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**PERSPECTIVES AND EXPERIENCES OF PARENTS OF CHILDREN WITH
COMMUNICATION NEEDS IN EARLY INTERVENTION**

A Dissertation in

Communication Sciences and Disorders

by

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ABSTRACT

Family-centered practice is characterized by relational and participatory practices with foundations in family systems and ecological systems theories (Bronfenbrenner, 1979; Dunst et al., 2002; Mandak et al., 2017; Minuchin, 1985). While services to infants and toddlers under Part C early intervention (IDEA, 2004) are legally mandated to include families in decision-making and be provided in natural environments, little is known about the experiences of parents of children ages 0-3 who struggle to use natural speech alone to meet their daily needs (Ronski et al., 2015). Given the importance of family participation in AAC intervention and the federal mandate for family-centered practice in EI under Part C (Infants and Toddlers program) of IDEA, as well as the lack of research related to current family practices and perspectives in AAC and EI, the current study investigated the following research question: What are the experiences and perspectives of parents of children who use a variety of means of communication during early intervention for children ages birth to 3? Specifically, this study utilized a series of semi-structured interviews to investigate the perspectives and experiences of six mothers of toddlers receiving Part C early intervention who used a variety of means to communicate. The data yielded four themes including factors related to: (1) The child receiving EI services, (2) Communication partners, (3) Supports, and (4) Challenges. The themes are discussed with consideration to family-centered practice, clinical implications, and future research directions.

Keywords: family-centered practice, early intervention, augmentative and alternative communication

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Chapter 1

Introduction and Review of the Literature

Augmentative and Alternative Communication (AAC) is a field of research and practice that supports individuals who are unable to use speech to meet their daily communication needs. Means of communication may be unaided, such as gestures or signs, or aided such as communication books, boards, or speech-generating devices (SGDs). For children who use AAC, their parents play a significant early role in the acquisition and implementation of AAC systems and strategies. Researchers have used a variety of surveys, focus groups, and interviews to investigate the perspectives and experiences of parents of individuals who use AAC. Parents have expressed the desire to be involved in collaborative partnerships with professionals and be acknowledged for the expertise they have regarding their own children, and the value that expertise contributes to informed decision-making and AAC service provision (Bailey et al., 2006; Mandak et al., 2017). Their abilities and desires to devote time and energy to the AAC intervention process fluctuates over time (Mandak et al., 2017; Goldbart & Marshall, 2004) and are influenced by the complex interplay of factors including their and their families' financial needs, health concerns, fatigue and stress, and caregiving responsibilities (Mandak et al., 2017). Parents have raised concerns that they devote a lot of time and energy to learning AAC systems, with limited support, and experience frustration with the AAC decision-making process and service provision (Anderson et al., 2014; Mandak & Light, 2017). Some families have found that unaided AAC is easier to use within the home (Mandak et al., 2017; McCord & Soto, 2004), and parents may be concerned about whether AAC will inhibit speech acquisition, particularly in young children (Ronski et al., 2015).

Mandak and Light (2018b) used online focus group methodology to investigate the perspectives of 13 speech-language pathologists (SLPs) working in the schools with children who use AAC. One of the participants reported that part of her caseload included preschool children. Other participants worked in elementary, middle, and high-school settings. They found that SLPs did recognize families as the primary communication partners of children who use AAC and the benefits of working with families including increased generalization of skills, skill maintenance, the accomplishment of communication goals, and the development of trusting relationships. The SLPs in this study recognized that the needs of families should be considered on an individual basis and expressed the desire to be family-centered in their service provision; however, they reported experiencing a discrepancy between how they desired to provide services and their actual practices, with some SLPs reporting that their services were more “teacher-centered” and “student-centered” than “family-centered.” They reported family involvement occurred mostly around meeting time and identified barriers to family-centered practice including scheduling and time, the school environment and demands, and disagreements between the family and SLP. Despite having a legal mandate to include families in decision-making (P.L. 102-119, The Individuals with Disabilities Education Act Amendments of 1991; Bailey et al., 2006), the extent and nature of family involvement with speech and language intervention programs generally, and AAC programs specifically, varies widely. The participants in Mandak and Light’s (2018b) study expressed the belief that it is easier to be more family-centered in the home and with younger students than with school-age students.

Early Intervention Services

In 1975, Congress ratified the Education of All Handicapped Children Act (EHA) to address the needs of school-aged children with disabilities. Upon reauthorization in 1986, Part H early intervention (EI) was added to address the needs of infants and toddlers (P.L. 99-457P). The federal program for infants and toddlers was reauthorized as Part C in the Individuals with

Disabilities Education Act (IDEA) in 1990 and its reauthorizations (1997, 2004). IDEA (2004) reiterated an emphasis on service provision in natural environments (ASHA, 2008b; Francois et al., 2015). “Natural environments” came to be generally accepted as the home, and between 1993 and 2004, the percentage of infants and toddlers receiving early intervention services in the home increased from 47% to 83% (Campbell & Sawyer, 2007; US Department of Education, Office of Special Education Programs, 2003, 2004). Speech and language intervention is the most commonly received Part C EI service, with more than 50% of EI participants deemed eligible (Hebbler, Spiker, Bailey, Scarborough, Malik, & Simeonson, 2007). The American Speech-Language-Hearing Association (ASHA, 2008) established four guiding principles for speech-language pathologists providing early intervention services: (1) Services are family-centered and culturally and linguistically responsive; (2) Services are developmentally supportive and promote children’s participation in their natural environments; (3) Services are comprehensive, coordinated, and team-based; and (4) Services are based on the highest quality evidence that is available.

AAC in Early Intervention

Early Intervention for young children whose speech is inadequate to meet their daily needs focuses on prelinguistic skills such as vocalizations and gestures to support intentional communication, as well as the development of a symbolic means to communicate to prevent frustration for the children and their families (Ronski et al., 2010). Augmentative and alternative communication (AAC) may be used to supplement unclear communication signals and introduce symbolic communication modes including pictures or signs (Cress & Marvin, 2003). AAC is often initiated by professionals, but may be initiated by parents, especially if the speech-language pathologist has outdated assumptions about prerequisite skills required prior to introducing AAC (Cress & Marvin, 2003) or has limited expertise in the area of AAC (Ronski et al., 2005). Parents occasionally obtain knowledge about AAC and make decisions about communication modes

using information available on the Internet (Ronski et al., 2005). While data are not available on the number of Part C EI participants who require AAC, Binger and Light (2006) found that at least 12% of preschoolers (aged 3-5) participating in Part B Early Intervention required AAC.

Ronski, Sevcik, Barton-Husley, and Whitmore (2015) synthesized 30 years (1985-2014) of research related to AAC and early intervention for children from birth to 6 years of age, including 22 articles in which the participants had a mean age from birth to 3. Of those, only six specifically incorporated parents into the investigation. Parents were trained to use signs (Clibbens, Powell, & Atkinson, 2002), tangible objects (Letto, Bedrosian, & Skarakis Doyle, 1994), and graphic symbols and photographs (Tait et al., 2004) to teach a variety of skills. Additionally, mixed-methods research revealed that parental stress and children's expressive language influenced parents' perceptions of the severity of their children's communication impairments (Smith et al., 2011). Overall, Ronski et al. (2015) identified a robust body of evidence suggesting that children with a variety of diagnoses and skills can benefit from AAC, with positive outcomes including: improved sign and symbol vocabulary for children 3 years old and under, multisymbol utterances and grammatical learning for preschool-aged children, and an increased variety of communicative initiations, turns, and functions across ages. Data also suggest that parents and other communication partners can be taught to use AAC with young children. Furthermore, parents view AAC positively and it does not increase their stress levels. However, despite the importance of the family context in early intervention and AAC, they found no investigations focusing specifically on family issues in AAC for children birth to 6 (Ronski et al., 2011; Ronski et al., 2015).

Family-Centered Practice

Services can be characterized on a continuum from professional-centered services to family-centered services. Services that are family-oriented in their approaches but do not quite meet the requirements for true family centeredness may be family-allied or family-focused

interventions (Dunst et al., 1991; Dunst & Trivette, 1996; Dunst, 2002). Traditional intervention services are often child- or professional-centered, focusing on the child's developmental or physical needs and the professional's expertise and judgment about what intervention approaches are best for the child (Campbell & Sawyer, 2007; Mandak & Light, 2018a). Family-centered, in contrast, "refers to a particular set of beliefs, principles, values, and practices for supporting and strengthening family capacity to enhance and promote child development and learning" (Dunst, 2002, p.139). Efforts to increase the family-centeredness of interventions have included a focus on parent-implemented interventions resulting from parent/caregiver training models, parent/caregiver coaching models, and participation-based models. These strategies may be an element of family-centered practice to the extent that they build capacity in the parents or caregivers and the procedures and outcomes are collaboratively generated and agreed upon by the parents. However, some of these interventions, as described in the literature, are more family-oriented and/or family-allied than family-centered.

Parent/caregiver training involves the use of predetermined training methods, routines and intervention contexts, and targeted outcomes. The trainer typically assumes responsibility for identifying the needs, choosing and modeling the strategies within the predetermined context while the parent observes, and then provides specific instructions on how to execute the strategies during the targeted activity. This may or may not include opportunities for the parents or caregivers to practice the strategies and receive specific feedback from the trainer (Brown & Woods, 2015). Examples of this in AAC literature are included in a meta-analytic systematic review by Kent-Walsh and colleagues (Kent-Walsh, Murza, Malani, & Binger, 2015). They investigated the overall effects of partner instruction interventions on the communication of individuals using AAC as well as the impact of characteristics related to the participant, intervention, and outcome characteristics. Two general patterns of teaching communication partners were identified including (1) cohesive strategy instruction as described by Kent-Walsh

and McNaughton (2005), and (2) individual skill training with less structured approaches that may include any number of the following strategies: (a) describing skills and strategies to be used, including the reasoning and potential benefits, (b) modeling how to implement the targeted communication skills and strategies, (c) verbal rehearsal of skills, (d) practice or role-play with the trainer, (e) guided practice, or gradual fading of cueing while the parent or caregiver is interacting with the individual who uses AAC, and (f) materials-focused instruction such as following a workbook. It should be noted that of the 17 studies identified for review, only those that focused on cohesive strategy instruction ($n = 7$), as well as one individual skill training (Datillo & Light, 1993), included opportunities for the communication partners to directly interact with the individual with AAC. On the continuum of parent/caregiver-implemented interventions, these are more likely to be useful for parent/caregiver coaching models as described below. It should also be noted that in the Kent-Walsh et al. meta-analysis, only 4 of the 53 participants who used AAC identified across studies were between ages birth-3 years, 0 months (ranging from 2;5 – 2;11 months).

Parent/caregiver coaching models are based on adult learning models and include systematically teaching the parent or caregiver to implement strategies and supports when the therapist is not present. Coaching models vary to the extent to which the interventionist, or coach, may have direct contact with the child. Kaiser and Hancock (2003) advocated for the parent's immediate success in implementing new skills and that the parent educator (coach) should be providing feedback to the parent only. This is also consistent with Campbell and Sawyer's (2007) participation-based model. Brown and Woods (2015), on the other hand, described coaching models in which there is a more gradual release of responsibility, and discuss the triadic interaction among parent, child, and interventionist, while the interventionist is supporting bi-directional parent-child interaction and communication.

Family-centered practices include both relational- and participatory practices. The relational component includes clinical skills such as active listening, compassion, empathy, respect, and beliefs pertaining to the capabilities and competencies of the family. The participatory component includes individualized, flexible, and responsive practices based on the concerns and priorities of families that provide families with opportunities to be actively involved in decisions and choices, and collaborating with families to support them in achieving desired goals and outcomes (Dunst & Trivette, 1996; Dunst, 2002). Family-centered practices are grounded in family systems theory and can further be informed by ecological systems theory.

Family Systems theory. Family-systems theory originated in family therapy (Minuchin, 1985; Mandak et al., 2017), but has served as a framework for understanding individuals within a family context and how factors such as disability and introducing AAC may impact them. Family-systems theory posits that a family is comprised of an interconnected group of subsystems including the parental subsystem and sibling subsystem. While each of these subsystems are separated by boundaries, each family has their own rules influencing interactions across boundaries. These change over time due to intrinsic factors such as aging of particular members of subsystems and extrinsic factors such as changes in parental employment or social support. Due to the interdependent nature of these subsystems, this paradigm asserts that consideration of the developing child outside of these subsystems would yield fragmented and invalid data.

Ecological systems theory. Families, of course, do not exist within a vacuum. Ecological systems theory (Bronfenbrenner, 1979) can extend our understanding of families by considering their participation within society. Traditionally depicted as a series of nested circles with the child at the center, ecological systems theory includes the microsystem, mesosystem, macrosystem, exosystem, and the chronosystem. The first circle around the child is the microsystem. The child's microsystem includes the immediate surroundings of the child including the family system (which includes the parental subsystem, interparental subsystem, and extended family) and other

relationships in the child's immediate environment such as daycare and school systems (Bronfenbrenner, 1979; Mandak, O'Neill, Light, & Fosco, 2017). The mesosystem refers to interactions between two or more microsystems that contain the developing person, such as the relationship between school or daycare and home (Bronfenbrenner, 1986; 1994). The exosystem (Bronfenbrenner, 1986; 1994) refers to interactions between two or more settings that have an influence on the developing child; however, at least one of those settings does not actually include the child. An example of this is the interaction between a parent and his or her workplace, and how that may influence the child's experiences at home. The macrosystem (Bronfenbrenner, 1994) refers broadly to cultural and societal influences characteristic of the micro- meso- and exosystems. The chronosystem introduces the element of time to the ecological systems. These time elements include advances in chronological age, life changes and transitions including changes in family structure, socioeconomic status, place of residence, or even the "degree of hecticness and ability in everyday life" (Bronfenbrenner, 1994, p. 40).

Family-Centered Practice in AAC

Mandak and colleagues (2017) proposed an adaptation of ecological and family systems theories using the illustration of nested circles with the family at the center, and described how such a framework might inform family-centered practice in AAC. They suggested tools to guide professionals in progressing from understanding the importance of family-centered services to actually delivering them. Suggested initial steps include: involving all relevant family members and respecting the expert knowledge they have on the communication needs of their children, being sensitive to the unique needs and burdens of each family and its subsystems, integrating AAC into existing family routines, establishing trusting and collaborative relationships with families, and providing culturally-sensitive services. To date, research in AAC and early intervention has focused primarily on the parental subsystem of the family (Mandak et al., 2017) and to a lesser extent, the sibling subsystem (Granlund et al., 2008). To be truly family-centered,

research and practice must extend throughout the microsystem, mesosystem, and beyond (Trivette et al., 2010). Bronfenbrenner (1979) noted:

Whether parents can perform effectively in their child-rearing roles in the family depends on the role demands, stresses, and supports emanating from other settings...Parents' evaluation of their own capacity to function as well as their view of their child, are related to such external factors as flexibility of job schedules, adequacy of childcare arrangements, the presence of friends and neighbors who can help out in large and small emergencies, the quality of health and social services, and neighborhood safety (p. 7).

Current Study

The purpose of this phenomenological study was to explore the experiences and perspectives of parents of children who use a variety of communication modes during early intervention for children ages birth to 3 in the specific region of Pennsylvania identified for data collection. Given the importance of family participation in AAC intervention and the federal mandate for family-centered practice in EI under Part C (Infants and Toddlers program) of IDEA, as well as the lack of research related to current family practices and perspectives in AAC and EI, the current study investigated the following central research question: How do parents of children who use a variety of means of communication during early intervention for children ages birth to 3 describe their experiences with speech and language intervention? Specific subquestions included:

1. What routines, communication modes, and strategies are used by children and communication partners during early intervention speech and language sessions?
2. What do parents perceive to be their roles and the roles of professionals in early intervention for children using multiple modes of communication?
3. How consistent are the experiences, as described and perceived by parents, with recommendations and legal mandates for family-centered practice?

Chapter 2

METHOD

Design

The current study employed a qualitative, phenomenological, semi-structured, repeated interview design. Qualitative research allows for a rich description of real-life contexts including the nature of the therapeutic relationship between clinicians and the individuals with whom they work (Eastwood, 1988). Damico and Simmons-Mackie (2003) defined qualitative research as “a variety of analytic procedures designed to systematically collect and describe authentic, contextualized social phenomena with the goal of interpretive accuracy” (p. 132). In the qualitative tradition of phenomenology, researchers attempt to describe the commonalities with a shared experience of a small group of people. This is often completed at a single “site.” For the purpose of this study, a single “site” was considered a single geographic region in which early intervention services are provided. In the state of Pennsylvania, Part C early intervention services are coordinated by each individual county. The principal investigator identified an initial county for data collection and then gradually expanded to adjacent counties during recruitment to obtain the targeted number of participants. The final group of participants represented three geographically adjacent counties.

The goal of phenomenological research is to investigate “what” and “how” participants experience the phenomenon of interest. These details provide valuable information for therapists and healthcare providers, and are often acquired through in-depth, repeated interviews (Creswell & Poth, 2018; Moustakas, 1994; Van Manen, 1990). Interviews may be effective tools for

determining the needs and priorities of families and designing family-centered assessments and interventions (Dunst et al., 1998; Jones, Angelo, & Kokoska, 1998; Parette, VanBierviliet, & Hourcade, 2000).

The Pennsylvania State University's Institutional Review Board approved this study.

Participant Recruitment

Sampling method. Consistent with the qualitative research paradigm, this study used a purposeful (also called purposive), rather than a probability sampling method. Criterion sampling was used to ensure that all participants had the shared experience of speech and language intervention for children 0-3 under Part C of IDEA using multiple modes of communication (Creswell & Poth, 2018).

Recruitment and participant selection. Participants were recruited systematically using a staggered approach expanding from an initial county identified for data collection, to adjacent counties, and then progressing to statewide professional networks. Participants were initially recruited via early intervention service providers and online social media groups targeting early intervention consumers in the specific Eastern Pennsylvania county identified for data collection. Limiting the subject pool to a single geographic region would allow for more targeted interventions to be developed to support clinical practice in the specified area, and is consistent with phenomenological research using a single "site." In order to allow rich, thick descriptions of the participants and their common experiences, this study sought 3-10 participants meeting criterion (Creswell & Poth, 2018; Dukes, 1984). The goal of qualitative research in general, and phenomenology specifically, is not to generalize the information, but to make clearer the details of the experience, as perceived by the participants. The researcher then presents the finding with enough description that readers are able to determine if the participants are representative of whom they are trying to understand (Creswell & Poth, 2018; Pinnegar & Daynes, 2007).

The principal investigator contacted administrators and/or service providers with these organizations and asked permission to post recruitment messages for parents. Parents were able to contact the researcher to express interest in the study via e-mail or phone. Upon expressing interest, parents answered eligibility questions, completed a demographic questionnaire and were provided with a written description of the study and implied consent form. Additionally, potential participants were contacted directly using a sponsored Facebook advertisement.

Participants

Six parents of children under the age of 3 who receive early intervention for communication skills under Part C (Infants and Toddlers Program) of IDEA participated in this study. To be eligible for participation, they were all (a) over the age of 18, (b) functionally literate, (c) fluent in English, (d) residents of the state identified for data collection, and (e) willing to be audio- or video-recorded for data collection. Parent demographic information is provided in Table 2-1. Child demographic information is provided in Table 2-2. Child communication modes are provided in Table 2-3. A brief explanation and expansion of this information for each parent-child dyad follows. To protect the confidentiality of participants, all names are pseudonyms.

Table 2-1: Participants' (Parent) Demographic Information

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Participant	Melanie	Lori	Danielle	Maria	Pam	Kristin
Gender	F	F	F	F	F	F
Age	43	26	37	28	29	38
Racial Background	White	White	White	White	White	White
Ethnicity	Not Hispanic or Latino	Not Hispanic or Latino	Not Hispanic or Latino	Hispanic/Latino	Not Hispanic or Latino	Not Hispanic or Latino
Level of Education	High School/GED	Some College	M.S.	Some College	M.Ed.	Some Technical School
Marital Status	Single	Married	Married	Married	Married	Married
Household Income	< 20,000	\$40,000-\$59,000	\$80,000-\$99,000	\$40,000-\$59,000	\$100,000-\$149,000	\$80,000-\$99,000
# of Children	4	3	6	2	1	1

Table 2-2: Child Demographic Information

Place Table Here

Child	Nahlia	Alex	Gabrielle	Miguel	Landon	Lila
Sex	F	M	F	M	M	F
Age	28 months	31 months	24 months	30 months	34 months	35 months
Racial Background	Biracial	White	White	White	White	White
Ethnicity	Hispanic/Latino	Not Hispanic or Latino	Not Hispanic or Latino	Hispanic/Latino	Not Hispanic or Latino	Not Hispanic or Latino
Diagnosis	Down Syndrome	Hypotonia, Developmental Delay	Developmental Delay, Suspected Childhood Apraxia of Speech	Sotos Syndrome	Developmental Delay, Autism Spectrum Disorder	Autism Spectrum Disorder

Table 2-3: Child's Communication Modes

Place Table Here

Child	Nahlia	Alex	Gabrielle	Miguel	Landon	Lila
Vocal	Speech	Speech	Nonspeech vocalizations	Speech	Speech	Speech approximations
Manual	Signs, gestures	Gestures	Signs	Signs, gestures	Signs, gestures	Signs
Aided	Communication boards	Single switch speech output device	Communication boards	Communication boards, iPad with TouchChatHD	Picture Exchange Communication System (PECS), iPad	iPad with TouchChatHD

Melanie and Nahlia.

Melanie was a 43-year-old white, non-Hispanic or Latino single female with 4 children. She had a high school education. Her annual income was less than \$20,000. Two of Melanie's children had documented disabilities. The youngest child, Nahlia, was participating in Part C early intervention. Nahlia was a 28-month-old, biracial Hispanic female, with a diagnosis of Down syndrome. She used speech, signs and gestures, and communication boards to support communication. Nahlia had history of tracheosophageal fistula (TEF) and feeding tube, and previously worked with her SLP on feeding concerns prior to initiating a communication goal. She had been working with her current SLP and physical therapist for a little less than a year at the time of this study. She had also been working with a special instructor (teacher) for one month to improve her attention and imitation skills. Within Nahlia's speech and language sessions, Melanie described communication strategies including offering choices, positioning items close to her mouth, and providing single word models. She described integrating these strategies into routines including snack, play, and shared book reading. Melanie had concerns about using routines and materials that were not available in her home. For example, Nahlia's speech therapist would bring books and bubbles into the home, which Melanie said were not materials Nahlia had access to in the home. Over the course of the study, Melanie decided she preferred not to use signs, as she had difficulty remembering them and did not think they would be effective once Nahlia was enrolled in daycare.

Lori and Alex.

Lori was a 26-year-old white, non-Hispanic or Latino female with some college education. She was married with 3 children and had a household income of \$40,000-\$59,000. Alex was a 31-month-old white, non-Hispanic or Latino male with diagnoses of hypotonia and developmental delay. He used speech, gestures, and a single switch speech output device to

communicate. Lori's two older children were typically at school or daycare during Alex's sessions. In addition to physical therapy, occupational therapy, and speech therapy, Alex participated in a community-based exercise group for children participating in EI run by a local physical therapist. Lori described strategies used in speech therapy sessions including "play with a purpose", songs and fingerplays, repeated models of single words and simple phrases, and providing wait-time to give Alex an opportunity to imitate. These were integrated into play routines and shared book reading.

Danielle and Gabrielle.

Danielle was a 37-year-old white, non-Hispanic or Latino female with a M.S. degree. She was married with 6 children total in a blended family, and had a household income of \$80,000-\$99,000. Danielle worked in healthcare and worked a schedule of 10-hour days with 4 days of working, followed by three days off. Gabrielle was a 24-month-old white, non-Hispanic or Latino female with a diagnosis of developmental delay. She used nonspeech vocalizations, signs, and communication boards to communicate. Gabrielle received speech therapy, physical therapy, occupational therapy, and special instruction. Two of her four older brothers also received special services, one for diagnosis of Autism Spectrum Disorder (ASD) and one for Attention Deficit Hyperactivity Disorder (ADHD) as well as gifted support services. One of the siblings had begun receiving services through his preschool and one not until kindergarten, so while Danielle was familiar with the educational service system, she had not previously been involved with Part C early intervention services. In addition to early intervention, Gabrielle was participating in outpatient serial orthopedic casting to help her walking. Over the course of this study, Danielle described routines including seated play, active play, shared book reading, and mirror play while working on animal sounds. She described strategies including modeling on communication boards, offering choices, and breaking words down into single sounds focusing on vowels. While Gabrielle had no formal diagnosis, her SLP suspected mild apraxia.

Maria and Miguel.

Maria was a 28-year-old white, Hispanic/Latino female with some college education. She was married with 2 children and had a household income of \$40,000-\$59,000. Miguel was a 30-month-old white, Hispanic/Latino male with a diagnosis of Sotos syndrome. He used some speech, signs and gestures, communication boards, and an iPad with TouchChatHD to communicate. Miguel received physical therapy, occupational therapy, special instruction, and speech therapy early intervention services. At the time of the first interview, Miguel had just participated in his first session with a new SLP, Miss Linda. He had worked with his previous SLP, Miss Mary, for 6 months. Maria was concerned that the previous SLP was regularly late for sessions, had limited “connection” with the family, and that Miguel had made very limited progress while working with her. Miguel wore braces for physical therapy, and sat in a “triangle chair” during sessions. Over the course of the study, Maria discussed routines including playing, reading, and singing. She discussed strategies including providing repeated models, offering choices, and oral motor work to support speech production.

Pam and Landon.

Pam was a 29-year-old white, non-Hispanic or Latino female with an M.Ed. She was married with 1 child and had a household income of \$100,000-\$149,000. Landon was a 34-month-old white, non-Hispanic or Latino male with diagnoses of developmental delay and Autism Spectrum Disorder (ASD). His ASD diagnosis was confirmed over the course of the study. His medical history was significant for pneumonia, ear infections, and polydactyly. He was also undergoing genetic testing and had a hearing test. His hearing test was inconclusive for the second time, and Pam was waiting for a phone call to schedule him for a sedated hearing test. Landon began music therapy and Pam was looking into hippotherapy. Landon used some speech, signs and gestures, Picture Exchange Communication System (PECS) and an iPad-based speech-generating device to communicate. During the fourth interview, visual schedules were being

introduced. Landon received occupational therapy, speech therapy, physical therapy, and special instruction. The four sessions described in this study were held at daycare with Pam present. Pam preferred this arrangement because it allowed for increased collaboration between Landon's therapist and his daycare teachers. Sessions included classroom routines including breakfast, play at centers, cleaning up and washing hands, and shared book reading. Strategies included physical prompting for picture exchange and signs, shared book reading, offering choices, and placing puzzle pieces out of reach to increase communication opportunities.

Kristin and Lila.

Kristin was a 38-year-old white, non-Hispanic or Latino female with some technical school. She was married with 1 child and a household income of \$80,000-\$99,000. Lila was a 35-month-old white, non-Hispanic or Latino female with a diagnosis of ASD. Lila used speech approximations, signs, and an iPad with TouchChatHD to communicate. She had previously used pictures and communication boards to support communication, but discontinued their use after acquiring a speech-generating device. Kristin was involved with the Talk About Curing Autism (TACA) support group and was coordinating an "Autism Round Table" monthly panel at her church that included a professional, a parent, and a child living with autism. This group was open to the public. Lila received special instruction, occupational therapy, physical therapy, and speech therapy through early intervention. She also received in-home applied behavior analysis (ABA) services. She participated in outpatient speech therapy and saw a chiropractor. Lila followed a gluten free/dairy free diet and was participating in biomedical interventions including vitamin B12 therapy. Lila was in the transition process to Part B (preschool) EI services. Kristin discussed routines including play with puzzles, flashcards, and shared book reading. She described strategies including modeling with the tablet and providing sufficient wait time. Therapy focused on matching, navigating multiple pages, answering yes/no questions, and concepts including colors, shapes, and emotions.

Materials

Data were collected using a semi-structured interview guide (Appendix A). The open-ended questions that guided the interviews were based on the literature related to family perspectives and experiences in AAC and early intervention for children 0-3. Follow-up questions were suggested in the interview guide, but were determined and adjusted based on parent responses to the guiding questions (Patton, 2002). Interviews were conducted by phone or Skype and were audio-recorded using SoundNote software.

Procedures

Semi-structured interviews were conducted by the principal investigator using the interview guide in Appendix A. Each participant completed a series of four interviews, so that they were able to answer questions about their involvement in their child's assessment and intervention prospectively over time. Interviews were scheduled to take place within 24 hours of an early intervention speech therapy session. All six participants had regularly scheduled speech therapy sessions one time per week. Three of the participants completed the series of interviews within four weeks. Due to cancelled therapy sessions related to either the child or therapist being absent, three participants required 5-7 weeks to complete the series of four interviews. Interviews ranged from 23 minutes to 72 minutes, depending on the length of the participants' responses. All interviews were recorded. Recorded interviews were transcribed verbatim into Microsoft Word, with all identifying information removed, and analyzed thematically using procedures adapted from McNaughton and colleagues (McNaughton et al., 2001). Answers to questions were broken down into thought units, or the smallest amount of meaningful information that expresses a complete idea. Thought units are typically one or two sentences in length. Thought units were then analyzed and organized into themes based on content using operational definitions. Themes were determined using initial open coding followed by focused coding to determine which initial codes best reflected meanings emerging from the data (Charmaz, 2006). The principal

investigator and undergraduate research assistant then used the operational definitions to independently code 20% of the data and calculate inter-rater reliability. Inter-rater reliability was calculated on a point-by-point basis (total number of agreements divided by total number of agreements plus total number of disagreements). Areas of disagreement were negotiated and adjusted based on areas of agreement and disagreement (McNaughton et al., 2001). Cohen's kappa (1965) was calculated to provide an estimate of agreement between observers that is corrected for chance. This measurement is calculated by: subtracting the proportion of expected agreements on the basis of chance from the proportion of agreements between observers on occurrences and nonoccurrences of the behaviors, and dividing this number by the proportion of expected agreements on the basis of chance subtracted from one. Observed Cohen's kappa was calculated to be .87. A Cohen's kappa value greater than .7 is considered acceptable agreement (Kazdin, 2011). After calculating agreement, themes were reviewed and coded for subthemes. To further ensure the accuracy and validation of the results, a member check was completed. All six participants reviewed the themes and subthemes and confirmed they accurately represented their experiences, and did not recommend any changes to them (Lincoln & Guba, 1985).

Chapter 3

Results

The data yielded a total of 5 major themes and 17 subthemes. Major themes that participants discussed included, (1) Child, (2) Environment, (3) Communication partners, (4) Supports, and (5) Challenges. Operational definitions of major themes are provided in Appendix B. See Table 4 for a summary of Coding themes, subthemes, and examples of issues discussed.

Table 3-1: Major Themes, Subthemes, and Examples of Issues Discussed

Themes	Subthemes	Examples of Issues Discussed	
Child	Physical characteristics	Diagnosis	
		Energy	
		Illness	
			Skills
		Behavioral and temperamental characteristics	Focus and activity level
			Early interaction skills
			Preferences
			Temperament
			Challenging behaviors
		Progress	Communication modes
			Independence
			Physical skills
	Environment	Access	Access to communication aids
Access to services			
Access to family members			
Access to materials			
		Routines	Communication modes
			Communication strategies
			Session activities
Communication Partners	Parental roles within the session	Observation	
		Interventionist	
		Collaboration and coordination	
		Nonparticipatory roles	
		Parental roles outside the session	Research and advocacy
	Planning		
		Coordinating caregivers and services	

		Facilitating carryover
		Providing access to “normal” experiences
	Therapist roles	Sharing professional expertise
		Decision-making
		Planning and preparation
		Direct intervention
		Responding to parent feedback
	(Other) Communication partner roles	Professional guidance and collaboration
		Facilitating carryover
		Providing access to “normal” experiences
Supports	EI therapeutic supports	Easily integrated strategies and materials
		Strong therapeutic relationships
	Familial supports	Spousal support
		Extended family
	Community supports	Preschools
		Outpatient therapies
		Complementary therapies
		Diagnosis-specific support groups
	Information supports	Handouts
		Websites
Challenges	Communication challenges	Receptive and expressive language needs
		Navigating communication modes
	Familial challenges	Socioeconomic
		Adjusting to having a child with complex needs
		Navigating the needs of multiple children
		Family members interfering in therapy process
	Community challenges	Accessible services
		Childcare
	Service/information challenges	Services for parents

Themes	Subthemes	Examples of Issues Discussed
Child	Physical characteristics	Diagnosis
		Energy

Major Theme 1: Child

Physical characteristics. Parents discussed a variety of physical characteristics of their children that either directly or indirectly impacted the therapeutic process including factors related to the child's diagnosis, energy, illness, and skills. The young children whose parents participated in this study were at varying stages of ongoing assessment and diagnostic processes, which influenced families' schedules due to appointments, as described by Pam:

His occupational and physical therapists think he has some sensory differences. That's why, between that and his communication delays, he goes for testing at CHOP for autism spectrum disorder...right now they think yes, they think he does, but they're having him come back for more assessments. He's also getting genetic testing because he had polydactyly when he was born, and his pediatrician thinks there could be some other things going on.

Nahlia was diagnosed with Down syndrome at birth, and while her therapy team was pleased with her progress, Melanie revealed that this diagnosis has influenced their expectations: "...she has Down syndrome, and for her diagnosis all her teachers and therapists agree she's doing great. They didn't think she would get this far." At the time of the study, Nahlia's medical history was also influencing her ability to obtain childcare. Melanie said, "She had the TEF when she was born, but she had the surgery to correct it, but if you tell a daycare your kid has history of a feeding tube they want a nurse with them all the time." Nahlia's history of tube feeding and the transition to oral feeding also directly influenced routines within therapy sessions. Melanie stated, "...that's how they got into the habit of the snack time routine."

Kristin described doctor's appointments in addition to her regular therapy schedule, to try new biomedical interventions. The full schedule did impact Lila's energy level and participation within sessions:

...yesterday was pretty crazy because that appointment took a little while; it kinda went into her naptime...so she didn't really sleep very much. And then she had ABA last night, but it went pretty well for her being you know, kind of tired and out of sorts all day.

After her second B12 injection, the treatment affected her energy level in a different way:

Lila was a little distant... they're working because her, she's definitely trying to, you know approximate more and make attempts, but her attention's been a little off because she has a little more energy...so today focusing was a little hard for her.

Fatigue also influenced the choice of what to work on within sessions. Pam stated "Landon was really tired....but what can you do about that? I didn't want to cancel and have him lose the time, and it ended up working out so that OT and speech could collaborate."

Physical capabilities also influenced the use of pictures for communication. Maria said, "Also she included "books", "toys", "food". They were large pictures about maybe 5x7, like a half a sheet of paper, maybe a little more, because Miguel uses his whole hands when he points, so she needs the bigger pictures."

Behavioral and temperamental characteristics. Participants discussed behavioral and temperamental characteristics of the child that influenced the therapeutic process including focus and activity level, early interaction skills, preferences, temperament, and challenging behaviors.

Participants discussed how their children's varying levels of attention and activity influenced sessions on a weekly basis. Pam lamented: "Some things are really unavoidable, such as Landon's wandering and needing to be redirected back to the tasks. There aren't many things that keep his attention, except food."

Danielle discussed Gabrielle's attention and early imitation and interaction skills as a perceived barrier to using a speech-generating device, stating:

I really want to try some AAC with Gabrielle, but her therapist said she isn't ready for it because Gabrielle is just...well, like today, she's just so busy. She doesn't sit for long so she can't be instructed in how to use it, and of course she probably wouldn't even carry it around with her so that wouldn't work, she would just leave it somewhere and forget about it. But I just think it could help, but her therapist said she doesn't, um, she doesn't have enough imitation or interaction skills. She doesn't try to point or show us anything or pay much attention when we try to point and show her things, so she has nothing to use the AAC for, so we have to work on verbal communication first and interaction and imitation first.

She was much more optimistic following sessions in which Gabrielle demonstrated more attention to tasks, stating, "Gabrielle was much more focused today, and that focus is what's going to be most supportive to learning language and any form of communication."

Lori also discussed the influence of imitation skills on using certain communication modes, stating: "We work on the songs because he has to be able to imitate movements before he can do signs and many of the signs are very complex."

Kristin discussed how Lila's preferences drove decision-making and therapeutic practices. Her affinity towards technology influenced the decision to pursue a speech-generating device:

I had talked to the therapist about the augmentative communication just in discussions. But, when I started researching a little bit more, and seeing how well Lila just did with technology in general, being able to navigate our phones, even though they're both different. Understanding like putting the two together, like, the remote gets me something from the TV, even as young as 16 months, and before, just understanding if I want to watch this, I can bring something to you. We, my husband and I, he's very big

into technology, so we looked at it is, you know, she's already receptive to the idea and she's already picking up on the pictures, so this is basically just one step further.

Lila's preferences, and her mother's understanding of how non-preferred activities could become preferred activities, also drove decisions related to session activities and transition planning:

Whether it's a simple task or you know, something large like that (transitioning), given enough time, Lila becomes comfortable and excels at things, but it's just all about how you introduce it to her. It can't just be like, here's school!" It has to be very gradual, baby steps all the way...when she started, she didn't like puzzles. It was here, "put one piece in" When she didn't want to, whatever it was, you know what I mean, it's just all about introducing it and making her comfortable with it.

Parents also discussed challenging behaviors and their influence on sessions. Challenging behaviors included overall lack of cooperation, whining, and screaming. Pam said, "She asked, 'Landon which do you want?' And that's where things got difficult, he was really whiny and didn't want to do any of the centers." Kristin said, "...it was a little frustrating; she was not super cooperative today. We had some little meltdowns and she was just not compliant. " Melanie said, "Yeah, oh yeah, you know if she's hungry. Like she will go to her high chair and shake the legs and scream. She just screams a lot."

Progress. Participants described the progress made by their children in terms of communication modes, increased independence, and physical skills. They also described how overall progress came slowly, but when they were able to identify specific areas of progress it provided them with hope and energy. Kristin described Lila's increased independence using her speech-generating device, stating:

We definitely see improvement, so that always adds a little bit of hope. And you know the device; the more she gets familiar with it and is using it you know, independently, that definitely helps.

Danielle said, “I feel really good about this week, which is funny because it was probably the worst session, I just feel at peace with this, totally fine with it, because overall she’s making progress.”

Maria described Miguel’s progress, stating:

Today was a very good session. I am excited to tell you Miguel said “o” and “baa” while singing. I feel he is much more vocal. His sounds are more and more speech sounds. He is waking up, using his pictures. Today he chose “ball” actually, instead of just pushing away objects or pictures to refuse what he doesn’t want, to tapped on the picture of the ball to request the activity.

Major Theme 2: Environment

All six participants discussed factors related to the environment. Two major subthemes emerged from the data: (1) Access and (2) Routines. Within the Access subtheme, parents discussed issues including: access to communication aids, access to services, access to people, and access to materials.

Access to communication aids. For the participants of this study, access to communication aids was influenced by factors including knowledge and use of signs, physical access to light-tech communication boards and PECS, and barriers to acquiring high-tech devices. Pam expressed that the language stimulation she was providing via sign language was influenced by her knowledge of signs, and the “target” list of signs that Landon’s SLP provided; she stated: “Miss Anna used some signs, but they aren’t on our list of ‘target signs’ so I don’t use them.” Physical location of light-tech communication aids may also have influenced their use. Regarding Nahlia’s communication board for meal and snack routines, Melanie said, “Right now it’s on the

refrigerator until speech comes.” Pam favored the idea of physical closeness of communication aids to facilitate their integration into classroom routines. She expressed, “I like the idea of putting visual schedules and picture cues throughout the classroom. After talking with his teacher I think that could work more easily and minimize the differences between Landon and his peers.” Pam also described how access to specific PECS influenced Landon’s snack-time routine:

We used PECS with four symbols. He had goldfish crackers, juice, mini marshmallows, and pieces of pop tart. Don’t tell his pediatrician! We have to use really high value treats, things that will be motivating for him, to motivate him to communicate, especially at times of the day when he’s tired. Usually he will eat anything, but we don’t have PECS for peppers and hummus - can you believe that’s what his class eats for snack? It’s great! – but we don’t have those PECS and even though he would have eaten them I just know he wouldn’t have requested them today. His teachers tell me to give him a chance to do things before I assume he won’t, but I know my son.

Regarding high-tech communication devices, participants discussed barriers to the acquisition of speech-generating devices. Pam described the delay in acquiring an iPad for Landon as a result of waiting lists for device loans and data collection:

The only thing we don’t have is an iPad that’s just for him yet. There’s some pretty significant lag time between getting on a waiting list for a device loaner, then completing the loan and the data collection. Then Miss Anna has to write the evaluation for his insurance company, and then I imagine we will have to wait again. It sounds like we won’t even be able to start the official loan from the state until after Landon turns 3, which will mean starting all over again. Miss Anna is going to see if she can just transfer the loan to his intermediate unit speech therapist, but we won’t know who that is yet until his IEP meeting. I don’t even have a date for that yet.

Despite this delay, Landon's SLP was able to provide access to a speech-generating device during his sessions. Pam stated, "It's Miss Anna's personal iPad. I'm actually not sure what the application she is using is called, but she requested a loaner device for him with a program called TouchChat."

In contrast, Danielle desired to trial a speech-generating device with Gabrielle, but did not acquire one over the course of this study. She stated:

I hope someday we can try the iPad, when Gabrielle's ready. And I think it would be good to, we've been using the same pictures for a while, so it would be good to increase the number of pictures she has...that's part of the other reason I would like to try the iPad, I think it would make it easier to organize the pictures we are using, instead of just carrying – I think we have 6 – boards around, all those would fit in one iPad.

Access to services. Participants in this study discussed access to services including the provision of services in early intervention and attempting to acquire additional services to meet their children's needs. Pam described the need to advocate for Landon in order to receive speech therapy services through early intervention. She stated, "I wish he was talking more, of course. But before this we had special instruction only, and I had to beg to get a speech pathologist in." She expanded on this by saying:

His pediatrician would really like him to have therapy two times per week, but his service coordinator said we can only have up to a maximum of one time per week in early intervention. So Landon is on waiting lists for all the outpatient speech providers that take his insurance and we will just go with whoever calls us back first.

Kristin was, however, able to advocate for a short-term increase in services for Lila as she approached the age of transitioning out of early intervention. She described this process when she said:

...looking down the road and seeing this huge transition for her with losing people she's been working with this year, and trying to start a preschool...I didn't want that all to happen at once; it'd be such a shock to her. So, you know, I called a meeting with our service coordinator and the team to let them know my approach, like, "hey listen, I think this is what I want to do; would you be okay with getting some extra hours for that?" It took a little persuading, but they ultimately said fine and it's now working great.

Access to family members. Parents discussed varying access to people throughout therapy session and during the week between sessions and their influence on service provisions. While the mothers in this study were physically available for each of the sessions described, they described varying degrees of presence. Lori stated, "I was in the living room with him just folding some laundry." Maria said, "We did our session at 10:15 again today, with Miguel in his triangle chair, and I went into the kitchen. Shondra was home from school so I was cooking breakfast in the kitchen for Shondra and getting Miguel's juice ready so it would be ready when he is done with therapy." Pam preferred to be more active in sessions despite their physical location at Landon's daycare; she stated, "Today we had an afternoon session because of all the rescheduling. Luckily I was able to leave work early to be there for the whole session."

Parents also described the influence of extended family on sessions. Melanie stated, "I think it would be really much better if I kept Natalie separate from Nahlia's session. I think it's better to separate them so Nahlia can really benefit from the stimulation more." She further described her desire to give Nahlia access to peers and begin having sessions at daycare. She stated: "If we find one. I think that would be really helpful. Especially if she can imitate the other kids. I think she needs to be around kids close to her age that aren't just Natalie."

Access to materials. Parents described the materials used for sessions. They described taking active roles in the acquisition and preparation of materials for sessions. For example, Kristin purchased and prepared materials specifically for use during sessions to meet

her daughter's goals: Regarding purchasing pictures to work on matching vocabulary goals, Kristin stated, "...[Large chain store] is great for them. They have a lot of picture cards of, you know, animals, shapes, colors, so we just kind of pick those up and I usually just buy 2 packs, so we can start by just matching." Kristin also explained how she prepared materials for transitioning to a new preschool classroom:

She's in the caterpillar room, so they have a little hungry caterpillar on the door, with all the kids' names, so we took a picture of that, and her little book nook where they sit and read; they have like little bookshelves, and her circle time, like the chart where they do the days and the numbers and the calendar.

Maria described selecting materials available for session to work on generalizing skills across activities; however, she also found that when using pictures to request, not all the pictures she needed were available:

Well today using objects Miguel also chose the latch board, kind of like a puzzle but with latches to open and close. I thought to put this out as a choice for him to request because when you open and close the latches it is different areas of the farm, and we have been reading the farm books and singing Old MacDonald, and I think this is a different way to practice this skill and these techniques, but of course there was no picture for this toy, but Miss Linda says she will bring one next time. Actually I think I may be able to, this week, just take a photograph and print it, we could use that just fine.

Danielle described a plethora of materials readily available in her home designed to meet the needs of multiple therapies:

We have the whole living room set up like it's therapy central for her in there. She has a trampoline, some mats to climb up and down, tunnels, all kinds of toys – toys for vision, toys for walking, toys for oral simulation to improve her eating, toys for pincer grasp and fine motor. It's just taken over our living room! If you need therapy supplies, come to our

house! She has a small table and chair in the living room, too, but she almost never sits there!

On the other hand, Melanie struggled with access to materials for Nahlia. She stated:

It's a little harder when we don't really have a lot of books Nahlia likes to read, or we don't have any bubbles. Sometimes they bring things that we don't have in the house, and like I'm not going to buy bubbles because it will turn into a sticky mess on my floors, at least not right now. Maybe in the spring when we can go outside. But I've really been trying hard to practice with Nahlia during snack time and, you know, at breakfast and lunch and dinner too. We have to do those everyday, so it's easier.

Melanie was also concerned with a suggestion the SLP made regarding going to the library to use community resources. She stated, "She suggested we go to the library this week. I'm not sure because Nahlia just puts everything in her mouth still."

Routines

Within the routines subtheme, parents discussed issues including: (a) communication modes, (b) communication strategies, and (c) session activities.

Communication modes. Participants discussed use of varying communication modes during sessions. Pam discussed using PECS with Landon. She stated:

...we have his PECS book which is really easy to use and we try to encourage his teachers to use it at daycare. We use it when we can at home, it has about 20 pictures in it. Miss Anna did a, uh, preference assessment to determine what pictures we needed to put in the book. We probably need to update that soon; he has a lot of new toys. We have puzzles at home and we try to read before bed.

Communication strategies. Participants described language stimulation strategies that were primarily direct in nature and targeted specific goals such as receptive vocabulary identification and filling in words. For example, Pam said: "...today we read *Baby Bear What Do*

you See? By Eric Carle. During the reading, we encourage Landon to point to different pictures after we point to them, and we pause to see if he will fill in words at the end of lines.”

Some participants were also able to describe the rationale for the strategies they were using. Lori said:

She was just saying the same words, over and over. She always says to just say the same single words and simple phrases again and again. Kids need to hear words hundreds and thousands of times before they will repeat them...so we just say the same things over and over.

Maria described the desire to take an active role in choosing communication strategies.

She said:

What I like about Miss Linda is that she will give several options. She will say, “This is how we can approach this, and give several options. Then she says “What would you like to do?” I think it is important for families to know the options. For example, today she said to me, “We can put Spanish words with the pictures, English words with the pictures, or both. What would you like to do?” And I said, “I would like to use English words with the pictures.” I would like to use English words with the pictures because even though in my family we can speak both English and Spanish, Miguel will have to speak English when he goes to school. I want him to learn as much English as possible and have the easiest time learning English as he can.

Participants also described communication strategies for attempting to integrate communication aids into daily routines. Kristin said:

So, it’s funny because we’re still getting used to it as far as like taking into places with us, and things like that. But we definitely kind of use it to like storyboard and tell her like, “ok this is where we’re going,” “these are the kinds of things you’re going to see” And kind of scroll through the different categories, and you know the different pages that

she is used to. Correlating like her show with, “we’re actually going to see it at the museum”, and “we’re going to take a ride to get there.”

Session activities. Participants discussed activities centered around the child and how they were chosen including activities that were selected because they: (a) were ongoing, (b) were recurring, (c) were preferred, (d) targeted specific vocabulary, and/or (e) targeted multiple skills.

Lori described the SLP’s tendency to integrate into ongoing activities when she arrived for Alex’s session:

...usually she just integrates herself into whatever we are doing...this is what we are supposed to do for this type of therapy for early intervention. So if he’s playing she just joins in or if he’s eating she just joins in. This is how the early intervention therapies go... we don’t plan it so much as we just sort of spontaneously do whatever he’s doing, for early intervention therapy.

Parents also found that routines-based intervention that included frequently occurring routines were beneficial. Melanie said, “But I’ve really been trying hard to practice with Nahlia during snack time and, you know, at breakfast and lunch and dinner too. We have to do those everyday, so it’s easier.”

Activities were also chosen based on preferences. Melanie found it logistically easier to complete tasks in the high chair; she stated: “Well they’ve been doing snack for a while and I like to put her in the highchair because the floor’s dirty because nobody helps around here cleaning and when she’s in her highchair she wants to eat. And Natalie will be all over her if she’s on the floor.” Kristin described working on new skills within activities that were preferred to the child. She said:

So, shapes, animals, we’re starting to work on colors, so just to kind of use that to see if, like I said, we can get away from the matching and actually identifying them. And we’re also, from the verbal aspect of it, we’re working on, she prefers puzzles, which is funny

because just a couple months ago, they were very not, but if you just work and work and work with her, it becomes a preferred activity. So, just taking the pieces out and really getting her to not just you know, an array of 5 or 6 pieces, not just know when we say, “Where’s the doll?” have her point to it but then also okay, “What is this?” and do the verbals, so we’re mixing up a little of the verbals and the receptives with an activity that she prefers.

Some activities were planned with regard to specific vocabulary based on the SLP’s recommendations. For example, Lori said: “She likes to include bubbles in the session because it keeps his focus and there are a lot of simple words and signs that can go with that activity.”

Others were chosen because they targeted specific, or multiple skills:

She is starting to work on like actions, like identifying running, jumping, swimming, so and it’s the way they have it there, she has they’re like word puzzles so its like the action and the word and you have to fit it together. It’s almost like a little jigsaw puzzle, so we work on actually we incorporate a little bit of motor skill because we have together to put the puzzle together with the action and then we say, okay, and we try to get her to at least approximate the word and then identify it on the tablet. So she’s kind of using that fine motor, trying to get her to vocalize a little bit, and she’s incorporating the tablet, and it’s all kind of just one activity.

Some parents found that there was little planning, or they were unaware of the planning that took place. Maria described her frustration with sessions with a previous SLP, stating: “We did not plan them. These discussions did not take place. She would come in and play for 45 minutes and then spend the remaining time doing paperwork. Then she would say “sign here” and we would do the same thing next week.”

Participants also described activities that did not directly involve the child, but were focused on discussion and problem-solving. Kristin said:

I mean, I've been seeing more of the in-home therapy getting a little challenging because, I think she is getting to the point, we actually discussed this in speech, where she developmentally might be getting to the point where she's kind of tired of doing all this in the house and you know, because she participates so well in school, and at her ABA center, and you know, there's hardly any meltdowns.

Major Theme 3: Communication partners

All participants discussed factors related to the major theme of communication partners. Four subthemes emerged from the data: (1) parental roles within the session, (2) parental roles outside the session, (3) therapist roles, and (4) (other) communication partner roles.

Parental roles within the session. Parents enjoyed dynamic degrees of participation within and across sessions, during which their roles included observation, interventionists, and collaboration and coordination. Danielle provided a detailed description of how her role within the same session alternated between completing non-participatory self-care activities to active interventionist managing behavior and providing aided language models:

It was good. Gabrielle was nice and focused again...I got to take a break from being her behavior manager to take a quick shower and it was awesome, not just because I got to take a shower and drink my coffee while I was in the shower (laughs) but because when I left to take the shower, Gabrielle was seated at her table, and when I came back out she was still seated at her table. She worked the whole time! I don't know what that means for the rest of the day...that may have just used up all her sitting time (laughs), but at least I got a shower and some coffee!

Later she contrasted this with the previous week's session when she primarily managed Gabrielle's behavior so that the therapist could provide the therapeutic intervention:

I think it went better than last week. There were few times when Gabrielle totally did her own thing, she was a little more responsive to directions and stuff today, uh, well I didn't have to physically move her anywhere so that's always a plus.

Maria also alternated between participatory and non-participatory activities within the same session:

...when Miss Linda arrived first I showed her how I have been doing the lip stretches and I gave to her the vibrating toothbrush. She said everything is good with the lip stretches, and she showed me how we will do the vibrating toothbrush and she gave me another handout on how to use the vibrating toothbrush. So after this I went back to this for my family.

When participating in a given session, parental roles varied from observation, to active in intervention, to collaboration and coordination with professionals. Multiple parents expressed that it is often helpful to them to "take a step back" and observe. Kristin stated:

...I definitely sat back a little bit more today, and just kind of watched because I was interested to see you know, the engagement being that she had been off for a week. And usually I'm a little bit more hands on, but I actually think it's a little more beneficial to not be.

Even when observing, parents felt actively engaged. Benefits of observation mentioned included learning new strategies, giving the opportunity for the child to practice skills with someone else, and providing an opportunity to reflect and problem-solve effective strategy usage. Kristin described how observing sessions allowed her to assess Lila's needs and to give Lila an opportunity to generalize skills across interventionists. She stated:

So you do have to pull back as a parent a little bit to be able to see that transition, to see what she needs help with, what she, and you know. And she needs someone else to do it differently than how I do, because when she goes to school, and when she's out in the

community, people aren't going to mimic an action like exactly what I do. They're gonna say it different, they're gonna look different. So, she needs to get used to that. So I think it was good to sit back and just let them work a little bit.

Melanie reflected on her observations and was able to identify supports she needed to help her use sign language with Nahlia:

She was signing with her and I even though I was watching I didn't catch all the signs. So I probably need pictures with the signs. Or better yet if she'd make a picture board to go with the book... because I'm thinking we're doing the signs and the words and the pictures, and maybe the pictures are the best and easiest to do. I have a hard time remembering all the signs.

When taking participatory roles within the session, parents acted as behavior managers and interventionists. At times, the role of the parents and role of the SLPs seemed fluid. Parents described what they were doing and what the therapists were doing separately as well as combining the roles, as evident in this description by Pam:

So this week Miss Anna didn't show him the iPad at all, she had me do it. So I offered him the centers, there were four centers – library, sensory, housekeeping, and dramatic play, which essentially is just dress up. So he chose dramatic play, which is different for him. He, as far as I know, doesn't show any interest in that type of play. But we helped him pick different pieces of a costume and dressed him up like a firefighter. We just used lots and lots of words and offering choices.

Beyond direct intervention, parents also planned, guided, and reflected on clinical decisions and directions. Parents voiced their preferences regarding communication modes. For example, over the course of the study Melanie found that she wanted to discontinue the use of signs with Nahlia. She stated:

I'm going to talk to her therapist about being done with signs. I don't want Nahlia to sign because no one at daycare will understand her. I really want to get Nahlia into daycare and then maybe some sessions can take place there. I think that would be less distracting than having Natalie in the sessions and the focus can just be on Nahlia.

Melanie developed a preference for communication boards, but wanted to use routine-specific communication boards, rather than the more general ones she was using at the time of this interview. She stated: "I don't really like using the same picture board for snack as we use for reading, so I'm really going to talk to her therapist about that, about what our options are."

Danielle, on the other hand, was currently using picture boards with Gabrielle, but wanted to try an iPad-based speech-generating device. Despite previously deferring to the SLP for this decision, she planned to revisit the issue at a later date, stating: "I'll probably wait a few weeks and pester her therapist again!" Danielle regularly participated in generating ideas for use within sessions. These ideas "come from talking with her other therapists, all her therapists, and from watching and participating in her sessions. Then I think about conversations we've had and I think, 'Hey we could try this'. Maria also described collaborative idea generation, stating:

I believe I would say they were generated between both of us, she combined the information I gave her with her expertise, and she said "Then I think next time we should do this." And I agree. But what I like is that I think if I said, "No no, we should try this." She would have said 'okay'.

Maria and Miguel's therapist had also discussed the possibility of a speech-generating device, and trialed it during a session. While the therapist had recommended against it at the time of the study, Maria was also considering revisiting it at a later date. She stated, "I said to her I would just like to have the option to try again with the tablet, if he does not progress with the pictures, and she agreed."

Reflection and collaborative idea generation within sessions was, at times, planned and other times, spontaneous. Spontaneous reflection occurred when children were no longer attentive to direct intervention, such as is described in the following quote:

...it seemed like we had gotten to the point where Gabrielle just wasn't going to do anymore, and to tell you the truth, I didn't really feel like playing behavior manager much more, so her therapist and I spent some time talking about the communication boards and I did mention what we talked about last week, with increasing the vocabulary and she said that was great.

For some intervention teams, it was a habitual aspect of every session when parents took less active roles with sessions, as Maria described:

I am very much a distraction to Miguel. He will not focus with me in the room, so I set him up in his triangle chair and I go back to the kitchen, where I can hear everything they are doing, and then he can focus with Miss Linda, and Miss Linda at the end of the session came and reviewed the paperwork with me, and went over the handout and strategies with me.

Team meetings were also held for quarterly progress reviews or on an as-needed basis to make adjustments to therapy plans. Melanie described a quarterly progress review in the following way: "We're doing her quarterly team meeting. All her therapists and her service coordinator will be here...we kind of review everything and decide on goals and talk about her progress."

Kristin also found it helpful to meet as a team when introducing a high-tech device, saying:

We had a meeting last week...so we unfortunately didn't get to work with Lila last week...she was there, but we were really discussing with the speech therapist and her behaviorist so we combined the session, and just really kind of set a path for the next

couple weeks of what we want to see therapy to look like in regards to the tablet, like introducing new things on it, just making sure that the team was kind of on board with everything.

Parental roles outside the session. Parents described a variety of therapeutic roles that took place outside their actual therapy sessions, including: research and advocacy, planning, coordination of caregivers and services, facilitating carryover, and providing access to “normal experiences.” Parents recognized the multitude of roles they played, as evidenced by Pam’s statement: “We’re doing a lot. I’m not sure we could handle doing anything else.” She did report trying to normalize her own parenting experience, stating “It adds to the schedule because of all the different appointments...but I figure if he were just a normal kid he’d have other activities going on too. I try to remind myself that, this is just parenting at this age.”

Parents described research and advocacy practices in which they engaged outside of sessions. Kristin’s research into technological options led to Lila’s acquisition of an iPad-based communication device before her second birthday:

So we basically, I had talked to the therapist about the augmentative communication just in discussions. But, when I started researching a little bit more, and seeing how well Lila just did with technology in general, being able to navigate our phones, even though they’re both different. Understanding like putting the two together, like, the remote gets me something from the TV, even as young as 16 months, and before, just understanding if I want to watch this, I can bring something to you. We, my husband and I, he’s very big into technology, so we looked at it is, you know, she’s already receptive to the idea and she’s already picking up on the pictures, so this is basically just one step further.

Maria also independently investigated communication modes, as described in the following quote:

Yes, we always speak the words and we have a few signs we will use with him. We will sign “toilet” and “more” and “all done” and “eat.” Do you know I looked those up on the Internet? Miss Mary [previous SLP] said “You want him to speak. We will do speech.” But I know there are other ways to communicate, and I want him to communicate with me in whatever way he can.

In addition to research so that one can be knowledgeable about therapeutic options, Pam described advocacy as a necessary parental responsibility:

There is a lot of waiting on other people, the way the system works. That’s why I advocate and push so hard, that’s why that’s my responsibility as a parent; otherwise I’d be waiting forever and Landon would be waiting forever.

Kristin also described advocacy necessary to access and increase services available to children as enter future service systems, “She will have two 45-minute speech sessions a week, which they wanted to give us two 30, so I had to kind of fight a little just to for the 45.

Parents engaged in a variety of planning tasks including planning materials and tasks and transition planning. Planning materials included preparation of low-tech communication aids, as described by Kristin:

So, I took pictures of that earlier in the year when she started, and laminated them, and took pictures on her device of the pictures. So, I said, “we’re gonna go to school tomorrow” and then that morning when we were eating breakfast, and we were using the device to you know, ask for more, and identify while we were eating. We talked about like, “look where you’re going to go today,” “you’re going to go to school,” “We’re gonna see Ms. Diana,” “we’re going to do story time,” just kind of showing that and she was fine there.

It also included ensuring availability of appropriate materials to work out targeted outcomes. Kristin described purchasing flashcards at a local department store: “...they have a lot

of picture cards of you know animals, shapes, colors, so we just kind of pick those up and I usually just buy 2 packs, so we can start by just matching.”

Parents also played an active role in transition planning, as described by Kristin:

So, back in September I started thinking about this month coming up and losing services, and starting with the IU and knowing that they push to do it at school, either in their school or another preschool, and that’s why I enrolled her in the preschool she’s at now.

Parents reported devoting significant time and energy to coordination of caregivers and services. Pam said:

Tonight after dinner we have physical therapy at home from 6:30-7:30. Pretty much my schedule goes: Therapy..work...Pick up Landon...Dinner..Therapy. Aaron has a work function tonight so he won’t be home until after Landon gets a back and goes to bed.

After he gets home I’ll review the therapy sessions with him because he likes to be involved even if it’s hard for him to use all the strategies with Landon...because really when he gets home from work, he wants to relax and not be thinking “Did I use the PECS card every chance I got? Do I know the sign for ‘whatever’? Did I remember to put Landon’s cereal in the lip bowl? Do I need to put his braces on?” Well, I always put the braces on his feet, but you know what I mean. I really coordinate all of that, and then sometimes we have to take breaks. But Aaron does like to know what is happening. Anyway, I talk to Aaron about it and then tomorrow he will leave before we do.

Parents described a variety of ways to facilitate carryover of strategies and activities between sessions. Melanie described the importance of this role when she stated “Today was good. The session was good, now I just have to keep her going during the week, because if I don’t, she loses it, then it’s weeks or months before we hear it again.” Kristin echoed this, saying:

But really, you have to take the lead on it because we’re going to see her all the time. We don’t show her that this is her, you know, model it for her and show her that this is how

she gets her needs met. I think she's smart and she could pick that up in sessions, but we really have to keep enforcing it throughout the day to show her that it's part of her life.

So, I think it's an important role for sure.

Melanie described how she integrated communication boards into meal and snack routines:

During the week...during the week sometimes I'll show her eat. Just when she's yelling. She yells a lot to get my attention and then she goes to her high chair and she wants to eat. So I've been trying to show it to her when she does that because when she goes to daycare people won't know what she means when she's just going to the highchairs and yelling. She has to be able to use words...even if it's just words on pictures.

Kristin described that, although strategies were integrated throughout the day, they tended to be in shorter spurts than during therapy sessions:

You know, when we're doing something on the floor, like before we start to get ready for bed, you know maybe pull out a puzzle and do it a couple times and then just introduce the tablet like, "oh hey well what is this?" like and just, you know maybe it's one or two shapes and then that's all I do during that little time period, just so that it's not, "ugh here we go" Just more like, "great job, high five! Alright let's do something fun now, "do you wanna play with the ball, do you want to turn a show on for a little bit?" Just to show her that it doesn't always have to be work, it can sometimes be fun.

Parents described that, despite the time and energy they put into facilitating carryover, they found it was "just part of life". Kristin said:

Oh, I don't think difficult at all. Because it's just, it sounds corny, but it's just our life now. Like, that's what we do. We just implement everything; it's a ton of work, and it's basically all day everyday, but we see the progress and you know, the hope is eventually

this all pays off and she's mainstreamed and integrated, and you know doesn't need all the stuff that we're doing now. So, we just try to get as much at her now, when she's young and doesn't really realize it.

Danielle stated,

I guess, that doesn't really change from week to week. Her needs are a continuous presence, and priority, for me. So every time we're doing anything, I'm thinking "How can I make her say or sign this?" Or get her closer to saying or signing during any activity. It's tiring, but it's worth it when a few weeks later I will notice that she's playing with sounds more or imitating more.

Finally, parents described how they tried to provide their children with as many "normal" experiences as possible. Pam said,

I guess we're kind of trying to not let them change our family dynamics too much. We make sure he gets that downtime with my Mom, and we try to keep our schedules as normal as possible. We want him to have normal experiences outside his therapy sessions and doctor's appointments.

Kristin said:

I don't think it'll be tough to be honest...we give ourselves a little bit of time at night anyway to sit down and kinda do some things and it's a nice chance to kinda get like ok, how can I work with this throughout the week, but not do it exactly; not make her feel like we're really in therapy.

Therapist roles.

Parents described the roles of therapists, including: sharing professional expertise, decision-making, planning and preparation, direct intervention, and responding to parent feedback.

Sharing professional expertise included sharing information related to communication activities, strategies, and communication modes, child development, and, when necessary, information related to necessary referrals. A major role of the therapist, as described by the parents in this study, was to identify activities within which to address communication skills. As identified in Theme 1, many of these activities were what was already going on in the household. However, as illustrated in the following quote, an additional important role was for the therapist to explain why and how communication strategies were to be integrated into the given activities. Maria stated:

It's important, when someone comes into your home, for there to be that connection between the child and the family and the therapist. Also Miguel worked with Miss Mary for 6 months and we saw very few gains. She would come in and sit on the floor with him and do the activities, she would play with his toys and read his books with him, and we can do that ourselves. It is not that we don't read and play with him, do you understand what I mean?

Therapists also shared their expertise regarding communication modes. Maria said,

We use the easiest for Miguel, to show objects that he wants and let him point to things. This is another difference between the therapists. Miss Mary says "You want him to speak, so you make him say it." My mother and sister and his doctor all tell me the same thing, so it may not be just Miss Mary, but Miss Linda says "Maybe he cannot say these things you want him to say right now, but he will say them eventually if we give him some tools." Miss Linda said we can keep using the objects he wants, so if he wants his juice and points to his juice we can give to him the juice, but we must label juice. Also she suggests we might put pictures on the refrigerator so he can progress from needing to see the actual objects to pointing to pictures on the refrigerator, and today she show me this tablet with communication pictures on the tablet, and she will try these with him.

Therapists also shared their knowledge of child development. Kristin described how, developmentally, it was possible her daughter would benefit from services outside the home:

We talked about it today. We kind of brainstormed and her therapist said, “look it may just be she’s almost 3; like developmentally she may be kind of done with us always in her space. She may be now starting to distinguish, “ok I leave the house and I go to school, and I go to the center and I do this when I’m here. I kind of just want to be here.” It’s frustrating to her a little bit I think.

Another therapist shared her views on the developmental appropriateness of certain communication modes and goals:

We have a lot of other expenses right now related to the kids’ various needs and activities and the special instructor said actually if the speech therapist wrote a letter to my insurance company, the insurance company would pay for an iPad for Gabrielle. But the speech therapist says Gabrielle isn’t ready.

When therapists needed additional information, they made professional referrals to healthcare providers, such as for hearing assessments: Pam stated “... Thursday Landon has a hearing test in Hershey. His speech therapist wanted him to get tested.” In Kristin and Lila’s case, a referral was made to an outside therapist to find the correct communication device for Lila. Kristin stated, “...thankfully our therapist was great saying like, ‘look, I don’t work with these a lot, I know a lot of speech techniques, but the device is not really my thing.’ You know, we brought in a specialist for that. We brought in someone that worked with both of us.”

Parents also relied on the expertise of the therapists for problem-solving and providing alternative options for activities, strategies, and communication modes when progress lags. Maria said:

I feel it will be better now, but it has not been very good or very quick. Miss Linda has said, “This may take some time,” but I am okay with it in her case because I feel that if he

is not making progress, she will communicate to me ways we can adjust or other things we can try, not just to wait for him to speak. If we want to just wait for him to speak, we do not need a therapist for that!

Participants in this study described the therapists' role in clinical decision-making.

Decisions were often made through collaboration with other professionals and then reported to the parent, such as Pam described:

This week should be easy because it's more of the same. I can't follow-up on the things they discussed like the new pictures until they're made and sent home, and I need to find out really what the final decision about "Break" and "all done" was.

Some decisions were made in collaboration with parents. Maria stated:

What I like about Miss Linda is that she will give several options. She will say, "This is how we can approach this, and give several options. Then she says "What would you like to do?" I think it is important for families to know the options. For example, today she said to me, "We can put Spanish words with the pictures, English words with the pictures, or both. What would you like to do?" And I said, "I would like to use English words with the pictures." I would like to use English words with the pictures because even though in my family we can speak both English and Spanish, Miguel will have to speak English when he goes to school. I want him to learn as much English as possible and have the easiest time learning English as he can.

Other decisions were felt to be made primarily by the therapists, as described by

Danielle:

Yeah but, ultimately it's the speech therapist's decisions whether or not we get to try it. I guess I could buy it myself but I wouldn't even know where to start. And her teacher... I mean, I guess she could point me in the right direction, but she's not an expert or anything. She brought it up because Gabrielle has been working on play and imitation

with her and she thought it actually might help her interaction skills, but the speech therapist said you can't add something to the interaction, first you have to have just interaction between people, then you add an electronic device. And ultimately most children with, um, apraxia, since the apraxia is just mild, they do usually end up speaking.

Therapists also played a vital role in planning and preparation for sessions. Planning and preparation tasks included designing and providing communication aids, and planning and preparation through collaboration with other team members.

Danielle described how her therapist provided communication board and pictures that Danielle took the responsibility for placing throughout a designated therapy area in her home:

Well I am going to place the communication boards, to post them on the wall throughout the therapy area, the ones were using. Then next week her therapist will bring some additional pictures. And of course we will continue the speech and signs too.

Maria described a similar situation in which Miguel's therapist brought pictures and a speech-generating device programmed with words that Maria had identified as a priority for her family:

Miss Linda brought with her the tablet, some pictures – they were, like animated pictures, just generic pictures but they actually looked almost the same as the pictures in the tablet, and included were words we discussed I would like him to say – Mama, Papa, Shondra or sister, toilet.

Other therapeutic decisions, including those pertaining to activities, were made by therapists taking into account the child's focus and vocabulary words. Lori said, "She likes to include bubbles in the session because it keeps his focus and there are a lot of simple words and signs that can go with that activity."

Planning and preparation for integrating high-tech devices also included securing equipment loans, funding requests, and transition planning, as described by Pam:

For me, it's pretty simple. The only thing is we don't have an iPad that's just for him yet. There's some pretty significant lag time between getting on a waiting list for a device loaner, then completing the loan and the data collection, then Miss Anna has to write the evaluation for his insurance company, and then I imagine we will have to wait again. It sounds like we won't even be able to start the official loan from the state until after Landon turns 3, which will mean starting all over again. Miss Anna is going to see if she can just transfer the loan to his intermediate unit speech therapist...

Collaborative planning and preparation was, at times, spontaneously incorporated into the sessions, such as when therapists co-treated unexpectedly due to scheduling changes:

Yes and then we cleaned up and washed his hands. Actually this was a good thing – his OT suggested using pictures for the steps in washing his hands and cleaning up. So Miss Anna is going to take care of making that. She also wants pictures of simple directions for snack, like visual cues for not stuffing food in his mouth and to use utensils. That was a really good thing about co-treating – they can collaborate on some of these things without my having to remind them.

Opportunities for collaborative planning and preparation was also incorporated at regular intervals during quarterly progress reviews. For example, Danielle said:

We meet quarterly where her whole team is here – her physical therapist, her case manager, her speech therapist, her occupational therapist, and her special instructor. And when they update the goals they update the strategies and tell me what we're going to do.

All parents in this study described therapists taking an active role in direct 1:1 intervention with their children. Direct intervention tasks primarily involved demonstration of therapeutic techniques, as described by Lori, “She said “all done bus...time for...” and laid down

his pictures. She grabbed two of his toys that were out, his blocks and his bubbles, and asked him to show her what he wanted.” While demonstrating strategies, therapists would describe why they were using specific techniques in relation to speech and language development: Lori said:

She was just saying the same words, over and over. She always says to just say the same single words and simple phrases again and again. Kids need to hear words hundreds and thousands of times before they will repeat them...so we just say the same things over and over.

Or the characteristics of the child, Danielle said:

So then Gabrielle sat and her therapist offered her choices of coins, “Do you want green or blue?” and then waits for her to request. And Gabrielle reached for “green” and the therapist, says “green”, say “ee”, green. She wants to do just one sound at a time because she thinks Gabrielle has...a mild apraxia. So she says just one sound at a time. Then Gabrielle put the green coin in and she says “green in.” Then she says, “Okay Mom, your turn”, and I sit down and offer “blue” or “yellow” and Gabrielle chose blue so I said “blue. Say b-lue”

An additional role of the therapist was to elicit and respond to input from parents. The importance of this role was emphasized by Maria when she said:

Today she sat down and she asked me, you know, about Miguel’s diagnosis. Miguel is diagnosed with Sotos Syndrome, and she is not very familiar with this diagnosis, but you can tell she is eager and enthusiastic to learn about it and how the speech and language of children with Sotos Syndrome develops differently from children who do not have this. Some therapists and doctors, some who are not specialists, will sit down and nod and pretend to know about a diagnosis or to pretend to know what you need, but Miss Linda, she sat down and listened and asked questions about what I could tell her. She asked

about my goals and what we need as a family. This is a step I can tell you many therapists and all professionals really skip.

(Other) Communication partner roles. Participants described the roles of other communication partners, outside the immediate parent-child-therapist relationship. These communication partners, including other caregivers and service providers as well as family acquaintances, fulfilled a variety of roles including professional guidance and collaboration, facilitating carryover, and providing access to “normal” experiences for the child with significant communication needs.

Kristin described the use of outside professionals in assessing the appropriateness of a speech-generating device for Lila: “...then a representative from [therapy agency] was the person to come out really to see if it would really work for her, you know, and within the first 30 minutes of the session, she was sold on it”. A coworker of Pam’s advised her to advocate for a speech therapist for Landon. She said:

Before this we had special instruction only, and I had to beg to get a speech pathologist in. The evaluation team felt that he had to learn to imitate and improve his attention before he could work directly on speech and language skills, but a speech pathologist I work with said I should push to get a licensed therapist on his team.

Due to busy family schedules, Pam reported expecting paid caregivers at Landon’s daycare to assist with carryover of strategies. She said:

Tomorrow Landon doesn’t have any therapy, but after I pick him up after work I will take him up to Aaron’s work and drop him off with him because I have to go to Allentown to ref. So him and Aaron will probably stop to eat on their way home. I’ll pack his bowl and utensils and his PECS in the diaper bag and everything, but it probably won’t get used tomorrow. I try not to feel bad about doing everything all the time...because there is just so much to do. Also quite frankly, we’re paying daycare so

they should do...I think they should do a lot of the strategies. We pay them a lot of money.

Pam also described the role of Landon's grandmother, who was occasionally present during therapy sessions, but also strove to provide opportunities for Landon to relax:

My mom is very permissive. When therapy happens at home when she's with him she tries to make him do work, but really once the therapists are gone, she just gives him bowls of snacks and lets him watch TV. She says we overschedule him so it's her job to balance us out.

Major Theme 4: Supports

EI therapeutic supports. Participants in this study discussed two major areas of supports within the early intervention system: (a) Use of strategies and materials that are easily integrated into daily routines, and (b) Strong therapeutic relationships

All participants discussed the importance of strategies and materials that are easily integrated into daily routines. Qualities of easily integrated strategies included materials that were already present in the natural environment and aided AAC systems that were easily integrated into the environment. An example of this is when Pam discussed using a visual schedule in Landon's daycare classroom, using routines that were already in place in the classroom:

....the concept of the visual schedule is really appealing to me, especially if his teachers can use them with all the kids in his classroom. That singles him out less. Aaron and I always say "we pay for him to be there" and want them to work with him and not leave his communication materials in the cubby...but I also understand that they have other kids to worry about throughout the day. So anything that can be used throughout the classroom easily is very good for all of us, most especially very good for Landon.

Easily integrated materials and strategies are readily available in the natural environment and include simple instructions, as discussed by Lori:

I think because we used Alex's toys it should be very easy. The best thing about especially speech with Shannon is that the directions, the strategies she gives us to use are not complicated. She says "offer choices", "offer pictures", "hold this next to your mouth". Those are very easy things to do under any circumstances.

As strategies are modified or advanced, they should include gradual, systematic changes.

Maria said:

Yes, and I am very happy with the progress, and I think what has gone well is that each session it is one small change. There are not totally new things, but small adjustments and additions to what we are doing. These make it easy to remember but also easy to see if there is progress. We are not stuck in the same technique constantly, but we take the time to let progress happen.

Parents often found that using handouts in addition to session notes was helpful for recalling strategies and/or target vocabulary and how to integrate them into daily routines. Kristin said:

And she actually gave me some information for assistiveware.com, so we can basically, which you're probably familiar with, they basically pick a core word of the week, and tell you different expressive ways to use it, getting and giving more information. So, it's basically a little summary of how to incorporate the core word, teaching it with specific grammar, ideas for using the word in activities, so it was a nice little 3 page thing she kind of brought in to really help me introduce appropriate, you know words or phrases for her right now.

Easily integrated strategies and materials were also characterized by structure, as described by Pam:

PECS is really the easiest part for me. I like how it's so structured. I like to know exactly what to do. I like having sessions at daycare when everyone can be there, so his teachers

can be involved, too. It's difficult when I have to be the middle person, explaining to the therapists what's going on at daycare and then explaining to his teachers what he's working on in therapy.

Overall, using easily integrated strategies and materials lent itself to repeated opportunities for practice, as discussed by Danielle:

I think that's the benefit of doing the same things from week to week is that I can get comfortable practicing, for example, I practiced this past week and now I have no trouble remembering to model just the vowels, sometimes you have to practice without the therapist right there, so that you can get accustomed to it, so this was helpful for me, this week. So actually I'm already comfortable with the strategies we used this session, so this upcoming week should be a piece of cake.

Participants found that positive therapeutic relationships between themselves and service providers as well as between and among the service providers themselves was supportive to an overall positive early intervention experience. Positive therapeutic relationships between families and service providers were characterized by parents feeling confident enough to ask questions and participate in all aspects of the EI process, as described by Kristin:

You know they say, you know, we don't, when I ask certain questions, they say, "we don't see a lot of parents like you, you're not the norm of just, you know we mention something in a session and you work on it all week and you come next week and the child is like, you know great at it. Like we don't see a lot of that. We see parents that either are into it but just maybe don't really get it, or we see some parents that see us as "okay I get a free hour now that you're here" And it's sad, and I think that we have to understand as parents that it can't just be all on them. The therapists are here to guide us and here to help the child, but you really have to pay attention and take part and be involved because it's 24/7 if you want improvement

It was important to parents to be included in the EI process and respected as experts as their children, as described by Maria:

You see, with Miss Linda, I am very comfortable. Because I am so comfortable with her, I feel allowed to contribute. I am allowed to contribute my knowledge of being mother of Miguel, and mother of a child with Sotos syndrome, to his therapy with Miss Linda. Also I am allowed to see and hear what they are doing in therapy and make my own adjustments. I feel comfortable doing this with Miss Linda. I can tell you I did not feel this way with Miss Mary and so it goes back to what I told you the very first day we talked so many weeks ago... There must be a good fit.

Positive therapeutic relationships included an ebb and flow to participation, with therapist's recognizing and respecting the preferred patterns of involvement on the part of the family member present for the session: Melanie said, "Just because I got to see her work with someone else and I got to pay attention to the other aspect that I probably wouldn't have before." Participants also looked to therapists for help navigating community supports. Melanie said, "Her physical therapist is really helping in terms of advice on daycare. I think I'm going to do what she said and just go in." Additionally, participants found it helpful when there were strong therapeutic relationships between and among treatment team members, evidenced by strong collaboration. Maria said: "Right now I am feeling like we have the right team in place and the best possible supports.

Familial supports. All the participants identified their families as strong supports to the therapeutic process. Spousal support came in the form of teamwork to support carryover as well as empathy for the needs of the spouse including when one needs a "break." Two primary forms of breaks were discussed by participants: breaks involving being physically and mentally/emotionally away from the demands of parenting, as discussed by Kristin "...go into the hall for an hour or two just to kind of take a break. He'll say, 'I'm meeting a friend for an

hour tonight'...we're pretty good with that with each other, kind of like understanding each other needs a break." Other breaks were those that still involved being present with the family and child with communication needs, but not actively engaged in using therapy techniques. Other familial supports mentioned specifically in the immediate family were family routines involving reflecting on communication strategies and effective communication between caregivers. These supports were discussed by Kristin in the following quote:

And it is, especially like we've talked about, my husband and I are very, this is what we do, I mean, obviously thankfully he has a job that I can stay home part time, and he's alright. But he deals with the reverse aspect of, he is the one working, and he's not at home all day with her, and then when he gets home, it's kind of just like I just want to enjoy her, I don't want to have to worry about doing kind of therapy and lessons with her. So, he battles with that, and then you get two people on edge, for different reasons, all pertaining to the child, which ultimately makes you feel guilty, but you just got to talk a lot about it.

Maria described taking turns with her husband in managing demands of therapy and childcare: "... it is important for parents to be a team in caring for children. Sometimes it is for him to do the therapy tasks and sometimes it is for him to entertain Shondra so I can do the therapy tasks with Miguel."

Extended family were also helpful, in terms of emotional support, household chores, and childcare. Maria identified her sister as "good to talk to." Pam stated that sometimes her mother assisted with laundry, and Danielle discussed her mother taking her other children to karate, stating: "It's a good chance for me to get some one on one time with Gabrielle."

Community supports. Participants in this study discussed a variety of supports to the therapeutic process that they found through the community. Some were related to early intervention providers, such as the program discussed by Lori:

It's just over at the library. [Therapy agency] runs it and that is who his PT is through but she is not the physical therapist that directs the program. It's basically like a Mommy and Me class with music and physical therapy exercises incorporated. They bring balance balls and mats and walking and jumping toys. But it's good exposure to other kids his age, close to his age.

Other community supports included preschools, outpatient service providers and complementary therapy providers. Kristin found a local preschool to be flexible and accommodating for assisting with transition planning. She said:

They were super flexible, and very nice and accommodating. So we just started, you know your hour session is going to be at the preschool, and just so that when this time rolled around, she wasn't losing all her therapists starting at a new location, with all new people. And I am so glad we did it because now she is comfortable with the preschool. I put her in the 2 and 3 year old room, so that when she turned 3, she wasn't going to lose the teacher there or the classroom. Like she keeps the kids and the teachers she's with right now all the way until she turns 4. So, for the next year she'll have the same little friends and really the only thing that is going to change in December is who accompanies her.

Kristin's outpatient therapist was the person to introduce her to AAC options:

I will say our outpatient speech helped kind of me understand it a bit more, just because we were seeing her twice a week at first, so we were seeing her a little more than early intervention. So, she was the one who was able to actually put a device in my hand just to practice, just because they have them at their center. So we were able to see that she picked up on it very quickly, and that's when I did a little bit more research and then tried to get it implemented through early intervention

Participants also sought out complementary therapies such as music therapy and horseback riding therapy. Pam said:

I haven't found anything...anything I've come across that we're not doing yet. I look online and I work for the intermediate unit so I ask around there. There's...music therapy at the Autism Society. You don't have to officially have the diagnosis yet to go, and there's openings for the toddlers/preschoolers group, so I think we'll start going to that too.

Kristin said:

I think we're going to look into the horseback therapy, the horseback riding therapy, so we're going to start that maybe in the spring. Like spring or fall of next year, we're going to kind of let her acclimate to all of this, just because I've gotten some good feedback about it, just with the whole socialization, well also the PT would help as well, just for the core strength and the muscle building. But just from kind of an emotional and that kind of connection, from what I've heard, it's crazy with that how the animals kind of feed off of that with you, and building those relationships.

Parents also discussed diagnosis-specific support groups, such as those for Autism Spectrum Disorder, as being helpful. Kristin was actively involved in "Talk About Curing Autism Now (TACA)", but also established her own community group, with the support of others, to fill in perceived gaps in supports. She said:

We're actually, like I said, we've started going to that coffee chat support group meetings on Thursday, which is nice but we've been involved with TACA. But actually, I host, and I don't know if I told you before, but I hosted this little like Autism round table discussion we called it. So, my church let us use some space that they have there and just for networking through people I know and therapists. I got in touch with one of the trainers from the intermediate unit from Chester County, which is the county my church

is in and where we used to live. But it's like 2 miles down the street. So, I had met with her a couple months back and we decided that we'd like to put something together and I actually asked her if she would speak at something I was trying to put together.

Pam was also beginning to get involved with the Autism Society of America. She said, "When Landon was first sent to start developmental testing at CHOP, and I started looking up Autism, I found the local Autism society. I went to my first meeting last week actually."

Less formal supports came in the forms of social networks from coworkers, church, and peer groups Pam said, "We know a lot of people through work and Aaron has a good relationship with Landon's pediatrician. The Autism Society is helpful, and Landon's therapists have been wonderful, and his daycare. Everyone loves Landon."

Kristin said, "A little bit, they've been very flexible up until having Lila, I was always a full-time worker, but I went down to three days a week just because with the amount of therapy she has, you know, it would be impossible, especially because she's not 3 yet. So everything is parent-based, you know, parent training, and child, so thankfully, they've been super flexible. And she still naps, so I basically go in when she's napping."

Maria said, "I will still use the Internet and his therapists to help guide us. Also, I did not think of this last week to tell you, but our church is very supportive. They help Miguel to practice his skills with other children, which I think is very important"

Participants also discussed community supports they desired, such as direct therapies for families and AAC-specific community resources. Danielle said, "I still am kind of hung up on the iPad idea. I wish there were like a place I could go just to try out a bunch of apps, just to see if it would work, like an [AAC] library." Maria said:

I have been thinking about when you ask if there are supports or resources I need, and I have been thinking "Wouldn't it be great if there were a community of parents...parents

who could share these pictures and ideas with each other?” I have checked on the Internet and haven’t found any yet.

Information supports. Parents expressed that they were continuously seeking more information and training supports. Pam said, “Nothing specific. We still just look for everything we can find, every article or activity or professional that might help.” Pam said, “I imagine when he gets a device...training.... Training actually on all the signs and the iPad and PECS. I think additional training for all of us is really important.” Melanie said, “It was a lot of the same, but I did ask her about books and she did give me a few websites for downloading books. “

Informational supports parents found helpful included handouts and websites. Maria said, “For the way therapy works best for us, with me outside the room, I find it very helpful. The section on the session note for practice ideas is very small, so these handouts are helpful because I will hang them on the refrigerator or put them in Milan’s therapy folder and then Max and I can both look at them and practice with him.”

Parents also described a desire for more literature and books or guides for extended family, doctors, and daycares and guides to early intervention. Danielle said, I guess if there were some kind of book for our families that was just like “Hey, this is what we’re working with right now. Help us or keep to yourself!” Pam said, “Someone should make a guide...an early intervention guide besides the one they give you that just says your responsibilities as a parent and attendance policies and stuff...there should really be a book with checklists that tell you what to do and who to contact next.”

Melanie said:

I have been thinking about this. I think it would be good if there was just, like, an instruction manual for people on working with kids with Down Syndrome, and it could explain how they communicate and how they eat, even if they’re not having trouble

eating anymore. There should be a guide for family and doctors and daycares. If people knew more they wouldn't be so discriminated against.

Kristin said:

So I think there just needs to be, I don't know, more literature on that or maybe you know, when the family gets into early intervention depending on the diagnosis, maybe even something where the county, even just offer 2 sessions with someone to see if maybe therapy is for you. And if it is, great; here's a center. If it's not, alright; you at least got some foundation of work as to what to expect emotionally and physically. Because it's a lot of work. It's a ton of work, and I think some parents get, maybe don't understand that or are overwhelmed by it, so maybe that deters them for being as involved as they could. I don't know what it is, I just talked a lot with our therapist, like I said we have a great team, so we're very open in communication.

Major Theme 5: Challenges

Participants in this study discussed challenges related to communication, mental load, familial challenges, and community challenges.

Communication challenges. Parents discussed communication challenges including those related to the receptive and expressive language needs of the child. Kristin said, "You worry that you're not getting every need met, or, you know, she gets upset being able to tell you what. So, it's super stressful to be quite honest, but that's why we've started with the pictures from like 18 months." Melanie echoed this, saying, "It's hard when she can't tell me what she needs, but most of the time I can figure it out." Danielle considered whether or not having multiple modes of communicate might actually be overwhelming for Gabrielle, stating: "I guess I can see that it would be overwhelming for Gabrielle to have all these ways of communicating at the same time, but I have trouble keeping track of is this a signing activity or a talking activity or a communication board activity especially when we use the communication boards to choose a lot

of activities but then don't use them during the activity..." Danielle also expressed that Gabrielle's communication challenges were impacting her childcare situation: "Her babysitter would find it much easier to care for her if she could express herself." Additional communication concerns arose around the integration of communication aids into daily routines, as described by Pam:

The big thing is with the PECS – having all his vocabulary there is so good and so important, but getting everyone to use the PECS is a challenge. Sometimes I go into his classroom and I think the PECS book has just been sitting in his cubby most of the day. Other times, especially at meals, they seem to use it. I worry about the same thing happening with the iPad. It's an expensive thing to be left sitting.

Parents also found it difficult to navigate communication mode options including applications for iPad-based speech-generating devices without the support of a therapist. Danielle expressed, "Yeah, and my husband's like 'Why don't you just download a free trial?' Well, the majority of them even the lite versions cost something, and I have no idea which one I would pick."

Mental load. Participants discussed the constant presence of their child's therapeutic and communication needs, which could be overwhelming at times. While the specific concerns varied from participant to participant, their intensity was apparent. Kristin described concerns about meeting Lila's needs: "I would still say it's the biggest struggle just because you don't want to ever feel you don't know what they need or what they want or what's happening. So that's still probably the biggest concern and you know, struggle..." Melanie's worries about all her children was fatiguing at times; she stated:

It's tiring...on a day to day...it's tiring because of all the guessing and trying to keep up with her needs and the other kids' needs. My other son is moving back in, but he doesn't

help, because he has his own problems to sort out and they're only half siblings 17 years apart, so why should he? Then Jay has his issues...and some days Nahlia's the easy one.

Danielle described the difficulty of organizing and integrating all that she learned from therapy saying:

I'm just going to have to figure out how to organize the approaches we are using...in my head... the problem is, there's an awful lot to keep in my head, like when therapies are and what strategies I'm using with who. I have all the notes from Gabrielle's therapy sessions in a neat little binder but really what should I do, reread every note before every moment I could possibly incorporate a therapy technique into?

Melanie expressed fear for her child with communication needs and emotional conflicts about meeting the needs of all her children. She said:

I'm scared. Even if I find a place that will take her Down Syndrome, how will I make sure she's safe and taken care of if she can't communicate? She'll get thrown out if she's still pulling hair and yelling. It's...I'm really in a no-win situation here. Nahlia needs me with her to help her communicate, but I need the job to do better by my kids. I don't get support or anything...from their dads...

Familial challenges. Participants discussed familial challenges including socioeconomic challenges, adjusting to having a child with complex needs, navigating the needs of multiple children, and family members such as siblings interfering in the therapy process. Melanie described financial challenges and their influence on the stability in Nahlia's life, saying "I gotta make more money and maybe get some help with housing or we're going to have to move again. It's hard to encourage Nahlia to be consistent when there's not a lot of consistency in our life." Maria alluded to the demands experienced by families and the emotional journey that occurs when a child has significant communication needs. She said

Everything I do...is for Miguel....for my children and my family. We are desperate for him to be able to communicate with us. We think... he is our gift from God. When you first have a child that you find out will be different from what you expected, you are not sure that you are up for it. But we know that having the right therapists and the right tools will let us bring him more into the world with us and have him make more progress. All our time and energy is to help him.

The need to dedicate herself to the complex needs of more than one family member was a challenge Danielle described:

I think you could say we just have some good days and some bad days. It can be overwhelming because it's not just the communication skills and needs. Everything she needs interacts with everything my son needs and everything my stepson needs...and then, you know, sometimes my husband and I have needs, or sometimes the cat or the dog needs something, or sometimes our extended family needs help with something and honest to God, I dread when anyone outside our house needs help with anything because I always have to say no, and I'm pretty sure everyone thinks I'm super selfish.

Even within sessions, other family members posed challenges. Specifically, Melanie described Nahlia's slightly older sibling and her impact on therapy sessions, "... so that part was rough. Natalie was crying because she wanted Nahlia's waffles, and Nahlia was crying because Natalie grabbed her waffles." The general consensus among participants seemed to be that, while they recognized many of the familial challenges they faced were common, they felt them to a larger extent due to their child's communication and related needs. Danielle stated, "It's just extra to do. I bet every parent worries about her kids, but I bet I worry more." Further, Danielle felt a lack of understanding from some family members: "They're, of course, like my Mom too, 'let your kids be kids' and 'Stop spoiling and giving in and she will talk.' They don't understand that's not how it works."

Community challenges. The primary community challenges discussed by participants were related to accessible services for children with complex needs, such as the childcare issues experienced by Melanie and Nahlia: “I’m not sure we’re going to be able to do it. I’ve called everywhere I can find. Her teacher, Miss Rhonda, even went on the department of welfare website to look up all the daycares that take kids her age. There aren’t any medical daycares in this county.” Melanie also had concerns about access to English-speaking childcare providers in her area: “There was one but the staff all speak Spanish and not to be racist but she as trouble enough with talking and I need to be able to understand the staff there too.”

Service/information challenges. Participants identified a variety of service and information challenges. Kristin expressed a desire for more therapies directly to support parents, stating:

But, really I think the big thing that’s missing, and I’ve talked to school parents, and to therapists and different resources, but there’s no real like kind of counseling or therapy out there for parents that are dealing with kids with a disability. So you know, even when she was diagnosed, we had a social worker assigned to us, and that’s the only question I asked her was, “is there someone in the area that specifically deals with parents that are navigating their life now with a special needs child?” That was in February, and I’ve yet to hear. So, I think that would be helpful.

Parents had concerns about scheduling including schedule frequency. Danielle said, “I do sometimes wish there were extra services to get, but early intervention only lets you do one time per week for any service.” Pam also expressed difficulty with schedule changes. She said:

Today was a little more difficult. Our schedule this week ended up not looking anything like I originally had on my calendar (laughs) – it’s a good thing I use pencil! Landon was sick and his occupational therapist was sick and his speech therapist had some sort of

scheduling conflict...So today his speech therapist and his occupational therapist ended up rescheduling actually to the same time, so it was a co-treating situation.

Parents also had concerns with actual service provision, including the apparent inconsistency between the recommendations and practices of her therapist identified by Danielle:

I guess the idea is that we want to keep things simple and not confuse Gabrielle, so it's either signing or speaking or the communication board for any activity...or part of the activity. But I'm starting to get confused because her therapist will sign and talk at the same time, but I'm not supposed to.

Chapter 4

Discussion

The purpose of the current study was to investigate the perspectives and experiences of parents of children who use multiple modes of communication in Part C early intervention services. Understanding the experiences and perspectives of parents, and their roles in AAC service provision and impact of AAC on their lives is necessary to ensure success of AAC intervention with infants and toddlers (Ronski et al., 2015). Understanding how parents describe their understanding of their interactions in early intervention, the roles they attribute to themselves and communication partners, their children's communication skills and modes, as well as other factors related to the family unit will allow professionals to provide more responsive, family-centered practices and guide future research and pre- and in-service training related to family-centered practice.

Because phenomenology aims to understand the essence "lived experience", the data from this study are analyzed collectively, looking at themes present across interviews. Through repeated semi-structured interviews correlating with the timing of early intervention speech and language intervention sessions, participants provided rich descriptions of their experiences including descriptions of the child with communication needs, the session environment, communication partners, supports, and challenges experienced throughout the early intervention process by families in a restricted geographic region. Using the limited geographic region as the "site" under study allows for the development of appropriate trainings and interventions for that specific area. Consistent with earlier literature (e.g., Light & Drager, 2007), participants in this study identified factors intrinsic to their children such as temperament and preferences as well as

factors extrinsic to their children including microsystem, mesosystem, exosystem, macrosystem, and chronosystem variables that significantly impacted their perspectives and experiences in Part C early intervention. Family subsystems provided both extensive supports such as childcare and providing a partnership in parenting and therapeutic tasks; as well as some barriers including a lack of understanding of the child's development and therapeutic needs and siblings interfering in therapy sessions. Microsystem variables that impacted the therapeutic experience included collaboration between and among service and childcare providers. Exosystemic supports included family support groups. Macrosystem variables discussed pertained primarily to the availability of services including early intervention and outpatient services. Chronosystem variables included the transition from Part C to Part B early intervention, changes in family dynamics, and the mental load and scheduling needs throughout daily and weekly activities.

Conclusions

Specific aims of this study included identifying the routines, strategies, and communication modes used in early intervention, understanding how parents perceived their roles in early intervention for multimodal communication, and exploring the consistency of their reported experiences with best practice guidelines and legal mandates for family-centered practice.

Routines, strategies, and communication modes. Families of toddlers of with significant communication needs in Part C early intervention are in the process of exploring and/or acquiring communication modes. These communication modes included signs and gestures, speech and approximations, light-tech communication systems including PECS and communication boards, and high-tech communication aids. The inclusion of participants using tablet-based communication systems is a significant contribution of this study, as previous research with infants and toddlers has not used high-tech communication devices in early intervention (Ronski et al., 2015). The data suggest that parents may be a driving force in the

use of speech-generating devices with infants and toddlers. Kristin described requesting and organizing the assessment and training for obtaining an SGD for Lila. Danielle and Maria both expressed interests in tablet-based systems and were approaching and were actively discussing or advocating for them with their family's SLP. Pam and Landon's SLP had initiated a SGD loan and was using her own personal tablet with Landon. Pam believed that the time required to complete the loan and submit a report to the insurance company and obtain a tablet would exceed the remaining time Landon was eligible for Part C early intervention services, suggesting that Pam and Miss Anna (SLP) may need to collaborate to ensure a seamless transition from Part C to Part B early intervention services. Strategies to enhance communication skills included embedding naturalistic language stimulation strategies throughout daily routines, oral-motor strategies and articulatory practice to enhance speech production, and aided modeling strategies using communication aids. Activities and routines were chosen collaboratively between and SLP and families and included play routines, shared book reading, and snack routines.

Roles in early intervention. Families described a variety of roles in early intervention, including parental roles within and outside the session; therapist roles within and outside the session; and roles of other communication partners. Family participation in sessions varied within and across settings according to family preference, SLP preference, and characteristics of the children in the home. Parental roles outside the session were significant. SLPs should support families in identifying and implementing the level of participation they desire in each session. This may be planned in advance through explicit discussion of routines and strategies, and predetermined criteria for the transition from SLP as the direct interventionist to the parent as the direct interventionist, but should be flexible to allow the parents to engage in other necessary roles during session times as needed, including taking non-participatory roles as appropriate. Because much of "family participation" actually takes place outside the session, the SLP's conceptualization of "natural environments" should not be limited only to physical location, but

should also include routines, materials, and people that are prioritized by the family. Mandak et al. (2017) identified the Social Networks Inventory (Blackston & Hunt-Berg, 2003), FACETS (Woods-Cripe & Lindeman, 2001) as well as the Family Impact of Assistive Technology Scale (FIATS-AAC) (Ryan & Renzoni, 2010) as tools for guiding conversations with families for identifying predictable and meaningful family routines for AAC intervention, relevant communication partners, and the priorities and participation valued by families.

Practice guidelines and legal mandates for family-centered practice. Overall, the perspectives and experiences reported by mothers in this study were consistent with legal mandates for including families in decision-making and that services should occur in natural environments. Parents described many elements that were consistent with Dunst's (2002) descriptors of family-centered practices and beliefs including services that: (1) treat the families with respect and dignity; (2) are individual, flexible, and responsive to family situations; (3) include sharing sufficient information for parents to make informed decisions; (4) provide family choice regarding any number of practices and intervention options; (5) focus on parent-professional collaboration as contexts for intervention; and (6) provide and mobilize appropriate family resources. Parents in this study described a variety of routines, strategies, and communication modes that were specific to their individual family's needs. They described supportive relationships with professionals and viewed themselves as collaborators. They described the SLPs they worked with as supports and important sources of information. There was evidence of efforts to be culturally and linguistically responsive and including families in decision making, such as Miss Anna asking Maria's preferences regarding choice of Spanish and/or English words on Miguel's choice boards. Participants discussed team meetings, evidencing collaboration between and among members with service coordinators present. Further, parents described an understanding of how the services supported their children's development and participation at home and daycare. However, not all services were consistent with current

research and recommendations and those same services were very often not fully consistent with principles of family-centered practice. While participants discussed collaborating with professionals in decision-making, they continued to view the SLPs as the ultimate decision-makers regarding activity and communication mode choices.

Clinical Implications

Families of toddlers with significant communication needs participating in Part C early intervention are in the process of exploring and/or acquiring communication modes. They take on significant roles within and outside the sessions. The mothers in this study viewed the early intervention team, community-based therapists, the Internet, and their extended social network as resources and supports for this process. At times, they expressed a lack of agreement with the SLPs pertaining to the desired communication modes. Additionally, some SLPs were reportedly providing misinformation to the parents. For example, Lori and Danielle both described situations in which the SLP working with their family advised them that prerequisite skills such as improved attention or imitation must be worked on prior to introducing alternative communication modes. Danielle and Maria described instances of being advised to use only one communication mode. This apparent pattern is notable given that it marks an interesting variation from previous research (e.g., McCord & Soto, 2004) in which SLPs have identified negative perceptions of parents pertaining to aided and/or high-tech AAC options as a barrier to effective service delivery and family-centered practice. Several possibilities for this variation exist. First, due to small sample sizes within such a heterogeneous population, the parents in this study may simply happen to have different perspectives on aided/high-tech AAC interventions. Second, it may be that the SLPs in prior studies misinterpreted the preferences of the families they were serving. Third, parents may be more receptive to augmentative and alternative means of communication while children are young. If this is the case, the SLPs in this study who were not responsive to the parents' preferences may, in fact, be inadvertently negatively impacting the

perceived acceptability and likelihood of parents to embrace these options at later stages of the child's development. Fourth, because many of the previous investigations into parent perspectives are from the late 1990s and early 2000s (e.g., McCord & Soto, 2004), it is possible that with the increase in mobile technology and awareness of AAC, over a decade later parents are beginning to experience more positive feelings related to aided/high-tech communication modes. Finally, it is also possible that parents misinterpreted what they were told by the SLPs.

Improving communication patterns between SLPs and parents would support improved family-centered practices related to high-tech device usage. Dunst and colleagues have identified that while endeavoring to provide family-centered services, therapy professionals are more skilled in relational components than participatory components (Dunst, 2002). In navigating the roles and goals of family-centered service provision, it is also essential that SLPs are providing the families with the most recent, up-to-date evidenced-based information so that families can make the most educated decisions possible (ASHA, 2002). Areas in which SLPs practicing in early intervention in this study might need support include candidacy for AAC intervention as well as implementing intervention using multiple modes of communication. A positive area is that the SLPs seemed to be using some evidence-based direct intervention strategies such as providing models on aided AAC systems as described by Kristin, Danielle, and Melanie. O'Neill and colleagues (2018) completed a meta-analysis on aided AAC input and found that interventions that included aided AAC models were highly effective across a variety of ages, skill levels, and disabilities. However, it should be noted that only 6 of the 88 participants included in the studies were toddlers, and participants with a receptive language age of less than 24 months had lower effect sizes than those with more advanced language development. Additional research is needed in this area.

SLPs should provide full, accurate information to families regarding child development, communication modes, communication strategies, and integrating modes and enhancing

communication throughout daily routines. SLPs should further be a connection for the family to other needed resources. One simple way to do this that seemed to be preferred by the mothers in this study is to provide written handouts to the families to support both their participation in decision-making as well as their ability to access and review information when the SLP is not present. Mandak et al. (2017) recommend tools including the Social Networks Inventory (Blackstone & Hunt-Berg, 2003) and the Family-Guided Approaches to Collaborative Early Intervention Training and Services (FACETS) to help guide professionals in collaborating with families to support their decision-making regarding how to utilize communication modes most effectively with different communication partners and in different settings.

Families who participated in this study described newly entering a variety of service systems including Part C early intervention as well as transition planning for Part B early intervention, outpatient rehabilitation and community-based therapeutic services, as well as complementary services and supports in the community. Additionally, each parent had different childcare needs and experiences, and even experienced parents with older children found that the significant communication needs of the toddler for whom services were being received posed unique challenges. SLPs should enhance their relational and participatory practices in a manner that promotes effective teaming with all service systems involved and connects parents to additional services. Again, written resources may be beneficial in supporting families in this regard. SLPs should be able to support families in navigating these systems accurately. For example, an SLP knowledgeable in multiple service systems should be able to support Lori in obtaining both outpatient services based on a medical model and Part C early intervention services. Mandak et al. (2017) identified the Family Resource Support Guide (Sexton & Rush, 2012) as a tool for identifying and responding to the needs of the family and identifying appropriate supports.

Limitations

While the data gleaned from this study provide valuable insights pertaining to the experiences and perspectives of parents participating in Part C Early Intervention services in a defined geographic region, several limitations should be acknowledged. First, generalizability of this study's results is limited due to several related factors including (a) small sample size, (b) limited geographic region, and (c) limited demographic variability. The intent in phenomenological research is not to choose a representative sample, but to describe in detail the experiences of a few individuals. Second, although it incorporated multiple semi-structured interviews, this study took place over a short period of time. Third, this study directly investigated only one family subsystem within the theoretical model for family-centered practice (Mandak et al., 2017). Fourth, this study was focused solely on the experiences of interest with parents. While recommendations for clinical practice, future research, and training are made in response to those experiences, it is important to acknowledge that that parent perceptions and the perceptions of SLPs may be different. Fifth, despite efforts to remove investigator bias, all qualitative research must acknowledge that it is possible that the way certain questions are asked or the interpretation of the researchers is subject to bias.

Future Research Directions

Future research into AAC use in Part C (0-3) EI services should be multifaceted. First, it is important to investigate the perspectives of additional stakeholders including speech-language pathologists. The focus on this study was on the perspectives and experiences of parents. However, it is possible that the events described from the parents' perspective would differ from the SLP's perspectives. It is also possible that neither perspective fully represent the actual occurrence. Phenomenological research ignores the objective world and focuses on the subjective experience of participants (Creswell & Poth, 2018). What participants report has occurred is equally important, in this paradigm, to actual occurrences. In addition to interviews, future

research should include triangulation of data from multiple sources including observations of sessions, such as through videos, and artifact analysis of session notes. Sampling procedures focusing on critically different cases may also be beneficial. For example, in this study, Melanie's low socioeconomic status (SES) brought additional layers of complexity to her experiences. Melanie's household income of less than \$20,000 for a family of 5 is well below the federal poverty guidelines of \$29,420 (dhs.pa.gov, 2018). She described living in a neighborhood in which she believed it was both unsafe to allow her children to play outside and unsafe to drink the water due to concerns about lead in the pipes. Despite receiving assistance from WIC (Women, Infants, and Children) food and nutrition service, during her third interview, Melanie described possible evidence of food insecurity, as there was not enough food to offer any choices during as snack time routine, and there was no drinking water, milk, or juice in the house. During the fourth session, the therapist brought choices of snacks for both Nahlia and a sibling, which Melanie described as being a support. While Nahlia received social security income (SSI), during the third interview, Melanie stated "her SSI is for her and we can't all be living on it." Melanie further described her eldest son as being transient, at times living with her and the youngest three siblings, and other times not. He moved out of the house and back in during the course of the study, but was looking for an apartment. The younger son, age 12, received mental health services and at the time of the second interview was in a partial hospitalization program. By the fourth interview he was also living in the home and was receiving outpatient mental health services, for which Melanie had concerns about obtaining transportation. During all interviews, Melanie described the ongoing struggle of finding a daycare that would accept Nahlia due to her complex medical history, which was restricting her from going back to work to improve her family's financial situation. Understanding complicated family experiences such as this are important for family-centered practice, especially the SLP's ability to identify and provide access

to appropriate resources to meet the family's needs. For example, the SLP or service coordinator in this situation might want to provide a list of local food pantries.

Next, it is critically important that we use pre- and in-service training to reduce the spread of misinformation and increase the availability of highly efficacious AAC intervention. One tool for doing this that could be far-reaching is online training. Douglas and colleagues (Douglas, Kammes & Nordquist, 2018; Douglas, Nordquist, Kames, & Gerde, 2017) have demonstrated that online training can be an effective tool for teaching parents to increase the communication opportunities they offer to their children with complex communication needs, resulting in improved communication outcomes for their children. In an unpublished (to date) doctoral dissertation, Mandak utilized online training to teach family-centered relational skills to 15 pre-service SLPs. This online training involved teaching the LAFF strategy (McNaughton et al., 2008; Thistle & McNaughton, 2015; Vosta et al., 2015), a comprehensive relational skills strategy that includes the following steps: (a) Listen, empathize, and communicate respect; (b) Ask questions, and ask permission to take notes; (c) Focus on the issues; and (d) Find a first step. This training was designed with special attention to evidence-based instructional strategies for effective e-learning and included a self-paced learning environment using video scenarios as teaching tools with pauses for opportunities for practice. Participants took an average of 61 minutes to complete the training. Following the training, they were evaluated on their use of LAFF skills during simulated interactions with parents. During these interactions, participants demonstrated improved relational skills based on a LAFF checklist, and were perceived by two parents as demonstrating increased family-centered skills. Because parents take such an active role in seeking out additional information, it may be beneficial to gear online trainings toward both professionals and parents. We must systematically investigate the use of available tools and training programs and actively develop new ones to improve family-centered service provision. To identify targets for extending previous research into parent perspectives and priorities, needs

assessments can be conducted. To implement family-centered research, we should develop and scientifically evaluate the materials and supports families are requesting. Finally, all these approaches should be tracked over time using quantitative, qualitative, and mixed methods.

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Appendix A

Semi-Structured Interview Guide

Thank you for meeting with me! I appreciate your time and this information will be very useful to clinicians and researchers providing and improving early intervention services for children and families using different modes of communication. I expect this will take 30-60 minutes. Is now still a good time? Remember, you can decline to answer any questions that make you feel uncomfortable.

To start, let's talk about your session (today/yesterday/day of the week).

1. Tell me about how it went.
 - a. Who was present?
 - b. Where did it take place?
 - c. What activities and routines did you/the therapist use?
 - d. Who chose the activities and routines?
 - e. What strategies did you learn or practice?
2. What do you think went well?
3. What do you think could have gone better? Is there anything you would do differently?
4. What's the plan for the next session?
 - a. Whose idea was that?
 - b. How comfortable are you with that?
5. How do you feel about your child's progress?

a. Is there anything else you would like to try?

- Where did you learn about that?

Next, let's talk about what else is happening in your family and life.

6. How easy do you think what you learned today will be to implement throughout the week?

7. Tell me about your schedule this week. What other family or work things do you have going on?

8. How are (your child's) communication skills and needs affecting you or your family right now?

a. Are there any supports or resources that are helping?

b. Are there any supports or resources you still need?

Appendix B

Major Theme Operational Definitions

Major Theme 1: Child: Statements related to characteristics of the child including diagnosis, behavior, preferences, needs, and progress

Major Theme 2: Environment: Statements related to the current or future physical context of the session including session location, routines, materials, and presence or absence of (access to) people and communication aids.

Major Theme 2: Communication Partners: Statements related to the role or participation of the caregiver, therapist, or other communication partner; action or inaction/decision-making in participating with the child

Major Theme 3: Supports: Statements related to the people, services, or materials that are helpful to the family unit

Major Theme 4: Challenges: Statements related to difficult circumstances or lack of resources that would benefit the family unit

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Publications

- Tobin, M., Drager, K., & Richardson, L. (2014). A systematic review of social participation for adults with autism spectrum disorders: Support, social functioning, and quality of life. *Research in Autism Spectrum Disorders, 8*, 214-229.
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Presentations

- Richardson, L. & Drager, K. (2018, March). *Perspectives and Experiences of Caregivers of Children with Communication Needs in Early Intervention in the United States*. Invited paper presented at the annual conference of the International Society for Augmentative and Alternative Communication, Denmark Chapter, Billund, Denmark.
- Richardson, L., & Drager, K. (2013, April). Using Aided Modeling to Improve Social Interaction in An Adult with Autism Spectrum Disorder: A Pilot Study. Poster session at PSHA in Harrisburg, PA.
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