social workers. One interventionist had a professional doctorate degree, one interventionist had a 4-year degree and seven interventionists have master degrees in their respective fields. The group represented experienced interventionists; they averaged 15 years (range = 3-26) working in EI. Refer to Table 1 for characteristics of interventionists, all participants were provided a pseudonym.

Table 1

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Age</th>
<th>Race/Ethnicity</th>
<th>Education</th>
<th>Professional Position</th>
<th>Number of years working in EI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Danielle</td>
<td>41</td>
<td>African American</td>
<td>MS/MA</td>
<td>Service Coordinator/Social Worker</td>
<td>20</td>
</tr>
<tr>
<td>Lila</td>
<td>38</td>
<td>Caucasian</td>
<td>MS/MA</td>
<td>ECSE Teacher</td>
<td>15</td>
</tr>
<tr>
<td>Jane</td>
<td>37</td>
<td>Caucasian</td>
<td>MS/MA</td>
<td>SLP</td>
<td>11</td>
</tr>
<tr>
<td>Mary</td>
<td>48</td>
<td>Caucasian</td>
<td>4-year degree</td>
<td>ECSE Teacher</td>
<td>26</td>
</tr>
<tr>
<td>Susan</td>
<td>52</td>
<td>Caucasian</td>
<td>MS/MA</td>
<td>ECSE Teacher</td>
<td>26</td>
</tr>
<tr>
<td>Veronica</td>
<td>40</td>
<td>Caucasian</td>
<td>Professional Doctorate</td>
<td>Physical Therapist</td>
<td>3</td>
</tr>
<tr>
<td>Christine</td>
<td>45</td>
<td>Caucasian</td>
<td>MS/MA</td>
<td>Service Coordinator/Social Worker</td>
<td>18</td>
</tr>
<tr>
<td>Karon</td>
<td>32</td>
<td>Caucasian</td>
<td>MS/MA</td>
<td>ECSE Teacher</td>
<td>5</td>
</tr>
<tr>
<td>Carol</td>
<td>49</td>
<td>Caucasian</td>
<td>MS/MA</td>
<td>ECSE Teacher</td>
<td>11</td>
</tr>
</tbody>
</table>

Note. ECSE = Early Childhood Special Education; SLP = Speech-Language Pathologist; MS/MS = Master Science/Master Arts

Data Collection

I gathered descriptions of participants’ experiences using semi-structured interviews. Table 2 contains sample interview questions. Participants were asked questions regarding
their experiences and contexts surrounding their experiences. Due to the interactive nature of the interviews, probing questions were needed in order to create a comprehensive account of their views of interventions. All interviews were conducted in person, audio-recorded and transcribed for analysis. Following the interviews, a reflection sheet was completed (and can be found in Appendix C). Data from self-reflection was used to increase awareness of my underlying assumptions; these assumptions were bracketed (Polkinghorne, 1989).

Table 2

<table>
<thead>
<tr>
<th>Sample Interview Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tell me about your experience in EI.</td>
</tr>
<tr>
<td>Describe the supports you provide?</td>
</tr>
<tr>
<td>What types of supports have been most helpful to families?</td>
</tr>
<tr>
<td>Tell me about interventions you use in your practice?</td>
</tr>
<tr>
<td>Is there anything I forgot to ask?</td>
</tr>
</tbody>
</table>

Data Analysis and Rigor

Data were open coded using two first cycle coding methods in order to identify initial topics and ideas (Esterberg, 2002). I simultaneously used in vivo and descriptive coding for first cycle coding (Saldana, 2009). In vivo coding refers to using one or more words from the qualitative data as a code (Charmaz, 2006), and descriptive coding summarizes the essential topic of the qualitative data into one word or a concise statement (Saldana, 2003). Table 3 provides examples of participants’ responses with corresponding in vivo and descriptive coding.
Table 3  
*Selected Examples of Participant Statements and Corresponding Coding*  

<table>
<thead>
<tr>
<th>Statement</th>
<th>In Vivo Code</th>
<th>Descriptive Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>I think that [communication with parent] is huge because a lot of times it is Mom 24-7. I know that a lot of times she might think she can take on the world but you know what – it is okay to have some help.</td>
<td>Mom 24-7</td>
<td>Supports for mother</td>
</tr>
<tr>
<td></td>
<td>Take on the world</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Help</td>
<td></td>
</tr>
<tr>
<td>I try to lay out the options – you are driving the car, whatever works for the family.</td>
<td>You are driving the car</td>
<td>Being Flexible</td>
</tr>
<tr>
<td></td>
<td>Whatever works for family</td>
<td>Functional for families</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Team</td>
</tr>
<tr>
<td>People that work full time, that have multiple children, that are super-young moms or have two little ones or whatever – it is a huge difference in the amount of time they spend with their children.</td>
<td>Work full time</td>
<td>Balance responsibilities</td>
</tr>
<tr>
<td></td>
<td>Children</td>
<td>Time issues</td>
</tr>
<tr>
<td></td>
<td>Young Moms</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Time</td>
<td></td>
</tr>
</tbody>
</table>

After the data were initially coded, patterning was used to assist in the formation of categories (Miles & Huberman, 1994), and themes were identified from categories and coded data using inductive analysis. I bracketed, or set aside personal experience (Creswell, 2007), my assumptions in order to better present the essence of the lived experience from the perspective of the practitioners (Gearing, 2004). Table 4 depicts two examples of bracketing.
Table 4
Two Examples of Bracketing

<table>
<thead>
<tr>
<th>Participant Statement</th>
<th>Bracket</th>
</tr>
</thead>
<tbody>
<tr>
<td>But if they [parents] don’t do it [intervention] when I am not there, then the growth is going to be slowed down.</td>
<td>[It is frustrating when I can’t think of ways to engage parents with a program.]</td>
</tr>
<tr>
<td>The focus was on learning the PECS [Picture Exchange Communication System] system and getting the words. So the PECS system was being worked on by the home interventionist and with us. The speech person does not come on until they [children] are 2-6 [30 months of age].</td>
<td>[Why wait until 2-6?]</td>
</tr>
</tbody>
</table>

Rigor was addressed using prolonged engagement, peer review and debriefing, clarification of research bias, member checking, and thick description (Glesne, 2006).

Prolonged engagement was employed using continued contact with interventions; I met with each interventionists several times before interviewing, and then had follow-up contacts with each respondent. Peer review and debriefing was completed using bi-monthly team meetings with key study personnel. Clarification of researcher bias was addressed using researcher memos and bracketing. Member checking was conducted using clarifying questions during the interview, transcripts and data analysis of this study were shared to ensure practitioners’ thoughts are fairly represented.

Findings

Practitioners shared their thoughts and experiences on the interventions they use with young children diagnosed with ASDs and their families. Four themes emerged from the practitioners’ responses: interventions utilized, influences on decision-making, perceived effectiveness, and concerns about interventions. These themes are depicted in Figure 1. In the following sections, findings are presented as themes in conjunction with an analogy of a carpenter choosing the ‘right’ tool for a job.
Theme 1: Interventions Utilized (What Tools are in the Tool-Box?)

When a carpenter is asked to do a job, she might think about the tools available to achieve the desired result. Just as the carpenter thinks about tools she has at her disposal, practitioners think about their tools or interventions. Respondents described several interventions they use with children diagnosed with ASDs and their families. All of the interventions discussed have been defined as focused intervention practices, which are practices designed to modify a specific behavior in a short time span (Boyd et al., 2010), and are presented in Table 5.
Table 5

*Focused Intervention Practices*

<table>
<thead>
<tr>
<th>Type of Focused Intervention Practice</th>
<th>Number of Respondents Who Mentioned Using in Practice</th>
</tr>
</thead>
<tbody>
<tr>
<td>Behavioral Intervention Strategy</td>
<td>8</td>
</tr>
<tr>
<td>Positive Behavior Support</td>
<td>8</td>
</tr>
<tr>
<td>Naturalistic Interventions</td>
<td>7</td>
</tr>
<tr>
<td>Parent-Implemented Interventions</td>
<td>8</td>
</tr>
<tr>
<td>PECS</td>
<td>9</td>
</tr>
<tr>
<td>Pivotal Response Training</td>
<td>2</td>
</tr>
<tr>
<td>Structured Work Systems</td>
<td>5</td>
</tr>
<tr>
<td>Visual Supports</td>
<td>9</td>
</tr>
<tr>
<td>Eclectic (multiple focused interventions)</td>
<td>9</td>
</tr>
<tr>
<td>Other</td>
<td>7</td>
</tr>
</tbody>
</table>

*Note. PECS = Picture Exchange Communication System.*

In this theme, respondents described the interventions used with families. Frequently, practitioners reported using an eclectic approach, or a combination of several interventions. One ECSE teacher described using multiple interventions, “There is no magic wand. If I am using a [visual] schedule and PECS, but it is not working for the family, I might use sign [basic sign language] to get the words [expressive speech] going.” A second educator reported,

“There are so many interventions right now, but I don’t know necessarily what to choose. A lot of the time I will pick and pull from different places. I try to think, what is best in this situation. I do some back tracking but sometimes what works for one family will not work for another. I think that is a big part of our job - being flexible.”

A speech language pathologist described interventions being complimentary.
“I might use PECS to get the communication going. But I like to use them with the visual schedule, especially when I am first introducing them. It lets the child know what is going on. It lets him know what to expect.”

At times, practitioners referenced “not knowing all the options.” A service coordinator/social worker talks about this uncertainty,

“Sometimes, I am just not sure what to do. I mean - I think one thing might help but maybe not. I know a lot of things to try, but what if the child needs something you are not thinking or even aware of, or a kind of program with more supports. Then what? I am not sure?”

Although early interventionists talked about ambiguity in choosing support strategies, it is important to note, all of the interventionists interviewed had access to other practitioners and administrators providing the opportunity to discuss intervention techniques.

**Theme 2: Influences on Decision-Making (What Tool to Use?)**

A carpenter might have several factors influencing decision making in her work. What has past experiences told her about the tools? What is the context of the job? What resources are at her disposal? What do her clients think? These are some of the factors that could influence a carpenter’s decision making? Just as a carpenter has factors influencing her decision making, so do practitioners. Respondents talked about two key categories influencing the choice of intervention, families’ needs and personal experience. These categories are depicted in Figure 2, under the theme influences on decision-making.
Families’ needs have influence on practitioner decision making. An ECSE teacher talked about choosing an intervention after considering families’ needs,

“I think it depends on the family. I work with such a broad range of families. I guess at this point I kind of automatically factor it [needs] in.”

Practitioners thought about stressors families are facing, and made decisions accordingly. As described by an ECSE teacher,

“I think it goes back to stressors and resources. I think if they [parents] are too stressed, they are not going to try first-then [intervention technique] or the pictures [PECS] because they feel it is too difficult right now. I might have to work on something else first and then come back.”

A social worker/service coordinator described modifying interventions after considering families’ needs,

“In that family, Mom was on board [with the intervention strategy] but Dad just thought his son was being a boy. I mean how much can I really ask Mom to do?
When Grandma was over, I think they could do more of the behavior and communication strategies, but I felt I had to go in baby steps.”

An ECSE teacher talked about families’ needs and communication with the parent,

“I think it is huge [communication with parent] because a lot of times it is Mom 24-7. I know a lot of time she thinks she can take on the world but you know what – it is okay to have somebody else help. We know she needs someone else to help but a lot of times she thinks she needs to do it all. She might not see it but we might.”

A second influencing factor on practitioners’ decision-making and interventions is personal experience. Interventionists talked about personal experiences transferring intervention strategies perceived to be successful between families. For example, a speech language pathologist suggests some parents provide their child an object to coordinate with a visual schedule when transitioning in the community, after the interventionist had a successful experience using the strategy with another family.

“She [mother of a child with ASD] mentioned [going to] the grocery store being a nightmare. And some objects helped with the transition. After she was telling me how good it [transitioning to the grocery store] was going, I would bring it up with other families. Before then, I was using the visual schedule but didn’t think of using the object to go along with it.”

Other practitioners cited interventions perceived to fail, and these experiences shaped their professional opinion. An ECSE teacher told a story about a family who tried an intervention called the Tomatis Method (Corbett, Shickman, & Ferrer, 2008) to accelerate the development of listening skills, language and communication,
“The mom told me that she just didn’t see a difference after the training. I haven’t really talked to a lot of people who have done the training, and I can’t remember where she went to do it. She wasn’t happy with the results, so I didn’t really look into it, and haven’t recommended it to any families.”

One practitioner stressed the importance of experience, “I think I have to see the technique work before I would believe it.” Although interventionists’ personal experiences influence their decision-making, as noted previously, all of the practitioners have access to administrators and peer early interventionists to guide decision-making.

**Theme 3: Perceived Effectiveness (How Effective is the Chosen Tool?)**

While working on a job, a carpenter might ask herself, how is the job going? Have the tools been effective in getting the work done? Practitioners considered family report and perceived child progress when determining perceived effectiveness of interventions. See Figure 3 for a representation of sources of perceived intervention effectiveness.

![Figure 3. Sources of Perceived Intervention Effectiveness](image)
A social worker/service coordinator talked about using family report to determine intervention effectiveness,

“When I work with a family, I don’t always know what they need. I try to see if what we are doing is working or not. If not, I need to make some changes. And I don’t know exactly where to start, but I need to start somewhere. I need to talk with the family, and find out how things are progressing.”

A physical therapist described how she used feedback from the family,

“I don’t necessarily know if what I am doing [intervention] is helping or not. Is this where the child was headed anyways, or was it something I was doing, or the family was doing? When I first started working in Early Access it was difficult to decide. Overtime, I get a sense of how well things were going from conversations with mom and dad. It gets a little easier the more time you can spend.”

An ECSE teacher talked about using conversations with the family to guide intervention,

“I try to figure out the biggest thing. Is it communication? Is it behavior? I ask the family, and work on that. If the family says the biggest thing is addressed, and I see the child improving – I go with it.”

Other times, practitioners used perceived child progress to determine effectiveness of interventions. When asked to explain how she knew if an intervention was effective, an ECSE teacher responded, “If the child is progressing and the family is happy, I think my interventions are working.” When determining perceived intervention effectiveness, practitioners described two main sources of information, family report and perceived child progress.
Theme 4: Concerns (Is It the Right Tool for the Job?)

A good carpenter is concerned about her work. She reflects on her trade, concerned she is doing the best work she can. Is there something else that can be done? Has she chosen the right tool for the job? Practitioners are concerned with limitations of certain approaches. One social worker/service coordinator expressed apprehension over the timing when speech language pathologists are included into teams,

“The home interventionist does the work until they [children] are 2-6 [two years and six months old], and then they [intervention team] start looking at the articulation part. So our home interventionists work on building the words, and beginning communication sounds. Then they are turned over to speech. But you have to wonder because other families from other agencies have different services. I wonder, is it a difference between caseloads? My thought is yes, it is.”

A physical therapist talks about feeling limited in treatment options due to time constraints,

“I take more of that functional approach – working on that specific skill we are trying to get to. I would say most typically I work in the home 2 times a month between 30 and 45 minute treatment sessions. I would like to work in more sensory [sensory integration], but this is an educational model and not a medical model. It is a parent education model so our main goal is to educate the family on how to take the best care of their child. It takes more time to do that than I have, so I pick what is most important and just try to monitor the rest.”

An ECSE teacher was concerned about the time required to use structured work systems. Structured work systems involve visually organizing play areas of the home,
“We use the structured sessions with centers. You know, how it is in the classroom, and I think it was great. But the thing is, it takes the entire session. By the end of working, he [child] could transition between 4 activities in 45 minutes, but I felt we didn’t work on so many of the other things I wanted to.”

The interventions addressed child needs, but often at the expense of other areas of concern. For example, if a family and early interventionist choose to focus on strategies addressing the child’s expressive communication needs, they might have less time to address the child’s ability to transition in the community. Due to time constraints, practitioners felt they were “making a difference”, but were concerned about “more effective ways” of implementing service.

**Discussion**

This study used a qualitative approach to explore practitioners’ views of interventions for young children with ASDs and their families. Findings suggest practitioners are familiar with several types of intervention approaches. Respondents often use multiple interventions in order to address child and family needs. This finding is supported by other research studies showing practitioners use an eclectic intervention approach in order to maximize treatment benefits (Francis, 2005). Despite using multiple approaches, interventionists show concern over perceived unaddressed issues due to time constraints.

Findings suggest practitioners draw from two sources when choosing an intervention, families’ needs and personal experience. This finding is supported by other studies that found practitioners have multiple factors influencing their decision making (Tavakoli et al., 2000). There are inconsistencies in the research literature regarding interventions used to address ASDs, (Howlin et al., 2009), and, therefore, it is not surprising personal experience is an
influencing component in choosing intervention. The lack of efficacy research regarding interventions for infants and toddlers diagnosed with ASDs (Boyd et al., 2010) might be related to interventionists looking into multiple sources for information in order to determine perceived effectiveness of a particular approach. It is important to note positive outcomes have been found from using different approaches including, but not limited to Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH; Mesibov et al., 2004) and the Picture Exchange Communication System (PECS; Frost & Bondy, 1994), and therefore evidenced based practices should be considered. Although positive outcomes have been found using different approaches, there are only limited longitudinal studies examining the effectiveness of interventions (Myer & Johnson, 2007). A perceived lack of time to implement interventions might be related to interventionists’ concern of a more effective way to support families.

Limitations

Limitations exist in this study. Three clear limitations are practitioner recruitment, service delivery model, and represented disciplines. First, practitioners recruited for this study form a subgroup of a larger study. All practitioners volunteered to be a research participant, and expressed an interest in the research process. Their thoughts on interventions may be different from other practitioners, and participation in another study may have changed how they view their work. Second, all interventionists worked in an educational service delivery model; the Department of Education is the lead agency for the state’s early intervention system (Early Access Iowa and Visiting Nurse Services of Iowa, 2011). Finally, practitioners from four different disciplines were interviewed. Data could be enriched by accessing views of interventions from people practicing other disciplines such
as occupational therapy, pediatrics, psychology and orientation & mobility. Despite these limitations, I think findings are transferable to other contexts. Some examples include having the findings apply to early interventionists in a different part of the country, in a state with a different lead agency, or in an area with a different service model. Transferability is primarily the responsibility of the reader, but the qualitative researcher can enhance transferability by thoroughly describing the research process and context (Esterburg, 2002). This means if enough similarities exist between two situations, the reader might be able to transfer findings from one study to their own situation.

Implications for Practice and Research

Due to the variance in children diagnosed with ASDs and their families, most likely one type of intervention is not going to be effective for everyone (Lord et al., 2006). Therefore, it is important to explore practitioners’ views on intervention strategies because they have significant influence in advising families on types of approaches to use (Lord & Richeler, 2006; Charmin & Howlin, 2003). Practitioners must be aware of intervention options, and understand the importance of choosing interventions that align with unique family characteristics (Ridge & Guerin, 2011). Interventionists should be aware of their personal experience with a particular approach because experience can influence intervention implementation. Although it is important interventionists have self-awareness about their personal experiences with interventions, practitioners should be familiar with evidence-based practices in order to better serve families (Horner et al., 2005). Evidence-based practices are associated with positive outcomes for both children diagnosed with ASDs and their families (Odom & Strain, 2002), and therefore, practitioners not considering evidence-based practice might be limiting effective support options that could be provided. Families might benefit
when practitioners sensitively consider intervention options, and individual family characteristics.

This study raises additional research questions. Do interventionists feel they have enough resources (e.g., knowledge of a range of strategies, information about effectiveness of various strategies, time) in order to implement an intervention, and monitor effectiveness? How do practitioners view their role in guiding families through the intervention process? What are practitioners’ (disciplines not represented in this study) views of interventions for young children with ASDs and their families? These are some questions that could be investigated to assist in the intervention process.

**Conclusion**

This study explored practitioners’ views of interventions for young children with ASDs and their families. Findings show how practitioners view those interventions. Practitioners used focused intervention strategies, often combining more than one strategy at a time. It is important to consider, some children diagnosed with ASDs have more positive results when using a single treatment when compared to an eclectic treatment approach, although both interventions have been shown to show improvements in behavior (Eikeseth et al., 2002). Interventionists discussed factors influencing their decision-making when choosing an intervention, and the strategies they use to determine perceived effectiveness of the approach. Overall, practitioners reported interventions were effective, but showed concern over implementing a more effective approach.

In addition to perception of intervention effectiveness, practitioners’ might benefit from using a systematic assessment of progress (Fuchs & Fuchs, 2006). It is important for children diagnosed with ASDs to make early progress in order to assist them on a positive
developmental trajectory (Dawson et al., 2010). Implications for practice include increasing practitioner awareness of possible intervention strategies, and ways to monitor effectiveness in the context they work. Future research studies might include exploring practitioners’ views of interventions from disciplines not included in this study. Interventionists are faced with a significant challenge in determining what intervention(s) to use, for what families, and how best to determine effectiveness of those interventions after considering available resources. Therefore, it is important to further investigate practitioners’ views of interventions used to support infants and toddlers with ASDs and their families.

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Chapter 4. Opening the Black Box of Home Visiting in Early Intervention: Parents’ of Children Diagnosed with Autism Spectrum Disorders and Interventionists’ Perspective

Abstract

In Early Intervention (EI), home visiting is the primary method of service provision for infants and toddlers diagnosed with Autism spectrum disorders (ASDs) and their families. This study used interviews with parents and interventionists, and field observations to investigate parents’ of children with ASDs and interventionists’ perceptions of the delivery of home-based EI services. The findings of this investigation suggest clear and distinct structures within the process of the home visit. The discussion focuses on implications for practitioners and suggestions for future research.

Introduction

This study deals with the structure and description of the EI home visiting process used by parents of young children diagnosed with ASDs and the interventionists who serve them. The effects on families who participate in home visiting programs have been studied (Trohanis, 2008), and research suggests families generally experience positive outcomes (Sweet & Applebaum, 2004), but only limited studies have examined the process used in home visits that might influence these positive outcomes (Campbell & Sawyer, 2007). Scholars of home visiting call for an investigation to understand how families and home interventionists spend their time together (Kormacher et al., 2008). Researchers suggest opening the “black box” of the home visit (Peterson, Luze, Eshbaugh, Jeon & Kantz, 2007; Roggman et al., 2001). One reason home visits are referred to as a “black box” is because they are private, taking place in families’ homes, making it difficult for evaluators to investigate them (Roggman et al., 2001). It might also be difficult to study home visits if the
home visitors and families feel intruded upon. Despite the inherent difficulty studying home visits, it is important to explore the home visit to better understand the characteristics needed to best support families (Hebbler & Gerlach-Downie, 2002).

Many families of children diagnosed with ASDs receive publicly provided EI services (Lord & Bishop, 2010). Although ASDs were previously thought to be a low-prevalence disorder, they are now considered much more prevalent (Newschaffer et al., 2007). One estimate from the Center for Disease Control (2012) suggests 1 in every 88 children in the United States have ASDs. As the number of children with ASDs has increased, so has the interest in the effect of ASDs on the family, (Meadan, Halle, & Ebeta, 2010), and information needs about the disorder in order to provide effective interventions and services (Boyd et al., 2010). In this study, I investigate the phenomenon of how parents of children with ASDs, and interventionists structure their time during home visits provided in EI.

**Legislation in Early Intervention**

Services provided to families of children with disabilities from birth to age 3 have been influenced by several public laws; Public Law 99-457 (PL99-457), which passed in 1986 as an amendment to the Individuals with Disabilities Education Act (IDEA) (Bruder, 2010). IDEA is the legislation directing the delivery of special education services to children and their families. PL99-457 mandates the delivery of special education services to families and children with disabilities from birth to 3 years of age (Schertz et al., 2011). This law, in conjunction with a series of legislative amendments, led to the Individuals with Disabilities Education Act of 1991, and later the reauthorization in 1997 and 2004 (Brorson, 2005). IDEA remained fairly constant through these reauthorizations with the exception services in
EI be carried out in the child’s natural environment (Bruder, 2005). The child’s natural environments are considered the home or community settings representative of the child’s age peers who are developing typically (Campbell, Sawyer, & Muhlenhaupt, 2009). One important reason EI services are provided in the child’s natural environment is to ensure children with disabilities, and their families are integrated into everyday home and community activities (Bruder, 2010). This legislation in EI service provision has led to the overwhelming majority of EI services being provided in the child’s home (Campbell & Sawyer, 2007).

**Autism Spectrum Disorders**

Autism spectrum disorders are a group of developmental disabilities that can cause social, communication and behavior challenges. There is growing interest in the effect of ASDs on the family; one reason may be due to the prevalence of children with ASDs. As previously noted, the CDC (2011) estimates an increased number of children in the United States have ASDs. This trend has been described as one of the most significant changes in demographics of developmental disability in recent history (Boyd et al., 2010), and has stirred a growing interest ASDs’ impact on families (Meadan, Halle, & Ebeta, 2010).

Researchers describe possibilities for treatment as behavioral, developmental or as a combination of both methods (Butter, Wynn, & Mulick, 2003; Kasari, Freeman, & Paparella, 2006). Some evidence based practices used by early interventionists working with families of children with ASDs are positive behavior support (Buschbacher & Fox, 2003), picture exchange communication systems (Yoder & Stone, 2006), pivotal response training (Jones, Carr, & Feeley, 2006), structured work systems (Ozonoff & Cathcart, 1998), and visual supports (Dauphin, Kinney, & Stromer, 2004). Regardless of the approach used,
interventions are implemented in the child’s natural environment – most typically through a home visit.

**Home Visiting Process**

As noted previously, home visiting is the most common method of service delivery in EI. There has been an emphasis to provide EI service within families’ activities and routines (Turnbull et al., 2007). For example, McWilliam and Scott (2001) recommend EI services use a routines-based intervention, Pretti-Frontczak and Bricker (2004) suggest integrating activity-based intervention strategies, and other researchers advocate the importance of learning opportunities (Dunst et al., 2000). All of these approaches guide interventionists and families but independent from the philosophy of approach used, services are provided through a home visit model.

General guidelines for home visiting have been suggested (McWilliam, 2012). For example, Axtmann and Dettwiler (2005) have placed and emphasis on observation and reflection in order to develop a comprehensive picture of a child, and uncover a strategy for intervention. Other guidelines promote coaching parents (Sheldon & Rush 2010), encouraging a wide variety of routines for children to participate (Dunst et al., 2001), and reinforcing caregivers’ implementing interventions in daily routines (Woods et al., 2004). Despite these guidelines, there is only limited research describing exactly what interventionists should do when working with a family during a home visit (Campbell & Sawyer, 2007).

Despite research supporting the effectiveness of EI for children with disabilities and their families (Gurlanick, 2008), and home visiting being the principal model for providing service (Klass, 2008), only a few studies have been conducted attempting to explore what
early interventionists and caregivers do during home visits (McBride & Peterson, 1997). Therefore, it has been recommended to explore the home visiting process in an attempt to better understand the mechanisms making EI an effective support for families (McWilliam, 2012; Kormacher et al., 2008). This study explores the home visiting structure used by interventionists and parents of young children diagnosed with ASDs.

**Qualitative Research Methods**

There is a scarcity of qualitative research efforts in early childhood special education (Odom et al., 2005). The dominant theoretical perspective in social science research is positivism, and therefore quantitative methodologies and methods are more commonly employed (Crotty, 1998). Despite being used less frequently, qualitative research methods are clearly useful in their ability to provide complex textual descriptions of how people experience a process (Creswell, 2007). I use qualitative research methods to describe the structure of the home visit used in EI from the perspective of parents and practitioners. More specifically, a phenomenological approach is used in order to illustrate the lived experience of several individuals (Creswell, 2007). It is important to remember all research paradigms have strengths and limitations, and it is my belief a phenomenological approach is best suited to investigate the structure and describe the home visiting process because the purpose of a phenomenology is to reduce experiences to a description of the essence of the phenomenon being studied (Moustakas, 1994).

There is only limited research detailing exactly how interventionists and families should most effectively spend their time together (Campbell & Sawyer, 2007). The purpose of the study is to explore the phenomenon of the home visit used by professionals and children with ASDs and their families in EI. Interventionists aware of the structure of the home visit
could use the framework to guide their sessions. For example, interventionists familiar with the structure of the home visit might be better able to individualize the home visit, within the core structure, to make them more effective for different family circumstances. The research question being addressed: “What are parents’ of children with ASDs and interventionists’ perceptions of the delivery of home EI services?” The findings of this study can be used to inform practitioners, and researchers about the home visiting method used with young children diagnosed with ASDs and their families in EI.

Method

Epistemology, Theoretical Perspective, Methodology and Methods

I used constructionist epistemology, grounded in symbolic interactionism theoretical perspective. Constructionist theorists suggest knowledge is constructed out of our engagement with the world by processes of interpreting interactions (Crotty, 1998). A phenomenological research methodology was used in order to describe, and interpret the meaning of the lived experience from the perspective of the respondents (Merriam, 2002). Interviewing was the primary method of data collection, and allowed for a thick description of meanings from the participants (Moustakas, 1994). Also, I completed 4 field observations; these observations supplemented interviews with both families and interventionists, and were used to gain perspective on the home visiting process.

Design and Data Collection

A phenomenological design is appropriate because it allows for a better understanding of the parents’ and practitioners’ perceptions of the delivery of home EI services. Two methods were used to collect data and increase credibility of the findings. Semi-structured interviews were completed with each respondent, and observations occurred
during four home visits. Please see Appendix D for the interview protocol form. The researcher is responsible to create an atmosphere that will allow the respondent to feel comfortable (Polkinghorne, 1989); this was typically addressed by beginning with a social conversation. The participants were asked general questions regarding their experience of the phenomenon. Due to the interactive nature of the interview, follow up and probing questions were needed in order to create a comprehensive account of the phenomenon. Following each interview, I completed an interview reflection sheet (please see Appendix C) to help me consider the conversation and make any needed modifications. All interviews were conducted in person, audio-recorded and later transcribed. Observations occurred during four home visits, and field notes were taken during and immediately after each home visit.

**Researcher as Instrument**

Patton (2002) states the researcher acts as the instrument of data collection and interpretation. Therefore, it is important to describe researcher subjectivity as well as the steps taken to ensure rigor throughout the research process. My professional and educational background has clear influence on my perspective as a researcher. I worked for several years as a physical therapist providing service to children diagnosed with ASDs and their families in EI. I currently work as research assistant on a project which has several interventionists working in EI. The majority of my professional work has incorporated the use of a home visiting model, and children diagnosed with ASDs and their families have comprised the largest portion of my caseload. This study was completed as a requirement for a doctoral program at a research intensive institution. I think my experiences will enable me to better understand perceptions of both parents and practitioners.
Participants

Purposive, referral, and convenience sampling (Esterberg, 2002) was used to select participants. All interventionists met three criteria: currently working in EI, have experience working with children diagnosed with ASDs, and currently utilizing the home visiting model. All parent participants met three criteria: primary caregiver of a child diagnosed with ASD, child was enrolled in EI services for at least six months, and either currently enrolled or transitioned out of EI services within the 12 months prior to their interview. Following Institutional Review Board approval, initial contacts with prospective interventionist respondents were made. Interventionists facilitated in the recruitment process of families. All of the parents interviewed partnered with at least one interventionist in this study, but some parents partnered with more than one interventionist.

The early interventionists \( n = 9 \) interviewed included five early childhood special educators, two service coordinators/social workers, one speech-language pathologist, and one physical therapist. The physical therapist reported recently completed a professional doctorate degree, one interventionist had a 4-year degree, and seven remaining interventionists had earned master’s degrees in their disciplines. The respondents averaged 15 years of professional experience working in EI with the most experienced interventionist having 26 years of experience. Table 1 includes characteristics of interventionists.
Table 1

*Characteristics of Interventionists (N=9)*

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Age</th>
<th>Race/Ethnicity</th>
<th>Education</th>
<th>Professional Position</th>
<th>Number of years working in EI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Danielle</td>
<td>41</td>
<td>African American</td>
<td>MS/MA</td>
<td>Service Coordinator/Social Worker</td>
<td>20</td>
</tr>
<tr>
<td>Lila</td>
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<td>Caucasian</td>
<td>MS/MA</td>
<td>ECSE Teacher</td>
<td>15</td>
</tr>
<tr>
<td>Jane</td>
<td>37</td>
<td>Caucasian</td>
<td>MS/MA</td>
<td>SLP</td>
<td>11</td>
</tr>
<tr>
<td>Mary</td>
<td>48</td>
<td>Caucasian</td>
<td>4-year degree</td>
<td>ECSE Teacher</td>
<td>26</td>
</tr>
<tr>
<td>Susan</td>
<td>52</td>
<td>Caucasian</td>
<td>MS/MA</td>
<td>ECSE Teacher</td>
<td>26</td>
</tr>
<tr>
<td>Veronica</td>
<td>40</td>
<td>Caucasian</td>
<td>Professional Doctorate</td>
<td>Physical Therapist</td>
<td>3</td>
</tr>
<tr>
<td>Christine</td>
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<td>Caucasian</td>
<td>MS/MA</td>
<td>Service Coordinator/Social Worker</td>
<td>18</td>
</tr>
<tr>
<td>Karon</td>
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<td>MS/MA</td>
<td>ECSE Teacher</td>
<td>5</td>
</tr>
<tr>
<td>Carol</td>
<td>49</td>
<td>Caucasian</td>
<td>MS/MA</td>
<td>ECSE Teacher</td>
<td>11</td>
</tr>
</tbody>
</table>

*Note.* ECSE = Early Childhood Special Education; SLP = Speech-Language Pathologist; MS/MS = Master Science/Master Arts

The family members (*n* = 6) interviewed included 4 mothers and 2 fathers. Each parent had one male child diagnosed with ASD ranging from 2 to 4 years of age. The parents’ ages ranged from 26 years to 44 years of age. All of the families reported ethnicity as Caucasian for themselves and child. One of the mothers had attended 1 year of college, three parents had 4-year degrees and two had graduate degrees. All respondents reported being married at the time of the interview. Table 2 contains demographic characteristics of parents.
Table 2

Demographic Characteristics of Parents (N=6)

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Age</th>
<th>Race/Ethnicity</th>
<th>Marital status</th>
<th>Employment</th>
<th>Education</th>
<th># people in household</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sarah</td>
<td>42</td>
<td>Caucasian</td>
<td>Married</td>
<td>Information Technologist</td>
<td>4-year degree</td>
<td>7</td>
</tr>
<tr>
<td>Jennifer</td>
<td>39</td>
<td>Caucasian</td>
<td>Married</td>
<td>Communication Specialist</td>
<td>Graduate Degree</td>
<td>6</td>
</tr>
<tr>
<td>Tara</td>
<td>39</td>
<td>Caucasian</td>
<td>Married</td>
<td>Nutritionist</td>
<td>4-year degree</td>
<td>6</td>
</tr>
<tr>
<td>Julie</td>
<td>26</td>
<td>Caucasian</td>
<td>Married</td>
<td>Homemaker</td>
<td>Some college</td>
<td>4</td>
</tr>
<tr>
<td>Michael</td>
<td>44</td>
<td>Caucasian</td>
<td>Married</td>
<td>Police officer</td>
<td>Graduate Degree</td>
<td>6</td>
</tr>
<tr>
<td>William</td>
<td>41</td>
<td>Caucasian</td>
<td>Married</td>
<td>Finance</td>
<td>4-year degree</td>
<td>7</td>
</tr>
</tbody>
</table>

Data Analysis and Trustworthiness

Data were simultaneously open coded using two first cycle coding methods, which refer to the process of initial coding, in order to enhance accountability and capture processes in the findings (Miles & Huberman, 1994). The two first cycle coding methods used were in vivo coding, and descriptive coding; these are considered to be elemental methods of coding (Saldana, 2009). In vivo codes use language directly from participants (Charmaz, 2006), and descriptive coding summarizes the topic of a passage (Wolcott, 1994). Next, the second cycle coding method of patterning (which assists to pull together material into a more meaningful unit of analysis) was used to search for explanations in the data and help formation of theoretical processes (Miles & Huberman, 1994). Second cycle codes facilitated the generation of categories, and themes were constructed from codes, and categories using inductive analysis. Researcher assumptions were bracketed in order to help describe the lived experience from the perspective of the individual (Gearing, 2004). Please see Figure 1 for a
visual representation of the data analysis process beginning with data collection and ending with reporting findings.

The specific approaches used to ensure trustworthiness are triangulation, peer review and debriefing, clarification of researcher bias, member checking, and thick description (Glesne, 2006). Triangulation was achieved by using multiple data collection methods from
multiple sources; multiple parents and interventionists were interviewed, and multiple home visiting observations were completed. Peer review, and debriefing was used to provide an external perspective on this study. Clarification of researcher bias was addressed using researcher memos, and bracketing. Member checking was completed using clarifying questions in the interview process, and interview transcripts and analysis of this study were shared with the participants in order to make certain their thoughts have been fairly represented.

**Findings**

Parents and early interventionists described the process of home visits. Responses pertaining to the overall structure of the home visit were similar, but the meaning of the home visit components differed between parents and practitioners. The home visiting process used by families and interventionists had six distinct structural components: *preparation, welcoming, direct service, sharing ideas, plan of action* and *scheduling*. These components are depicted in Figure 2. *Preparation* takes place before the home visit, and families and interventionists *welcome* each other when the interventionist arrives at the home, but after *welcoming*, the home visiting process is non-linear. The structure of the home visit does not necessarily transition from one theme to the next theme, but the structure can change order or cycle between two different themes. Although the six structural components were found, the components had different meanings to parents and practitioners. These components of a home visit are presented as themes, and described from both the parents’ and interventionists’ perspective.
Theme 1: Preparation

Families and interventionists took preliminary measures in order to prepare for the home visit. Preparation for families has three meanings: reflection on interventions, physical appearance of the home, and availability for the home visit. Families reported taking opportunity to reflect on the interventions recommended by their interventionists. They thought about appropriateness and effectiveness of interventions. After tirelessly attempting to implement picture exchange communication systems (PECS™), a type of alternative communication system that uses pictures instead of words to help children communicate (Ganz, Simpson, & Corbin-Newsome, 2007), a father of a son diagnosed with ASD said, “It is just not effective for us now, but it is all over the classroom [preschool] and we wanted him [son] to get exposure to it”. Despite the father thinking PECS had limited short term effectiveness for his son, after learning from interventionists that the PECS program was
frequently found in preschool programs in his area, he was willing to continue using the strategy keeping in mind the potential long term benefits to communication. A mother of a son diagnosed with ASD had this to say about PECS, “It was better when we switched from sign [sign language] to PECS. I felt like I could understand what he [son] was trying to tell us.”

Families also prepared for the home visit by readying the physical appearance of their home. One mother self-consciously stated, “Sometimes I feel embarrassed looking around at this mess, and thinking I do have company [interventionist] coming over later.”

The third way families prepared for the home visit is by arranging to be available. Some parents needed to make only minor accommodations in their schedule, but other families took significant actions. A social worker/service coordinator talked about a father of a child enrolled in EI who changed employment in order to be available during traditional work hours. She explained,

“He took a job working nights at a factory in the Plainfield [pseudonym] area, that way he would be at home during the day so Mom could go to her job, and someone would be at home with their son to meet us.”

Whether parents reflected upon strategies, physically prepared the home or rearranged their work/family schedule, families prepared for the home visit.

Interventionists’ preparation means reflecting on interventions, considering potential modification of interventions, and logistically readying for the home visit. One speech language pathologist (SLP) reflected on a transitioning intervention she was working on with a family,
“It has taken a long time, but now Evan [pseudonym] can work through 4 activities in one session. This is huge and I think it will help him in preschool.” Interventionists prepare for a home visit by considering intervention modifications. An early childhood special education (ECSE) teacher said, “We have been working a lot on the words, but I have been thinking we might have to go back and focus on behaviors.” A second ECSE teacher talked about intervention modifications,

“I think it depends on what the family is open to and what their biggest concern is but that can change. You also have to find what is motivating for the child, but that changes too. I think we need to be flexible in our work.”

The final way interventionists prepared for a home visit is logistically. Logistical preparation was described as organizing, packing supplies such as developmentally appropriate toys, and considering travel time. Interventionists mentioned, “getting the bag ready”, “getting assessments around”, and “spending most of the day in the car”. Although families and home interventionists both prepare for the home visit, preparation has different meanings for the two groups.

**Theme 2: Welcoming**

Families and interventionists welcome each other when the interventionist arrives at the home. This greeting is done in a manner similar to a friend entering the home of another friend. In a field observation, a father of a two year old child with ASD cordially said to his son’s SLP as the interventionist walked through the door, “Hey there, c’mon in! Can I give you a hand with anything? How are you today?” The SLP replies, “Hi, I am fine! How are you? Let me set down my stuff (toy bags/folders) here before we talk.” In this interchange, the family is welcoming the interventionist into their home, and the interventionist welcomes
the family into her speech language therapy session. Even when the \textit{welcoming} is brief, a distinct greeting occurs symbolizing the beginning of the home visit for both the family and interventionist. It is important to note, although the \textit{welcoming} component of a home visit could be concise, it is not limited to a brief interaction at the door. For example, in the instance a family and interventionist engage in prolonged conversation about the child, I think \textit{welcoming} transitions into \textit{sharing ideas} (please see Theme 4: Sharing Ideas for a description).

\textbf{Theme 3: Direct Service}

\textit{Direct service} has different meanings for families and interventionists. For families, \textit{direct service} means the parent(s) observes the practitioner providing an intervention strategy, and then demonstrates the technique back to the interventionist before receiving feedback. For interventionists, \textit{direct service} means observing the child, observing parent-child interactions, and implementing an activity designed to assist child development. \textit{Direct service} comprised the majority of time in the home visit. Figure 3 depicts the theme \textit{direct service} with corresponding categories and patterns.
Parents observed interventionists working with their child, learning how to perform a particular intervention. One mother stated she had “some information on PECS”, but felt she “had a better idea how to do PECS after watching Jane (interventionist pseudonym).” A father said he benefited from watching the interventionists work,

“There was one point when he (son) wasn’t talking and because of that we were not talking as much either. I think that was one good thing we found out about – still talking with him, making sure to explain things. It helped to watch them (interventionists) work. It (talking with son) helps develop his understanding.”
Direct service for families also means obtaining feedback from interventionists. A mother talked about strategy she was using with her son to facilitate transitions,

“I was trying this transitioning game. We (Mom and son) are going between these 5 activities. Working on one for a few minutes and then moving on. It wasn’t working. Samantha (interventionist pseudonym) would keep telling me – you are doing fine, you are doing great – and might add something or tell me when to switch games. Now he is doing better. We can do four games now and it doesn’t end with him screaming at me.”

Families describe direct service as a way to observe practitioners working one-on-one with their child, but also as a way to obtain feedback on their ability to administer intervention strategies.

Interventionists use direct service for the majority of their session with the family. Direct service for interventionists means observing the child, observing parent-child interactions, and applying an intervention. One ECSE teacher talked about child observation and making necessary service modifications,

“When I walked into the home and saw Kyle (pseudonym) screaming and running away, I thought it is going to be hard enough to get instructional control. No way am I doing picture/object matching. I need to rethink this.”

Direct service was used by the interventionist to observe parent-child interactions. Interventionists observe the parent/caregiver demonstrating a skill previously instructed by the interventionist. One practitioner stated,
“I need to see Mom doing the activity. When I see Mom doing the activity I think – okay now she knows. Moms need to be on-board or what am I even doing here? I come in once or twice a month. What can I really do but teach the parents?”

The direct application of a particular intervention occurred when the practitioner actively worked with the child in a manner designed to promote child development. Strategies were designed to improve the child’s development either through one-on-one intervention or by educating the parent in their parent-child interactions.

**Theme 4: Sharing Ideas**

*Sharing ideas* occurs when families and interventionists discuss their thoughts about the child. For families, *sharing ideas* included their thoughts regarding child progress, current intervention strategies, and future for their child. *Sharing ideas* for families also included confirmation of professional opinion. One father said,

“I thought we were on the right track with this picture schedule, but I like hearing what they (interventionist team) think. I was thinking John (son pseudonym) is getting to be more expressive with his speech, but I see him every day and they (interventionists) are documenting and have the tests to support it.”

*Sharing ideas* for interventionists meant discussing problem solving strategies, parent education, and addressing parent concerns. An ECSE teacher talked about the importance of sharing ideas with one particular mother,

“I think it is huge (communication with parent) because a lot of times it is Mom 24-7. I know a lot of time she thinks she can take on the world but you know what – it is okay to have somebody else help. We know she needs someone else to help but a lot of times she thinks she needs to do it all. She might not see it but we might.”
There is a variety of topics that can be covered during the sharing ideas component of the home visit; one consistency is parents and interventionist share ideas and attempt to gain information from each other.

**Theme 5: Plan of Action**

Families and interventionists decide on a *plan of action* to use between meeting times; this *plan* contains two components, task delegation and time frame. Task delegation refers to the activities that will be completed. One parent talks about a type of communication intervention, “I was excited that he (son) had moved onto the next stage in PECS, the one where we can keep the book in another room.”

Time frame refers to when these activities will be done. For families, this could refer to a time of day, number of times an activity is attempted or number of trials before the next home visit. For example, one father talked about his son’s utensil use,

> “We worked on using a fork during snack (after father’s work) every evening of the week, but on the weekends with the 4 other kids out and about everywhere, we usually slide on the fork until Monday. But I think he (son) gets enough practice in.”

Similar to families, task delegation for interventionists refers to specific activities to be completed, and time frame refers to when the activities will be completed. An ECSE teacher agreed to “have the new picture from Board Maker ready” by “the next session.” Families and interventionist have unique responsibilities in the *plan of action*.

**Theme 6: Scheduling**

*Scheduling* is a brief and interactive event typically taking place toward the end of the home visit. Typically after the *plan of action* is completed, an arrangement for the next meeting is *scheduled*. During one home visit observation, an ECSE teacher asks the mother,
“Can we look at our schedules?”, and the mother responds, “Absolutely, I have it with me.”

The family integrated the home visiting scheduling process into their routines to the point it was an expectation. Other times, scheduling is not as seamless. One interventionist talked about the importance of scheduling in the summer months,

“The summer can be kind of tough to schedule with families, you know, we are trying to take sort of a break, otherwise you can burn out like that (snaps her fingers).

Families take vacations and kids have things going on, so I like to have the next visit scheduled before I leave. It is way easier than trying to call everyone after you left.

That never works.”

Although scheduling at certain parts of the year were more difficult than other times, neither parents nor interventionists expressed a desire for change. Scheduling is a shared undertaking which allows the families and early interventionists to organize the intervention process.

**Discussion**

The findings of this investigation suggest there are structures within the process of the home visit. I have identified six structures that consistently appear within the home visit: preparation, welcoming, direct service, sharing ideas, plan of action and scheduling.

Although practitioners interviewed described how they individualize their service, which is an important part of EI (Odom, 2009); they detailed the way these six structures of the home visit are individualized. The individualized strategies existed within these essential structures.

It is important to note, structures of the home visit are not necessarily linear in nature. For example, a parent and practitioner could welcome each other and then schedule the next home visit.
Parents of children with ASDs and interventionists apply different meanings to each component of the home visit. Parents and interventionists complete the preparation portion of the home visit in order to be ready for their meeting. Some components of the home visit such as the welcoming, and scheduling are highly collaborative but have different meanings. During welcoming, the family greets the interventionist and welcomes her into the home, and the interventionist greets the family and welcomes the family to her service. Scheduling allows the families and interventionists the opportunity to organize services. During other components, such as direct service, sharing ideas and plan of action, families and practitioners have different ways to show accountability. Interventionists use direct service as a way to observe and apply an intervention while families viewed direct service as an opportunity to learn how to address their child’s needs. Sharing ideas was used by parents and interventionists as a chance to discuss their existing knowledge in order to best help the family. Typically, after the parents and interventionists have shared ideas they develop a plan of action each will address before reconvening. The degree of collaboration and meaning of each component is different between families and interventionists but the focus on the child remains constant throughout the home visiting process.

Certain guidelines for effective home visiting in EI have been recommended (McWilliam, 2012). For example, it is recommended interventionists promote active caregiver participation (Campbell & Sawyer, 2007), and parent-child interactions should be facilitated (Peterson, Luze, Eshbaugh, Jeon, & Kantz, 2007). Despite recommended guidelines, only limited research exists that addresses the needs of young children with ASDs and their families (Boyd et al., 2010), and the most effective way to serve families using a home-based service delivery model (Wallace & Rogers, 2010; Roberts, et al. 2011). Findings
from this study align with other research findings regarding the format of a home visit (Brorson, 2005). Home visitors informed on the structure of a home visit might be better prepared to implement strategies that are naturalistic, accepted by caregivers, and align with family routines (Cook & Sparks, 2008). Interventionists informed on the structure of the home visit from the perspective of both parents and other practitioners used with young children with ASDs and their families may be in a better position to incorporate recommended guidelines for effective home based EI services.

**Limitations**

There are several limitations in this study. Two of the most noteworthy limitations are geographic location and family recruitment. One limitation is geographic location; all of the families and interventionist live in a similar area of one Midwestern state. A second restriction is all of the families interviewed or observed in this study were recruited by the interventionists interviewed. These limitations make the findings of the study unable to be generalized to other populations. That being stated, the goal of this research is to have findings that are transferable, meaning the reader notes specifics of the situation and compares them to the specifics of a situation they are familiar. In the event that enough similarities exist, readers may decide the results of the study would be similar in their own context. Showing that findings have applicability in other contexts, is an important part of rigor and important to evaluating its worth (Lincoln & Guba, 1985).

**Implications**

Despite identified limitations of this study, findings have implications for practice and research. Results suggest the home visit is divided into structural components; each component was described from the perspective of families and interventionists. In terms of
practice, findings from this study might assist interventionists. One way these findings can be used is to assist practitioners with individualization of service. It is necessary families receive individualized service in order to meet the unique needs of their family (Odom, 2009). Practitioners who are aware of the structure of the home visit might be better able to individualize service delivery within these six structural components in order to better meet the needs of the child and family. Some research suggests interventionists’ practice during home visits do not always align with recommended practices (Campbell & Sawyer, 2007; McBride & Peterson, 1997). Interventionists who are aware of the components of the home visiting process can use the information to inform their decision making and better understand how he/she is using his/her time during the home visit.

These findings can be used to raise new research questions. What are the structural components of the home visiting method used by practitioners to provide services to children with disabilities (other than ASDs) and their families? What are the most effective ways families and practitioners can spend their time together during the home visiting process?

**Summary**

Qualitative research methods can be useful for researching complex service delivery models (Stainback & Stainback, 1984), such as the home visiting method in EI. This study used a phenomenological approach to describe the structure of the home visit in EI. Findings support six structural components to the home visit. Knowledge about these findings can be incorporated into the practice of early interventionists, providing information to improve quality of service. Interventionists working with young children diagnosed with ASDs and their families who are aware of the structure of the home visit might be better able to individualize service delivery within these six structural components and better meet the
specific needs of families. Individualization of service is an important principle in the field of EI due to the uniqueness of families (Guralnick, 2008). This study does not allow for information describing the characteristics of interventions that make EI effective, but it does provide a frame future research studies can use to explore these characteristics.

References


Chapter 5. General Discussion

The findings in this study draw attention to the experiences of parents of young children diagnosed with ASDs and the practitioners serving them. This study explored parents’ views on supports they feel are most effective in addressing stress, EI practitioners’ views on interventions, and the structure of the home visit. The purpose of this research was to explore the experiences of parents and practitioners to have more information about the process in order to better support families. Through interviews and observations, I addressed three research questions. What supports do parents of children with ASDs view as being most effective in addressing stress? What are practitioners’ perceptions of interventions for young children with ASDs and their families? Finally, what are parents’ of children with ASDs and interventionists’ perceptions of the delivery of home EI services? Findings to these research questions are shared along with implications and future research questions.

Autism Spectrum Disorders and Stress

Parents of young children with ASDs discussed supports perceived effective in managing stress. Supports described as most helpful are informal and formal, information about child development and strategies to help improve child behavior, and addressing communication. Informal support systems include families and friends, and formal supports include agency support. These findings support existing research suggesting families receiving informal support from their social networks and formal support from an organization are more likely to have less stress (Hastings & Johnson, 2001). Parents report having information about child development and behavior improvement strategies assist to control stress; this result is related to the work of Whitaker (2002) who found parents frequently expressed concern over unmet information needs about ASDs. Addressing
communication in the family assisted to address parent stress, and supports research with related findings (McConachie & Diggle, 2007). Practitioners could use these results to inform practice. Interventionists aware of the stress parents are under, and the supports thought to be effective in addressing stress can make more informed decisions in their practice supporting families. One direction for future research might include, what is the best way to connect parents of children with ASDs with the resources they need?

**Early Intervention Practitioners**

Practitioners’ discussed their views of interventions for young children with ASDs and their families. Findings show practitioners are familiar with several types of intervention approaches, and use multiple interventions in order to address families’ needs. Francis (2005) found practitioners use multiple interventions in order to capitalize on treatment benefits. Practitioners think about families’ needs and personal experiences before implementing an intervention, and consider multiple sources of information when reflecting on intervention effectiveness. Other studies found practitioners have several issues influencing their decision making (Tavakoli et al., 2000). One concern interventionists expressed was a perceived lack of time to implement interventions. This is not surprising considering the debate over appropriate programming for young children with ASDs and their families (Schwartz & Sandall, 2010). Practitioners might use these findings to reflect on their own views of interventions in order to better align interventions with children’s and families’ needs. Families might be better supported by practitioners who consider intervention options and individual family characteristics. For example, interventionists might better serve families by considering the informal support network available to the family. One course for future
studies is to explore practitioners’ views of their role in guiding families through the intervention process.

**Home Visiting**

This investigation identified six structures within the process of the home visit: *preparation, welcoming, direct service, sharing ideas, plan of action and scheduling*. These components form the framework of the home visit, and although the structures are consistent, the meanings and interpretations of these structures to parents and practitioners are different. For example, the structure of *direct service* is consistent in home visits, but the perceived responsibilities of parents and practitioners are different. Practitioners can use these findings to assist individualizing services for families. Interventionists aware of the structure and the interpretation of these structures might be better able to individualize service delivery in order to meet the unique needs of the families they support (Odom, 2009), because variations in home visiting structure may be one factor determining the effectiveness of a home visiting program for families (Roggman, Boyce, Cook, & Jump, 2001). Interventionists aware of the components of the home visit can use the information to better plan how he/she is using his/her time during the home visit. This leads to the question, what are the most effective ways families and practitioners can spend their time together during the home visiting process?

**Concluding Self-Reflection**

Before embarking on this study, I thought about my experiences as an EI practitioner. I worked for several years supporting young children diagnosed with ASDs and their families in a home visiting setting. I had many questions regarding the best way to serve young children and their families, and this study allowed me the opportunity to address three of
those questions. I enjoyed exploring the supports parents say manages stress, practitioners’
views on interventions, and the structure of the home visit from both the parent and
practitioner perspective. I think early interventionists aware of information presented in this
study will be better prepared to work with children diagnosed with ASDs and their families.
From the dissertation process, I learned about the discipline required in writing, and
perseverance required in research. I am thankful for having the chance to research topics I
consider important, and hopefully give something back.

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APPENDIX A. INSTITUTIONAL REVIEW BOARD (IRB) APPROVAL

IOWA STATE UNIVERSITY
OF SCIENCE AND TECHNOLOGY

Institutional Review Board
Office for Responsible Research
Vice President for Research
1138 Pearson Hall
Ames, Iowa 50011-2207
515 294-1506
FAX 515 294-4207

Date: 5/20/2011
To: Jason Peck
73 LeBaron Hall
CC: Dr. Gayle Luze
51B LeBaron Hall

From: Office for Responsible Research

Title: Families' Perceptions of Intervention Characteristics

IRB Num: 11-197

Approval Date: 5/20/2011
Continuing Review Date: 5/19/2012

Submission Type: New
Review Type: Expedited

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

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

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

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

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

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

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

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

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

INFORMED CONSENT DOCUMENT

**Title of Study:** Families’ and Interventionists Perceptions of Intervention Characteristics

**Investigators:**
- Jason Peck PT, M.Ed. (Principal Investigator)
- Gayle Luze Ph.D.
- Kere Hughes-Belding Ph.D.
- Mary Jane Brotherson Ph.D.
- Kimberly Greder Ph.D.
- Steve Garasky Ph.D.
- Nancy Peck M.Ed.
- Mindy Heinz
- Aisha White

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

**INTRODUCTION**
The purpose of this study is to explore families’ and interventionists’ perceptions of intervention characteristics used to address potential stressors that families face. I am interested in perceptions of families who have a child currently enrolled or recently discharged (within the past year) from the Early Access. I am also interested in perceptions of interventionists who are currently working in Early Access. You are being invited to participate in this study because you have accessed Iowa’s Early Access Program or you are an interventionist currently working in Early Access.

**DESCRIPTION OF PROCEDURES**
If you agree to participate, you will be asked to take part in an interview (s). Interview (s) will consist of a series of questions that I will ask that will be audio–recorded for record keeping, you will be aware of the presence of the recorder. You may be asked to complete multiple interviews or to reflect on the interview questions in writing. Interview questions will be asking about intervention characteristics and your perceived stress. Your participation might last for 30 to 60 minutes for one to two interviews. Also, you may be asked to be a part of an observation during a home visit. The researcher will observe and document interactions in field notes – you will be aware of the presence of the researcher.
**RISKS**
There are no physical or financial risks known in this study. I will be asking about potential stress, if you feel uncomfortable with this you may decide not to answer any particular questions or to not participate in the study.

**BENEFITS**
If you decide to participate in this study there may be no direct benefit to you. It is hoped that the information gained in this study will help other interventionists and families to better understand how to provide support for stressful situations.

**COSTS AND COMPENSATION**
You will not have any costs from participating in this study. You will not be compensated for participating in this study.

**PARTICIPANT RIGHTS**
Your participation in this study is completely voluntary and you may refuse to participate or leave the study at any time. If you decide to not participate in the study or leave the study early, it will not result in any penalty or loss of benefits to which you are otherwise entitled. You can decide to not answer any specific question.

**CONFIDENTIALITY**
Records identifying participants will be kept confidential to the extent permitted by applicable laws and regulations, and will not be made publicly available. However, federal government regulatory agencies, auditing departments of Iowa State University, and the Institutional Review Board (a committee that reviews and approves human subject research studies) may inspect and/or copy records for quality assurance and data analysis. These records may contain private information. To ensure confidentiality to the extent permitted by law, the following measures will be taken: data will be stored in a locked office, information stored on a computer will be password protected and information obtained in the interview process that could potentially identify a participant will be changed. A pseudonym will be provided for all participants. If the results are published, your identity will remain confidential.

**QUESTIONS OR PROBLEMS**
You are encouraged to ask questions at any time during this study.

- For further information about the study contact Jason Peck (jpeck@iastate.edu) or Gayle Luze (gluze@iastate.edu; 515-294-4045).
- If you have any questions about the rights of research subjects or research-related injury, please contact the IRB Administrator, (515) 294-4566, IRB@iastate.edu, or Director, (515) 294-3115, Office for Responsible Research, Iowa State University, Ames, Iowa 50011.
PARTICIPANT SIGNATURE
Your signature indicates that you voluntarily agree to participate in this study, that the study has been explained to you, that you have been given the time to read the document, and that your questions have been satisfactorily answered. You will receive a copy of the written informed consent prior to your participation in the study.

Participant’s Name (printed)

__________________________________________

(Participant’s Signature) (Date)
## APPENDIX C. INTERVIEW SUMMARY SHEET

### Interview Reflection Summary Sheet

<table>
<thead>
<tr>
<th>Name of person being interviewed:</th>
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<tbody>
<tr>
<td>Date of interview:</td>
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<tr>
<td>Brief description of setting:</td>
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<tr>
<td>Describe general impression from the interview:</td>
</tr>
<tr>
<td>What went well from the interview?</td>
</tr>
<tr>
<td>What was difficult about the interview?</td>
</tr>
<tr>
<td>Are there questions to add / delete / modify before the next interview</td>
</tr>
<tr>
<td>Is there anything that needs to be addressed?</td>
</tr>
</tbody>
</table>
## APPENDIX D. INTERVIEW PROTOCOL FORM

### Family Interview Question guideline

**RQs:**

A. What stressors do families and interventionists view as affecting families of young children with autism?

B. What intervention characteristics that families and interventionists view as effective in meeting the family needs for families of children with autism?

C. How do families view interventions as meeting their needs related to their life stressors?

| Family Characteristics | The purpose of the study is to explore how families and interventionists perceive intervention characteristics to address stressors? What have you experienced? What situations have influenced your experience?
<table>
<thead>
<tr>
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<tbody>
<tr>
<td>1. Tell me about yourself.</td>
<td>• Prompts could include demographic related questions e.g. education, career, health</td>
</tr>
<tr>
<td>2. Tell me about your child.</td>
<td>• Prompts could include: disability, temperament</td>
</tr>
<tr>
<td>3. Tell me about your experience in EI.</td>
<td>• Prompts could include: services, support</td>
</tr>
<tr>
<td>4. What type of support is available?</td>
<td>• Prompts could include: marital relationship, family, friend, community network</td>
</tr>
<tr>
<td>5. What type of support has been most helpful?</td>
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</table>

<table>
<thead>
<tr>
<th>Family Patterns of Interaction</th>
<th>6. Describe how you typically communicate with your child?</th>
</tr>
</thead>
<tbody>
<tr>
<td>7. What does a typical day look like for your child?</td>
<td>• Prompts: family and community</td>
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<td>Question</td>
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<td></td>
<td>8. Does your child have any health concerns?</td>
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<td></td>
<td><strong>Child Development</strong></td>
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<td><strong>Stressors</strong></td>
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<td><strong>Intervention</strong></td>
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<td></td>
<td><strong>DEC Best Practices</strong></td>
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<td></td>
<td><strong>Other</strong></td>
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<td></td>
<td>Thank you for your time and help in this process.</td>
</tr>
</tbody>
</table>
**Interventionist Interview Question Guideline**

**RQs:**

<p>| | |</p>
<table>
<thead>
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<tbody>
<tr>
<td>A</td>
<td>What stressors do families and interventionists view as affecting families of young children with autism?</td>
</tr>
<tr>
<td>B</td>
<td>What intervention characteristics that families and interventionists view as effective in meeting the family needs for families of children with autism?</td>
</tr>
<tr>
<td>C</td>
<td>How do families view interventions as meeting their needs related to their life stressors?</td>
</tr>
</tbody>
</table>

**Family Characteristics**

The purpose of the study is to explore how families and interventionists perceive intervention characteristics to address stressors?

16. Tell me about yourself / families.

- Prompts could include demographic related questions e.g. education, career, health

17. Tell me about the children you work with.

- Prompts could include: disability, temperament

18. Tell me about your experience in EI.

- Prompts could include: services, support

19. What type of support is available?

- Prompts could include: marital relationship, family, friend, community network

20. What type of support has been most helpful

**Family Patterns of Interaction**

21. Describe how you typically communicate with the child?

22. What does a typical day look like for your family?

- Prompts: family and community

23. Do some children have any health concerns?

- Prompts: health insurance issues, neighborhood concerns
| **Child Development** | 24. What are some strengths of the children?  
  
  - Prompts: domains |
|----------------------|---------------------------------------------------------------|
| **Stressors**        | 25. How is stress, if at all, influencing families’ lives?  
  
  - Prompts: information needs, interpersonal and family distress, resource needs, and confidence to make decisions related to child’s disability or other, how was intervention chosen |
| **Intervention**     | 26. Could you describe the support you provide?  
  
  - Prompts: service providers, frequency, duration, specific interventions used how intervention was chosen |
| **DEC Best Practices** | 27. What is your awareness of DEC best practice guidelines?  
  28. What are some things that make it hard (easy) for families to get through the day (general life, child disability)?  
  
  - Prompts; use visual prompts |
| **Other**            | 29. Is there anything that I forgot to ask? Is there anything you want to tell me? |

Thank you for your time and help in this process.
### Article # 1: Be where you are: A qualitative study of parents’ of young children with ASDs views on support perceived effective in managing stress

<table>
<thead>
<tr>
<th>Themes</th>
<th>Categories</th>
<th>Patterns</th>
<th>InVivo &amp; Descriptive Codes</th>
<th>Sample statements</th>
</tr>
</thead>
</table>
| Building Bridges | Formal Supports             | AEA      | • AEA  
• Explain the options  
• Supportive  
• They taught us  
• Set expectations                                                                 | Having a professional (from AEA) to talk with really helped (manage stress).                                                                                                                                                        |
|               | Other Agency Support        |          | • I didn’t feel like it was enough  
• Using an IPad  
• Trying to find another avenue  
• Hippotherapy  
• ABA                                                                 | I thought it was good (support from AEA), but I didn’t think he (son) was getting everything he needed. When he was being seen by AEA and Pediatric Intervention Service (pseudonym), then I thought he is getting what he needed. So that made me feel good. |
| Informal Supports | Family                     |          | • I want my family here  
• Family understanding  
• Family is fantastic  
• Extended family support  
• Family lives around                                                                 | We have become the household where all the family gatherings take place. So, Christmas and birthdays and Easter the extended family travels here. The family has been very good about understanding. My family is fantastic! |
|               | Friends                     |          | • Great friends  
• Having friends over  
• Talking  
• Friends                                                                 | Yes we even stopped going to church – even to the cry room. He (son) was just getting to rambunctious and it |
| Having a Map | Information Needs | Child Development | Child Behavior ||
|---|---|---|---|
| | | • Surrounding yourself with the people who want the best for your child | • Don’t know what to expect  
• What to expect  
• Wasn’t typical  
• Compared to twin  
• Regressed | It was really helpful because the program director was willing to give us more time. And he (son) did transition fairly well because we were all on the same page. |
| | | | • Play a long time  
• Line up trains  
• So focused  
• Meltdown  
• He didn’t interact with any other children | One of the other things we realized when it comes to food is that he wants to touch everything with his hands. He is not interested in a fork and spoon. When you think of all of the foods that are out there – when you think of touching them all. It is pretty incredible. It was frustrating for a while because he just would not try to use them (utensils), but after I thought about it (eating) from the sensory point of view. It made sense. |
| Open Lines of Parent to | | | • Ability to communicate  
• Started talking more | So it (PECS) was not effective for us yet. |
### Communication

**Child**
- Intervention strategy
- Communicate with us
- Express needs
- Successful communication
- Still talking with him

**Parent to Other Family Members**
- Spouse to spouse
- Parent to extended family
- Assistance from family
- Very understanding
- Extended family travels
- Support from extended family
- Sibling issues

**Parent to Interventionist**
- Parent interventionist partnership
- On the same page
- Empathy
- Additional services
- Consistent terms

But they (interventionists) have continued to work with it because it is all over the classroom. That is the main communication device they use. I feel good knowing he is getting exposure to it.

I knew it was something we needed to do - no matter how busy we got.

So now we all communicate on a regular basis, so that if someone finds a success of a way that works with him (son), no matter what the strategy, they communicate to each other and to all other parties so we can all do the same thing everywhere.

---

**Article #2: A Phenomenological Study: Practitioners’ Perceptions of Interventions for Young Children with Autism Spectrum Disorders and their Families**

<table>
<thead>
<tr>
<th>Themes</th>
<th>Categories</th>
<th>Patterns</th>
<th>Invivo &amp; Descriptive Codes</th>
<th>Sample statements</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interventions Utilized</td>
<td>Communication</td>
<td>• PECS</td>
<td>• Getting the Words</td>
<td>There is no magic wand. If I am using a (visual) schedule and PECS but it is not</td>
</tr>
<tr>
<td></td>
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<td>----------------------</td>
<td>-----------------------------------------------------------------</td>
<td>-----------------------------------------------------------------</td>
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</tr>
<tr>
<td><strong>Behavior</strong></td>
<td>• Behavior plan</td>
<td>Sometimes I give families a behavior plan.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Address behavior</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• PBIS</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>• Change how they respond</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>• Replacement behavior</td>
<td></td>
<td></td>
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</tr>
<tr>
<td><strong>Manner Implemented</strong></td>
<td>• Modeling</td>
<td>We try to do some modeling with food with the OT.</td>
<td></td>
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<tr>
<td></td>
<td>• Direct Instruction</td>
<td></td>
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<tr>
<td></td>
<td>• Organize session</td>
<td></td>
<td></td>
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</tr>
<tr>
<td></td>
<td>• Structuring</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Examples</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Influences on Decision-Making</strong></td>
<td>• Social support</td>
<td>I think that [communication with parent] is huge because a lot of times it is Mom 24-7. I know that a lot of times she might think she can take on the world but you know what – it is okay to have some help.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Sibling</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>• Social stuff</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Social</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Getting along with siblings</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Transition</strong></td>
<td>• Can’t go to the grocery store</td>
<td>But then when you get to know the parents well – it is more like I feel I can’t get them to the grocery store.</td>
<td></td>
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</tr>
<tr>
<td></td>
<td>• I can’t go anywhere</td>
<td></td>
<td></td>
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</tr>
<tr>
<td></td>
<td>• Transitioning</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>• Decrease access to community</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Can’t go out</td>
<td></td>
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<tr>
<td><strong>Balance</strong></td>
<td>• Find balance</td>
<td>People that work full time, that have multiple children, that are super-young moms or have two little ones or whatever – it is a huge difference in</td>
<td></td>
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</tr>
<tr>
<td></td>
<td>• Respite</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>• Out of control</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>• Family struggling</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>• Emotional support</td>
<td></td>
<td></td>
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</tr>
<tr>
<td><strong>Language</strong></td>
<td>• Working on Communication</td>
<td>working for the family, I might use sign (basic sign language) to get the words (expressive speech) going.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Personal experience</td>
<td>Resources</td>
<td>the amount of time they spend with their children.</td>
<td></td>
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<td>---------------------</td>
<td>-----------</td>
<td>--------------------------------------------------</td>
<td></td>
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</tr>
<tr>
<td></td>
<td>Involved</td>
<td>(Dad) He is kind of out of the picture.</td>
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<tr>
<td></td>
<td>20 hours of instruction</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Frequency of service</td>
<td></td>
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<tr>
<td></td>
<td>Time with children</td>
<td></td>
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<tr>
<td></td>
<td>Limited access to services</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Communication</td>
<td>Listening to families</td>
<td>I think it was that she didn’t want anyone to suggest she parent her child in a different way.</td>
<td></td>
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</tr>
<tr>
<td></td>
<td>Listening</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>What the family is open to</td>
<td></td>
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<tr>
<td></td>
<td>Communication with family</td>
<td></td>
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<tr>
<td></td>
<td>Communication with providers</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Supporting Families</td>
<td>You are driving the car</td>
<td>I try to lay out the options – you are driving the car, whatever works for the family.</td>
<td></td>
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</tr>
<tr>
<td></td>
<td>My role</td>
<td></td>
<td></td>
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</tr>
<tr>
<td></td>
<td>Functional for families</td>
<td></td>
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<tr>
<td></td>
<td>Make easier on parent</td>
<td></td>
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<tr>
<td></td>
<td>Team</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Work as a team</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Perceived Effectiveness</td>
<td>Family Report</td>
<td>Communicating with Family</td>
<td>Perceived Child Progress</td>
<td>Transition</td>
</tr>
<tr>
<td></td>
<td>Feedback from parents</td>
<td>Overtime, I get a sense of how well things were going from conversations with mom and dad. It gets a little easier the more time you can spend.</td>
<td></td>
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</tr>
<tr>
<td></td>
<td>Talk with family</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>What are they telling me</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>How are things going</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Talk with Mom</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Tolerating a good 30 minutes</td>
<td>Toward the end he was tolerating a good 30 minutes transitioning between activities.</td>
<td></td>
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</tr>
<tr>
<td></td>
<td>Transition to church</td>
<td></td>
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<tr>
<td></td>
<td>Able to go</td>
<td></td>
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<tr>
<td></td>
<td>Tolerating transitions</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>He could transition</td>
<td></td>
<td></td>
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</tr>
<tr>
<td></td>
<td>Child progress</td>
<td>If the child is progressing and the family is happy, I think my</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Increased communication</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
- Headed in right direction
- Building the words
- Positive results

**Interventions are working.**

**Concerns** | **Resources** | **Family engagement**
---|---|---
- Enough time
- Enough resources
- Rural Iowa
- Time
- Family having enough time

It is a parent education model so our main goal is to educate the family on how to take the best care of their child. It takes more time to do that I have so I pick what is most important and just try to monitor the rest.

- Family follow through
- Lack of engagement
- Mom was stressed
- Carry over
- Wasn’t receptive

But if they don’t do it when I am not there then the growth is going to be slowed down.

**Article #3: Opening the Black Box of Home Visiting in Early Intervention: Parents’ of Children Diagnosed with Autism Spectrum Disorders and Interventionists’ Perspective**

<table>
<thead>
<tr>
<th>Themes</th>
<th>Categories</th>
<th>Patterns</th>
<th>InVivo &amp; Descriptive Codes</th>
<th>Sample statements</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>FAMILIES</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| Preparation | Reflection on interventions | • Successful  
• Unsuccessful | • 6 months – no progress  
• Twice a month to me is nothing  
• Not much community exposure  
• He used words again  
• Effective | It was better when we switched from sign (sign language) to PECS. I felt like I could understand what he (son) was trying to tell us. |
|  | Physical appearance of the home | • Playroom  
• Things around  
• Clean up  
• Make a plan | Sometimes I feel embarrassed looking around at this mess and thinking I do |
<table>
<thead>
<tr>
<th>Availability for the home visit</th>
<th>Flexible</th>
<th>Have company (interventionist) coming over later.</th>
</tr>
</thead>
<tbody>
<tr>
<td>He took a job working nights at a factory in the Plainfield (pseudonym) area, that way he would be at home during the day so Mom could go to her job and someone would be at home with their son to meet us.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Welcoming</th>
<th>Quit school</th>
<th>He took a job working nights at a factory in the Plainfield (pseudonym) area, that way he would be at home during the day so Mom could go to her job and someone would be at home with their son to meet us.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Come on in</td>
<td>Quit school</td>
<td>He took a job working nights at a factory in the Plainfield (pseudonym) area, that way he would be at home during the day so Mom could go to her job and someone would be at home with their son to meet us.</td>
</tr>
<tr>
<td>Good to see you</td>
<td>Work</td>
<td>He took a job working nights at a factory in the Plainfield (pseudonym) area, that way he would be at home during the day so Mom could go to her job and someone would be at home with their son to meet us.</td>
</tr>
<tr>
<td>Conversation</td>
<td>Routine</td>
<td>He took a job working nights at a factory in the Plainfield (pseudonym) area, that way he would be at home during the day so Mom could go to her job and someone would be at home with their son to meet us.</td>
</tr>
<tr>
<td>Greetings</td>
<td>Scheduled around my work</td>
<td>He took a job working nights at a factory in the Plainfield (pseudonym) area, that way he would be at home during the day so Mom could go to her job and someone would be at home with their son to meet us.</td>
</tr>
<tr>
<td>Exchange pleasantries</td>
<td>Make arrangements</td>
<td>He took a job working nights at a factory in the Plainfield (pseudonym) area, that way he would be at home during the day so Mom could go to her job and someone would be at home with their son to meet us.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Direct Service</th>
<th>Transition</th>
<th>There was one point when he (son) wasn’t talking and because of that we were not talking as much either. I think that was one good thing we found out about – still talking with him, making sure to explain things. It helped to watch them (interventionists) work. It (talking with son) helps develop his understanding.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Observation practitioner providing an intervention strategy</td>
<td>Communication</td>
<td>There was one point when he (son) wasn’t talking and because of that we were not talking as much either. I think that was one good thing we found out about – still talking with him, making sure to explain things. It helped to watch them (interventionists) work. It (talking with son) helps develop his understanding.</td>
</tr>
<tr>
<td>Behaviors</td>
<td>We wanted him to find his own voice</td>
<td>There was one point when he (son) wasn’t talking and because of that we were not talking as much either. I think that was one good thing we found out about – still talking with him, making sure to explain things. It helped to watch them (interventionists) work. It (talking with son) helps develop his understanding.</td>
</tr>
<tr>
<td></td>
<td>He didn’t like change</td>
<td>There was one point when he (son) wasn’t talking and because of that we were not talking as much either. I think that was one good thing we found out about – still talking with him, making sure to explain things. It helped to watch them (interventionists) work. It (talking with son) helps develop his understanding.</td>
</tr>
<tr>
<td></td>
<td>Communication with him</td>
<td>There was one point when he (son) wasn’t talking and because of that we were not talking as much either. I think that was one good thing we found out about – still talking with him, making sure to explain things. It helped to watch them (interventionists) work. It (talking with son) helps develop his understanding.</td>
</tr>
<tr>
<td></td>
<td>Responding very well</td>
<td>There was one point when he (son) wasn’t talking and because of that we were not talking as much either. I think that was one good thing we found out about – still talking with him, making sure to explain things. It helped to watch them (interventionists) work. It (talking with son) helps develop his understanding.</td>
</tr>
<tr>
<td></td>
<td>Improving transitions</td>
<td>There was one point when he (son) wasn’t talking and because of that we were not talking as much either. I think that was one good thing we found out about – still talking with him, making sure to explain things. It helped to watch them (interventionists) work. It (talking with son) helps develop his understanding.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Demonstrating technique &amp; Feedback</th>
<th>Adjustment</th>
<th>There was one point when he (son) wasn’t talking and because of that we were not talking as much either. I think that was one good thing we found out about – still talking with him, making sure to explain things. It helped to watch them (interventionists) work. It (talking with son) helps develop his understanding.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Expectations</td>
<td>There was one point when he (son) wasn’t talking and because of that we were not talking as much either. I think that was one good thing we found out about – still talking with him, making sure to explain things. It helped to watch them (interventionists) work. It (talking with son) helps develop his understanding.</td>
</tr>
<tr>
<td></td>
<td>Try this</td>
<td>There was one point when he (son) wasn’t talking and because of that we were not talking as much either. I think that was one good thing we found out about – still talking with him, making sure to explain things. It helped to watch them (interventionists) work. It (talking with son) helps develop his understanding.</td>
</tr>
<tr>
<td></td>
<td>Integrating techniques into family ADL’s</td>
<td>There was one point when he (son) wasn’t talking and because of that we were not talking as much either. I think that was one good thing we found out about – still talking with him, making sure to explain things. It helped to watch them (interventionists) work. It (talking with son) helps develop his understanding.</td>
</tr>
<tr>
<td></td>
<td>Don’t want to push too far</td>
<td>There was one point when he (son) wasn’t talking and because of that we were not talking as much either. I think that was one good thing we found out about – still talking with him, making sure to explain things. It helped to watch them (interventionists) work. It (talking with son) helps develop his understanding.</td>
</tr>
<tr>
<td>Sharing Ideas</td>
<td>Child progress</td>
<td>Positive</td>
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<td>--------------</td>
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<td>----------</td>
</tr>
<tr>
<td>Intervention strategy</td>
<td>Routine</td>
<td>Changes in routine</td>
</tr>
<tr>
<td>Future for their child</td>
<td>Hope</td>
<td>Hope</td>
</tr>
<tr>
<td>Confirmation of professional</td>
<td>Perspective</td>
<td>We think he is here</td>
</tr>
<tr>
<td>Opinion</td>
<td>He probably could</td>
<td>Knowing when to push and when not</td>
</tr>
<tr>
<td>Plan of Action</td>
<td>Task delegation</td>
<td>Things to work on</td>
</tr>
<tr>
<td>Time frame</td>
<td>Frequency</td>
<td>Once a day</td>
</tr>
<tr>
<td>Scheduling</td>
<td>Make an appointment</td>
<td>Look over schedule</td>
</tr>
</tbody>
</table>

**INTERVENTIONISTS**

| Preparation | Reflecting on | Families’ needs | Making a | It has taken a long


<table>
<thead>
<tr>
<th>Interventions</th>
<th>• Efficacy</th>
<th>• Difference</th>
<th>• Effectiveness of interventions</th>
<th>• Thinking about how things are going</th>
<th>• Empowering the family</th>
<th>• Positive results</th>
<th>• Thinking about how things are going</th>
<th>• Empowering the family</th>
<th>• Positive results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Considering potential modifications of interventions</td>
<td>• Necessary to change</td>
<td>• Add structure</td>
<td>• Not working for family</td>
<td>• Adjusting support</td>
<td>• Addressing need</td>
<td>• Choice-making</td>
<td>We have been working a lot on the words, but I have been thinking we might have to go back and focus on behaviors.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Logistics of the home visit</td>
<td>• Travel</td>
<td>• The bag</td>
<td>• Things ready</td>
<td>• Day in car</td>
<td>• Toys</td>
<td>• Boardmaker</td>
<td>…getting the bag ready…</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Welcoming</td>
<td>• On the floor</td>
<td>• How are you?</td>
<td>• Good to see you?</td>
<td>• Engaging</td>
<td>• Informal conversation</td>
<td>Hi, I am fine! How are you? Let me set down my stuff (toy bags/folders) here before we talk.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Direct Service</td>
<td>• Observing the child</td>
<td>• Behavior</td>
<td>• Behavioral concerns</td>
<td>• Replacement behaviors</td>
<td>• Appropriate behaviors</td>
<td>• Getting the words</td>
<td>• Building the words</td>
<td>When I walked into the home and saw Kyle (pseudonym) screaming and running away, I thought it is going to be hard enough to get instructional control. No way am I doing picture/object matching. I need to rethink this.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Communication</td>
<td>• Behavioral concerns</td>
<td>• Replacement behaviors</td>
<td>• Appropriate behaviors</td>
<td>• Getting the words</td>
<td>• Building the words</td>
<td>• Behavioral concerns</td>
<td>• Replacement behaviors</td>
<td>• Appropriate behaviors</td>
</tr>
<tr>
<td></td>
<td>Support</td>
<td>• Choice-making</td>
<td>• Improved quality of routines</td>
<td>• More support</td>
<td>I need to see Mom doing the activity. When I see Mom doing the activity I think – okay now she</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Implementing an activity designed to assist child development</td>
<td>Communication</td>
<td>PECS</td>
<td>Basically, I would just try to work in as many things into the session that I can.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Behavior</td>
<td>Behavior plan</td>
<td>PBIS</td>
<td>Sign language</td>
<td>Working on communication</td>
<td>Picture exchange</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sharing Ideas</td>
<td>Discuss problem solving strategies</td>
<td>Support</td>
<td>Direct to social worker</td>
<td>Multiple interventions</td>
<td>Help from sibling</td>
<td>Informal support</td>
<td>Listen to the parent</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent education</td>
<td>Connected</td>
<td>Connected in system</td>
<td>Resources for social component</td>
<td>Finding a balance</td>
<td>Routines</td>
<td>Parent-child interactions</td>
<td>I would explain that you need to reinforce and explain why.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Addressing parent concern</td>
<td>Resources</td>
<td>Finding resources to meet families’ needs</td>
<td>Kicking</td>
<td>Difficult to manage behaviors at home</td>
<td>Too much to handle</td>
<td>Transitioning</td>
<td>I think it is huge (communication with parent) because a lot of times it is Mom 24-7. I know a lot of time she thinks she can take on the world but you know what – it is okay to have somebody else help. We know she</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
into the community needs someone else to help but a lot of times she thinks she needs to do it all. She might not see it but we might.

<table>
<thead>
<tr>
<th>Plan of Action</th>
<th>Task delegation</th>
<th>• Family engagement</th>
<th>• Carry over • Buy in • Follow through • Entire family • Biggest concern</th>
<th>…have the new picture from Board Maker ready.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time frame</td>
<td>• Appropriate</td>
<td>• More often • For next time • By next session • Before long • Before next time</td>
<td>…the next session.</td>
<td></td>
</tr>
<tr>
<td>Scheduling</td>
<td></td>
<td>• Appointments were made • Try to connect • Tough over the summer • Scheduling • Working together</td>
<td>The summer can be kind of tough to schedule with families, you know, we are trying to take sort of a break, otherwise you can burn out like that (snaps her fingers). Families take vacations and kids have things going on, so I like to have the next visit scheduled before I leave. It is way easier than trying to call everyone after you left. That never works.</td>
<td></td>
</tr>
</tbody>
</table>
APPENDIX F. RECRUITMENT LETTER

Recruitment Letter

Jason Peck
Iowa State University
Human Development and Family Studies

Hello, my name is Jason Peck. I am writing to request your participation in a qualitative study I am conducting for my dissertation at Iowa State University. I am interested in studying how families of children with Autism Spectrum Disorder (ASD) perceive intervention strategies as meeting the needs of their family. Essential criteria for family participation include being currently enrolled or recently discharged (within past year) from Iowa’s Early Access program and are willing to participate in an interview and have the data recorded. To explain my interest in this topic, I think it is necessary to share some of my professional experiences.

My first experience working with families of young children with ASD was during a student internship in Fort Collins, Colorado. I worked with the staff physical therapist to provide interventions for families in both the clinic and home setting. This internship was completed as a part of my physical therapy training at Daemen College. After completing the physical therapy training I worked at United Cerebral Palsy Children’s Center in Central New York providing physical therapy service to families who have children diagnosed with ASD. These experiences provided the ground work for me to start a private practice, that I owned/operated for several years before deciding to attempt a Doctoral Program in the Human Development and Family Studies Department at Iowa State University. I currently work as a research assistant on a research project partnered with Iowa’s Early Access program interventionists and am employed on a per diem basis as a physical therapist at ChildServe in Ames, Iowa. I have enjoyed the opportunity to work with dozens of families who have children with special needs. These experiences have increased my interest in studying families of young children with ASD. Therefore, I decided to do my dissertation research on the topic of families’ of young children with ASD perceptions of intervention strategies used in Early Access.

I would like to interview you at least one time for approximately 60 minutes to create a description of what families have experienced and how they have experienced intervention strategies. Topics that I hope to cover include stressors families view as affecting families of
young children with autism, intervention characteristics that families view as effective in meeting the family needs for families of children with autism and how families view interventions as meeting their needs related to their life stressors? The interviews will be conversational in nature, allowing you to talk about your experiences. By conducting these interviews my goal is to gain a better understanding of the experiences of families who have a child diagnosed with ASD. This information may be used to inform the development of intervention strategies.

If you are interested in being a participant in this study or have questions regarding the study, please feel free to contact me by phone at (607) 331-6400 or email: jpeck@iastate.edu. Your participation is voluntary. This research project is being completed independent from Iowa’s Early Access Program and will not interfere with services you may be currently receiving. I am conducting this research because of my own professional and academic experiences.

Sincerely,

Jason Peck
ACKNOWLEDGEMENTS

This dissertation would not have been possible without the guidance and the help of several individuals who contributed and extended their valuable assistance in the preparation and completion of this study.

I am thankful to my major professor, Dr. Gayle Luze, whose encouragement and guidance from the initial brainstorming to the final submission enabled me to develop an understanding of the research process. Also, I thank the members of my graduate committee for their guidance and suggestions. Dr. Kere Hughes-Belding, for her support and advice; Dr. Mary Jane Brotherson, for sharing her expertise in the topics of family and qualitative research; Dr. Kimberly Greder, for her encouragement and expertise in qualitative research; and Dr. Debra Satterfield, for her insights into the topics of disability and family stress. I appreciate your support. I extend sincerest gratitude to each of the parents and practitioners who participated in this research. Thank you for helping me to better understand autism spectrum disorders, family, and for sharing your story.

I would like to thank my family, especially my wife, Nancy, and my daughter Sophie Grace. Nancy, without your support I would not have finished this “paper,” and Sophie for sacrificing so many mornings without your “Dada.” Without your understanding, it would have been easy to give up. I love you both so much - thank you.