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Defining Support: Families of Children with Special Needs and the Role of the Speech-Language Pathologist

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Abstract: Speech and language disorders are the most common reason for early intervention services in children under the age of five because these impairments can occur in isolation or with other disabilities. Early intervention seeks to lessen or even eliminate the need for therapy later in the child's life by providing therapy for the child and education for the parents on how to foster their child's language development. Parents of children with special needs often have more complex needs than families with typical children. This qualitative study seeks to determine what emotional supports families with children who have special needs require, and to examine how well speech-language pathologists are able to meet the needs of these families. The relationship between the speech-language pathologist and parents has been compared to a dance, with each partner bringing their own talents and grace to the floor (Brotherson et al., 2010). It is anticipated that speech-language pathologists are well equipped to provide information and resources to families, but may not be as comfortable providing emotional support. The results of this study could serve as a training tool for speech-language pathologists in meeting the needs of the families they serve.

Keywords: *families, special needs, support, speech-language pathologists*

I often feel that being a non-traditional student is of great benefit to me. While time seems to be in short supply, with transporting children to their sports, therapies, and helping them with their homework all while trying to complete my own, I feel that in return I have gained a perspective that few will ever know. I have the perspective of being a speech-language pathology student as well as a parent whose three children have received speech-language services in the past. As a family, we have had the pleasure of working with some truly gifted speech-language pathologists, both in the schools and in early intervention services.

Even though all three of my children have received speech-language therapy, it was my experience with my second-born son that has most affected me. My son was born blue and lifeless after a long and difficult delivery eight years ago. His umbilical cord had been wrapped around his neck three times, and after the doctors worked to revive him for what seemed like an eternity, his weak cry finally was heard. Not surprisingly, my son did not escape his birth circumstances entirely unscathed. It became evident around 9 months of age that he was developmentally delayed and we

turned to our pediatrician for advice on where to turn for help. Frequent fluid in his ears affected his speech and hearing and his overall muscle tone was weak. We started receiving early intervention services in our home until he turned 3; then we were fortunate enough to be placed at a developmental preschool that focuses on meeting the therapeutic and educational needs of students with special needs, but in an inclusive environment with typically developing peers.

As a part time teaching assistant in one of the classrooms at the developmental preschool that my son attended, I had the pleasure of meeting some truly phenomenal families. I can juggle my home life and my school life, but never come anywhere close to understanding the strain that some of these families live under. Not only were the women each dealing with the roles of mother and wife, but also the added role of advocate for their special needs children. Insurance never seemed to cover enough and there never seemed to be enough time to take care of themselves after caring for their families.

Families of children with special needs have their own distinct set of obstacles that differ greatly from the "typical" family. It was seeing

this dynamic in person that inspired me to return to school and become a speech-language pathologist, with the additional perspective of being a parent. Families of children with special needs tend to stick together. While my son's needs were minor compared to most, I was welcomed into their community with open arms and 5 years later, they are among my loudest cheerleaders. We have a lot in common as we have all received early intervention services. It has made a difference in all of our lives.

Early Intervention Background

Early childhood intervention involves the process from the identification of the speech language disorder through the intervention. The early childhood period is considered to be the period between the ages of birth and age 8, but in regards to early childhood intervention, children receiving intervention are between the ages of birth to 5 years of age. The National Early Childhood Technical Assistance Center estimates that in 2011, over 342, 000 children under the age of 3 received early intervention services (*Annual Appropriations and Number*, n.d.). Likewise, in 2004 approximately 260,700 children from 3 to 5 years of age received treatment for speech and language impairment under the Individuals with Disabilities Education Act (IDEA) part B (Hooper & Umansky, 2009). While some of these children had disabilities such as cleft lip and palate that require additional medical supports, others were considered delayed in speech and language development and were expected to "catch up" to their peers with additional therapy support.

Part C of IDEA primarily focuses on the familial unit, providing services in the child's natural environment, encouraging familial input in the planning process, and including the family in the individualized family service plan (IFSP). Because part C revolves around the family, it is important that the family is included and supported as much as possible throughout the assessment, diagnosis, treatment, and eventual transition to IDEA part B services. For parents and caregivers dealing with the IFSP process on top of the news that their child is developmentally

delayed can be emotionally and financially draining. These families may find that additional support systems are needed to help the family unit thrive (Brandes, Ormsbee, & Haring, 2007).

Just like any other relationship, the relationship of the parent and the speech-language pathologist is complex and multifaceted. Although professional in nature, there is still a very personal element to the speech-language pathologist who provides therapy in the child's home. The therapist becomes part of the child's routine, is familiar with siblings and other family members, and spends a significant amount of time with the family.

What makes the parent-therapist relationship successful? Brotherson and colleagues (2010) compare the parent-therapist relationship to a dance, where each partner brings his/her own talent and skill to the dance, and the success of the dance depends on the effort that each partner makes. In the most successful of relationships, the therapist and the parent shared a sense of urgency to help the child and a sense of hope for the future of the child. Both the parent and the therapist had their emotional needs met by the relationship, and the therapist believed in early intervention and sincerely wanted to help the family (Brotherson et al., 2010). Parents have stated that their therapists felt like family, such as reported by Minke and Scott (1995). When family and staff were questioned about their relationships and what made them successful, both the staff and family said that they had bonded. The parents felt that they had been supported unconditionally during therapy. Parents also felt that their emotional needs had been met and that they were encouraged to participate, which increased their confidence.

RESEARCH QUESTION

Early intervention services are intended to provide additional support to children with disabilities or are at risk for developmental delays. My family's communication needs were met through early intervention services, but my friends who have children with extensive needs have not always been so fortunate. When dealing with

families with young children who require speech-language pathology services, there are three basic questions that need to be addressed:

- What supports do parents of children with special needs require?
- How are speech-language pathologists meeting the needs of the families they serve?
- Is there a gap between the supports needed by families and the supports given by speech-language pathologists?

I hypothesize that parents need emotional support from speech-language pathologists that extend beyond what is typically provided. Some speech-language pathologists primarily focus on the developmental and educational speech and language needs of the child. But, it is equally important for the family to feel adequately supported. In addition, it is also important for the speech-language pathologist to be satisfied in their work and for families to know that their therapist is invested in the future of the child.

Research on early intervention services is abundant; multiple sources dating back to the 1990s could be found during my search, but more recent research was harder to find. Prior research has been devoted to either the perspective of the parent of special needs children, or from the experiences of the speech-language pathologist, but little research has been done regarding the perspectives of both speech-language pathologists and parents. Additional research on this topic of supports needed by families of children receiving early intervention services could assist in training speech-language pathologists about how to more effectively meet the needs of the families that they serve.

LITERATURE REVIEW

Whenever a child is born into a family, the dynamic changes. Often a new addition to a family is a drastic change under the best of circumstances, however, for parents who have a child born with a disability, the family not only has to deal with the changes that a new baby

brings, but also has the challenging task of caring for a child with a physical disability.

Children with disabilities receive services under IDEA. IDEA part C is specific to infants and toddlers with disabilities who may receive therapy services for a number of reasons, including speech-language disorders, physical, mental, and/or social/emotional disabilities that have a high risk of causing a developmental delay later; while Part B is specific to children who are 3-5 years old (Witsken, 2008). Hooper and Umanksy (2004) report that speech and language disorders are the most prevalent impairment in children between the ages of 3-5 years as speech and language impairments usually occur with other disabilities. Speech and language disorders are treated most commonly by a speech-language pathologist (SLP).

According to Mahoney, O'Sullivan, and Dennebaum (1990), when 527 mothers were questioned about their child's early intervention services, the mothers reported that access to resources was more important to their family than familial/personal support. Despite this information, approximately 20% of the mothers stated that their familial support was extremely low, and the emotional support needs of the family were not being met. The authors express that parents may feel that emotional support was outside the scope of early intervention services, therefore they do not expect that their needs be supported by the early intervention service provider. Reichman, Corman, and Noonan (2008) also speak of the need for more assistance in their editorial. Abundant support is available to parents of children with special needs, but many parents are unaware of how to access this support. Sibling support groups, parent support groups, and respite care are often offered by communities to assist families dealing with the difficulties of raising a special needs child. The authors also mention that the United Kingdom has recently implemented a national organization that integrates services and support for families of children with disabilities. A program like this can lessen the isolation and fear that parents with children with special needs

struggle with, and leave more time and energy to focus on the family unit.

A child who is under the age of 3 who receives therapy for an identified delay or disability receives early intervention services. These services are meant to lessen the need for therapy later in the child's life, or even eliminate the need for services later on (Blackman, 2002). Children can receive services from special educators, occupational therapists, speech-language pathologists, or physical therapists in the child's natural environment. The child's natural environment is where a child spends time during the typical day (e.g., home, day care). Because child care varies from family to family, this therapy could take place in a child care center or in the child's home. After the age of 3, the child typically receives services in a preschool environment (Mahoney, O'Sullivan, & Dennebaum, 1990).

At the heart of early intervention is the Individualized Family Service Plan (IFSP). This document is the prescribed course of treatment for the child with a disability and his or her family and focuses not only on treatment of the child, but also the goals of the family and the transition of the child into the public school system. The IFSP puts the focus of treatment on the family unit, while the Individualized Education Plan (IEP) is child focused. The family still has input into the design of the IEP and goal selection, but the implementation of the IEP falls on the educators. The movement to family-centered care was intended to increase positive outcomes for children with disabilities by fostering improved interactions between caregivers and children, and by providing assistance for families who are in the difficult situation of raising a child with a disability (Mahoney & Bella, 1998).

Including Parents

The family-centered therapy movement was ushered in by the passing of P.L. 99-457, a public law that ensured that infants and toddlers with disabilities receive early intervention services. Now titled IDEA Part C, the goal of family-centered early intervention is to ensure that

parents and educators are effective collaborators. The centralization of the family in the IFSP shows respect to families and their individual needs and values, and recognizes that the family is the most important aspect in a child's life (Rounds, 1991).

It is the presence and influence of family in the child's life that shapes the child, thus parents know their child best. When parents express concerns about their child's development, their needs should be taken seriously. Chung, Liu, Chang, Chen, Tang, and Wong (2010) revealed a strong correlation between the degree of parental concern and the incidence of developmental delay in 273 children in Taiwan. Language and motor concerns were the most reported cause for concern, and only 22 of the parents were unconcerned about their children's development when referred to the clinic where the study was conducted. The correlation between concern and diagnosed developmental delay shows that parental concern is a strong factor that should be considered when assessing children for early intervention and implementing therapy into the child's routine.

Parents As Therapists

Considering the amount of time that parents spend with their children and the different contexts of the daily life of the parent and child, parents are considered to be their children's first teachers. Vigil, Hodges, and Klee (2005) found that parents of children with typical language development and parents of children with language impairment did not differ significantly in the amount of interaction with their children; however the language of the parents of typically developing children was more diverse and complex than the language used with children who had language impairment. The parents of the children with language delay initiated more conversation with their child but were less responsive to their children's conversational turns. Meanwhile, the parents of children with typical language development often verbalized their internal dialogue to the child as a running commentary throughout the day, exposing their child to a more rich and diverse vocabulary in a

variety of different contexts (Vigil, Hodges, & Klee, 2005). The LENA foundation, an organization that analyzes the amount of conversational turns, word counts, and vocalizations that a child produces in their natural environment also found that a parent's conversation with their child had a strong impact on their child's language later in the child's life. Children who had the most language exposure between the ages of 2 months and 6 months scored higher on the Preschool Language Scales fifth edition (PLS-5) at 24 to 36 months. Additionally, children in the 50th percentile on the LENA assessments had exposure to over 12,000 words, had over 474 conversational turns, and over 1,900 vocalizations at 24 months. Compared to children with autism, typical children had at least 140 more conversational turns per day (Gilkerson & Richards, 2009).

Language development in children is most affected by the parents or caregivers in their environment, and the responsiveness of the caregivers, the amount of interaction that the parents lead, the language support strategies that the parents offer, and the language input that the child receives are all important in how the child develops language. When gauging the effectiveness of parent-led intervention strategies, Roberts and Kaiser (2011) reviewed 18 studies previously conducted to find a link between the success rates of intervention and the involvement of the parents. Roberts and Kaiser found that in 10 of the 18 studies, when parents were trained to provide intervention the level of responsiveness increased, as well as the quality and quantity of the parent-child interactions.

Stressors

Parents who are already struggling with the stress involved with raising a child with special needs may wonder how they can fit anything else into their schedule, but because of the amount of time that the child spends with their parent, the role of teacher is a natural one for the parents to fill. Parent coaching has been successful in improving the parent responsiveness to the child. Ingersoll and Dvortcsak (2006) held a rigorous 9

week parent coaching session that covered direct and indirect teaching and discipline strategies for parenting children with special needs. While the homework was considered the least enjoyable part of the sessions, the majority of the families felt that the sessions were helpful. Prior to and after the coaching sessions, the parents were given a quiz about treatment strategies and implementing them in a naturalistic setting. Prior to the sessions, the parents scored an average of 29% correct; however, after the training the correct responses jumped to 75%. Additionally, the parents rated the program effective and found the program mostly enjoyable. A parent training program can help ease parent concerns that they are not capable or qualified enough to help their children.

Speech Language Pathologist Characteristics

Dinnebeil, Hale, and Rule (1999) also considered the personal characteristics of service providers and satisfaction levels. When 623 parents and service coordinators were surveyed, the majority was positive about the collaboration between family and staff. One of the parents spoke of the attempts to take the parents needs and concerns into consideration, and another parent appreciated the open communication between providers and parents. The personal characteristics of the service provider were also crucial to the relationship between the provider and the families, as well as the support provided to families of children with special needs. Personal characteristics of the providers included extensive knowledge in child development, as well as enthusiasm and an outgoing personality. Support included collaboration with doctors and other service providers, and holding meetings at times where family members could attend. Identified hindrances to the successful collaboration between family and providers involved a lack of funding for programs, and difficulty in managing different agencies and coordinating services (Dinnebeil, Hale, & Rule, 1999).

Meanwhile, mismatches between the therapist and family were evident when the parent failed to follow through with the strategies given by the

therapist, or when the therapist did not share the sense of urgency that the parents felt regarding therapy (Brotherson et al., 2010). This is especially true in families that are at risk; the therapist can do everything possible to encourage participation from the family, but the family may feel that they do not have the confidence to participate in therapy. Minke and Scott (1995), when investigating relationships between therapists and parents, found that the therapists felt that the parents, in at least some of the cases, did not have the best interests of the child at heart, did not implement suggested strategies in the child's therapy, and lacked the skills or knowledge to effectively help the child succeed at therapy. The therapists expressed concerns that the resources that they were providing were enabling the parents to continue to make poor decisions, and as one therapist says, "I'm not trained in social work and I've experienced, I'm worried about feeling burnout" (Minke & Scott, 1995). It is worth noting that half of the parents in this study were under the age of 18, while another 3 children were in foster care. The remaining 3 families were in 2 parent households with mothers who had at least a high school diploma.

For the most part, parents want to be involved in their child's services and consequently felt more positively about the experience. Ronski, Sevcik, Adamson, Smith, and Cheslock (2011) found that parents felt more encouraged about their child's progress when included in the decisions and implementation of therapy. Parents felt most optimistic after their child had completed intervention successfully and the ability of the child to communicate with the parent had increased. In particular, the children had completed intervention that either focused on speech to meet communication goals, or intervention that integrated augmentative and alternative communication (AAC) devices that allowed the child to interact with their parent. These intervention strategies may have increased the positive emotions associated with the children, lessening the parent's anxiety about communicating with their child and further alleviating their concern about the severity of their

child's impairment. Overall, the experiences tend to be more positive when the parents are involved and feel that they have options for services.

As mentioned previously, families of children with special needs have more complex issues than typical families. While there are certainly positive aspects of raising a child with special needs such as a more tightly bonded family unit, the negative aspects can be daunting. Insurance companies that refuse to pay for services considered not medically necessary can put financial strains on an already tense family. Caregivers often quit jobs to care for the child full time as placements in daycare can be difficult to find, compounding the financial burden of these families (Reichman, Corman, & Noonan, 2008). The family dynamics of raising a child with significant special needs can be challenging to the family structure as well. When evaluating the stressors affecting families of children with epilepsy and intellectual disability, Buelow, McNelis, Shore, and Austin (2006) found that while the majority of parents who had divorced did not blame the child directly for the divorce, the lack of communication between the parents is what ultimately led to the dissolution of the marriage. This lack of communication was the result, in the parent's opinion, of the excess requirements of managing a child with special needs. Additionally, some of the parents felt that their other children were unable to receive the attention that they deserved because of the disproportionate amount of time and energy devoted to caring for their sibling with disabilities (Scott, 2010).

The intricacies of raising a child with special needs are complex, as is the need for emotional support. Mahoney and Bella (1998) found that an almost equal number of families felt that their needs were being met by early intervention services as not. A discrepancy was evident between families who felt they were receiving a high level of support compared to families receiving a self-described low amount of support in terms of personal family resources, resource assistance, and resource availability. The families who felt that they were receiving a higher level of support felt that they had better access to

counseling, social activities, and community resources to support their emotional needs.

The number of families living with a child with a disability is hard to determine, because the term “disability” is hard to establish. A disability can be developmental, physical or emotional in nature, or it can be a chronic disease. The family living with a child with a disability is considered to be a family with special needs (Reichman, Corman, and Noonan, 2008). Families of children with disabilities tend to struggle with emotions often compared to the grief cycle in bereavement, including anger, bargaining, and acceptance, but these parental emotions continue to reoccur throughout the child’s life (Keller & Sterling Honig, 2004). Anderegg, Vergason, and Smith (1992) presents a visual representation of the grief

cycle that parents move through when learning of a child’s disability (See Figure 1). Anderegg and colleagues studied 130 parents of children with disabilities to change the grief cycle model commonly associated with bereavement to incorporate the feelings associated with raising a child with a disability in hopes of facilitating improved interactions between parents and educators. Parents tend to enter the grief cycle at the confrontation phase, adjust as much as possible, and adapt by adjusting their expectations and lives around the child’s disability. On the model, the phases of confronting, adjusting, and adapting are circular and parents can experience periods of regression from phase to phase. This cycle is not exited, even in the event of the death of the disabled child.

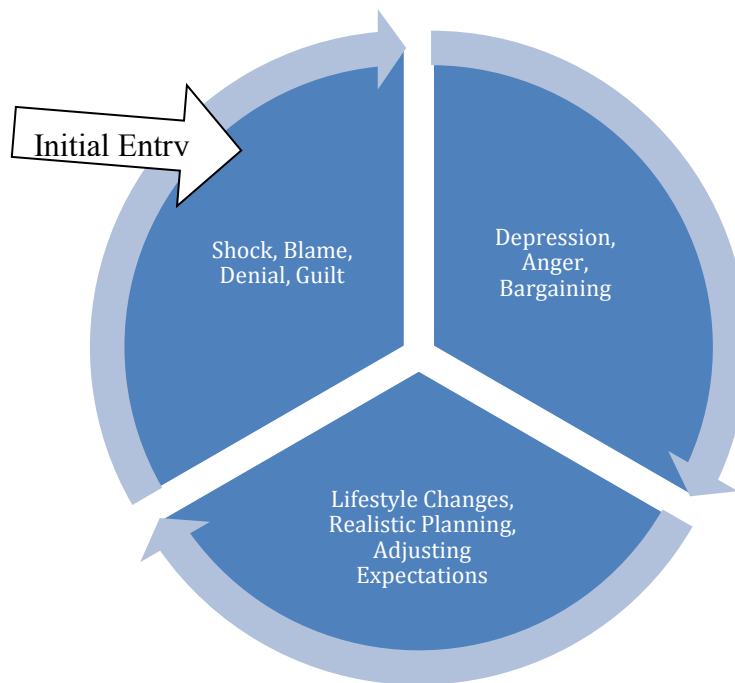


Figure 1. Visual representation of the grief cycle entered by parents of children with special needs. Initial entry is denial, shock, and guilt. The cycle is fluid and parents can move forward in the cycle or backwards. Adapted from "A visual representation of the grief cycle for use by teachers with families of children with disabilities" by M.L. Anderegg, G.A. Vergason, & M.C. Smith, 1992, *Remedial and Special Education*, 13, p. 19.

In addition to the grief cycle, parents have more stress regarding emotional and financial matters when raising a child with a disability. A

commentary by Reichman and colleagues (2008) reported that families of children with disabilities are under extra stress, but research regarding the

exact circumstances of this population is hard to find. Parents of children with disabilities are more likely to be disconnected from society, more likely to divorce, and more likely to have a caregiver that cannot work due to the care demands of the child. These pressures can lead to an increased need for financial support to make ends meet (Reichman, Corman, & Noonan, 2008). The mother who juggles both a career and family life before the birth of a child with special needs may find that quitting her job to care for her child full time is an isolating and financially straining experience. For some mothers who quit careers to stay home with their child involuntarily there is an increased incidence of anxiety, fear, and depression (Scott, 2010).

The support needs for families of children with special needs reveal additional stressors that families of typical children usually do not face. At the same time, the importance of the relationship between the SLP and the parents is highlighted. It was the emotional needs of the families and

determining if SLPs are providing adequate support to these families that inspired this research.

METHODS

The Scottish Rite Foundation of Colorado has a long history of helping at-risk youth or children with disabilities by providing financial support for speech and language therapy services. The Scottish Rite Foundation supports 11 speech-language sites across the state of Colorado that provides speech-language services for children. Six Scottish Rite supported sites agreed to participate in this study, which provided interview data on 15 caregivers and 22 SLPs. Because my mentor collected the data during a previous study, I have access to the typed transcripts from the interviews and focus groups. All of the participants' names have been changed to protect their anonymity, but a brief summary of the participants follows:

**Table 1 (continued on next page)
Parent/Caregiver Participants**

Allison and Russel	Parents to Matthew, a young child who was born prematurely and has an extensive medical history.
Sarah	Mother of a four year old boy with a speech/language delay
Anne	Mother of a four year old boy with a speech/language delay
Trish	Grandparent of a five year old boy born with a cleft lip/palate
Ashley	Mother of an almost-three year old son who was born with craniosynostosis, a cranial disorder where the bones of the newborn's skull fuse together prematurely
Rebecca	Mother of a young boy with a seizure disorder who has had many surgeries and complications
Mallory	Mother of a three year old daughter with childhood apraxia of speech
Laura	Mother of a three year old son with childhood apraxia of speech
Danielle	Mother of a young daughter who was premature at birth and has a speech/language delay

David	Father of three children, one with autism, one who is suspected as having autism, and a daughter who has a speech/language delay
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Table 2
Speech-Language Pathologist Participants

Sally	A speech-language pathologist with 37 years experience
Paula	A speech-language pathologist with over 25 years experience
Melissa	A speech-language pathologist with 17 years experience
Claire	A speech-language pathologist with over 12 years experience
Marisol	A speech-language pathologist with over 9 years experience
Kim	A speech-language pathologist with 4 years experience
Mallory	A speech-language pathologist with 12 years experience
Symposium	Anonymous therapists with varying years experience

DATA COLLECTION AND ANALYSIS

Data Collection Procedures

Parents of children who are receiving speech-language intervention services were asked to describe their experiences with early intervention and early speech-language intervention in particular. They were asked many questions about their child's therapy, including the length and frequency of services, what their child needs in order for early intervention services to be effective, who do they turn to for support, and upon initial diagnosis, where did they seek information. SLPs were asked similar questions, such as how do they include parents in therapy, what they think parents need most from therapists, and if they think they are meeting the needs of parents (See Appendix A Interview Guide). The SLPs were asked to describe ways that they support and include families of children with special needs. These interviews and focus groups were recorded via tape recorder, and the

recordings were transcribed using pseudonyms for family member and site names.

Data Analysis Procedures

For this phenomenological case study, I explored the experiences of families of special needs children through the transcripts of parents and SLPs. Because my data was previously collected and transcribed, I read each transcript numerous times to fully acquaint myself with the content of each transcript. I then reflected on the ideas of each paragraph and developed codes for the ideas conveyed. I sought to explore the emotional supports needed by families of children with special needs, and determined if there is a gap between the emotional support needed by families and the emotional support provided by SLPs.

FINDINGS

Returning to the Brotherson et al. (2010) analogy of the dance, the skill level and abilities

of the dancers determines the success of the dance. In the grief cycle, parents who are in the initial phase of the grief cycle (shock or denial) or even the second phase of the grief cycle (depression and anger) will find it difficult to dance while dealing with the complex emotions, despite the ability of the SLP to lead. However, parents who are moving through the grief cycle toward acceptance and implementing lifestyle changes will find that their comfort level in the dance will increase, as well as the comfort level of their SLPs. When the parents are more comfortable with the dance, and the SLPs are able to lead, the resulting dance is more fluid and graceful. Even with SLPs effectively leading the dance, and the parents becoming more comfortable with their role in the dance, sometimes the dancers are effective but lack chemistry.

The Grief Cycle

As mentioned previously, parents of children with special needs often enter into a grief cycle upon the diagnosis of the child (Anderegg et al., 1992). This cycle was evident and mentioned frequently by both parents and SLPs in the interviews and focus groups. The beginning entry into the grief cycle was often guilt, shock, blame, and denial, and even when the parent feels that they have moved out of the initial phase of the grief cycle, it is possible to move back into blame and guilt at a later time in the child's life. Of the parents interviewed, 63% mentioned feelings of guilt, denial of the severity of the child's impairment, and a hard time accepting their child's condition. David, a father of a young boy with autism said, "...It was shocking, heartbreaking. It was more rough on his mother than me because I was more 'Okay, let's deal with it' where she was more in denial for the longest time." Likewise Sarah, a mother of a young son who receives speech therapy, physical therapy, and occupational therapy, discussed the guilt associated with her son's condition, stating, "I had such empathy for this, you know, bright little child and he just didn't have the...the tools, and I...wish I...I knew how to give those to him earlier." Just coming to the realization that raising

this child will not be the experience that the parents were expecting is a harsh reality for most parents to face. Rebecca speaks about learning that her child has a disability.

There's a mental struggle too. I know I struggled with that in the beginning—accepting, the first time I was working with—I don't know if it was a school or a social service or something trying to get him the help and to actually say, 'Yes, he has a disability' just brought me to tears. It was devastating for me to speak it because when you say it. It's your accepting it. That was very difficult because you want your kid to be normal. I don't care how perfect or how much I love him, it is still hard for me to realize what he's not going to have and not going to be.

Even when coming to terms with the child's disability, the realization is still difficult for parents to cope with, sometimes even years after the initial diagnosis.

Moving forward in the grief cycle, parents often experience anger and depression regarding their child's diagnosis. One parent interviewed mentioned depression directly, but not as feelings that he was experiencing, but rather his wife's struggles. When the idea of support groups for parents was presented to David, he says, "Well, I know that there's a lot of groups out there, you know, for parents to get together...but my wife doesn't really want to get involved with that kind of stuff. She thinks it will just make her feel more depressed about it." In the same interview, David repeatedly mentions that his wife has not come to terms with his son's autism diagnosis. In fact, his younger son is showing signs of autism, but he says, "...I don't think anyone wants to tell her [his wife] that he might have autism and she comes out and says, 'Well, look at what he's doing now. That shows that he doesn't have autism.'"

When moving through the grief cycle, coming to terms with the diagnosis of the child with disabilities includes acceptance, implementing lifestyle changes, and adjusting parental expectations. While acceptance is

mentioned directly by the parents interviewed, many stated that they were advocates for their child, which could be considered part of the implementation of lifestyle changes and expectation adjustments. Parents indicated that advocating for their child was crucial in getting services that the child needs, whether that advocating was gaining more services for their child or fighting for a particular therapy that was found to be effective. Ashley, the mother of a child with developmental delays that may be related to her son's craniosynostosis talks about advocating to find the right fit for her family.

When we came to Seville I've gone through three or four different doctors for Aaron, because you have to stop and say, 'okay, this doesn't work for me.' It's not the doctor, is not necessarily the program. It's just the personalities and not fitting it and making it comfortable. You have to be able to stop and say, 'okay, wait a second. If I'm not comfortable, obviously Aaron's not going to be comfortable.'

It seems that advocating is a large part of parent's lives, whether advocating for additional services for their child through the school system or fighting insurance to pay for more sessions.

Parents and SLPs alike expressed the need for the family to advocate for the child. One parent indicated that she had researched a therapy technique that her SLP was not comfortable implementing. Her daughter was diagnosed with childhood apraxia of speech (CAS), a speech disorder where the child has difficulty learning to produce sounds and sequence them in words. The mother sought the opinion of an expert on CAS, and after meeting with the expert, decided on a course of treatment for her daughter. Because her SLP did not follow the prescribed treatment plan, the mother sought private therapy for her daughter. She also moved the child to another school. The mother reported, "... we tried to get him [the therapist] to implement the plan...and it wasn't really working and you know, we tried several times, actually. And so we actually switched schools....The new school SLP has, it

seems, more experience with apraxia. And I think the last school SLP didn't. I think it was just new territory for him."

Another mother recounted her struggles finding an agency that would provide services to her son. Her son, although delayed, was not considered delayed enough to qualify for physical therapy services through the local agency that served the county in which she lived. Says Allison, "She [the physical therapist] said, 'well, I'm too busy and he's not bad enough.' And I thought, 'why do we have to wait until the child is "bad" ...to get a physical therapist to look at him.'" Eventually the mother found services through a private therapist.

SLPs also mention the need for parents to advocate for their children. During a focus group, an anonymous therapist said, "...If they're not familiar with the education system or, you know, how to navigate the medical system, then we can educate but at the same time also advocate for how they can really use and understand the system to get the best possible education and medical services for their child." SLPs also state that they advocate for more services for children by sending regular progress reports to insurance companies.

SLPs indicated that the grief cycle plays a role in how much information is shared with family members. During a focus group interview, Kim, a SLP with over four year of experience, says, "I also think it's helpful to learn about the parent and what their needs are and kind of where they are. It could be 'your child is having difficulty saying /f/.' Or it could be that this is a really new thing and there is a lot going on and this is really overwhelming. I think I like to read the parent and kind of read that before I jump too much."

Another concern of SLPs is that too much information will be given to the parents, overwhelming them. The term "overwhelmed" appears in the half of the interviews conducted with SLPs, and not so directly in the remaining texts. Marisol, a SLP, shares an experience about parents being in denial about their child

I was just with a friend this morning who is also an early interventionist and we were talking about this and she has a family who keeps telling her ‘you know what? I don’t really think there’s an issue’ and they went through the Child Find and had done the assessments, qualified for services and the parents are sort of in this denial process. Depending on where the family is in terms of really recognizing their child’s issues.

Parents who are having difficulty coming to terms with the extent of their child’s disability may have more difficulty processing the information provided by SLPs.

Defining Support

Beyond the grief cycle, the need for support became clear from the transcripts. From this support, two themes were evident: the need for emotional support and the need for educational support. Emotional support was considered to be listening to parents, offering reassurance and encouragement, and finally, having access to support groups of families with similar diagnoses or disabilities. Educational support was considered to be having credible information regarding the child’s specific diagnosis, helping the parent navigate paperwork and services, and providing access to resources.

Emotional Support

Emotional support was an often mentioned area of need from parents of children with special needs. Parents indicated a number of stressors in their lives, including medical concerns regarding their child, problems finding balance with their other children, finding time for therapies, and often, losing the ability to work outside of the home because of the high needs of their child. Most of the stressors indicated by parents were outside of the scope of the SLP’s practice. However, many of the SLPs interviewed did empathize with the families’ stressors. Mallory stated,

Sometimes I think about how I’ve heard parents say, ‘instead of soccer, we do this.’

He’s got so much on his plate...with homework and this. It’s like they know they need it because they need to get better on these other things, but it’s this one extra thing and a lot of times the siblings have to be there too and so it really interrupts their life. It’s just an extra added...thing that makes life more complicated. And I’m sure some families find it financially hard, as they drop out for sure, and the unknown too. It’s like, ‘we have some answers, but how long is this going to be?’

The SLPs know that parents have a lot on their plates, but other than offering support, they are limited in their ability to ease parental stress. The SLP’s scope of practice is defined by the American Speech-language Hearing Association, or ASHA. In regards to counseling, ASHA states, “counseling individuals, families, coworkers, educators, and other persons in the community regarding acceptance, adaptation, and decision making about communication and swallowing,” (Scope of practice, 2007). It can be determined that counseling regarding acceptance and adaptation can include helping parents come to terms with their child’s disability and help them progress through the grief cycle.

While many of the issues affecting families of children with special needs were beyond the scope of the SLP, there were some issues that could be addressed. The need for emotional support included listening to the families’ concerns and frustrations and referring the families to support groups of parents who have children with similar needs. Rebecca mentioned how important receiving encouragement from her SLP is. She said, “All of a sudden they plateau and they’re sort of stuck and it seemed like... ‘he hasn’t learned anything new for three months’ and Sally [therapist] would say, ‘hang in there, he’s doing great’ and she reminds me of all the things he was doing or she’ll show me his test: ‘Look where he was and look where he is!’That constant feedback.” Allison mentioned the need for a support group for parents of children with special needs, saying, “....I knew I wasn’t the only parent who had a child premature and stuff, but it would

be nice to be able to have a network where we could all come together within this society....I think it's very important because we could have caught so much of his speech issues so early if I would have been able to have something like that."

The need for someone to listen and validate concerns was mentioned often by the parents and by the SLPs. Parents who notice that their child is behind siblings or peers developmentally want to know if their concerns are warranted and SLPs are aware of this need. Laura, a parent of a child receiving speech-language intervention services, says, "...it was like, finally I was so frustrated I called ChildFind and they referred me 'cause he was under 3, and they referred me to SkyView. And when we went to SkyView it was like, 'Oh my gosh, he needs help' and I was like, 'thank you.' And I finally felt vindicated that somebody was listening." SLPs mention the importance of listening to parents, reassuring them, and encouraging them. Paula said, "They [parents] need validation that they're not a bad parent. They need validation, support, to help their child learn the language skills that they've not learned."

Education

Educational support is a broad area of need for parents. Some of the areas of education included more specific information regarding the child's diagnosis, the need for SLPs to coach parents on how to foster language development, information regarding typical versus atypical development in children, and help navigating services. Returning to the dance analogy, this was where the SLP takes the role of the leading dance partner.

SLPs are regarded as experts in speech and language development in children. Because of this, parents indicated that the role of coach and teacher was high on the priority list in supports needed by SLPs. Sarah, a parent, stated that she felt involved in the process, but the SLP helped teach her how to interact with her child as a therapist:

I feel like I get lots of information and I always talk with Katie [therapist]

afterwards and I get feedback and I know...they're very clear about what they're working on and...very savvy in terms of giving me techniques and things to practice on so I...don't feel like I'm out of the...loop. ...I really admire their expertise in some ways.

Other parents echoed these sentiments throughout the transcripts. Rebecca talks about how her therapist is a coach and educator when she says, "I just don't think that we would have pushed him [her son] as much or expected as much from him without the therapist directing you and telling you 'you know, don't do this.'"

Another area of need for education involves teaching parents about what milestones are typical for development compared to those that are atypical. Parents indicated that information was abundant when the child was under 1 year old and was handed out to parents at each well-child check at the pediatrician's office. Ashley mentions this briefly when she says, "They have books and books and books it seems out there in the first year what kids should be doing, but it seems like once they hit that toddler stage it is really difficult to find the resources of where they should be. It's just not as easy as it was when he was an infant." Laura, a mother of a son with CAS talks about her pediatrician's response to her concerns, "'Oh, you know, it's a developmental thing. He'll get there.' And it's like, 'but he's not getting there.' You know, he never showed any of the normal developmental milestones."

Laura also expanded on this theme when she said, "And it took until last November, a year ago, when they finally, and the only reason something happened was because he was looking out the window and ...just jabbering but not making one word. And she goes, 'Oh, I see what you mean.' And it was like, 'yes, now help me fix this', you know? And so he really started late." Many parents shared similar experiences in their interviews, stating that often physicians first stated that their children were fine, only to refer the child to an early intervention team later.

Regarding developmental milestones, Rebecca had pointed out how she was not aware that her child was developmentally delayed when she said, “I think as a parent, you see your child is normal. You don’t see that there’s anything wrong and so I didn’t even realize that he was...you know, we were just so happy to have him. And we didn’t know that there was anything missing or that he was so far behind.” This experience of not knowing that is developmentally appropriate is mentioned by Paula, a SLP with over 15 years experience. She says “Last semester one of our grad students needed another portfolio item so she planned a group kind of session for...things to do at home and a little bit about what normal development is because we also had a family here last semester that didn’t really seem to know where their child should be and what kind of skills they should have.” Giving information to parents regarding what developmental milestones to expect would help parents identify delays sooner and seek referrals from their pediatricians.

SLPs are aware of this need for education and are planning sessions accordingly. Most SLPs indicated the importance of staying current on research in order to give their families the most up-to-date information regarding their child’s condition. Additionally, SLPs spoke of the importance of teaching parents how to foster language development by making the parents the therapist. Melissa, a SLP, talked about how important parent coaching is, especially in a complicated diagnosis such as a feeding disorder. She says, “There are some where it’s...feeding for example, where it’s vital to have the parents involved...to train them not only on skills, but you’re training them on what language to use.”

Parents expressed concern about how difficult it is to balance therapies, paperwork, and family life. A few of the parents mentioned the need for a coordinator or assistant to keep everything straight. Often times, the child who receives speech therapy will receive other therapies as well. Sarah stated:

I often joke....that you almost need like a coordinator. You almost want a

coordinator to like come on board. I’ll hire you and we can sit down and map through these, cause...you’re trying to navigate your own schedule and...the schedule of your other children and then...make sure they get to therapies and...it’s overwhelming, I think.

When dealing with children with multiple therapies, it becomes even more difficult to juggle a busy schedule and fit it all in. Mallory acknowledges her role as a navigator in one interview, stating,

I consider us to be one of their [parent’s] primary resources as far as that [educator] is concerned, and also just a navigator. Somebody to help because a lot of kids aren’t in tidy neat little speech and language boxes. It might be speech and language, but then as it unravels and as you get into it, there’s different things. And that’s why [I] collaborate with OT and PT and psychology and behavior specialists and medical a lot of medical issues.

When parents research their child’s disorder online, the information is not always reliable. Having access to resources can help the parents come to terms with their child’s diagnosis and give the parents a good indicator of what to expect in terms of the child’s development. Parents expressed the desire for reliable information specific to their child’s diagnosis that could be accessed online. Another parent indicated that having a place to contact with questions or concerns regarding services available in the community or their child’s development to help parents of newly diagnosed children. Allison has a vision of what she would like to see:

I’d like to see ChildFind get a little more expanded for families that don’t know a lot to have doctors in certain specialties come on board, um, nurses, PA’s, therapists, to give these families more knowledge,...I would like to see that they are able to, ChildFind says, ‘Okay, these are the doctors are within our group that

have volunteered, saying that you can call them, get an appointment, talk to them.’ You know, you want to talk to a PA [Physician’s Assistant] or a nurse about something.

There were many different responses by SLPs regarding this area of need. Specifically, SLPs were aware of the need for reliable information for the parents. Mallory states, “I was just thinking that it would be good to go through...the ASHA Leader has websites. And a lot of it is just for...speech pathologists and different things like that but it has some parent ones too and I should have a master list of really good places to go.” Kim, another SLP from the same interview, agreed. “Especially in the field of autism. I feel like that one can get really messy. Not that everything out there is wrong or right, but parents are like, ‘what about this treatment?’ And that is such a hot topic right now and there’s so much going on. There’s so much information out there and some can be misleading so just helping.”

SLPs also expressed the importance of just listening to their client’s parents. Paula stresses the importance of listening to clients, stating, “I think we need to tell students that they have to respect parents and not belittle them. I think we need to make sure that our students know to listen to parents and hear what [they] are really telling us and to figure out that deeper meaning than just the surface meaning and try to meet those needs.”

Hopes for the Future

When asked what their hope for their child’s future was, there was an emotional response from many of the parents interviewed. Some parents had specific hopes for their children’s future, such as speaking intelligibly, being self sufficient or even finding a friend. Laura says, “My hope is that he’ll be able to speak and have people understand him and be able to get his point across. And be intelligent sounding, you know, where people won’t look at him and turn around and just walk away...’cause they can’t understand him.” Ashley echoes these sentiments in a different interview, “I mean, I think every parent wants their kids to be an active member of

family, society, life.” David wants his son who has autism to gain some independence.

Other parents hoped that their child would be happy. Sarah gets emotional when describing her hope for her son’s future, “I just want him to be happy. I mean, really, it’s that, it’s truly that simple. I...want him to...live to his fullest potential, whatever that potential is, you know? So, I get weepy thinking about it.” Rebecca says something similar about her son, stating, “I don’t want him to feel different or special. He’s just Todd.”

CONCLUSIONS

As dance partners, the skill level, motivation, and chemistry of the partners determines the success of the dance. For parents who are struggling to come to terms with their child’s diagnosis or disability, it can be difficult for them to follow the lead of the SLP, resulting in a less than graceful dance. As the parent becomes more comfortable with the diagnosis, their grace becomes more apparent, as does the SLP’s comfort level. This leads to a successful experience for both.

Based on the transcripts, parents express the need for more support from their therapists, both educational and emotional. The educational support seems to be provided well, with the SLPs anticipating the needs of parents and stepping in to meet those support needs. However, there appears to be a gap between the emotional support needs of parents and the support given by SLPs. Could this be due to a lack of training from SLPs in their educational programs? Counseling is considered to be part of the SLP’s scope of practice, but are SLPs uncomfortable providing this emotional support?

Initially, I expected that there would be a gap in between the needs of parents and the services provided by SLPs. For instance, counseling is interwoven in graduate courses in speech-language pathology, but more is needed. Often times, the SLP is the one giving the parents test results that confirm a speech and/or language disorder that could alter the family permanently.

During this part of the dance, the SLP may feel that the dance is floundering as they struggle to provide the emotional supports parents need but may not be comfortable asking for. As SLPs provide ongoing support throughout intervention services, it is hoped that the parents will become more at ease with the dance, more familiar with the SLP and the child's disabilities, and the dance will become more graceful and fluent.

SLPs tend to be meeting or even exceeding the needs of parents when it comes to educational support. This makes sense, as SLPs are considered to be experts on child speech and language development and are well trusted as a result. This part of the dance appears to be fluid, led by the experienced SLP and the comfortable parents, who after coming to terms with their child's diagnosis, are able to contribute equally to the dance.

IMPLICATIONS FOR FUTURE RESEARCH

The results of this research could be used as training for future SLPs completing their degree programs. Especially in early intervention, where the focus is on the family, learning how to best support families of children with special needs would be helpful in many ways. With the number of children receiving early intervention services growing, the ability to provide support to families should be a high priority for SLPs, especially immediately following the child's diagnosis. This time can be overwhelming for parents, and experienced SLPs can help the family learn the proper steps and become more efficient dancers. Additionally, training in counseling can help new SLPs help parents cope with the emotions associated with the grief cycle. The results of this study could assist graduate programs in speech-language pathology to infuse counseling in a more systematic fashion into graduate courses. This is especially important in courses where students are learning to work with children and their families.

Not only could this study be beneficial to speech-language pathology graduate students, it can be beneficial to parents as a resource on what services are available for themselves and their special needs child. Reading the experiences of

parents who are currently in the system and dealing with children with special needs can assist parents of children who are newly diagnosed. For instance, one of the parents interviewed mentioned that music therapy was beneficial to their child, but it was never mentioned as an option before. Through trial and error, the parent discovered that music therapy was immensely helpful to their child. A parent new to special education may find that this type of therapy may be helpful to their child as well by reading the other parent's experiences.

SLPs, both those who are new graduates and those who have many years of experience can find this study beneficial in how they provide information to families. Many SLPs mentioned the importance of gauging the parent's comfort levels to prevent overwhelming them with information. However, new SLPs who are giving information to parents and have little experience delivering this type of news may misgauge parents and unintentionally overwhelm them. SLPs that have more experience may learn additional resources to help families through a difficult time. Some parents mentioned the importance of having places to go for information, such as websites or support groups, but may not be comfortable asking their therapists for this information. Having a binder of available resources to give to parents, or even gauging that the parents need more support or information can help SLPs more effectively serve the families of special needs children.

Limitations

Because of the qualitative nature of this study, one limitation of the study was the possible bias of the researchers involved. The data were collected by a professor of speech-language pathology, and then analyzed by me, a speech-language pathology student, so there is potential for bias in analyzing the data. However, I feel that bias is unlikely as I have been a parent of a child receiving speech services and am also a student. Additionally, because the interviews and focus group sessions had already been collected and transcribed to paper, it was sometimes difficult to read the emotions in the interview unless it was

specifically pointed out. For example, in one specific interview, one of the participants began crying; a detail that I would not have picked up on unless the interviewer mentioned it specifically.

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Appendix A Interview Guide

Sample Focus Group Questions – Parents

- *The first three questions provide me with some background regarding the services your child receives. I would like each of you to answer these.*
- How long have you been involved in speech-language services for your child? What other services does your child receive?
- What is the format of the services your child receives? (one child to one clinician; small group of children to one clinician; small group of children to two or more clinicians; other)
- What is the length of your child's sessions and how many sessions does your child participate in each week?
-
- *The remaining questions seek your insights individually and collectively about early intervention services. There is no set order as far as who answers, and if you have nothing further to add, you need not feel compelled to answer.*
- What does your child need in order for early intervention to be effective?
- What do you need in order to most effectively support your child in intervention?
- What are the ways you have participated in your child's speech-language intervention?
- Which of these activities met your needs?
- What activities would you like to have available to you as part of your child's intervention?
- What do you typically do during your child's sessions?
- What factors would increase your participation in your child's intervention?
- What are the barriers you see that prevent you from participating in your child's intervention?
- When you first discovered that your child had a speech-language disorder, what sources did you rely on for information? What sources do you rely on now?
- Who did you turn to for support initially? Who do you rely on for support now?
- What is the role of your spouse or other family members?
- What do you hope for regarding your child's future?
- Who will be involved as you help your child plan for the future?
- What do you think is the role of the speech-language pathologist in your child's services?
-

- **Sample Individual Interview Questions – Parents**

- **If the parent was part of the focus group, do not ask the focus group questions again. Start with this set of questions. If the parent is new (not part of focus group) use the focus group questions AND this set of questions.*
- Please tell me about your family.
- Tell me more about your son/daughter receiving speech-language intervention (and other) services.
- What types of developmental needs does your child have?
- What is your experience with early intervention services?
- What have these experiences been like for you?
- What challenges have you had? Successes?
- What would you tell other parents who seek services for their child?
-

- **Sample Individual Interview Questions – Speech-Language Pathologist**

- How long have you (and site) been providing speech-language services to preschool children?
- Describe the formats for speech-language intervention sessions. (group, individual, child-centered/play-based, home services, clinician-directed, length of time per session, number of sessions per week).
- How are parents included in speech-language intervention sessions?
- What types of options do parents have to participate in intervention?
- What do you think your parents want/need most from speech-language intervention services?
- What do you think your parents like best about speech-language intervention services?
- What do you think your parents like least about speech-language intervention services?
- How do you think you are meeting the needs of parents?
- What do you think you should do to improve the ways in which you meet parent needs?
- What roles do you have in your work with parents?