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CAREGIVER PERCEPTIONS OF SPEECH-LANGUAGE PATHOLOGIST (SLP)  
COMMUNICATION:  
EXAMINING HOW SLPS TALK WITH CAREGIVERS ABOUT CHILD LANGUAGE  
DISORDERS

A Dissertation

Submitted to the Graduate Faculty of the  
Louisiana State University and  
Agricultural and Mechanical College  
in partial fulfillment of the  
requirements for the degree of  
Doctor of Philosophy

in

The Department of Communication Sciences and Disorders

by

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## **ABSTRACT**

The purpose of this study was to identify how SLP communication regarding language disorders was perceived by caregivers. Employing a qualitative methodology, the caregivers of 10 children, identified with a language-based reading impairment, participated in semi-structured interviews concerning their experiences communicating with SLPs. As a whole, the findings showed the value caregivers place on receiving clear, concrete, and timely diagnostic information, the variability and complexity associated with caregivers' understanding of language disorders, and the reciprocal relationship between key SLP communication practices, caregiver knowledge, and effective collaboration. Some of the key themes emphasized in regard to SLP communication practices included: recognition of the importance of diagnostic labels to caregivers, recognition of the potentially different ways caregivers may interpret diagnostic labels, recognition of the need for initiating and following-up on communication opportunities with caregivers, recognition of the necessity of checking for caregiver understanding of messages, recognition of how caregiver roles and responsibilities influence caregiver collaboration, and recognition of the importance of providing caregivers with informational resources across time that increase their knowledge and understanding of the diagnostic and intervention process.

## CHAPTER ONE: INTRODUCTION

Speech-Language Pathologists (SLPs) are allied health professionals who diagnose, treat, and support individuals with communication disorders and their caregivers (ASHA, 2007). To accomplish these goals, SLPs must competently communicate with clients and/or their caregivers in a manner that encourages trust and mutual collaboration (Blackstone, Ruschke, Wilson-Stronks, & Lee, 2011; Crais, Roy, & Free, 2006a; A. Ferguson & Armstrong, 2004). The importance of effective SLP-client/caregiver communication is recognized by the American Speech-Language Hearing Association, (ASHA 1997; 2006; 2008), and is emphasized as an important principle of service provision in the literature (A. Ferguson & Armstrong, 2004; Hand, 2006; Walsh, 2007). As noted in ASHA's statement of *Preferred Practice Patterns* (2004), clients and their caregivers are to be acknowledged as significant partners in service provision. However, without the development of understanding among all parties, practices that truly integrate family values and encourage cooperative decision making are not feasible. Therefore, communicating with clients and their caregivers regarding communication impairments in a manner that supports client/caregiver understanding is a key component of the SLP's roles and responsibilities.

Recently, literature has emerged in the field of communication disorders discussing the communication practices of SLPs and acknowledging the need for increased awareness of SLP communication practices (e.g., Burns, Baylor, Morris, McNalley, & Yorkston, 2012; A. Ferguson & Armstrong, 2004; Hester & Stevens-Ratchford, 2009; O'Malley, 2011; Payne, 2009; Rao, 2011; Simmons-Mackie & Damico, 2009, 2011). For example, clinical discourse analyses completed by Hand (2006), Leahy and Walsh (2008; 2010; 2007), and Hengst and Duff (2007) provided descriptions of SLP talk with various types of clients during clinical encounters. Simmons-Mackie and Damico (2009) explored how a clinician's communication practices can

encourage group member engagement in aphasia groups, and Stone (1992) presented two case studies illustrating how changes in clinical interactions can influence the clinician-client relationship. Fourie (2009) and Stoner et al. (2006) examined client perceptions of therapy and the therapeutic relationship, and Simmons-Mackie and Damico (2011) overviewed various clinician interaction styles and discourse patterns in clinical settings.

A common theme across the referenced studies is that SLPs must think about how they conduct themselves in a clinical setting, not just what kind of evaluation or treatment approach they are providing. While these studies provide a good start to the discussion, they are limited or narrow in focus. None of the studies focused on how SLPs share information with clients or caregivers, and none directly examined how the clients/caregivers perceive the communication practices of SLPs. Furthermore, Aphasia, an adult language disorder, represented the only specific communication disorder explored in the above mentioned studies. Given the increased emphasis on early intervention and prevention practices, caregiver education, and collaborative treatment models, the lack of research examining SLP communication with caregivers of children constitutes a significant gap in the literature (Association, 2013-2014).

SLPs devote a large percentage of their time to working with children with language related disorders, up to 38% of their caseload in early intervention settings (ASHA, 2013) and up to 83% of their caseload in school settings (ASHA, 2012). Furthermore, child language related disorders present as complex and varied disorders with serious associated long-term academic and social consequences. This complexity makes it very challenging for the SLP to effectively communicate clear and accurate information to caregivers regarding the origin, characteristics, and prognosis associated with their children's language impairment (e.g., Dale & Cole, 1991; Goffman & Leonard, 2000; Lahey, 1990; Schuele & Hadley, 1999). The consequences of child language impairment also have an effect beyond the immediate family, as

childhood language impairments are associated with greater medical, educational, and public service costs over a lifetime (Law, Zeng, Lindsay, & Beecham, 2012; Sciberras et al., 2014). The long-term cost to children, their families, and society appears to be especially high when the language deficits lead to impaired reading ability because poor literacy skills have been associated with decreased independence, lower levels of educational attainment, and fewer occupational opportunities in young adults (Conti-Ramsden & Durkin, 2008; Johnson, Beitchman, & Brownlie, 2010). Thus, an exploration of how SLPs define and describe child language delay and impairment to caregivers and how effective caregivers perceive SLPs to be in communicating this information will contribute valuable information to the literature regarding effective SLP communication practices.

The purpose of this study was to explore how caregivers of children with communication disorders perceive and interpret their communication experiences with SLPs. Since children with communication disorders represent a wide and varied population, this study focused more specifically on children who have been identified as having language related communication delays or disorders. Using a qualitative approach, I explored caregiver perceptions of how SLPs talk with caregivers about language delays and disorders, as well as how effective caregivers believe SLPs are in communicating with them in a clear, understandable, and collaborative manner. Gaining a better understanding of how caregivers perceive their child's language disorder and the diagnostic information they receive from SLPs can provide clinicians with guidance in how to talk with caregivers about language related child disorders. As there is a lack of literature to draw from related directly to SLP and caregiver communication, my study was exploratory in nature. A qualitative methodology presented an appropriate method for beginning the exploration of a phenomenon that is largely unstudied and undefined in the literature. Using previous works from the health care and educational literature as a model (Angell, Stoner, &

Shelden, 2009; R. Fourie, 2009; Shelden, Angell, Stoner, & Roseland, 2010), I utilized a collective case study approach (Stake, 1998) in which each caregiver (or caregiver pair) of a child with a language based disorder represented one case. Data were collected primarily through semi-structured interviews, allowing the caregivers to share their perceptions and feelings about SLP communication.

## CHAPTER TWO: REVIEW OF LITERATURE

This chapter explores literature from four key areas that support the purpose and methodology of this study. The first section provides an overview of the health communication literature and discusses how it can be applied to SLP and caregiver communication. The health communication literature has been driven primarily by concerns about overall patient satisfaction, long-term patient health outcomes, the use of preventative strategies, and the appropriateness of services for an increasingly diverse clientele (Blackstone et al., 2011; Hidecker, Jones, Imig, & Villarruel, 2009; Kreps, 2003; Lindblad, Rasmussen, & Sandman, 2005; Ok, Marks, & Allegrante, 2008). Several studies have found that there is a significant association between health care provider communication practices and overall patient health outcomes, with certain types of communication behaviors leading to more positive outcomes (Stewart et al., 2000; van Zanten, Boulet, & McKinley, 2007; M. B. Wanzer, Booth-Butterfield, & Gruber, 2004). The health communication literature provides background regarding the importance of examining health care provider communication and a context for the examination of SLP-caregiver communication behaviors.

In the second section, literature examining SLP and client/ family practices and collaboration is reviewed. The importance of family involvement and collaboration have been emphasized by several researchers in the field of speech-language pathology and highlighted by ASHA (ASHA, 2004; Crais, 1991; R. Fourie, 2009; Robert Fourie, Crowley, & Oliviera, 2011; Geller & Foley, 2009; Hidecker et al., 2009; e.g., D. Luterman & Kurtzer-White, 1999a; D. M. Luterman, 2001; Woods, Wilcox, Friedman, & Murch, 2011). The literature reviewed in this section overviews some of the work that has been done examining client perceptions and needs and SLP and client interactions. Some of the challenges of effective SLP communication

include the difficulty of providing clear diagnostic information to clients (Hand, 2006) and the ambiguity often associated with child language disorder labels (Schuele & Hadley, 1999).

Next, literature related to childhood language disorders is summarized. In particular, I focus on describing the characteristics and outcomes associated with specific language impairment (SLI). SLI is the preferred term in the literature to describe children with significant language disabilities that stand alone and are not caused by neurological or cognitive deficits (Hadley, 1999). The connection between language and reading impairments is also explored, as reading difficulties have been shown to be a persistent concern for both children with language delays and those with an identified language impairment (e.g., Catts, 1995; Catts, Adlof, & Weismer, 2006; Catts, Fey, Tomblin, & Zhang, 2002; Hogan, Catts, & Little, 2005; L. Justice, Mashburn, & Petscher, 2013; Nation, Clarke, Marshall, & Durand, 2004; H. S. Scarborough, 2001; Snowling & Hulme, 2006).

Finally, in the fourth section, I discuss why I chose a qualitative methodology for this study and why a multiple case study approach was employed (Damico & Simmons-Mackie, 2003; Stake, 1998). I will also discuss the purpose and utility of semi-structured interviews as a tool for exploring caregiver perceptions of SLP communication (R. Fourie, 2009; Robert Fourie et al., 2011). Following the review of the literature, the proposed research questions guiding the study are presented.

### **Health Communication**

The US Department of Health and Human Services defines health communication as “the study and use of communication strategies to inform and influence individual and community decisions that affect health.” (Office of Disease Prevention and Health Promotion, 2014, para. 1). The scope of health communication includes disease prevention, health promotion, health care policy, and the business of health care as well as enhancement of the quality of life and health of

individuals within the community. Research within the scope of health communication encompasses theories and models across several disciplines, including behavioral and social sciences, mass communication, social marketing, and medical/health fields, making it a truly multidisciplinary focus of study. Most health communication research falls into one of three general categories, mass or public health communication, health self-management, or medical interpersonal communication (Parrott, 2004).

Mass communication research typically focuses on the effectiveness of public campaigns or how society views a health related issue such as an examination of the effectiveness of child abuse prevention campaigns, (Martin, Green, Gielen, & Jackson, 2007) or the study of the public's influence on motor vehicle injury prevention (Waller, 2001). Self-management based health communication research typically focuses on the individual and how he or she perceives or manages health related conditions such as AIDS (e.g., Hoy-Ellis & Fredriksen-Goldsen, 2007) or cancer (e.g., Gotcher, 1993). Finally, medical interpersonal communication focuses on the direct interaction between individuals and their health care providers. Though a few studies have examined nurses' communication with their patients (e.g., Propp et al., 2010), communication between hospital staff and patients (Wanzer et al., 2004), communication between social workers and their patients, (Liechty, 2011), and communication between allied health professionals and their clients (Carlson, 2002; Parry, 2008), the majority of the research investigating communication between health care providers and the individuals they serve has focused on doctor/patient and/or doctor/caregiver interactions (e.g., Burstein, Bryan, Chao, Berger, & Hirsch, 2005; Hagihara & Tarumi, 2006; M. B. Wanzer et al., 2004).

In investigating the communication behaviors that health care providers employ with their patients, many researchers have focused on patient centered communication (PCC) practices. PCC practices are defined as "the array of communicative behaviors that can enhance



the quality of the relationship between the health care provider and patient or the patient's family” (M. B. Wanzer et al., 2004, p. 364). In essence, PCC behaviors can include any behaviors that focus on better knowing what the patient and/or their caregiver needs. One manner in which the effectiveness of PCC behaviors has been studied is through examining specific behaviors in relation to patient satisfaction outcomes.

For example, Wanzer et al. (2004) examined the relationship between several PCC communication behaviors and patient satisfaction. Their participants included 195 parents of children receiving care at a large children’s hospital in the eastern United States. The parents were asked to fill out a survey evaluating the communication behaviors of the doctors, nurses, and staff members they interacted with during their time in the hospital. The specific PCC behaviors that participants were asked to rate included: health care provider’s use of introductions, their level of clarity in information giving, their expression of empathy, their use of immediacy behaviors (nonverbal behaviors that reduce physical and psychological distance such as smiling), their listening skills, and their use of appropriate humor. The survey instrument consisted of Likert style questions that asked the participants to rate their providers’ use of each PCC behavior on a scale from 1 to 5, with 5 being the health care provider demonstrated this behavior very often and 1 being never. A 5-point Likert scale was also used to assess each parent’s satisfaction with the health care providers’ communication behaviors and with the overall medical care received.

Results indicated a strong positive relationship between the amount of PCC behaviors perceived by the patient and the patient’s overall satisfaction with the communication skills of the doctors, nurses, and staff members that interacted with them ( $r = .73$ ;  $r = .61$ ;  $r = .59$ ). Additionally, a strong positive correlation was found between the amount of PCC behaviors perceived by the patient and the patient’s overall level of satisfaction with the medical care they

received from the doctors and nurses who treated their children ( $r = .67$ ;  $r = .61$ ). PCC behaviors were also found to be predictive of the participants' satisfaction with their children's health care providers' communication abilities, and their provision of medical care. Using multiple regression analyses, the researchers found that the combination of the six PCC behaviors resulted in a significant predictive model for patient satisfaction with doctor,  $R^2 = .60$ , nurse,  $R^2 = .41$ ; and staff communication,  $R^2 = .42$ , as well as for patient satisfaction with medical care received from doctors,  $R^2 = .52$ , and nurses,  $R^2 = .50$ .

PCC behaviors have also been shown to improve the overall interaction experience and assist in establishing mutually productive health care provider and patient relationships, an essential component of engaging in true collaboration (Dawood & Gallini, 2010; Donovan, Hartenbach, & Method, 2005; Heery, 2000; Propp et al., 2010). One aspect of involving the patient collaboratively is ensuring that the patient is educated about the health concern and what can be done, as this allows the patient to feel some level of control (Brown, Stewart, & Ryan, 2003). Donovan et al. (2005) studied the perceived control of 279 female patients with ovarian cancer. The women included in the study were members of the National Ovarian Cancer Coalition, primarily Caucasian (93.5%), and had some level of college education (87.5%). Participants were asked if they had discussed their most noticeable symptom/s with their doctor in the last month, and if they had received any symptom management strategies from their doctor for the symptom discussed. Only 61% of the women reported having discussed any of their most noticeable symptoms with their doctor in the last month, and only 50% reported having ever received a symptom management recommendation. The researchers found that the women who had discussed management strategies with their doctors, in addition to discussing their symptoms, had a higher perceived self-rating level of control,  $M = 2.09$  on a 0-4 scale, as compared to the average rating ( $M = 1.07$ ) for those who had not received management strategies

from their doctors. Additionally, researchers found that there was no significant difference in perceived control between the women who had recently discussed their symptoms with their doctor ( $M = 1.78$ ) and those who had not ( $M = 1.84$ ) when no recommendations for management were given. These results suggest that it is the combination of symptom discussion and receipt of recommendations rather than one or the other that was key to helping patients gain control over their symptoms.

Finally, a fundamental aspect of PCC is that it focuses on the patient as a whole, recognizing the individual as part of a larger system of family and community, rather than focusing only on the biological illness or health concern (Wanzer et al., 2004; Hare et al., 1989). In recognizing that each patient is not served as only an individual, families have also become an important part of health related research. After all, health is an important aspect of family functioning. How a family communicates about health, their attitudes and beliefs about health, and their health behaviors as a family all impact how the individuals within the family interact with health care professionals (Pecchioni & Keeley, 2011). To communicate effectively with caregivers, health care professionals including SLPs, must be sensitive to the role of previously established family attitudes and beliefs in the caregiver's interpretation and understanding of the communicative interaction. As such, a theoretical lens that focuses on how families and health interact makes sense in the exploration of health care provider and caregiver communication.

### **Health Communication and Family Systems Theory**

Family systems theory, originally derived from general systems theory (GST) took root initially as a guiding paradigm for clinical family therapy research (Galvin, 2006). Over time it has become the dominant framework of family analysis across a broad spectrum of fields including sociology, psychology, home economics, social work, and health communication (Broderick, 1993). The basis of family systems theory is that the family itself is "an open,

ongoing, goal-seeking, self-regulating, social system" (Broderick, 1993, p. 37). A systems theory perspective insists that one cannot look at the individual or even the family independently of the systems which they create and are a part of. There is a constant flow of exchanges among individuals within a family and between a family and its external systems. These exchanges lead to constant change, as well as a level of interdependency among individuals and systems. The almost unlimited potential for exchange leads to a complicated and complex relationship between individuals within a family and families and their external systems (Galvin, Dickson, & Marrow, 2006; Pecchioni & Keeley, 2011). Since each part of a system is in an interdependent relationship with the other parts, when change occurs in one part, the whole system must adjust (Segrin & Flora, 2005). In the same way, when one individual within a family faces a health crisis or developmental issue, the whole family is affected by this change and must adapt.

Recognition of this concept has driven emerging ideas regarding best practices in health communication that emphasize the importance of evaluating and treating the whole family system rather than just the individual's presenting concern (Galvin, Dickson, & Marrow, 2006; Segrin & Flora, 2005; Wanzer et al., 2004; Hare et al., 1989). To treat the whole family system and build a foundation for effective communication with the whole family system, it is important to better understand how family systems function especially in relation to a presenting health concern (Hare, Skinner, & Kliewer, 1989). Family systems theory provides a meaningful way to evaluate family functioning with a particular focus on adaptation and coping styles as well as on family dynamics and communication styles.

There are several examples in the literature where family systems theory and its related models have driven the exploration of how families function and cope in the face of illness and long-term impairment. A few specific examples that have been examined in the research include families coping with traumatic brain injury, stroke, autism, and leukemia (Altiere & Kluge,

2008; Clark, 1999; Hare et al., 1989; Kosciulek & McCubbin, 1993; Manning, Wainwright, & Bennett, 2011; McCubbin, Thompson, Thompson, McCubbin, & Kaston, 1993; Pakenham, Sofronoff, & Samios, 2003; Xu, 2007). These studies used a family systems framework to explore many aspects of family functioning including how families communicate with each other and their health care providers, and perhaps most importantly how their unique sociological and cultural differences influence their expectations and perceptions of their communication with health care providers.

For example, Manning et al. (2011) examined the role of stress and support factors in studying how families in the United States adapt to raising a child with Autism. Their sample included 195 families from varying backgrounds (59% European American; 17.4% African American; 10.8% Latino; 6.7% Asian; 5.6% Multiracial; .5% Native American). The majority of the participants reported some level of college education (72.5%). The factors examined using hierarchical linear regression were based on the Double ABCX model, a family systems centered model that examines family coping outcomes (xX) in relation to the families' stressors (aA), resources (bB), and definition of the event (cC) (McCubbin et al., 1983). For their study, the researchers chose the following related factors to predict family functioning and parental distress: life stress, Autism severity, child behavior severity, support of family, friends, parents, and others, reframing or redefining of event, subjective social status, coping by relying on family and friends, and coping by seeking spiritual support.

All of the above factors were measured via surveys completed by the parents of children with Autism. Overall, Manning et al. found that their model predicted 28% of the variance in family functioning, and 46% of the variance in family distress. Behavior severity ( $\beta = -.21$ ), the family's ability to reframe or redefine the disorder ( $\beta = .37$ ) and the family's subjective social status ( $\beta = .29$ ) were noted as the most unique predictive factors in both models. Additionally,

cultural differences were noted for some of the factors. African Americans and Latinos reported significantly higher reliance on seeking spiritual support than European Americans, whereas European-Americans and Asian Americans demonstrated significantly higher levels of receiving informal support from family and friends.

### **Caregiver Education and Perceptions**

Critical aspects of the effectiveness of the health care provider and patient communication are the perception and understanding of the caregiver. If the caregiver does not understand the information provided by the health care professional or attribute the same meaning to the information as intended by the health care professional, there will be a lack of follow through and likely frustration on both sides. One example of this is found in a study examining caregivers' understanding of growth charts (Ben-Joseph, Dowshen, & Izenberg, 2009). The majority of the participants were Caucasian (77%) and had some level of college education (74%). The participants responded to questions about growth charts via an online survey. The researchers found that although the majority of the parents (64%) thought doctors should use growth charts to show parents how their child was growing, a large percentage of the parents who participated in the study could not accurately identify a child's weight when plotted on a growth chart (46%), or a child's plotted percentile on the growth chart (32%). Moreover, 44% could not explain the meaning of the term percentile. Overall, the researchers found that only 8% of the parents correctly interpreted the provided charts with plotted points for both height and weight. Thus, the parents in this study, while they reported liking the growth charts, did not fully understand the implications of the weight and height charts. These results illustrate a common concern when evaluating health care provider and patient communication, as resources are often provided that may initially appear to be helpful, but upon further investigation are found to be vague or confusing (Cloutier, Lucuara-Revelo, Wakefield, & Gorin,

2013). It is important that the health care provider find ways to evaluate their patient's understanding and seek ways to clarify and enhance their patient's knowledge as needed.

The concepts explored in the health communication literature can provide helpful insights to SLPs in regard to their communication with clients and caregivers. SLPs face many of the same challenges as doctors and nurses in regard to sharing information effectively, encouraging follow-through on recommendations, increasing positive outcomes, and ensuring satisfaction (Burns et al., 2012; Cortazzi & Jin, 2004; A. Ferguson & Armstrong, 2004; M. Ferguson & Spence, 2012). However, the SLP and client/caregiver relationship is different in nature and scope from the doctor-patient or nurse-patient relationship, thus suggesting several potential differences in SLP communication practices. For example, SLPs often engage in habitual and long-term relationships with their clients and clients' caregivers, sometimes interacting on a bi-weekly basis over the course of many years. In some cases, SLPs meet with clients/caregivers in their homes. In fact, SLP services that are centered on client and family needs are a key component in ASHA's (2005) evidence-based practice initiative that seeks to improve the quality of service provision.

### **SLP and Client/Family Centered Practices**

The importance of family centered practices, practices which consider family values and involve the client and their families in the decision making process, is well recognized within the field of speech-language pathology (Crais et al., 2006a; Hidecker et al., 2009; Payne, 2009). Established professional practices outlined in various ASHA guidelines promote extensive family involvement particularly when providing services to young children and elderly adults (e.g., ASHA, 2008; 2006; 1997). Family involvement in the evaluation and treatment process is emphasized by special education law (IDEA 04) that mandates family participation in the creation of Individual Education Plans (IEPs) and Individualized Family Service Plans (IFSPs).

Practice guidelines within the field of communication disorders support the importance of focusing on the whole family system as opposed to just the individual with a communication disorder, noting that effective treatment must always consider a client's environment for therapy to be truly effective (Andrews, Andrews, & Shearer, 1989; Crais, 2011; Hartshorne, 2002; van Kleeck, 2013). The significance of the client's larger environment is especially noteworthy when considering that children are typically very dependent on their caregivers. Children are frequently limited in the information they can provide, and they often have a limited level of active control over their environment. Therefore, children with language disorders are rarely served as an individual unit, but rather within the context of their family or caregivers. Early intervention services for example, are often provided in the family's home, and services provided through the school system or private clinics typically involve caregivers in the evaluation and therapy process (Crais et al., 2006a; Hidecker et al., 2009).

In order for the SLP to provide optimal services, an ongoing and trusting therapeutic relationship must be established between the caregiver and the SLP (Simmons-Mackie & Damico, 2011). Information must be exchanged and mutual acknowledgement of each party's contributions and competencies must be recognized. This requires ongoing communication, much of which is directed and encouraged by the SLP. Opportunities for SLP and caregiver communication manifest themselves in many ways over the course of the initial evaluation and treatment process (A. Ferguson & Armstrong, 2004). Initially, SLPs gather information about the communication concern and try to assemble a full picture of the child's history and current status from the child's caregivers. In addition to learning about the child's communication abilities and weaknesses, this process involves identifying the family's primary concerns and needs, as evidence-based practice dictates that evaluation and treatment decision making must consider what is important to the family (ASHA, 2004; Hidecker et al., 2009).



Lutterman and Kurtzer-White (1999) examined caregiver perceptions of necessary supports during the diagnosis or identification process. Seventy-five caregivers of children with a diagnosed hearing loss were surveyed regarding how they felt about their experiences in being informed of their child's hearing loss. The participants primarily lived in the Boston area and had participated at some point in a program for the deaf and hard of hearing at Emerson College. The researchers collected responses via a five-question survey. Specific questions focused on the timing of the information, the manner in which the information was given, who gave the information, and what resources would be the most helpful to parents of children with a newly identified hearing loss. The questions were left open-ended so that parents were not restricted in the information they could provide. Despite the open-ended nature of the questions, there was a great deal of consensus in several of the responses, and several key points were noted.

First, timing was a common theme. The majority (83%) of the parents wanted to be informed of their child's hearing loss as soon as possible, but perhaps even more importantly, many of the parents noted the importance of carefully timing the sharing of further information about the disorder. The researchers found that while the caregivers desired to know detailed information about the disorder, they often felt overwhelmed if too much information was provided too quickly without time to process. To avoid overloading caregivers with too much information, professionals must find a balance between giving caregivers the information they need and not providing an overwhelming number of details too soon. The caregivers also emphasized the importance of having the information shared with them in an empathetic and companionate manner. Eighty-two percent of the participants used words such as "kindness, sympathy, calm, support, gently, and with honesty" when describing how the information should be shared. Additionally, the parents in the study connecting with other parents raising children with a hearing loss (69%), receiving unbiased information (46%), and receiving emotional

support from the health care professional who diagnoses and/or treats their child (26%). While providing appropriate family centered support can look different across families, this study suggests that there are some common needs across families, especially when focusing on a single disorder. Other studies examining caregiver needs have found similar themes including the provision of truthful and unbiased information, acknowledgment of the caregiver as a capable contributor, assistance in finding timely, appropriate and, accessible resources, and finally sensitivity and awareness to the changing needs of the client and their caregivers (Fitzpatrick, Angus, Durieux-Smith, Graham, & Coyle, 2008; Fitzpatrick, Graham, Durieux-Smith, Angus, & Coyle, 2007; D. Luterman & Kurtzer-White, 1999a).

Providing clear, detailed, and unbiased information to caregivers during the initial evaluation and throughout the treatment process can be a challenging task. Hand's (2006) analysis of discourse between SLPs and caregivers revealed that SLPs were not as informative or clear as they thought they were during initial diagnostic interviews. The study examined the information given to caregivers of children with varying communication concerns (voice, stuttering, language, speech). Only one of the twelve caregivers had previous experience with a speech and language evaluation. Additionally, the majority of the caregivers represented non-dominant cultural backgrounds in Australia where the study took place (e.g. Lebanese, Malaysian, Iranian). Types of information that were examined included information regarding the purpose and procedures of the assessment, the purpose of the information requested or tested by the clinician, and information about the nature of services provided. Overall, Hand found that limited information was given, and the information that was given was not conveyed in a systematic and competent manner, nor were strategies used to ensure that the information being provided was understood. As her sample included SLPs with a variety of years of experience, Hand contended that effective communication skills do not necessarily come with experience.

Hand (2006) did not ask the caregivers in her study how well they understood the diagnostic information provided to them. However, the importance of clients and/or caregivers having a clear understanding of the disorder and the purpose of therapy has been noted consistently in the literature exploring SLP and client/caregiver collaboration (e.g., R. Fourie, 2009; Robert Fourie et al., 2011; Simmons-Mackie & Damico, 2011; Woods et al., 2011). Fourie et al. (2011) explored how children perceived their therapeutic relationship with SLPs. Using a qualitative “phenomenological” approach, which focuses on description of how multiple individuals collectively describe and interpret a common lived experience, such as receiving speech therapy, Fourie and colleagues interviewed six Irish monolingual children between the ages of 5 and 12 years with varying communication impairments (e.g. phonological delay, speech and language delay). During the interviews, the researchers asked the participants questions about their experiences in therapy such as “tell me your best memory about working with [name of clinician]” and “what would you change about your speech and language therapy” (p. 314). The interview responses were analyzed and coded by the researchers, first by the researcher who had conducted the interview, and then by the participating researchers. Several themes emerged including the identification of the SLP as fun and therapy as a ritual or routine. However, one of the emerging themes of particular note was that the participants frequently did not understand the role of the SLP or the purpose of therapy. This is a concerning theme as the lack of clear roles and purpose can have detrimental effects on reaching treatment goals (Sharynne McLeod & Bleile, 2004). Therefore, it is important that in communicating with clients and client’s caregivers, everyone’s roles are clearly established and the goals of intervention are understood and agreed upon by those involved in the process. The level of understanding and clarity required to establish a productive relationship varies depending on the client’s age, needs, and desire for information. However, having an appropriate knowledge base

of the communication disorder being treated is an important first step for the client/caregiver (Crais, 1991; Woods et al., 2011).

### **Caregiver Communication and Language Disorder Labels**

In order to ensure that the caregiver of a child with a language disorder can engage in a collaborative relationship with the SLP, the SLP must assist the caregiver in understanding what constitutes a language disorder (Schuele & Hadley, 1999). Considering that children with language disorders present with a variety of complex characteristics and challenges, it can be very challenging for an SLP to define language disorders to a caregiver in a comprehensive and understandable manner. Therefore it is important, that SLPs make intentional, strategic choices about how they share information with the caregiver of a child with a language delay or disorder (Woods et al., 2011). According to some researchers, one of the strategic choices that SLPs can make when communicating with caregivers regarding language disorders is the use of a consistent and meaningful diagnostic label in the identification of children's language impairment (D. V. M. Bishop, 2014; C. Dollaghan, Nelson N. W., & Scott, C., 2012; Schuele & Hadley, 1999).

A variety of terms or labels have been used to describe children with language impairments. Some terms used over the years include speech/language delay, late talker, speech/language disorder, speech/language impairment, childhood aphasia, developmental dysphasia, developmental language disorder, primary language impairment/disorder, specific language impairment (SLI), language learning disability (Schuele & Hadley, 1999). Currently, SLI is the preferred term in the research literature, however, it is infrequently used as a diagnostic label in the clinical setting (C. Dollaghan, Nelson N. W., & Scott, C., 2012; A. Kamhi, 1998; L.B. Leonard, 2014; Mabel L. Rice, Wexler, & Cleave, 1995; Schuele & Hadley, 1999). The lack of continuity in the terms from one SLP to the next used to describe children

with SLI can lead to confusion and a potential misunderstanding when communicating with caregivers; leaving the caregiver uninformed regarding the nature of their child's impairment.

Several professionals have offered opinions and suggestions regarding diagnostic labels and their potential importance (e.g.; Aram, Morris, & Hall, 1993; D. V. M. Bishop, 2014; A. Kamhi, 1998; A. G. Kamhi, 2004; Reilly et al., 2014; Schuele & Hadley, 1999; Silliman & Berninger, 2011). Schuele and Hadley (1999) point out that providing caregivers with a diagnostic label can help caregivers understand *why* their child has difficulty with language. Additionally, applying an appropriate diagnostic label can assist in clarifying the need for, and purpose of intervention. Finally, giving caregivers a diagnostic label can potentially help them access a large body of knowledge related to their child's language disorder, helping them better understand the disorder, how it affects their child, and the role they can play in improving their child's outcomes.

However, a diagnostic label is not enough on its own. In providing the diagnostic label, SLPs still must educate caregivers regarding the associated characteristics of childhood language disorders (C. Dollaghan, Nelson N. W., & Scott, C., 2012; Schuele & Hadley, 1999). The following section will provide an overview of how childhood language disorders are defined in the literature and what is currently known regarding cause, prevalence, long-term consequences, and primary characteristics. The information presented in this section represents a fairly large selection of information that an SLP could share with caregivers regarding child language disorders depending on the age, severity, and presenting concerns of the child being evaluated/treated.

### **Childhood Language Disorders**

Children with language disorders are a complex and heterogeneous group that can be difficult to accurately identify and describe in a comprehensive manner, especially for children

who present with language as their only or primary impairment. Generally, language disorders in children are divided into two broad categories, secondary and primary. Secondary language disorders are language impairments that occur as the result of some other disability or developmental factor such as cognitive impairment, a genetic syndrome, or a neurological deficit (Laws & Bishop, 2003). In contrast, children with a primary language impairment present with a significant and persistent difficulty in their language understanding and/or production, but no clearly identifiable cause or precipitating factor such as neurological impairments, cognitive delays, or genetic syndromes (Tomblin, Records, & Zhang, 1996). Currently, two terms are frequently used in the literature to describe children with language as a primary concern; late talkers and children with specific language impairment or SLI (Paul, 1996; Schuele & Hadley, 1999). Late talker is a term applied to young children, typically toddlers, who are delayed in meeting their speech and language developmental milestones. SLI is a diagnostic term applied to children who have demonstrated a consistent and significant impairment in ability across multiple domains of language development.

### **Late Talkers**

Children may be identified as having a language delay or as being at risk for a language impairment as early as 18-24 months of age. Children identified as having a language delay at this early age are often referred to as late talkers. The key identifying characteristic of a “late talker” is delayed expressive vocabulary development, in other words, a child that is not producing words as expected. Expressive language, or spoken language delays are usually defined in toddlers as a vocabulary consisting of fewer than 50-70 words and a lack of word combinations (Ellis & Thal, 2008). In addition to expressive or productive language delays, some late talkers are also identified as having poor receptive language skills, meaning they do not demonstrate age appropriate language comprehension abilities. Unlike children with only

expressive vocabulary delays, children with comprehension delays typically use fewer gestures than their peers (Thal & Tobias, 1994). Children with both expressive and receptive language delays are usually at higher risk than those with expressive only delays for being identified as language impaired in the future (Paul, 1996).

Not all children who are initially categorized as late talkers go on to have diagnostically significant language impairment. In fact, the research shows that late talkers will fall into one of three categories. Some late talkers will spontaneously catch up with their peers, sometime between the ages of 3 and 5 years, and develop typical language (Ellis & Thal, 2008). Other late talkers will move forward in their language development after a period of delay and will not exhibit a diagnostically significant impairment. However, due to the delay, their language development will likely always lag behind their typically developing peers. The research suggests that many of these children struggle academically even though they typically do not meet many of the standardized definitions of language impairment; however, some of these children are later identified with language related concerns such as reading and/or writing impairments (Ellis & Thal, 2008; Rescorla, 2002; Mabel L. Rice, Taylor, & Zubrick, 2008; Weismer, Murray-Branch, & Miller, 1994).

Finally, a smaller percentage of late talkers (16-17%) will experience continued oral language difficulties. This final set of late talkers will go on to have long-term language impairments that will significantly affect all aspects of their life (Paul, 1996; Rescorla, 2002; Mabel L. Rice, 2004; Mabel L. Rice et al., 2008). In the research literature, these children are the ones who are typically identified as children with specific language impairment (SLI).

### **Specific Language Impairment**

Children with SLI are characterized by significant and lifelong limitations in language ability not attributable to other developmental or acquired factors such as low cognition,

seizures, poor environment, or neurological impairment (L.B. Leonard, 2014; Mabel L. Rice & Warren, 2005). There is evidence of a genetic component that suggests SLI may be an inherited disorder (D. M. V. Bishop, Price, Dale, & Plomin, 2003; Dorothy V. M. Bishop, Laws, Adams, & Norbury, 2006; Li & Bartlett, 2012; Mabel L. Rice, 1997; Mabel L. Rice & Warren, 2005; Tallal, Ross, & Curtiss, 1989). Some of the characteristics of children with SLI include the late appearance of first words, poor lexical development, delayed production of word combinations, noticeable difficulty in the acquisition and production of morphosyntactic structures, a restricted mean length of utterance (MLU), poor phonological awareness, constrained linguistic processing, and overall difficulty formulating coherent and cohesive discourses and/or narratives in comparison to their peers. Children with SLI may also demonstrate poorer speech intelligibility than their same age peers, as well as difficulties with conversational regulation and topic maintenance, both of which can have significant effects on their social language opportunities.

For research purposes, children with SLI are identified by a set of inclusionary and exclusionary criteria: 1) language scores below -1, -1.25, or -1.5 standard deviations of the normative mean, 2) a typical non-verbal IQ score above -1 standard deviation of the normative mean, 3) typical hearing, 4) social skills that are within-normal limits, 5) no oral structure or oral motor abnormalities, and 6) no evidence of a neurological disorder (L.B. Leonard, 2014; Mabel L. Rice, 2004). However, despite these common exclusionary factors, SLI is generally considered a heterogeneous disorder as children with SLI demonstrate varying levels of weakness across their semantic (vocabulary knowledge), morphology (word structure), syntax (sentence structure), and/or pragmatic (social language) skills (e.g.; Bedore & Leonard, 1998; Conti-Ramsden, 2003; Paul & Alforde, 1993).



The diverse presenting characteristics that exemplify SLI make it a challenging disorder to discuss with caregivers. However, there are several key concepts that stand out in the literature as crucial to understanding what constitutes SLI and its potential consequences. The following sections provide an overview of information SLPs could potentially share with caregivers regarding SLI over the course of a therapeutic relationship. Areas addressed include the disorder's possible origins and prevalence, common characteristics, long-term consequences, and connection to reading disorders.

### **Family history and prevalence**

While the specific cause or origin of SLI is not known, there is clear evidence in the literature that SLI may be inherited. Multiple studies have shown possible links between language disorders and certain genetic regions and regulatory genes (e.g., Bartlett et al., 2002; Consortium, 2002; Li & Bartlett, 2012; M. Rice, 2012; M. L. Rice, Smith, & Gayan, 2009). Regulatory genes are genes that influence the function of other genes and three in particular, KIAA0319, CNTNAP2, and FOXP2 stand out in the current literature as potentially relevant to the etiology of SLI (M. Rice, 2012; Wright, 2007). Further research is needed, but KIAA0319 has shown promise in genetic and epigenetic<sup>1</sup> studies. CNTNAP2 has been consistently associated in the research with early language development, and FOXP2, a gene that directly regulates CNTNAP2, has been connected in individuals with a rare and severe form of language impairment characterized by both motor speech and language deficits.

In addition to the research focused on identifying genes related to SLI, several studies that examine family history and current family member language status have also contributed to the evidence of a genetic component of SLI. For example, some studies have used retrospective information obtained through collecting the family histories of those identified as SLI (e.g., D.

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<sup>1</sup> The study of modifications in gene expression caused by DNA, or associated proteins, being manipulated through chemical reactions.

V. M. Bishop & Edmundson, 1986; M. Rice, 2012; Mabel L. Rice, Haney, & Wexler, 1998; M. L. Rice et al., 2009; Robinson, 1991; Stake, 1998). Although incidence levels of affected family members varied (20% to 60%) depending on how SLI was defined, the research presents a clear pattern of higher incidence in families that included children with SLI in contrast to the control families who presented with incidence levels ranging from 3% to 6%. A weakness in these studies is that they relied on reported data from families, often without verification of a diagnosis or lack of diagnosis. In other words, with only family report, incidences of SLI may have been under or over reported due to lack of family awareness. In the same manner, incidences could have been over reported with families inaccurately identifying SLI in an individual. To address this concern, some researchers have conducted direct testing in addition to the family history questionnaires in their studies, obtaining direct test data from family members of children with SLI (Plante, Shenkman, & Clark, 1996; Tallal et al., 2001).

In a study that conducted testing on related family members (parents and siblings) of children with SLI, (Tallal et al., 2001), the authors found that when neither parent presented with a language impairment, 13% of their offspring (other than the child with SLI) were identified as language impaired. However, when one parent presented as language impaired, the rate of offspring language impairment increased to 40%, and when both parents presented as language impaired, the rate of affected offspring increased to 71.4%. Additionally, the authors compared the impairment rate they would have attained through questionnaires only with the rates they obtained through testing and found that their rates were similar, suggesting the validity of family report.

Prevalence rates in the general population are not as high. In an epidemiological study including 2,084 kindergarten children from various urban, suburban, and rural locations in the Midwestern United States, researchers found prevalence rates of approximately 7% (Tomblin et

al., 1997). Tomblin's study included children from a variety of race/ethnic backgrounds and socio-economic statuses. The results did suggest that the Native American and African American children presented with the highest rates of prevalence (approximately 11%), and the Hispanic children with the next highest (approximately 8%). However, as Tomblin et al., point out, some of the assessments used in the study could have been culturally and linguistically biased. Furthermore, the confounding effects of socioeconomic levels and parental education cannot be discounted.

Typically children with SLI are identified around 4-6 years of age; however, as Tomblin et al. (1997) also found, many children with SLI may not ever be identified. Out of the 216 children who met the research-based criteria for SLI in their study, only 29% had a previously reported clinical diagnosis. There are a variety of possible reasons why children with language impairments may be under identified. Unlike speech sound production errors or severe dysfluencies, language impairments are not always as immediately visible. The signs of SLI can go unrecognized by both caregivers and professionals who may not understand the complexities of language development or who may attribute potential indicators of language delay to shyness, poor attention, poor academic ability, or even low intelligence.

Another reason that children who meet the criteria for SLI may not be clearly identified as such possibly relates to the variability in diagnostic labels used to describe childhood language impairments (Dollaghan, 2012). As noted earlier in the discussion of diagnostic labels, many clinical and school based settings do not utilize the term SLI, but may apply a different label or diagnosis. One example to support this claim can be found in verbiage within the Individuals with Disabilities Education Act (IDEA; Department of Education, IDEA Website, 2006). Within the IDEA system, many children who receive services in the schools for a language problem are actually classified under the broad category of speech or speech-language eligibility (Department

of Education, IDEA Website,2006). Therefore, while the nature of the speech-language impairment should be specified in the individualized education program (IEP), an actual label identifying the child as having a language impairment may or may not be noted. Additionally, many children with language impairments are found to have learning or reading impairments as well. Frequently, these children are classified as learning or reading impaired children, and may or may not be identified as also having a language impairment.

### **Linguistic profile**

While there is no one defining marker of SLI, children with SLI do tend to have a distinctive linguistic profile, characterized by weaknesses across vocabulary, morphosyntactic, narrative, and phonological development. In the next few sections, some of the studies that have documented these weaknesses are reviewed. Again, though, the literature documenting the deficits of children with SLI is fairly expansive and an SLP may or may not share details of all these studies with families.

**Vocabulary.** Children with SLI show a clear pattern of slower vocabulary growth as evidenced early on in their delayed word production and word combinations. While the severity of the delay varies depending on the study, in general the research suggests that children with SLI do not begin expressing their first words until close to the age of two and do not begin combining two word phrases until age three or later (L.B. Leonard, 2014; Trauner, Wulfeck, Tallal, & Hesselink, 2000). This is significantly behind the typical expectation of expressive language development that suggests first words should be acquired around 12 months of age, and two word phrases around 18 to 24 months of age (ASHA, 2014).

The differences become more complex as children enter their preschool and school age years. While some studies have found that preschool children with SLI can acquire a similar number of words as their peers, some distinct weaknesses continue to be noted . For example,

children with SLI appear to have more difficulty than their peers with fast mapping, the ability to connect a word and its meaning after only one or two presentations. Dollaghan (1987) found that four to five-year-old children with SLI had more difficulty than typical controls in correctly producing a word taught through fast mapping (Typical Peers  $N = 11$ , 64%, SLI  $N = 11$ , 9%), and Rice et.al., (1994) found that children with SLI showed word learning when the word was presented at least ten times (Pretest  $M = .6$ ,  $SD = .84$ ; Posttest  $M = 3.1$ ,  $SD = 1.1$ ), but not when the word was presented three times (Pretest  $M = 1.2$ ,  $SD = .92$ ; Posttest  $M = 1.4$ ,  $SD = 1.08$ ). In the same study, it was also noted that while the children with SLI did learn new object and action words after multiple presentations, they did not retain the action words when retested a few days later (Posttest  $M = 2.0$ ,  $SD = .67$ ; Retention  $M = 1.2$ ,  $SD = .92$ ), indicating some level of difficulty associated with verb learning.

This pattern of difficulty with verb learning appears to continue into the school years. In another study (J. B. Oetting, Rice, & Swank, 1995), children with SLI were able to learn nouns, demonstrating gain scores ( $M = 1.07$ ,  $SD = 1.05$ ) that were similar to their typically developing peers ( $M = 1.6$ ,  $SD = 1.28$ ). However, the children with SLI showed significant weaknesses in their ability to learn verbs ( $M = -.11$ ,  $SD = 1.66$ ). Some researchers have suggested that children's difficulty with verbs may be related to the morphosyntactic difficulties experienced by children with SLI, as verbs carry grammatical content that is also difficult for children with SLI. Overall, children with SLI tend to exhibit less variety in their lexicon, especially in relation to certain categories such as verbs, often relying on a handful of high frequency options (Goffman & Leonard, 2000; L. Leonard, 1998; Sheng & McGregor, 2010b).

Children with SLI also demonstrate word finding issues (McGregor, Newman, Reilly, & Capone, 2002) which can manifest themselves in a variety of ways. The child may use more non-specific terms such as "stuff" when unable to recall a specific name, choose to use a

synonym (e.g., pants for slacks) or closely related word, or abandon the communication attempt altogether. Accuracy is not always the issue though. In studies examining word finding, children with SLI as a whole, were consistently slower than controls in responding, but showed variance in their ability depending on the context of the presentation and how much linguistic information was provided (Kail & Leonard, 1986; Lahey & Edwards, 1996; Laurence B. Leonard, Nippold, Kail, & Hale, 1983). For example, Kail and Leonard (1986) found that children with SLI were better able to name a picture presented when it followed as the logical “completion” to a sentence than when the children were presented a word without a sentence prompt.

Some research has also suggested that children with SLI may show differences in their lexical–semantic organization that could contribute to word finding difficulties (e.g., Dockrell, Messer, George, & Ralli, 2003; McGregor et al., 2002; Sheng & McGregor, 2010a). Lexical-semantic organization can be described as a network of nodes (the conceptual representation or word), links (the relationship between words) and spreading activation (stimulation of one node leads to activation of related nodes; Collins & Loftus, 1975). In other words, when an individual hears the word *horse*, semantically related words such as *black*, *fast*, *barn*, should be readily available in the individual’s thoughts. Sheng and McGregor (2010a) compared the lexical-semantic organization of children with SLI (N = 14) to their age matched peers<sup>2</sup> (N = 14), and vocabulary matched peers<sup>3</sup> (N = 14). The children in the study were given common object or action words such as *mom* or *cut* and asked to provide a semantically related word. Responses were coded into three categories, semantic associations (e.g., *dog-pet*), clangs (a made up word that alliterated or rhymed with the prompt, e.g., *cow-how*), and errors (e.g., *spoon- July*). The

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<sup>2</sup> Typically developing children who were matched to the SLI group based on similar chronological age, within  $\pm 3$  months.

<sup>3</sup> Typically developing children who were matched to the SLI group on based on similar expressive vocabulary ability, within  $\pm 6$  raw score points on the Expressive Vocabulary Test.

researchers found that children with SLI produced significantly fewer semantic associations ( $M = .57$ ,  $SD = .29$ ) and more errors ( $M = .26$ ,  $SD = .04$ ) and clangs ( $M = .17$ ,  $SD = .08$ ) than their age matched peers ( $M = .85$ ,  $SD = .13$ ;  $M = .14$ ,  $SD = .03$ ;  $M = .01$ ,  $SD = .00$ ). Children with SLI also produced fewer semantic associations and produced more errors than their vocabulary matched peers ( $M = .69$ ,  $SD = .24$ ;  $M = .18$ ,  $SD = .03$ ). These results suggest that children with SLI may have a less robust and efficient lexical-semantic network, making it more difficult for them to access vocabulary quickly and thus contributing to their word finding difficulties.

**Morphosyntax.** Morphosyntax stands out as a particular weakness for children with SLI. In an effort to identify a clinical marker or unique linguistic feature that helps to accurately identify children with SLI an extensive body of literature has focused on studying the morphosyntactic abilities of children with SLI (e.g., Cleave & Rice, 1997; Hadley & Rice, 1996; Leonard, Caselli, Bortolini, & McGregor, 1992; Laurence B. Leonard et al., 2003; Loeb & Leonard, 1991; Oetting & Horohov, 1997; Polite & Leonard, 2007; Redmond, 2003; Mabel L. Rice & Oetting, 1993; Mabel L. Rice & Wexler, 1996; Mabel L. Rice et al., 1995). Overall, these studies have found that children with SLI consistently present as having a limited grammatical system in comparison to their peers, especially in regard to morphemes that are related to tense and agreement marking (e.g., yesterday, he walk\_). Table 1 illustrates some of the major morphosyntactic deficits found in children with SLI on a consistent basis.

In addition to noting the presence of morphosyntactic errors, it is also important to note the frequency or proportion of errors present in a child's speech. Researchers have found that some of the same morphosyntactic patterns that present in children with SLI are also present in children who speak a variety of non-mainstream English (NMAE) such as African American English (AAE) and Southern White English (SWE) (J. B. Oetting & McDonald, 2001). Oetting and McDonald (2001) identified 35 non-mainstream patterns that occurred in both AAE and

SWE including the five patterns identified in Table 1. While several of these patterns can occur in the speech patterns of both children who speak NME and children with SLI, several studies have found that morphosyntactic omissions like the ones listed in Table 1 occur with significantly greater frequency in the speech of children with SLI (J. B. Oetting & McDonald, 2001; Seymour, Bland-Stewart, & Green, 1998). For example children who spoke AAE overtly marked past tense 91% of the time, while children with SLI marked past tense only 50% of the time.

Table 1. Common Morphosyntactic Omissions Exhibited by Children with SLI

Morphemes	Examples	Citation
3 <sup>rd</sup> person singular	“Daddy fix cars”	Leonard et al., 1992 Rice et al. 1995, 1996
regular past tense	“He push him”	Leonard et al., 2003, Oetting & Horohov, 1997; Redmond, 2003; Rice & Oetting, 1993
copula <i>be</i>	“Sara happy”	Leonard 1992, Cleave & Rice 1997, Polite and Leonard, 2007
auxiliary <i>be</i>	“She walking”	Rice et al., 1995, Hadley & Rice, 1996
auxiliary <i>do</i>	“Katie not work today”	Hadley & Rice 1996, Leob & Leonard, 1991, Rice et al., 1996, 1995

Two theories attempt to explain why tense and agreement weakness is part of the linguistic profile of children with SLI. According to the extended optional infinitive theory, children with SLI continue to treat tense as an optional marker past the time that children typically begin to mark tense in an obligatory manner, thus resulting in significantly more omissions of tense related morphemes (Mabel L. Rice et al., 1995). In contrast, the surface theory suggests that several of the morphemes that are difficult for children with SLI are short in



nature and unstressed in speech, leading them to be less noticed and more difficult to learn and comprehend (Leonard et al., 1992). By the time children reach kindergarten, most have mastered of Brown's morphemes including copula and auxiliary *be* and auxiliary *do*, so the difficulty children with SLI have with these morphemes affects their continuing language development and sets them up to be behind from the start of formal education.

Current research suggests that the difficulties with tense and agreement experienced by children with SLI begin in the early stages of language development and continue through the lifespan. Rice et al. (1998) found evidence that children with typical language development demonstrated consistent use of tense and agreement marking between the ages of 3 and 4, while children with SLI were still struggling with consistent tense and agreement marking at 8 years. Hadley and Short (2005) examined tense productivity over time, and found evidence of a delay in onset of tense productivity in the participants who were considered at risk for SLI. Overall, the pattern of difficulty present in the literature suggests that tense and agreement marking is a consistent and distinguishing deficit for children with SLI that can assist clinicians in the diagnostic process (e.g. Conti-Ramsden, 2003; Krantz & Leonard, 2007; Laurence B. Leonard et al., 2003; Laurence B. Leonard et al., 2002; Marchman, Wulfeck, & Weismer, 1999; Oetting & Horohov, 1997; Owen, 2010; Owen & Leonard, 2006; Redmond, 2003; Mabel L. Rice & Oetting, 1993; Mabel L. Rice et al., 1995; Mabel L. Rice, Wexler, & Hershberger, 1998).

**Narratives.** Children with SLI also exhibit difficulty with syntactically complex sentences and tend to use embedded clauses such as, *the girl who wore the red dress*, less frequently than their peers (Gillam & Johnston, 1992). While these difficulties may or may not interfere with children's conversational communication, these types of difficulties become especially apparent when children are faced with academic language requirements such as narrative production. Written language and oral narrative construction, (such as telling or

retelling true or fictional stories), requires more complex sentences than conversational language, and many children with SLI do not have the level of language sophistication required to construct elaborate noun phrases, embed adverbial clauses, or even combine two related sentences. The stories children with SLI produce and/or retell tend to be less grammatically accurate, contain fewer cohesive devices, and include shorter and less complex utterances than their peers (e.g., Fey, Catts, Proctor-Williams, Tomblin, & Zhang, 2004; Gillam & Johnston, 1992; Norbury & Bishop, 2003; Scott & Windsor, 2000). This difficulty in expressing complex and cohesive descriptions significantly impacts children with SLI's overall performance in the classroom, limiting them in their ability to answer questions appropriately and engage in classroom discussions at the same level as their peers.

**Phonology.** A small percentage of children with SLI have difficulties with phonology, the system and rules of sound production. Language production is closely tied to phonology as children must understand how to produce and connect sounds efficiently and accurately in order to produce words in a language. Some research suggests that delayed phonological development or poor speech intelligibility may present as an initial sign of a deeper language problem (e.g., Paul & Shriberg, 1982). However the research also indicates that other than a potential delay, the overall phonological development of children with SLI is often similar to their peers (Leonard, 2014).

First of all, children with SLI appear to show the same pattern of speech sound development as their typical peers. In other words, they tend to acquire sounds in the same order as typically developing children (Leonard, 2014). While there is a great deal of variability in speech sound development depending on the specific speech sound, most speech sounds are mastered between the ages of 3 and 8 (S. McLeod & Bleile, 2003). In a small number of cases though, children with SLI may present with a delayed pattern of development, acquiring the

expected sounds at a later age than their peers (Shriberg, Tomblin, & McSweeney, 1999). For example, one study (Shriberg et al., 1999) found that approximately 5-8% of six year old children with SLI experienced delays in speech production that influenced their intelligibility.

Additionally, children with SLI present with many of the same phonological processes as their typically developing peers such as consonant cluster reduction (*so* for *snow*), liquid gliding (*wed* for *red*), and final consonant deletion (*so* for *soap*; Leonard, 2014). A few notable exceptions include the process of initial weak syllable deletion (*nana* for *banana*), a process that appears to be more prevalent in children with SLI, and pre-vocalic voicing (*du* for *two*), a process that appears to be less frequent in children with SLI (Ingram, 1981). While the pattern of differences between children with SLI and children with typically developing language do not present as overly distinct, early delays in phonological development could impact other areas of development, particularly vocabulary and early literacy skills (L.B. Leonard, 2014).

### **Pragmatics**

In regards to socialization, children with SLI have difficulty interacting appropriately with their peers (Brinton, Fujiki, & Higbee, 1998; Brinton, Fujiki, & Powell, 1997; Brinton, Fujiki, Spencer, & Robinson, 1997; Brinton, Spackman, Fujiki, & Ricks, 2007; Fujiki, Brinton, Isaacson, & Summers, 2001; Fujiki, Brinton, Morgan, & Hart, 1999; Fujiki, Brinton, & Todd, 1996; Kravetz, Faust, Lipshitz, & Shalhav; M. L. Rice, 1993; Mabel L. Rice, Sell, & Hadley, 1991; Stanton-Chapman, Justice, Skibbe, & Grant, 2007). Considering the role that language abilities play in the formation of relationships, it is possible that difficulties with vocabulary, morphosyntax, or even phonology, could potentially interfere with the ability of children with SLI to understand and share messages effectively.

Rice (1993) found that preschool children with SLI were less likely to initiate conversations with their peers and more likely to respond to conversational attempts with

shortened or nonverbal responses. The authors noted that even in preschool, both the children with typical language abilities and the children with SLI appeared to be aware of their communication abilities relative to their peers and showed a preference for interacting with the more competent communicators. The social rejection may in turn lead to less exposure to language and fewer opportunities to refine conversation skills, thus compounding the problem. As noted by Gallagher (1991) social interaction plays a large role in the learning process, especially in regard to language learning.

Children with SLI also have difficulty in maintaining topics and effectively collaborating with peers. Brinton, Fujiki, and Powell (1997) documented this in their study of 30 elementary-aged children (SLI N= 10, Language Controls<sup>4</sup> (LC) = 10, Age Controls<sup>5</sup> (AC) = 10). Topics were presented in two manners, object-verbal (i.e. presenting an object and making a comment regarding the object) and verbal only (i.e. making verbal comments only). Regardless of the presentation format, the children with SLI made more inappropriate comments when trying to discuss a topic introduced by the researcher than their peers (SLI M = 4.3, SD = 5.27; LC M = .02, SD = .6; AC M = .3, SD = .48). They also appropriately maintained a topic only 70% of the time, as opposed to the 96% topic maintenance evidenced by controls. In another study, researchers examined peer participation and collaboration of children with SLI in a cooperative learning task (Brinton et al., 1998). Children with SLI had trouble entering into group interactions, whereas all of the age-matched and language-matched peers in the study successfully entered into groups. Also, the children with SLI who were able to enter the group participated less in the collaborative activity, participating in the activity only 53% of the time as opposed to the respective 90% and 86% of the age-matched and language-matched controls.

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<sup>4</sup> Typically developing children who were matched to the SLI group on similar language scores on the CELF- R, within  $\pm 6$  months on age equivalent score.

<sup>5</sup> Typically developing children who were matched to the SLI group based on similar chronological age, within  $\pm 6$  months.

## **Reading deficits**

The relationship between language and the acquisition of reading has been studied extensively in the literature. (e.g.; Catts, 1986, 1995, 1997, 2001; Catts, Adlof, Hogan, & Weismer, 2005; Catts et al., 2006; Catts, Fey, & Proctor-Williams, 2000; Catts, Fey, et al., 2002; Catts, Fey, Zhang, & Tomblin, 1999; Catts, Gillispie, Leonard, Kail, & Miller, 2002; Catts & Hogan, 2003; Catts, Hogan, & Fey, 2003; Catts, Petscher, Schatschneider, Bridges, & Mendoza, 2009; Fey et al., 2004; Hogan et al., 2005; A. G. Kamhi & Catts, 1986; McCardle, Scarborough, & Catts, 2001; Nelson et al., 2001). Many of the foundational skills necessary for reading have been shown to be related to early language abilities. Studies have consistently shown that children with language impairments have an increased risk for later reading impairments, including those children who only show delays, rather than significant impairment (e.g., ASHA, 2002; Catts et al., 2006; Catts, Fey, et al., 2002; Hogan et al., 2005; Hulme & Snowling, 2011; Nation, Cocksey, Taylor, & Bishop, 2010; Nation & Snowling, 1998; Nation & Snowling, 2004; Rescorla, 2002; H. S. Scarborough, 2001; Snow, Burns, & Griffin, 1998; Snowling & Hulme, 2006, 2011).

Catts and colleague's (1999) followed up with 604 of Tomblin et al.'s (1997) participants and found that over 70% of the students in the study who had language concerns in kindergarten had difficulties with reading in 2<sup>nd</sup> grade. In another study, focused on children identified with SLI (Catts, Fey, et al., 2002), the researchers found that 40% to 65% of the children identified with SLI in kindergarten were found to present with a reading disability in the 2<sup>nd</sup> and 4<sup>th</sup> grade. Even children who appear to recover from early language delays such as late talkers are more likely to encounter difficulties upon entering school and beginning formal reading instruction (Rescorla, 2002; H. S. Scarborough, 2001). While there are many factors that contribute to the development of a reader, the simple view of reading suggests that there are

two key factors that contribute to the success or failure of a reader — their word recognition skills and their language comprehension skills (Scarborough, 2001).

For many children identified with reading disabilities, the primary concern is difficulty with word recognition. Word recognition skills involve phonological awareness, the ability to think about, segment, blend, rhyme, and manipulate sounds in the context of syllables and words, decoding, the ability to recognize letter-sound correspondence to identify and pronounce a written word, and sight word recognition, the ability to remember and easily identify familiar words on sight. Measures of overall phonological awareness have been found to be highly connected to and even predictive of future reading ability (e.g., Catts, Gillispie, et al., 2002; Hogan et al., 2005; Scarborough 2001; Swanson, Trainin, Necochea, & Hammill, 2003). For example, Scarborough's meta-analysis (2001), found that the average correlation between phonological awareness and later reading scores across 27 studies was  $r = .46$ . Additionally, Nation et al.'s (2001) and Snowling et al.'s (1997) studies demonstrated that children with impaired reading abilities consistently presented greater difficulties with phonological skills indicating a complex reciprocal relationship between phonological awareness and reading abilities.

Word recognition also involves decoding, identifying letters and connecting them to the appropriate sound sequences, and sight word recognition, identifying familiar words by memory. Strong phonological awareness skills can assist a reader in decoding or figuring out the pronunciation and meaning of words. Furthermore, the ability to recognize letters and connect specific sounds to letters requires an understanding that individual phonemes are combined to create words. Especially for early readers, using phonological cues to decode unfamiliar printed words is an important skill. Scarborough's (2001) meta-analysis found the mean correlation between letter-sound knowledge/letter identification and reading ability to be  $r = .57$  and  $r = .52$

respectively, when correlated individually, making decoding along with phonological awareness two strong predictors of reading ability.

Children with a reading impairment characterized by poor word recognition skills are often identified as poor decoders or children with dyslexia (Catts, 1995). Children with dyslexia struggle with phonological awareness, sounding out words or decoding, and sight word recognition. Typically, children with dyslexia are distinguished from children with other reading disorders by their intact comprehension abilities. Even though these children struggle to recognize words in print, if the words are read to them, children with dyslexia typically demonstrate a good understanding of the material (Catts et al., 2006).

However, dyslexia is only one type of reading impairment. Many school aged children demonstrate a different kind of weakness in their struggle to comprehend the written words of a text. Children who only struggle with the comprehension piece of reading are often referred to in the literature as poor comprehenders (Catts et al., 2006; Catts, Fey, et al., 2002). Poor comprehenders demonstrate notable deficits in language comprehension but not in their word recognition skills. Several abilities directly related to oral language proficiency, particularly comprehension of language are also essential to the development of an individual's reading competence. Children who struggle with comprehension may successfully decode the text, but lack several critical component skills necessary to allow the reader to understand what is being read. Finally, in addition to poor decoders and poor comprehenders, some children demonstrate deficits across both word recognition and language comprehension skills. These children struggle both to decode the word as well as to understand the word (Catts et al., 2006).

Needed skills for comprehension of a text include critical background knowledge to interpret meaning, vocabulary knowledge to recognize the words being read, syntactic and semantic rule knowledge to understand the relationship of the words, verbal reasoning skills to

make inferences and interpret metaphors, and finally, a basic knowledge of literacy and print concepts to understand the form and function of written texts (Catts et al., 2006; H. S. Scarborough, 2001). In Scarborough's (2001) meta-analysis, she found that the highest average correlations between measures of oral language proficiency and later reading scores were found for general language ability (both expressive and receptive) at  $r = .46$ , expressive vocabulary ability at  $r = .45$ , and sentence or story recall ability at  $r = .45$ . Familiarity with print concepts (familiarity with the mechanics and purpose of reading) also correlated with later reading scores with a mean across studies of  $r = .46$ .

### **Long-term outcomes of SLI**

Individuals who have been identified with SLI typically demonstrate difficulties related to their language impairment throughout school and into adulthood, career/educational (Conti-Ramsden, 2003; Conti-Ramsden, St Clair, Pickles, & Durkin, 2012; Johnson et al., 2010; Poll, 2010; Mabel L. Rice, Hoffman, & Wexler, 2009). Even when improvements are seen, the lingering effects of language impairment continue to affect academic success and socialization of individuals with SLI. Some of the challenges that children with SLI face over their lifetime include ongoing manifestations of language delays, significant struggles with academic and literacy skills, difficulties with peer socialization and collaboration, and lack of autonomy or independence from caregivers (Conti-Ramsden & Durkin, 2008; Schuele & Hadley, 1999). These consequences potentially affect educational attainment, future relationships, and occupational status. While there is limited literature studying adults with SLI, a few researchers have investigated autonomy (Conti-Ramsden & Durkin, 2008), comprehension of legal rights (Rost & McGregor, 2012) achievements (Conti-Ramsden & Botting, 2008; Conti-Ramsden, Durkin, Nippold, & Fujiki, 2012; Durkin, Simkin, Knox, & Conti-Ramsden, 2009; Johnson et



al., 2010), and quality of life (Johnson et al., 2010; Records, Tomblin, & Freese, 1992). Table 2 summarizes the key results.

Table 2. Long-term Outcomes for Individuals with SLI

Articles	Topic	Findings
Conti-Ramsden & Durkin, 2008	Autonomy/Independence	Per parental and adolescent self-report measures, adolescents with SLI were found to be less independent than their typical language peers.
Rost & McGregor, 2013	Comprehension of Legal Rights	Individuals with SLI were significantly poorer than their peers with normal language at defining Miranda vocabulary and applying Miranda rights in hypothetical situations.
Johnson, 2010 Conti-Ramsden & Botting 2008 Conti-Ramsden et al., 2012 Durkin et al., 2009	Career/Educational Achievements	Young adults with a history of SLI show lower levels of educational attainment and occupational status than their peers with typical language.
Johnson, 2010 Records, 1992	Quality of Life/Satisfaction	No notable differences in subjective perception of quality of life in comparing individuals with SLI and individuals with typical language.

Conti-Ramsden’s and Durkin’s (2008) work offers one example of a study focused on the long-term consequences of SLI in adolescents. They examined the impact of SLI on adolescent’s ability to develop independent functioning. The study included 120 adolescents (M age = 15;9) with a history of SLI and 118 adolescents (M age = 15;11) with typically developing language attending mainstream schools in England. The researchers measured independent functioning through parental and adolescent questionnaires that focused on the adolescent’s ability to complete everyday activities independently such “*Are you/is he able to go to a local shop to do some shopping?*” and “*Can you/can he take a phone message?*” (Conti-Ramsden &

Durkin, 2008, p. 74). In total, 11 questions were asked of the parents, and seven questions (of the parent's 11) were asked of the adolescents.

The results, based on a minimum possible score of 0 (no independent functioning) to a maximum possible score of 11 (high independent functioning), showed that adolescents with a history of SLI were reported by their parents to be significantly less independent ( $M = 7.0$ ,  $SD = 2.7$ ) than adolescents with typical language development ( $M = 9.7$ ,  $SD = 1.0$ ). Self-reports from the adolescents with SLI indicated that they also perceived themselves to be less independent ( $M = 4.7$ ,  $SD = 1.6$ ) than their peers with typical language development ( $M = 6.2$ ,  $SD = 0.8$ ). Additionally, regression analyses controlling for nonverbal IQ showed that measures of expressive language and reading comprehension accounted for approximately 16% of the variance in independent functioning, emphasizing the significance of language competence and literacy skills in independent living. Their results reflect one of many examples in the literature that connect language and reading abilities.

### **Summary of SLI Literature**

In summary, children with SLI present with several defining characteristics that combine to form a complex and unique profile. First of all, there are clear indications of a genetic basis for SLI (Li & Bartlett, 2012; M. Rice, 2012). Multiple genes have been consistently connected to SLI in genetic and epigenetic studies, and prevalence rates in children with a family history of SLI are significantly higher than those in the general population. Information related to cause and prevalence may be especially important for SLPs to share when caregivers express a desire to understand the cause of their child's language disorder. For some caregivers, understanding the origin of their child's language disorder is crucial to their acceptance of the disorder and recognition of the role of treatment (Schuele & Hadley, 1999).

Secondly, the linguistic profile of children with SLI is characterized primarily by significant delays in vocabulary and morphosyntactic development (L.B. Leonard, 2014; Stake, 1998). In particular, children with SLI have been shown to struggle with learning verbs and with consistently marking tense and agreement. These persistent delays can lead to negative academic consequences particularly in the areas of reading, writing, and narrative development. In addition to academic consequences, children with SLI may also face social challenges due to their difficulty in initiating conversations and engaging in collaborative activities. Information related to their child's strengths and weaknesses may help caregivers anticipate challenges and engage in preventive collaboration with SLPs, teachers, and other professionals early on. Additionally, a good understanding of the characteristics of SLI can assist caregivers in understanding the purpose of intervention strategies and be actively involved in choosing appropriate goals for their child's needs (Woods et al., 2011).

Finally, the long-term consequences of both the academic and social limitations faced by children with SLI can be long reaching, influencing personal, educational, and occupational success. Reading difficulties in particular stand out as a concern, as many children with language difficulties also struggle as readers, further impacting their future educational and occupational opportunities. Understanding the long-term consequences of SLI can potentially help caregivers to have realistic expectations of their child's progress over time, as well as encourage them to be proactive in addressing potential areas of concern such as reading and daily living skills (Conti-Ramsden, Botting, & Durkin, 2008; Conti-Ramsden & Durkin, 2008; Durkin et al., 2009).

Based on the information presented in the literature, SLPs need to be prepared to share a variety of information with caregivers regarding SLI. Information related to the disorder's origins, prevalence, characteristics, long-term consequences, and connection to reading could all

serve to increase a caregiver's understanding of what SLI is, and encourage a caregiver's ongoing involvement in treatment. The exact nature of the information that should be shared likely varies depending on the age of the child, the manifestation of the language disorder, and the point in time at which an SLP is interacting with a caregiver. Overall, the SLI literature presents a good foundation of information that SLPs can draw from to educate caregivers about SLI and language related concerns such as reading disorders. However, there is currently no empirical research that provides clear guidance regarding what language disorder information SLPs should share with caregivers in order to encourage effective collaboration and intervention.

### **Qualitative Research**

The goal of this study was to learn about how caregivers perceive SLP's communication about language. Given this, the data were primarily gathered through talking with caregivers of children with language related disorders. A qualitative research methodology was employed to explore caregiver perceptions regarding how SLPs talk with them about language disorders. Qualitative research as defined by Damico and Simmons-Mackie (2003) "refers to a variety of analytic procedures designed to systematically collect and describe authentic, contextualized social phenomena with the goal of interpretive adequacy" (p.132). Qualitative methods are typically considered most appropriate for exploring a largely undefined phenomenon that is complex in nature, does not necessarily present with defined variables, and therefore cannot be adequately addressed by traditional statistical measures. Unlike quantitative research where narrow and specific questions are preferred, the best questions in qualitative research are broad questions that allow the researcher "to explore the general, complex set of factors surrounding the central phenomenon and present the broad, varied perspective or meanings that participants hold" (Creswell, 2014, p. 140). Furthermore, Strauss and Corbin (1998) note that "qualitative methods can be used to obtain the intricate details about phenomena such as feelings, thought

processes, and emotions that are difficult to extract or learn about through more conventional methods” (p. 11). For the current study, a collective case study approach was utilized and data were collected via semi-structured participant interviews and a review of diagnostic reports that had been written by the SLPs and given to the caregivers.

### **Case Studies**

A collective case study approach explores phenomena by looking at one or more cases within a setting or context, and commonly involves the collection of in-depth data, typically through multiple sources such as observations, interviews, and material reviews. Case study research has been defined by Stake (2005) as the entity the researcher chooses to study rather than as a methodological choice, while other researchers view it as a methodology or type of qualitative research design, as well as the unit of study (Creswell, 2007; Yin, 2003). A case can include an individual, a role, a small group, an event, or any phenomenon that is defined by some context. Individuals or cases in a collective case study may possess both similar and dissimilar characteristics allowing the researcher to better understand and explore both the individual voices and the commonality of a shared experience or phenomenon (Stake, 2005). By exploring concepts and themes within and across cases, the researcher identifies important patterns and contrasts (Miles, Huberman, & Saldana 2014).

The collective case study has been used fairly extensively in the field of communication disorders as well as in the related area of special education to explore topics connected to professional and family relationships (Angell, Bailey, & Stoner, 2008; Angell et al., 2009; Bailey, Parette, Stoner, Angell, & Carroll, 2006; Brady, Skinner, Roberts, & Hennon, 2006; R. Fourie, 2009; Robert Fourie et al., 2011; Shelden et al., 2010; J. Stoner, Angell, House, & Bock, 2007; J. B. Stoner et al., 2006; J. B. Stoner et al., 2005). For example, Angell and colleagues (2009) used a collective case study approach to examine the nature of trust between parents of

children with disabilities and school personnel. Through examination of the individual cases, as well as comparisons across the participants, the researchers obtained detailed information regarding how the parents defined trust, what they viewed as authentic caring, and how school climate influenced the building of trust.

In another study (Angell, Bailey, & Stoner, 2008) that examined the perceptions of caregivers of children with dysphasia, a collective case study approach was utilized to learn more about what factors caregivers believed facilitated or inhibited effective dysphagia management in the schools. Cross analysis, an analysis of each participant/case transcript individually, followed by a comparative analysis of all participants/cases transcripts, was employed to examine each caregiver's perceptions and responses. The resulting data offered generalizable, yet detailed information regarding the types of SLP practices or behaviors that caregivers felt were facilitative or inhibitory to their child's dysphasia management. In both of these examples, the qualitative nature of the study allowed for greater details and deeper understanding of the phenomenon of interest while still including multiple perspectives.

### **Semi-structured interviews**

The semi-structured interview is a commonly used method of data collection in qualitative research and is used frequently as the primary source of information. The interview process is especially useful when seeking to gain an individual's perspective regarding a phenomenon they have experienced or are experiencing. While similar to a conversation, a qualitative research interview has an added structure and a purpose that is pre-determined by the research question/s the researcher is endeavoring to answer. Through the interview process, the researcher attempts to understand the phenomenon being explored from the informants' or participants' point of view.

Semi-structured research interviews represent an organized yet open ended method of collecting participant viewpoints. Kvale (1996) defines the semi-structured interview as “an interview whose purpose is to obtain descriptions of the life world of the interviewee with respect to interpreting the meaning of the described phenomena” (Kvale, 1996, p. 5-6). Its purpose in qualitative research is to provide a structured manner through which the researcher can better understand the participants’ experiences and perspectives. While a level of control is exercised in that specific themes or topics are covered, the semi-structured interview remains open in that the researcher is not tied to a specific set of required questions but rather focuses on guiding the conversation with a few open-ended questions, and follow-up comments or questions, in a manner that encourages the interviewee to expand upon the desired theme. Unlike questionnaires or surveys, the semi-structured interview allows the researcher to engage in face-to-face encounters with participants, encounters that allow for the researcher to engage in clarifying or follow-up questions and check his/her understanding and interpretations of meaning with participants (Kvale, 1996).

Semi-structured interviews have been used as the primary method of data collection in several qualitative research studies within the field of communication disorders (R. Fourie, 2009; Robert Fourie et al., 2011). Fourie (2009) examined how relationships evolve between the client and the SLP using a semi-structured interview approach. As seen in Table 3, the researcher formulated general open ended questions, designed to elicit theoretically relevant data using a grounded theory approach (Glaser, 2002; Skeat & Perry, 2008). Follow up questions were asked as necessary to clarify when answers were vague or lacking in relevance.

In a similar study, Fourie et al. (2011) also explored how children perceived their therapeutic relationship with SLPs. The researchers used a similar interview process, choosing general open ended questions first (e.g., “Tell me about ...”), followed by more direct questions

(e.g., “What did you do with .....”). In contrast to the adult interviews though, the researchers engaged in arts and crafts and interactive games with the children while asking questions.

Table 3. Fourie, 2009 Interview Questions

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1.	What were you expectations of speech and language therapy and were these expectations met?
2.	Aside from the exercises or activities your therapist did with you, were there any particular things the therapist said or did that you found especially helpful in therapy?
3.	What advice would you give a therapist in the future who had a client like you?
4.	Could you tell me the story of your best and worst therapy sessions?

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The semi-structured interview used by Fourie et al. (2009; 2011) and other researchers (e.g., Angell et al., 2008; Angell et al., 2009; Shelden et al., 2010) provides an appropriate methodological model for examining caregiver perceptions of SLP communication. The interview format allows caregivers to express a variety of opinions, feelings and perspectives regarding their experiences communicating with SLPs. Additionally, the use of broad open ended questions allows caregivers to share the information that they feel is most applicable and true to their experiences without being restricted to pre-selected choices that could limit their input. Finally, the semi-structured interview allows for individualization as appropriate, providing the researcher opportunities to ask follow up questions and further explore specific experiences or responses expressed by caregivers (Kvale, 1996).

### **Goals and Research Questions for Current Study**

The goal of this study was to learn more about SLP communication practices, in particular how SLP communication about language disorders is perceived by caregivers of children with language related disorders. As noted in the discussion of childhood language disorders and SLI, there is a great deal of information regarding language disorders that SLPs



could potentially share with a caregiver depending on the caregiver's needs and the needs of his or her child. Also of interest, was how SLPs share information with caregivers. Other studies examining health care provider and SLP communication have noted that the timing of information, the clarity of information, as well as the manner in which the information is shared can influence how caregivers perceive and recall the information received (e.g., Hand, 2006; D. Luterman & Kurtzer-White, 1999a; M. B. Wanzer et al., 2004).

There are relatively few studies in the literature that have examined the professional interpersonal practices of SLPs, and none identified in the literature that focus on how SLPs communicate with caregivers about childhood language disorder. Therefore, as an exploratory study, no specific aspect of information related to language disorders or manner of sharing information was specifically targeted. Rather, this study sought to discover from the caregivers' perspective what types of information caregivers recall receiving from SLPs regarding language disorders, how they understood and interpreted that information, and what aspects of that information they considered to be helpful to them and their child. However, based on caregiver responses to open-ended questions, the researcher did ask follow-up questions regarding specific content information (see Appendix A). The following research questions were addressed:

1. How do caregivers of children with language related disorders perceive SLP communication with them regarding language delay and disorders?
  - a. What information do caregivers describe receiving from SLPs regarding language delays and disorders?
  - b. How do caregivers describe their understanding of language delays and disorders?
2. What SLP communication practices do caregivers of children with language related disorders identify as effective or non-effective in building the therapeutic relationship?

- a. What SLP communication practices or resources do caregivers perceive to be helpful or unhelpful in increasing caregiver knowledge of language disorders?
- b. What SLP communication practices or resources do caregivers perceive to be helpful or unhelpful in increasing caregiver involvement/collaboration?

## CHAPTER THREE: METHODS

### Participants

A purposeful sampling technique was employed in choosing participants because it allowed the researcher to intentionally select individuals who would assist in learning about a particular phenomenon (Creswell, 2012). Therefore, participants were recruited from among clients at a university speech and language clinic. Based on the research reviewed in chapter two, the criteria for inclusion were:

1. Each participant was a caregiver of a school age child with a diagnosed reading disorder, confirmed by a clinical evaluation report on file at the university clinic. The research indicates a strong connection between language delays/disorders and reading, caregivers of children with reading disabilities presented as a population that should be receiving information regarding language disorders (Catts et al., 2006; Catts, Fey, et al., 2002). If the study had restricted its focus to children formally diagnosed with SLI, many potential caregivers would have been excluded, as children with a primary language impairment or SLI are not commonly identified as such in the school setting (National Dissemination Center for Children with Disabilities, 2012; J. B. Tomblin et al., 1997).
2. Each participant was the caregiver of a school age child who had been evaluated for reading and language concerns at the university speech and language clinic within the past 1 and ½ years. This criterion ensured that each participant included in the study had at least one relatively recent opportunity to communicate with an SLP regarding their child's language.
3. Children of participants had recent (within 1 and ½ years) language evaluation information on file. The research indicates that language performance can change over time, and that even children who appear to have recovered can continue to present with

language weaknesses (Dale, McMillan, Hayiou-Thomas, & Plomin, 2014; Hollis S. Scarborough & Dobrich, 1990). Therefore, it was important to have a recent evaluation in order for the researcher to have the most accurate picture of the child's current language status.

4. Children of participants and participants were all native English speakers.
5. Children with concomitant speech disorders were included. The research indicates that some children with language delays and disorders also demonstrate delays in phonological development (Shriberg, Tomblin, & McSweeny, 1999).
6. Children of participants presented with no documented cognitive, developmental, or neurological disorders that would have indicated a secondary rather than primary language disorder (Leonard, 2014).
7. Caregivers were all part of the household in which the child primarily or jointly resided and participated in the decision making about the child's care and education.

After receiving IRB approval from both the university where the study was conducted and the university where the researcher was a doctoral student, the potential participants were approached with the assistance of the SLP working directly with the family. Every participant who was approached agreed to participate. A total of twelve caregivers participated in the study, and two of the caregivers (a married couple) were interviewed together. Each participant was given information about the study and asked to sign a consent form before being interviewed. The interviews lasted approximately 45- 60 minutes. Monetary compensation was not offered as the site where the study took place did not encourage financial compensation for participation in research. The potential research and clinical benefits for caregivers and SLPs were shared with the participants. Additionally, all participants were given the opportunity to have a follow up meeting with the researcher, following the researcher's initial analysis of the

interviews. The follow up meetings allowed the participants to be informed of, and comment on the researcher's findings.

The researcher recruited caregivers from 10 family units. Eight of the ten family units recruited consisted of one primary caregiver participating in the interview. Two married caregivers represented one family. Additionally, two divorced caregivers represented one family. The research is limited regarding how many interviews are necessary to provide comprehensive data, but saturation of data is the objective. Some studies have suggested that this can be achieved with as few as 5-6 participants (e.g.; Guest, Bunce, & Johnson 2006; Kummerer, Lopez-Reyna, & Hughes; Fourie, 2009; Shelden, Angell, Stoner, & Roseland 2010). Since this is an exploratory study, a variety of caregiver/family types were included in the sampling. Demographic and social information was collected from each participant as part of the interview (see Table 4 for details).

As illustrated in Table 4, caregivers came from a variety of educational and occupational backgrounds, though it was noted that four of the twelve caregivers worked in healthcare related fields. Most of the participating caregivers were mothers, however, two fathers participated. Caregivers' level of experiences with SLPs varied. For some, their only experience had been at the university clinic, but others had multiple experiences to draw from including experiences with early intervention providers, school based providers, and the university clinic providers. All of the caregivers had some level of college education, with most having a bachelor's degree, possibly a characteristic that led them to seek services at a university clinic. Finally, the participants lived in both rural and city locations. Location was included as it may have influenced caregiver choices in seeking out SLP services. Of the caregivers who lived in the city, four of the five were receiving services from the university clinic. Of the five participants who live outside of the city, only one was receiving services at the university clinic.

Table 4. Caregiver Characteristics

Caregiver	Caregiver Role/s	Caregiver Occupation	Caregiver Education	Marital Status	Previous SLP Contact	Rural/ City
Mrs. A	Mother	Stay at home mom/ Home schools	Bachelors in education	Married to child's father	Yes	City
Mr. & Mrs. B	Father/ Mother	Biomedical engineer/ Daycare provider	Associates of Arts/ Associates of Science	Married to each other	Yes	City
Mrs. C	Mother	Student/ Substitute Teacher	Bachelors/ Working on 2 <sup>nd</sup> Bachelors in Education	Divorced from child's father	Yes	Rural
Mrs. D	Mother	Realtor	Bachelors	Married, not child's father	No	City
Mrs. E	Mother	Registered Nurse	Bachelors	Married to child's father	No	Rural
Mrs. F	Mother	Registered Nurse	Associates Degree	Married to child's father	No	Rural
Mrs. G	Mother	Administrator	Some college	Widowed	Yes	City
Mrs. H	Mother	Data management coordinator	Associates Degree	Married to child's father	No	Rural
Ms. I	Mother	CNA	Some college	Single	No	City
Mrs. J	Mother*	Nurse	Bachelors	Divorced from child's father	Yes	Rural
Mr. J	Father*	Farmer/ Salesperson	Bachelors	Divorced from child's mother	Yes	Rural

\* Same child, interviewed separately

Table 5 provides relevant details regarding each participant's child. All demographic, social, and diagnostic information was current at the time of the interview. While the ages and grades varied, all of the children were school aged, and most were enrolled in public schools. One child was enrolled in a private school and one child was homeschooled. All of the children

were receiving some type of intervention at the time of the interview, either through their school, the university clinic, or both.

Table 5. Identified Child's Characteristics

Caregiver's Child	Age/ Grade	Siblings	Months Since Evaluation	Diagnosis
Mrs. A	8/ 2nd	2 younger	10.5	Mixed Reading Disability
Mr. & Mrs. B	9/ 4 <sup>th</sup>	1 younger, 1 older	11.5	Dyslexia
Mrs. C	8/ 3 <sup>rd</sup>	2 older	8	Dyslexia
Mrs. D	10/ 4th	2 younger	8.5	Dyslexia & possible language
Mrs. E	8/ 2nd	2 older, 1 younger	11	Mixed Reading Disability
Mrs. F	14/ 8th	1 older, 3 younger	5	Reading Comprehension Deficit
Mrs. G	9/ 4th	1 younger	5	Dyslexia
Mrs. H	16/ 9th	5 older	16	Mixed Reading Disability
Ms. I	11/ 5th	2 younger	17	Dyslexia
Mr. & Mrs. J	9/ 3rd	2 older	9/1*	Mixed Reading Disability

\* Mr. J attended and discussed the first evaluation/ Ms. J attended and discussed the second evaluation

## Data Collection

### Interviews

Data was collected through individual, face-to-face, semi-structured interviews with each caregiver or caregiver unit (e.g., two parents) by the researcher. Interviews were conducted in a private location chosen by the caregiver (e.g., university clinic = 4, caregiver's home = 7). A set of primary interview questions to address the research questions guided the interviews (See Appendix A). As each interview was conducted, the interviewer made requests for clarification, or additional information as necessary. Researcher observations and notes were made throughout the interview process. All of the interviews were audio recorded and transcribed verbatim to ensure accuracy of the provided information. Two graduate students were

responsible for transcribing the interviews. Both students were trained through transcribing previously collected practice interviews under the researcher's direction. Modified SALT (Miller & Iglesias, 2012) transcription procedures were followed in order to ensure the consistency across the transcripts (see Appendix B). Additionally, each of the transcripts was cross-checked, a minimum of two additional times. The second pass was completed by a trained graduate student and the third pass was completed by the researcher to verify accuracy. Both graduate students completed appropriate IRB approved training before participating in the study, and understood their obligation to keep any information they learned through transcription confidential.

### **File Reviews**

As part of the provided consent, caregivers were asked to allow the researcher to review their child's university file/documents. This consent allowed the researcher to review previous evaluations, reports, and progress notes as well as the demographic and social information provided in these files. The files served primarily as an additional source of data to verify each child's diagnosis and support evaluation and intervention information provided through the caregiver interviews.

### **Follow Up Interviews**

Follow up interviews took place a few months following the initial interview, after all of the interviews had been transcribed and initial analysis had begun. Nine of the eleven original participants participated in a follow-up interview. One of the participants who did not participate in a follow up interview was never reached by the researcher despite multiple attempts at contact. The other participant was reached and promised to call the researcher at a later time, but did not follow through. Four of the follow-up interviews were completed in person at the university clinic at times that were convenient for the caregivers (e.g., typically while their children were in



an intervention session). The remaining five were completed over the phone. Caregivers were provided with a written transcript and a written record of the demographic information that they had provided prior to the follow up interview and asked to review it. During the follow up interview, the researcher asked any follow up questions that were needed, shared basic themes or ideas that had stood out in a caregiver's interview (e.g., getting a diagnosis was important to them, the lack of follow through was frustrating), and asked the caregiver/s to provide any additional information that he or she would like to provide.

The follow up interviews lasted from 15 to 30 minutes. Some caregivers were more engaged and eager to continue sharing information than others. With one exception, the caregivers who participated in the in person follow up interviews appeared to be comfortable and in no hurry to finish the meeting. This may have led them to be more open and conversational. The follow-up interviews conducted over the phone tended to be shorter than the in person follow ups, and the caregivers tended to elaborate on the information less. While the researcher attempted to set up suitable times for the follow-up phone conversations ahead of the time, some of the caregivers seemed to be distracted during the phone conversations, and others seemed more reserved than they had been in person. However, both the in person and phone follow ups yielded an equal amount of new information, with four of the caregivers adding additional details that they had recalled (2 on the phone and 2 in person). All of the caregivers who participated in the follow up interviews indicated agreement with the demographic information collected, the accuracy of the transcriptions, and the researcher's interpretation of their interview responses.

### **Data Analysis**

As noted, all caregiver interviews were transcribed for analysis. Additionally, the researcher took notes during and after each interview, documenting observations of the participants and overall interactions. The research questions drove the analysis, leading the

researcher to focus on caregiver references to how they perceived SLP communication regarding language delay and disorders, as well as which SLP communication practices they perceived as helpful or unhelpful. The analysis consisted of three general phases including data condensation, data display, and conclusion drawing/verification (Miles, Huberman, & Saldana 2014).

Data condensation includes the researcher's process of selection, simplification, and transformation of the obtained data as conclusions are drawn, codes are assigned, and categories or themes emerge. The data for this study was primarily collected from the interview transcripts, with observation/notes, file reviews, and follow up interviews serving as supporting data when appropriate. Using ATLAS ([www.atlasti.com](http://www.atlasti.com)), a qualitative program, the researcher reviewed each interview transcript individually, identifying both codes that emerged from the caregivers' comments (e.g., poor memory, focus on speech) and codes that related to the research covered in the literature review (e.g., long-term outcomes, language-reading connection). Initially, after reviewing each transcript the first time, over 150 potential codes were created. The researcher narrowed these codes down to less than 60 through a combination of strategies.

First of all, several codes that initially had different names across different transcripts were determined to exemplify the same idea and were merged into one code. For example, codes describing a variety of the educational difficulties (e.g., spelling difficulties, reading difficulties) experienced by the caregivers' children were merged into a single educational difficulties code, and codes describing various caregiver reported oral speech-language concerns (e.g., speech sound production issues, word finding issues and poor sentence construction) were merged into a single unclear speech and language code. Secondly, the researcher re-examined each code in relation to the research questions proposed for this study and determined if the code truly contributed to the focus of the study. Codes that did not further the current research question were deleted (e.g., humor, caregiver-child relationship). Finally, as themes and

categories related to caregiver perspectives began to emerge across the transcripts, the researcher determined which codes contributed to the developing categories and which codes did not continue to be meaningful or were repetitive. Following this process, 59 unique codes remained, six of which represented opposing ideas (e.g., given a label versus not given a label).

As noted, several categories began to emerge through grouping the codes and examining the caregivers' responses in light of the primary research questions. Broad categories related to caregiver perceptions of SLP communication, and caregiver perceptions of collaboration were created and adjusted as each transcript supplied new, complimentary, or contradictory data. The researcher used ATLAS's network feature to visually display and examine the connections between various codes and make adjustments to the categories both with individual transcripts and across the transcripts. Figure 1 provides an example of an early developing network focused on caregivers' descriptions of information they received from SLPs regarding their child<sup>6</sup>. This process assisted the researcher in identifying several general themes that presented consistently across most of the caregivers. Though some of the caregivers presented with unique concerns and experiences that were noted by the researcher, these individual concerns did

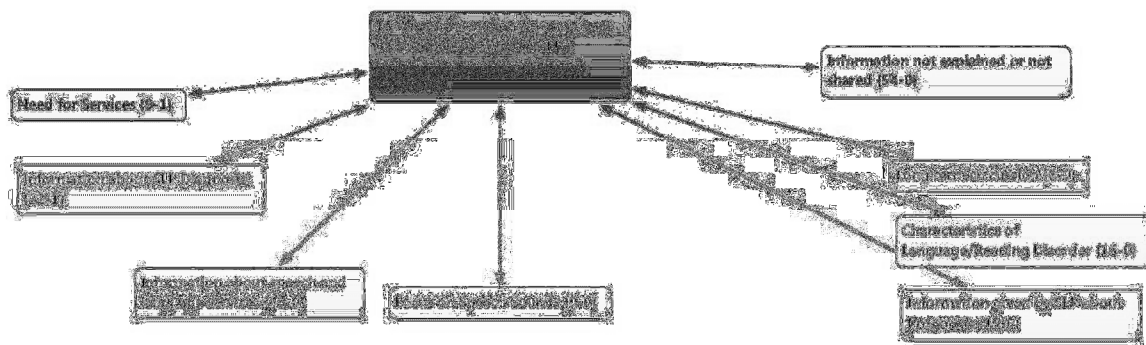


Figure 1. Network Illustrating Themes Related to Caregiver Descriptions of Receiving Information From SLPs.

<sup>6</sup> The numbers in Figure 1 represent the current number of associated caregiver “quotes” with a particular theme at the time this visual was copied. These numbers changed several times throughout the analysis process.

not contradict the general agreement that was found across caregivers in describing their perceptions of SLP communication and the collaborative process.

### **Validation and Reliability Strategies**

Confirmation of the validity or trustworthiness of the information obtained is an important aspect of research. Therefore, it was necessary to verify the conclusions drawn from the analysis process. Several methods may be employed to confirm the quality of the analyzed data and interpretations. The researcher primarily utilized two strategies; triangulation and member checking (Creswell 2007; Miles, Huberman, & Saldana 2014). Triangulation, a method of verifying information received through obtaining multiple independent measures was utilized throughout the study process. As noted earlier, in addition to conducting and audio recording each interview, the researcher took detailed notes and reviewed client files to verify and gain elaboration on the information being provided. Additionally, as a member of the university staff and a practicing SLP, the researcher had general knowledge of the caregivers' probable experiences and interactions.

In addition to having file documents and observations, several of the caregivers' responses suggested overlapping and consistent experiences and feelings. The inconsistent or conflicting experiences actually tended to reinforce the general perceptions rather than weaken them. For example, a negative experience with descriptions of what did not happen (e.g., the clinician did not follow-up with the client) tended to strengthen the importance of what did happen when the experience was a positive one (e.g., the clinician did follow-up with the client). One independent measure that was not included in this study was corroboration from the SLPs (beyond what was obtained in the report) who had conducted the evaluations or provided the interventions. While SLP confirmation or disconfirmation might have added meaningful data to

this study, it was beyond the scope of the current study and not essential for examining caregiver perspectives.

Member checking occurred through confirming the researcher's conclusions with the study participants. The researcher accomplished this in two ways. First, the researcher checked for understanding throughout the interview process, restating participant comments and directly asking participants as necessary to confirm the researcher's interpretation of their comments. Secondly, the researcher set up follow up interviews with nine of the caregivers. During each follow up interview, the researcher shared her interpretations and conclusions associated with that individual caregiver's interview. Each caregiver who participated in the follow up interview provided agreement with the researchers' interpretations.

Finally, in order to ensure the reliability of coding procedures, the researcher sought to establish inter-coder reliability by having an additional coder independently code a percentage of the transcribed interviews using established codes. A graduate student was trained to ensure agreement between coders (the researcher and the graduate student). The student was given a detailed codebook (see appendix C) and practice items to ensure her understanding of the codes. The researcher reviewed the practice items with the coder and made sure there was understanding of the codes. The coder was given approximately 10% of the coded transcripts (one of the longest transcripts of the 11 transcripts), as well as a list of working codes. The researcher's coding and the student's coding reached a satisfactory level of agreement achieving a Cohen's kappa = .836 (95% CI, .764 to .908),  $p < .001$ . This indicates strong agreement (Viera & Garrett, 2005), providing evidence that the agreement reached in the coding was significantly different than expected by chance. Items on which the coders disagreed were discussed between both coders until agreement was reached.

## CHAPTER 4: FINDINGS

The findings of this study are divided into three primary sections. The first two sections address Research Question 1, focusing specifically on what information caregivers described receiving from SLPs about their child's language disorder, and how caregivers described their own understanding of their child's language disorders. Section three addresses both parts of Research Question 2, examining what SLP communication practices caregivers of children with language related disorders believed to be most effective in increasing their knowledge and/or their participation in the therapeutic process.

### **Findings for Question 1a: Information Caregivers Receive from SLPs**

For many caregivers, information is one of the primary resources they are seeking when bringing their child in for a speech and language evaluation. In some cases, the caregivers may have already sought out information independently or from other professional sources. Either way, they typically are not satisfied with the knowledge they have yet or are seeking affirmation from a specialist. While SLPs frequently provide a great deal of information to caregivers, especially during and following an initial evaluation, how caregivers perceive and retain that information is instrumental to developing both the caregiver's understanding of their child's disorder and the potential future relationship between the SLP and caregiver. As Mrs. G, one of the caregivers, shared with regard to a doctor-patient communication experience, it doesn't take much for a misunderstanding to occur; "they [family member] said the doctor said I have whatever and it is not what he [the doctor] said, but it sounds like it's a similar word, and so then everybody freaks out going oh my god you're dying and no, no you're not". While her personal example was not related to her child's diagnosis, it illustrates how challenging it can be for a health care professional to share accurate information and ensure that it is perceived by the patient or client as intended. Therefore, to better understand how caregivers perceive SLP

communication, it is important to first examine what information caregivers recall receiving about their child's language delay or disorder from their child's SLP. This question is noted in

Research Question 1a:

How do caregivers of children with language related disorders perceive SLP communication with them regarding language delay and disorders?

- a. What information do caregivers describe receiving from SLPs regarding language delays and disorders?

Caregiver descriptions of the information they received throughout the evaluation and intervention process was examined. Although the focus was not limited to information received during an assessment, it was noted that many of the caregivers' responses focused on sharing information that they received during an initial speech and language evaluation. Each caregiver reported receiving a range of types and levels of information from the SLP/s with whom he or she communicated. However, five themes emerged as the most significant in describing caregiver perceptions of information received from SLPs, including the diagnosis, incomplete information, services provided, memory of information received, and quality of experience.

### **The Diagnosis**

The first theme, diagnosis, encompasses both caregiver perceptions of being given diagnostic information, particularly a diagnostic label, and the clarity and understandability of the diagnostic label. Some caregivers reported receiving a label from their child's SLP, while other caregivers claimed that no label was ever provided. One key factor that appeared to influence caregiver perceptions of being given a diagnostic label was the clarity of the diagnosis. Caregiver descriptions of the diagnostic information they received suggests that some diagnostic labels are more easily understood by caregivers than others.

#### **Label versus no label**

The diagnosis was the most sought after information from the caregiver's perspective. As Mrs. G shared when discussing the importance of *the results*, "as a parent you want to know."

Her sentiment was echoed by many of the caregivers including Mrs. C, “parents want to know something right away. That would be pretty huge if you walked away not knowing anything.” Therefore it was not surprising that many of the caregivers, when asked what information had been shared with them, focused first and foremost on the diagnostic information they had received, particularly if they had a diagnostic label to share:

“They [SLP team] actually labeled him as being dyslexic.” (Mr. B)

“They [SLP team] said she definitely had dyslexia.” (Mrs. G)

“I don’t remember a degree being given at that point in terms of mild, moderate, severe but I remember it being dyslexia is what we [SLP team] are looking at here.” (Mrs. C)

In many cases, the caregiver came to the clinic feeling certain something was wrong, and was relieved to have documentation or an expert opinion to verify that feeling. Mrs. A, for example, expressed relief at finally having proof to share with her skeptical relatives:

I got the paperwork saying you know this is the level she’s at, and I really liked seeing that because we knew she was low but at least we had it documented. We have family members that aren’t accepting this whole thing, and so it’s black and white and here it is.

Mrs. C, who had been working with her daughter’s teachers to get assistance for her daughter’s reading difficulties, found that having a documented diagnosis opened the necessary doors for a 504 plan<sup>7</sup>. “Having a diagnosis I was able to walk into a new school and show them, and there was no longer a fight. It was ok, this is what we need to do.”

For some caregivers getting a diagnosis was particularly significant because they felt like they had been searching for a label or diagnosis that explained their child’s difficulty for a long time. Mr. B expressed frustration when asked what he had been told about his son’s difficulties, “they would not label him...it was just oh well he might have *this* issue.” When asked what beneficial information had been shared with him during the speech and language evaluation, Mr.

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<sup>7</sup> 504 plan - Individualized plan used by a general education student with special health needs who is not eligible for special education services. Lists accommodations related to the child’s disability and required by the child so that he or she may participate in the general classroom setting.



B immediately responded “them labeling that he had dyslexia.” Mrs. B agreed, “Yeah they actually labeled him.” When asked what she had been told about her son’s difficulties previously Mrs. B said “they [school’s IEP team] would not label him at all...it was just more like he may need help with reading you know.” She felt that “just a reading issue” was a vague description of her son’s difficulty, and wondered if the school professionals could adequately help her son saying “it’s like they couldn’t pinpoint it.” The lack of specificity led both Mr. and Mrs. B to feel like there was limited to no individualization in their son’s IEP. Frustrated, Mrs. B shared that she and her husband tried to get more information and a referral for a second opinion. When they set up a speech and language evaluation for their son at the university clinic, their primary goal was to identify what was wrong and find out if they could do something more for him. In response to getting a diagnosis Mr. B said “Now we have something to look at, this is his problem.” Mrs. B broke in “this is what we are going to do - work on the solution you know more dedicated stuff to his problem.” Mr. B finished “that has been proven to help with those issues<sup>8</sup>.”

As illustrated in several of the caregivers’ comments, a diagnosis was an expected outcome of a speech and language evaluation, and caregivers greatly appreciated receiving this information. However, not every speech and language evaluation results in a definite diagnosis. Some of the caregivers shared experiences where no clear label was provided. Mrs. D and Mrs. E for example, both reported not receiving a label verbally or in writing after their child’s speech and language evaluation. An examination of the written reports in both children’s files confirmed their accounts. Both reports, while providing detailed description of the child’s areas of strengths and weaknesses stopped short of providing a label. Mrs. E, recalled in our interview that the SLP had had difficulty labeling her daughter:

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<sup>8</sup> Per the modified SALT Conventions (see Appendix B), the hyphen ( - ) represents revisions in the caregivers train of thought.

I think they [SLPs] had a hard time like labeling her. I know that she was a little bit slower...They didn't want to label her like a learning disability, but I remember her saying that she is a little bit slower in the reading part.

While Mrs. E had not received a diagnosis, she indicated that she had received a lot of information about her daughter's strengths and weaknesses and appeared to be generally satisfied with the information she had received. The fact that the evaluation, even without a clearly stated diagnosis, was instrumental in getting her daughter help at her school (her daughter is currently on an IEP) and services at the university clinic may have contributed to her overall satisfaction as well.

Mrs. D also reported receiving a lot of information regarding her son's abilities and difficulties, "I thought it was pretty good detail," referring to the amount of descriptive information included in the report, however she continued to feel frustrated. When asked if anyone had ever stated what was wrong she responded, "There was never - I don't think any - and I still don't know that I know for sure what." Unlike, Mrs. E, Mrs. D did not recall anyone reviewing the report with her or explaining the diagnostic information. Mrs. D noted that the lack of an explanation left her confused and unsure of what was going on with her son.

The participant responses regarding labels clearly indicate that many caregivers viewed the label or diagnosis as an important piece of information, one that needs to be addressed. Furthermore, the difference in perspectives offered by Mrs. D and Mrs. E highlight the importance of also talking with the caregiver about the lack of a clear label if one is not given. Understanding why the SLP chose not to provide a specific label may help to alleviate the disappointment that can occur when expectations are not met. Even when a diagnosis is given though, there is potential for misunderstanding, especially if the label is unfamiliar to the caregiver.

### Clarity of diagnosis and dyslexia

In discussing various diagnoses with the caregivers who participated in this study, it was evident that some diagnoses were easier to explain or make clear to caregivers than others. As noted in chapter 3, all of the participants in this study, had a child who had been diagnosed with a reading and or language related impairment. Therefore, prior to participating in this study, each caregiver had received some level of diagnostic information regarding his/her child. However, in talking with caregivers, it became obvious that some diagnoses were clearer than others. Dyslexia in particular stood out as a label that caregivers were aware of and felt comfortable with as a diagnosis.

The five caregivers whose children received a standalone dyslexia diagnosis from the SLP all recalled and reported the diagnosis of dyslexia accurately (Table 6). In contrast, multiple caregivers of the five children who received a more complex diagnosis (e.g., mixed reading disorder, reading comprehension deficit), reported either conflicting diagnoses or demonstrated a lack of awareness of the given diagnosis. For example, Mrs. F, who was unsure about the

Table 6. Diagnosis Reported by Caregiver Vs. Diagnosis Stated in Report

Caregiver	Caregiver Reported Diagnosis	Diagnosis Stated in Report
Mrs. A	Language Processing	Mixed Reading Disability
Mr. & Mrs. B	Dyslexia	Dyslexia
Mrs. C	Dyslexia	Dyslexia
Mrs. D	None Given	None Specifically Stated*
Mrs. E	None Given	None Specifically Stated*
Mrs. F	Dyslexia	Reading Comprehension Deficit
Mrs. G	Dyslexia	Dyslexia
Mrs. H	Dyslexia	Dyslexia
Ms. I	Dyslexia	Dyslexia
Mr. & Mrs. J	None Given	Mixed Reading Disability

\* Description presents as Mixed Reading Disability

diagnosis and indicated that she did not still have a copy of the report stated; “I know there’s something in there about the dyslexia.” She also shared that she had been told her daughter had dyslexia by her daughter’s teachers and doctor. However, per Mrs. F’s daughter’s speech and language report, her daughter “exhibits a reading comprehension deficit characterized by difficulty recalling information from a text (e.g., specific details and information), answering questions, and incorporating important details.” Yet, the caregiver’s only reference to her daughter’s language comprehension difficulties was in response to a question regarding her child’s language ability to which Mrs. F responded “I just remember that she had you know trouble with parts of it.”

Other caregivers also focused on the dyslexia diagnosis over other diagnoses. Mrs. A, whose child had received a diagnosis of a mixed reading disorder per the clinic report, frequently mentioned the dyslexia diagnosis that she had received from her daughter’s “vision therapist”. Mr. and Mrs. J (who were interviewed separately) both indicated that they were unsure if a diagnosis had been given for their son. Mr. J recalled, “No I don’t think he was diagnosed with anything at the time... I think the clinic told us one time that they did not believe that he had dyslexia,” suggesting an awareness of dyslexia over the actual diagnosis. Mrs. J, who had set up the evaluation, but had not been present for it indicated that she had specifically requested a dyslexia evaluation. She expressed frustration over what she viewed as a lack of a clear diagnosis, saying that the report she had received had been vague and just said something about “speech-language.” During our follow-up conversation, Mrs. J shared that she had communicated further with her son’s SLP and now understood that her son did not have dyslexia, but something more mixed. Though she could not recall exactly what the SLP had called it, when asked if it had been “mixed reading disability,” she responded “yes, that’s what they called it!” Even though she still had some difficulty recalling the exact label, believing that

she had a label made a difference. Mrs. J seemed to have a much stronger understanding of her son's diagnosis during our follow up conversation.

Overwhelmingly, the term dyslexia was recalled and understood by parents as a reading disorder. In fact, every caregiver who brought a child in for a speech and language evaluation at the university clinic, cited dyslexia as the primary concern:

“I think I had asked if maybe he did have like a form of dyslexia or something.” (Mrs. D)

“My concern still was dyslexia, or was it something else.” (Mrs. J)

Caregivers frequently used the term dyslexia when describing their children versus other labels or diagnoses. When dyslexia was not the given diagnosis, caregivers often indicated that no label had been given, or that they only knew that it was not dyslexia, rather than recalling other diagnoses provided in the written report such as mixed reading disorder, and reading comprehension deficit. The word cloud provided below (see Figure 2) visually illustrates the number of times that caregivers used the word dyslexia versus the other labels. The word cloud was created using Wordle ([www.wordle.net](http://www.wordle.net)). Wordle allows you to enter large amounts of text into a field, and then analyzes the word count frequency. Using the word count frequency, Wordle creates a visual “cloud” of the words used most frequently (Saldaña, 2013). As illustrated in Figure 2, caregivers used the label of dyslexia with the greatest frequency, and the phrase “I still don't know” with the second greatest frequency. While recalling the label was an



Figure 2. Word Cloud Illustrating the Diagnoses Most Frequently Provided by Caregivers to Describe their Child.

important step to understanding the label, recalling the label did not always equate with an understanding of the label. Some of the caregivers who sought speech-language services for their toddler aged children, clearly recalled being told that their child had a speech delay, but did not demonstrate a full understanding of the given diagnosis.

### **Clarity of diagnosis and the term speech/language delay**

In addition to the difficulty of clearly defining reading and language labels, some caregivers noted the lack of clarity associated with the terms speech or language delay. Of the five children who had early communication difficulties, two of them presented with the typical characteristics of a late talker. When asked if they had been given a diagnosis when their child was initially evaluated, the caregivers indicated that they had not:

“No I don’t think he was diagnosed with anything at the time.” (Mr. J)

“Just a delay in speech and language.” (Mrs. J)

“They just told us that he had a speech delay. That’s all they told us.” (Mrs. B)

Essentially, the caregivers did not interpret speech or language delay as a diagnosis. This interpretation did not necessarily change for older children or when the term speech or language disorder was used. Mrs. J made a similar statement regarding her son’s lack of a diagnosis, following his more recent speech and language evaluation at a university clinic, saying “it had speech and language on it too.” In her statement, she compared her son’s more recent evaluation at nine years, to his earlier speech and language evaluation from when he was three. Neither report provided her with the clear diagnosis she was looking for.

The diagnosis is an essential piece of information for caregivers of children with language related disorders. In many cases, getting a diagnosis is one of the primary reasons that caregivers seek out a speech and language evaluation in the first place. However, providing caregivers with a clear and understandable diagnosis presents with significant challenges,

especially when the diagnosis is complex and unfamiliar to the caregiver. As noted in the caregiver conversations, caregivers automatically associated familiar terms such as dyslexia with a diagnosis, while less familiar terms such as speech-language delay did not automatically register. Kamhi (2004) notes that language based disorder terms are often misunderstood because they lack the simplicity often attributed to a diagnosis such as dyslexia. Caregivers believe they know what dyslexia is, but they typically have an undeveloped understanding of the complex components of speech and language development. Alternately, caregivers may also simply view terms such as “speech delay” as descriptive adjectives or identified symptoms, used to describe their child’s current speech production status rather than as a diagnostic label. If this is the case, while caregivers appreciated descriptions of their child’s communication disorder, they did not hold descriptions in the same esteem as a diagnostic label. Either hypothesis highlights the importance of SLPs clearly identifying diagnostic labels to caregivers.

### **Incomplete Information**

A few topics stood out in my conversations with the caregivers as not well understood or well explained. First, the lack of information concerning long-term outcomes was notable, especially in regard to late talkers. Secondly, most of the caregivers recalled minimal to no information regarding the connection between language and reading. As both topics are extensively discussed in the literature and were brought up during the interview by caregivers, I asked caregivers to elaborate on what information had been shared with them.

#### **Long-term consequences**

Caregivers were very interested in the long-term consequences of their child’s language impairment. Mrs. A expressed that her daughter’s future was a regular topic of conversation between her and her husband, “You know honestly we just don’t know where her future is at this point. We are hoping we get more understanding and more language out of her and more

reading... We talk about that a lot.” However, most of them reported receiving little information in this direction, especially initially. Typical responses from caregivers when asked if information had been given to them about possible long-term outcomes or consequences of their child’s speech and language impairment included:

“Not that I recall.” (Mrs. E)

“Nothing.” (Mrs. A)

“No, it was kind of more like just more you know keep working and trying.” (Mr. J)

Overall, caregivers described receiving little to no information about their child’s prognosis or likely outcomes. The lack of clear prognostic information was particularly highlighted in two cases involving late talkers.

As described in the literature review, late talkers are children who are slow to begin speaking. Two of the children included in this study presented as late talkers. Both children received early intervention services from an SLP for a speech and language delay. Neither Mr. and Mrs. B or Mr. and Mrs. J recalled receiving any cautions regarding their sons’ futures. Mrs. B’s description of what they were told about their son’s late speech and language emergence suggested to her that her son would outgrow the issue. “I mean they just told us, get him started and surely you know a lot of kids you know overcome it you know by the time they’re in kindergarten, first grade, that they’re you know on board with everybody else.” Later in the conversation when asked if she sought out any other resources, Mrs. B responded “I didn’t just because I think I thought oh this is just a minor thing we’re just gonna blowover. So, I just thought oh with extra little help before school starts we’ll be good to go.” Mr. B agreed saying he thought at the time, “He’ll get over it.”

Mrs. J described a similar experience, saying that she had not been given any information about future concerns during her son’s initial time in speech therapy or when he was dismissed.



Her son, who was dismissed from speech services right before kindergarten, was re-enrolled in speech services about a year later. Mrs. J noted that at the time of dismissal she had not realized that there still might be potential concerns:

I wish the speech lady would have said you know Mom he's met this goal now but you know in the future sometimes we see blank blank; and that you know don't be afraid to reach out and this is how you do it. This is the process.

Overall, none of the caregivers expressed anger at the lack of a prognostic warning, just regret.

Mrs. J said, "I wish they [SLP team] would have shared with me more that you know this could be a long-term thing, but maybe they [SLP team] didn't even know at the time since we were just mainly there for the speech."

A few of the caregivers did report receiving some long-term information. However, most of the examples the caregivers provided suggested that other health and educational professionals were the first to address the long-term issues with caregivers. Mrs. F shared that her daughter's pediatrician had informed her that since her daughter was pre-mature, she could potentially have struggles in school, "they said she doesn't have any major medical problems, when she got in school maybe she'd have some problems." Mrs. A shared that her daughter's vision therapist had been the first to articulate the seriousness of her daughter's reading disability:

The biggest thing that we got out of the diagnosis and the talk with the therapist was that she has it pretty severe, to the point of that she may never be capable of reading, or she - if she is, she is going to be way below grade levels, several grades behind... That was the first time we had had anybody say you know in the long run this is going to affect her for a very long time.

Finally, Mrs. J said that her son's IEP team, specifically the principal, had shared with her and her ex-husband that their son's learning disability was a long-term diagnosis, "he actually sat down with Mr. J and was like Mr. J he has a true learning disability, it's not gonna go away."

Notably the majority of the examples caregivers provided of receiving long-term information, occurred after years of intervention rather than early on. Caregivers whose children

received early intervention services did not recall discussing long-term challenges with their children's SLPs, but rather were hopeful that intervention would be temporary. Ultimately though, caregivers wanted to know about future concerns and challenges. As Mrs. A said, "we were hoping we could eventually get her past that [her daughter's reading difficulty], and so that [learning her daughter may never read like her peers] was a little frustrating but it was good to know." Mrs. A went on to explain how once she realized that her daughter would not outgrow her reading disability, she more actively sought appropriate help for her daughter, "I know I can't get her past it and so I knew I needed to reach out and find help somewhere." As Mrs. A expressed, several of the caregivers articulated an openness to seeking further services once they understood that their child was not necessarily going to outgrow his/her disorder, but it was important that the information regarding potential long-term issues be shared with caregivers.

### **Language and reading connection**

Reading and other educational difficulties are often one of the long-term consequences of language impairments. As caregivers reported minimal conversations regarding the long-term consequences of language impairment, it is not surprising that several caregivers also reported minimal to no conversations about the connection between language and reading, especially early on:

"Nothing has really been said about her reading." (Mrs. A)

"Not during Head Start or anything." (Mrs. B)

"I don't [recall having a conversation about reading and language]." (Mrs. C)

Caregivers who did report recalling a conversation about the connection between language and reading only recalled it being addressed by the SLPs at the university clinic<sup>9</sup>. However, even

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<sup>9</sup> While ASHA (2007) clearly states the literacy falls under the SLP's scope of practice, there is a great deal of variance in the public schools in how involved SLPs are in evaluating and providing interventions to children with reading disabilities. Many public schools hire reading specialists or special education teachers, who may not be trained to recognize a language disorder, to address reading issues. Additionally, some SLPs who work in the public

the caregivers who recalled the conversation struggled to remember details. For example, when asked if the SLP had talked with her about the connection between language and reading, Mrs. G responded, “Yeah I know she did some.” When asked if she remembered anything about the conversation, Mrs. G responded, “Not really.” Mrs. G’s response exemplified a typical response from several of the caregivers who recalled the topic being addressed, but could not recall details. Mrs. H recalled a little bit more, “Just how sometimes you can have the language but not being able to comprehend and just different forms of that I can’t remember exactly but there was something about that.” Overall, even when the information was given, there appeared to be a lack of understanding and recall on the caregivers’ part suggesting that further information and follow up may be needed for most caregivers on the topic of language and reading. Caregiver education may be a factor to consider when discussing the connection between language and reading with caregivers. Two caregivers who felt they had an understanding of the relationship between language and reading, attributed their understanding of the topic to previous knowledge from their education/occupational background:

“In my own education I do understand that piece.” (Mrs. C)

“Yes as a nurse, yes just basic.” (Mrs. F)

These caregivers noted that the topic of reading and language was a challenging topic to discuss. Even caregivers with backgrounds to support an understanding of the language and reading connection did not express a strong understanding of the concept.

### **Services provided: What my child is working on in therapy**

In contrast to the lack of information caregivers reported receiving regarding long-term outcomes and the language reading connection, caregivers described receiving an abundance of information about the speech and language services provided for their children. All of the

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schools may not feel confident or well trained in addressing literacy issues and the language-reading connection, as literacy is a relatively new area of focus.

children represented in this study had received some level of speech and language services at the time of the interviews. Information caregivers shared receiving ranged from service options that were presented for their child, specific goals and objectives their children were working on, and descriptions of activities their child engaged in during interventions.

### **Service needs and options**

When asked about information shared, all of the caregivers expressed that their child's need for services had been presented:

“I remember that they did think that he would benefit from some services.” (Mrs. D)

“They didn't make us feel stupid for not getting the help that she needed sooner, but it was we need to get this help going and we need it *now*.” (Mrs. A)

Additionally, in several cases, multiple service options were presented.

“They were very thorough on the services that SHE would need, the services that they [the clinic] had to offer. We discussed IEPs and where do we go from here, and what's best for the child.” (Mrs. G)

“They had given me other places I could go to, if I needed.” (Mrs. E)

While several of the children evaluated at the university speech and hearing clinic did end up being served at the university clinic, other options were explored as well, especially for the children who lived farther away. Telepractice was employed for one child who lived over an hour from the clinic. For another child, through collaboration with the child's teacher and school, an evidence-based spelling program was put into place at the child's school. Several children, like Mrs. E's daughter took advantage of the summer programs. “I was concerned like when school was over last year I thought what am I going to do? And then that's when they mentioned that they had the summer program and I thought oh that's wonderful she can go there.” Overall, caregivers expressed being given lots of options regarding services for their children.

## Goals and progress

In addition to being aware of their multiple service options, most the caregivers presented as knowledgeable and aware of the services being provided to their child. While caregivers did not typically name specific strategies or techniques, most of them clearly had an understanding of what was being worked on during their child's therapy sessions. Several of the caregivers were also able to refer to specific goals and objectives that had been shared with them by the SLP. Mrs. A, whose daughter receives speech and language services from both the university clinic and the public school, described how the services differed, "here [the clinic] she is getting just reading help" and her SLP at the public school is "working with her on the three step directions ... her /r/'s, it's something with her tongue not moving right...and then the memory recalling, like you can read her two to three paragraphs and she can't remember anything." Mrs. B, whose son received speech services through early intervention, the public schools, and most recently the university clinic, described a little bit of what he was working on in each setting. In early intervention:

They came to our house. And she brought - I think they were more or less like flashcards, and she would actually give - she had special techniques to get the /t/ sound or the /th/ sound out like hand sign language is what I want to call it, but different cues for his tongue you know so he could put it together.

In the schools:

I think it was just more of those just the sounds and those like blending sounds ... To blend it all together instead of just trying to just sound it out chunk by chunk trying to get it to flow... trying to get that last sound out clear. They were working on front and back, he was leaving them off.<sup>10</sup>

Summer Reading Program at the university clinic:

"They did send home a packet of stuff of like what they were working on and like the pictures... I mean it was to help him maintain."

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<sup>10</sup> Per the American Psychological Association (APA) guidelines, the three spaced ellipsis points (...) represent omitted material from the original source (APA, 2010).

Mrs. C, whose daughter received services at two different public schools, compared and contrasted some of the different methods of addressing the same goals.

I think the difference from before, it was just drill. We're just going to sit here and drill on it, and really I think cumulatively between home and school she was getting hours of flash cards a day. Whereas now it's more made into games they're using more technology putting it into games, and the difference I see in DAUGHTER is she's willing to read now. Outside of school she wants to take a book to bed and read it on her own. Whereas before she - I think was so turned off that it - while she was making progress the desire wasn't there. She was just done, but now there's more desire I guess. She's developing that love to read.

Mrs. D described the focus on reading as well as the addition of new goals to address her daughter's educational needs.

They would focus on the story like telling a story you know where it would take place and the action, the setting, and doing all of that. I think they focused on that quite a bit and then they would bring in books. They would read books together and decode the words and try to figure out the meaning of the story...She would have to draw a picture and then she would have to tell the story. I know that this year they also work on her spelling words...so they kind of slowly are adding different things for her.

Mrs. H also described her son's focus on decoding words.

He works with somebody for like 45 minutes to an hour on different words and learning words and stuff. Being able to break a word down phonetically and sound it out was one thing that was one of the weaknesses that they were really trying to work on the different phonetic sounds that are grouped together and get those groups of words to get him familiar with those sounds.

While many of the caregivers felt comfortable describing their child's intervention focus,

Mrs. D was an exception. She did not feel like she knew what was going on during her son's intervention sessions, stating that one of the difficulties for her was that she could not come and watch the sessions. Therefore she missed out on regular opportunities to discuss her son with the SLP.

I didn't bring him. We had hired a babysitter for the summer...she would drop him off in the morning and then pick him up so you know I was kind of not really in the loop. .. If I would have been the one bringing him and dropping him off, picking him up whatever, I would have been like well what did you do today or whatever, but I couldn't do that 'cause I was at the office at that time. When I

would ask him about it that's the thing I think that maybe is a difference between boys and girl if I ask my daughter how school was she will tell me all kinds of things that happened at school. If I ask the boys how something was, 'fine.' What did you have for lunch, 'I don't remember.' I mean I get nothing at all ...so I did get a follow up report at the end of the summer I can't remember, I did read it obviously, but I don't remember.

Mrs. D went on to say that she would have preferred a conversation with the SLP over a written document. She felt like she understood things better when she was able to have a discussion and ask questions as they came to her.

Some caregivers also described receiving regular information about progress. Most intervention settings, including early intervention, public schools, and the university clinic had consistent routines or times that caregivers could expect to receive information. Early intervention for example offered the caregiver easy access to the SLP when the caregiver came to the home to provide services. For example, Mrs. B described observing her son's sessions in her home and talking with the SLP: "They came to our house...She had special techniques to get like the /t/ sound or the /th/ sound out...she just told us like what they were working on." The university clinic setting also offered consistent opportunities for SLP communication. For example, Mrs. D recalled how she regularly received information about how sessions went and how her daughter was progressing before or after speech-language sessions at the university clinic: "after every session they you know they told us what she worked on... they would praise her on the things that she did well." However, watching the intervention weekly sessions was not always an option. Sometimes caregivers relied on written progress notes or semester summary reports in order to receive progress. Mrs. D who was unable to continue bringing her daughter to the intervention sessions shared:

My mother's been taking her more this year, but I always get the print out...they would say you know at the beginning of the year they do like I want to say like a test type thing or just to see where she is at, and then they compared it to the end and it was just amazing how she had improved.

Both Mrs. B and Mr. J noted that while they did not get to watch anymore once their sons transitioned to the public school services, they still received regular progress reports and participated in annual IEP meetings. They felt like they were kept well informed of the goals and the progress through these reports and face to face meetings:

I mean they just I mean we go in we usually go in once a year because he had ended up having a, you know an IEP for speech. I mean it was more or less the same thing we always got a piece of paper that showed us his goals and then usually every nine weeks they'd send home like a progress report to say like he's met 80% of this sound or this chunk. (Mrs. B)

We have went through IEPs. I think that they do that about once a year and they set a goal for the next year. I think at the time it was just his language was lacking, his and his ability to form sentences...I think that they were going to work on getting like a three sentence paragraph. I think different things like that to try and build him up. (Ms. J)

Generally, no matter the setting, caregivers seemed to be aware of their child's speech and language goals and informed of their child's progress.

### **Speech sound focus versus language focus**

In discussing the types of speech-language interventions that were provided, one observation that stood out consistently, per the caregivers' reports, was that some of the children currently diagnosed with language and/or reading issues were initially treated primarily for, or only for, speech sound issues. This observation applied in particular to the three children who had received early intervention speech-language services and speech-language school services<sup>11</sup>. For example, in describing her son's speech-language services, Mrs. B described an apparent focus on speech sounds; "she would actually give like she had special techniques to get like the /t/ sound or the /th/ sound." When asked to share in more detail what the SLP had been working on, Mrs. B continued;

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<sup>11</sup> The other seven children did not receive speech-language services prior to their speech and language evaluation at the university clinic.



I think it was just more of those, just the sounds and like blending sounds I think ...To blend it all together into a - instead of just trying to just sound it out chunk by chunk trying to get it to flow...trying to get that last sound out clear, they were working on front and back depending on...Or he'd add like an /s/ or something. I mean he was adding different things to it or he'd start it with different, there wasn't that one sound.

Mrs. B further explained that based on her son's initial speech-language assessment, receptive language skills had been a strength for him, so language had not been seen as an issue from her perspective. As her son continued receiving services in his school, the focus on speech continued. "At this point in time his goal and a lot of his was I think and I still think to this day is the /th/. The /th/, making /th/ sound, getting the /th/ that sound out...that's what they worked with throughout." Mrs. A describes a similar focus for her daughter's early intervention speech-language services, "they said that her speech was definitely not where it should be." However, Mrs. A did not recall being provided any information regarding her daughter's language. Her daughter's school based services were also speech focused:

She (the school SLP) was very positive that she could get C farther along and stuff with the speech and, you know the one thing we addressed with her too was C's tongue doesn't move right and so that was something that she worked on with her a lot.

Per Mrs. A's report, only recently had the focus in speech-language intervention moved beyond speech. Mrs. A explained that once she realized that SLPs could address issues beyond speech sounds, she talked with her daughter's school SLP about her concerns regarding her daughter's language and memory. The SLP was responsive to her concerns and added goals focused on memory and language to her IEP. It is difficult to know without further documentation or conversations with the SLPs involved, the exact reasons why the SLPs chose to focus on speech sounds. It is also possible that the SLPs did provide a broader intervention plan, but the caregivers did not recognize the language based components. The conclusion that can be drawn

though, is that the caregivers perceived early intervention and public school services to be one dimensional in nature and focused on speech sound production.

### **Caregiver Memory**

In light of discussing what caregivers recalled from their conversations with SLPs, the issue of caregiver memory was a recurrent theme throughout all of the interviews. Caregivers frequently reported not remembering all of the information that was shared with them at the evaluation. In many cases, they would remember a few general details, and then when asked if they could recall more, they would respond in the negative:

“I can’t remember a whole lot.” (Mrs. A)

“Not really I was really pregnant.” (Ms. D)

“No no not right off the top of my head I don’t remember.” (Mrs. G)

It was somewhat expected that caregivers, whose children had been in speech-language therapy for several years, may have trouble recalling their early conversations with SLPs. However, several caregivers struggled to remember details from six months to one year ago regarding key information they should have received.

In some cases, caregivers expressed a belief that they had received the information, but could not recall details. When asked to share more about his son’s speech-language services Mr. J responded “I can hardly remember I think they would read a book or something they would...I don’t know I don’t, that has been so long ago. I don’t even exactly know. I remember watching them play or different things.” Phrases like *I think* and words like *maybe* were common statements utilized by the caregivers, emphasizing that they were not sure of the information they were sharing. Several caregivers talked about how they were certain they had understood the information at the time it was given, but simply could not remember the exact information anymore:

“I remember that being an informative part of it and I remember the clinician explaining that to me but I can’t remember what she said.” (Mrs. E)

“There were some specifics about which type of testing that they were doing, that she had trouble with this, but she did well reading this that made sense at the time, but I don’t remember what it was.” (Mrs. F)

As noted earlier, the diagnosis a child received also played a role in caregiver memory.

Caregivers whose children had been given a diagnosis of dyslexia tended to remember and identify dyslexia as their child’s diagnosis. In contrast, caregivers whose children had been given other diagnoses such as mixed reading disorder or language impaired were more likely to say:

“I can’t remember what the diagnosis was.” (Mrs. J)

“I need another copy of the report... I know there’s something in there.” (Mrs. F)

Several of the caregivers did reference the speech and language evaluation report they had received following the evaluation and said that they could look up information about the diagnosis or recommendations if they needed to do so. However, at least one caregiver (Mrs. F) admitted that she did not have her copy anymore.

While a caregiver not recalling information does not mean it was not shared, it does indicate that for some reason the information is not staying with the caregiver. Difficulty recalling information was a common theme described by every single caregiver. SLPs need to be aware of the limited memory caregivers may have, especially for the complex and potentially overwhelming amount of information caregivers may be receiving. Additionally, SLPs need to consider how they can best address the issue of memory with caregivers, as it is important for caregivers to retain information beyond the initial evaluation.

### **Quality of Experience**

In the health communication literature, the ability of the health care provider to share clear and appropriate information with the patient is positively correlated with patient

satisfaction (e.g., van Zanten, et al., 2007). Caregivers of children with language related disorders also place a high value on receiving information from the SLP. When asked about their experiences communicating with SLPs, caregivers consistently related their level of satisfaction with the level of information they received during their child's assessment or intervention experience. Caregivers who experienced feelings of frustration with the assessment or intervention experience cited minimal to no explanations from the SLP:

“It was a very bad experience. They didn't explain things.” (Mrs. A)

“I kind of left feeling like I wasn't sure what was going on you know... a little more concrete information would have been - would've made me feel better.” (Mrs. F)

In contrast, caregivers who recalled a constructive experience connected their positive feelings with the provision of helpful information.

“They came in and went over the results with me...they did a real good job of checking him out I thought.” (Mr. J)

“They did really good. They detailed it really good for us so she (daughter) could understand along with me.” (Ms. I)

Mrs. G attempted to explain the magnitude as a caregiver of receiving or not receiving information, “I had exhausted all my resources and I was here to hand them off to you [the SLP] to figure it out. So I really didn't feel like I came with a lot to offer...I was looking at help us! What do we need to do to help you help us...I'll do whatever you need!” Mrs. G went on to explain that she did not need every detail, just enough information to help her child, “You know I didn't need a five hour meeting on it, I just need to know is it - is there something going, is there not, and what do we do next.”

### **Summary of Information Received from SLPs**

In summary, caregivers recalled receiving a great deal of information from SLPs. Most of the information was focused on their child's diagnosis and related service options to address their child's disorder. Receiving a diagnostic label was particularly important to caregivers as it

was the primary piece of information they had sought in scheduling the speech-language evaluation. However, some diagnoses were easier for caregivers to understand than others. Dyslexia was perceived by caregivers as a clear and explanatory label, while mixed reading disability was often difficult for the caregiver to understand and recall. It was also noted that caregivers did not perceive some common speech-language labels, such as “speech delay” to be a true diagnosis. Caregivers often felt frustrated and unsatisfied if they were not provided with a clear diagnostic label.

Another area of concern for caregivers in regards to information sharing was the lack of clear and complete information provided concerning prognostic outcomes and the language-reading connection. Caregivers often worried about their child’s future, but felt uninformed regarding their child’s likely long-term outcomes. Furthermore, caregivers who had sought services for their toddler-aged children reported no conversations about their child being at risk for future language and reading concerns. Caregivers also reported receiving limited information regarding the language-reading connection. Caregivers either reported that the language-reading connection had not been discussed or they noted that it had been mentioned but they could not recall what the SLP had shared. While prognostic information and information about the language-reading connection was limited, most of the caregivers were satisfied with the level of information they received regarding their child’s intervention services. Several caregivers reported receiving a wide range of service options for their children and regular updates on their children’s progress. Caregiver descriptions of child goals and objectives suggested that accurate speech sound production was a primary focus of intervention for several of the children included in this study prior to their speech-language assessment at the university clinic.

While caregivers were able to recall and share several significant pieces of information they had received from their child’s SLP, difficulty recalling information was also a common

theme throughout the caregiver interviews. In addition to having difficulty recalling information regarding the language-reading connection, several caregivers described difficulty recalling details about their child's speech-language evaluation and the diagnostic information they had received. Even caregivers who recalled the diagnostic label, frequently struggled to recall specific information they had received regarding the specific characteristic of their child's disorder. The issue of poor memory likely influenced caregivers' perceptions of information received or not received and thus their overall satisfaction with their experience.

Overall, caregivers greatly appreciated receiving information about their child's diagnosis and their child's intervention. The more information caregivers believed they had received, the more satisfied they were with their overall experience communicating with their child's SLP. In contrast, caregivers often felt frustrated and unsatisfied when they did not feel that information about their child was consistently shared with them. Finally, it was important that the information be clear and understandable to the caregiver, as caregivers relied on the information they received from their child's SLP in formulating their own understanding of their child's disorder.

### **Findings for Question 1b: Caregivers Understanding of Language Delays/Disorders**

In addition to asking caregivers to recall the information they had received from SLPs regarding their children's language delays/disorders, caregivers were also asked to share their personal understanding or definition of their child's disorder. Caregiver interpretations of their child's language related impairment may influence how he or she perceives SLP communication regarding language delays/disorders. This question is addressed in Research Question 1b:

How do caregivers of children with language related disorders perceive SLP communication with them regarding language delay and disorders?

- b. How do caregivers describe their understanding of language delays and disorders?

Caregivers defined their children's language delays and disorders in many different ways. Some of their definitions emerged from information given to them by professionals, while some of their definitions were developed through personal experiences and knowledge. No one caregiver's definition was exactly the same as another's. However, several key themes were found to be consistently important to caregivers in how they defined their child's language impairment. The six primary themes addressed in this section include: the relationship between diagnostic labels and solutions, the characteristics and behaviors caregivers associate with their children's disorder, the conflict between viewing their child's disability as a problem or not a problem, the manner in which previous knowledge and experiences influence caregiver understanding of their children's disorder, the future expectations caregivers have for their children, and, the ease or difficulty caregivers experience in trying to understand their children's disorder.

### **Diagnostic Labels Equal Solutions**

As noted earlier, caregivers were very interested in obtaining a diagnostic label for their child. The reason caregivers were intent on obtaining a label was expressed multiple times throughout the interviews and was consistent across caregivers. Diagnostic labels were viewed as the path to the solution. As Mr. A said, "how can you start addressing the issue until you know what the issue is and you can match it with good evidence based interventions?" In his mind, determining the best intervention for his son was directly tied to identifying the cause of his son's reading difficulty. Without an identified cause, he expressed concern that there could not be individualization and evidence based intervention. The concept of the diagnosis being an essential step to helping their child overcome their difficulty was expressed by several caregivers:

"To me the most absolute helpful thing was just having a diagnosis." (Mrs. C)

As a parent you want to know...are they ok is it something we can fix?  
How treatable is it? Is it going to you know is this going to affect them  
the rest of their life or is this something we can double down on get them  
past. (Mrs. G)

Some caregivers expressed the need to have a diagnosis before taking additional steps.

Mrs. J talked about waiting to take further actions until she knew for sure about a diagnosis, "I'm waiting to just to hear from [the clinic] to see if it is dys - what do I need to you know. I mean I've read on dyslexia you know. I've talked lots and lots with my cousin that has it, so but I'm just waiting because I don't want to label him with that if it's not." Mrs. A, whose daughter has several diagnoses, was not satisfied because she believed that some of her daughter's difficulties were still unlabeled, "the next step we're kind of talking about is seeing if they could test her for her working memory and see if there's more going on 'cause we still feel like there's some things undiagnosed."

Some caregivers, however, acknowledged the negative side to labeling, Mrs. F and Mrs.

A both shared concerns about having their child labeled and put in a box:

She [child's doctor] was pushing you need to have, she needs an IEP, she needs this, she needs that...part of the reason I didn't push was because K was a new student. She was having trouble adapting, she was in middle school. The last thing I wanted to do was stick her in special ed. (Mrs. F)

I just feel like sometimes kids get labeled and then that's the label they're always into like oh this kid always will have trouble reading. I don't you know. He needs to move, be put in some place else too instead of being in the classroom, and I just I feel like that's wrong in all sorts. (Mrs. A)

However, as Mrs. A noted as well, the labeling happened either way, by the teachers and other children who treated her son differently. She believed that having a diagnostic label could help facilitate a real change for her son and that the benefits far outweighed any negatives.

### **Characteristics/Behaviors: How This Affects My Child**

While the diagnosis was an essential component to how caregivers understood their children's disorder, the practical implications of how the disorder affected their child were



important as well. Caregivers were very aware of their child's strengths and weaknesses, and discussed at great length some of the noteworthy characteristics and behaviors they associated with their child's language/reading disorder. While a variety of characteristics and behaviors were attributed to each child's disorder, three common categorizations emerged. First of all, educational difficulties, particularly trouble with reading, writing, or spelling were commonly noted. Secondly, unclear speech and language was often noted, including trouble with word finding, trouble putting sentences together, and garbled unintelligible speech. Finally, in addition to the problematic characteristics, several of the caregivers shared some of the strategies or tools that helped their children, such as using visuals or having someone read to them.

### **Educational difficulties**

Language related disabilities often have a negative influence on children's educational progress. For many of the caregivers, educational difficulties were the first sign that something was wrong and a common focus in describing how the disability affected their child. Difficulty with spelling, reading, and writing stood out as the most frequent educational barrier. Mr. J summed up his son's educational difficulties as a language arts problem. . . . po described how even with help, her son continues to struggle to master grade level work, "his grades just aren't very good you know, and he always needs additional help...he doesn't have the whole list of spelling words like all the kids do, they give him a reduced list." Mrs. B discussed her son's difficulty in mixing up his letters, spelling his name backwards, and in general not keeping up with his classmates:

I know like he will write his some of his letters backwards I notice b and d a lot. And he has both those in his name and he still - I mean /d/ is every day and he still messes that up...if he reads it his comprehension is way down. It always seems like he's about a year behind on the grade level on his reading.

In addition to the difficulty their child had performing educational tasks, some of the caregivers noted that the struggle took an emotional toll. Mrs. G talked about the extreme anxiety her daughter experienced due to her spelling difficulties:

The spelling component she has struggled with to an emotional level, and I don't believe a child should ever cry over school work or homework. Now they don't have to like it. I never said a child would like homework, but it shouldn't cause a level of degree of hyperventilating and major tears and meltdowns over the thought of starting the process.

In talking about her son's educational difficulties, Mrs. D summed up the general attitude that many of the caregivers believed their children had toward school, "it's always been a struggle... We never get caught up, and he is always at the bottom of his reading level. School isn't something he likes."

### **Unclear speech and language**

While not as universal as educational difficulties, multiple caregivers referred to their child's speech and language difficulties when describing their child, both past issues and more current issues. When asked to describe her daughter's speech and language concern, Mrs. A began by describing how her daughter's "garbled speech" had led her and her husband to seek speech-language services. She said, "I think she was about a year and a half old, and her speech completely stopped. We couldn't understand a word she was saying." Mrs. A went on to note that speech production was still an issue for her daughter, who is continuing to address her production of /r/ in her speech therapy sessions. However, in addition to speech sound production, Mrs. A's daughter also has "memory" and "language processing" difficulties. Mrs. A noted that her daughter has trouble retelling information from a story that she has heard and following multi-step directions.

Mrs. B talked about her son having no speech and language as a toddler, "ever since he was probably two - three he just really didn't - speech was really delayed. I mean he was one

word like at the age of 3. It was no sentences, no nothing.” While his expressive language has improved over the years, both Mr. and Mrs. B noted that their son still has some difficulties expressing himself. Mrs. B explained, “I don’t know if he stutters, he does a lot of ums, more than \_like a stutter, trying to find a word.” Mr. B added, “trying to find the order.” Both Mr. and Mrs. B agreed that even though their son has trouble reading and occasionally struggles to express his thoughts clearly, he has always had excellent comprehension. They recall that both the SLP from his early intervention assessment, and the SLP from his more recent reading assessment, reporting that comprehension was a strength for him.

Mr. and Mrs. J also made observation regarding their son’s language, noting a history of speech and language delays, as he was a late talker, “[he] didn’t really start talking until - making like even normal baby noises probably till he was one, and then I really, we knew - I knew he was delayed]. Both Mr. referred to his son’s difficulty with speech sound production, and sentence creation, “I think a lot of annunciations and yeah, phonics. I think that was the main focus back then, and how to pronounce groups of letters and things like that... And I think at the time it was (it was) just his language was lacking. His - and his ability to form sentences]. Both Mr. and Mrs. J expressed the belief that he had improved in his “speaking” ability, but still struggled with his reading.

While some of the caregivers had known something was wrong with their child’s speech and language early on, several of the caregivers, whose children were not evaluated for speech and language concerns prior to school age, discussed how surprised they were when they realized something was wrong. Mrs. E, whose daughter is receiving services for a mixed reading disorder at the university clinic and a learning disability at her school, explained that she had never been concerned about her child’s language development prior to her struggles with reading in school.

I am trying to remember back I never - nothing really clicked that there may have been something wrong...I don't like to compare my children, but I know my oldest one - things just came very easy to her. I remember her talking sooner, but then I had a son and it's very [different], and I don't think I was ever too much concerned with J.

Mrs. E first became concerned when she noticed that her daughter was not keeping pace with her peers in school, particularly in her ability to read grade level stories and recall information that either she had read or had been read to her.

Mrs. G, whose daughter was diagnosed with dyslexia, described her daughter's early speech and language skills as above average.

She was advanced, she was advanced in everything...if anything she uses words that are too big for her and I wonder where she's getting them, because there are times where I'm looking at her and I think how do you know what that means? (Mrs. G)

Mrs. G further described her daughter as an excellent student, noting that she did not become concerned until in first grade, her daughter started having trouble on her spelling tests at school.

Notably, the caregivers who did not recall any early history of concern were looking back several years, and may not have recalled potential red flags.

### **Strategies for coping**

In addition to discussing some of the problematic characteristics associated with their child's disorder, some of the caregivers also shared behaviors that their child employed to compensate for their disorder. Mr. J and Mrs. J both recalled how their son utilized good memory and strategic guessing skills in order to hide his reading disorder. Mrs. J explained:

I think it was last year he started writing some of his words backwards and the teacher noticed that he just wasn't keeping up with the kids, the other kids. We found out then too K was really good at memorizing things and that's kind of how he's survived through school so far. So this year we're noticing too how he has memorized like sight words and things, and he doesn't - say he'll see a *t* and it should be *train* and he says *the*.

Mrs. B explained that her son demonstrated good comprehension on academic tasks if someone else read the material to him, “if he reads it, his comprehension is way down, but if somebody else reads it to him it’s all very good. He gets almost every question right if it’s read to him.”

Mrs. E provided another example, describing how her daughter used pictures to help her comprehend a new story, “J, she relates things by pictures. She could tell a story with the pictures, but she couldn’t if there were no pictures.” Mrs. E also shared that she had been happy to learn from her daughter’s SLP that using pictures was an acceptable strategy that could be built upon, “I know looking at the pictures you shouldn’t rely on that, but they told me you know it’s ok to be looking at the pictures, it kind of helps her you know you see the word and you kind of look at the picture and then oh that’s right that’s what it is.”

Overall, caregivers’ descriptions of their children focused on education and communication based difficulties. The focus on education and communication characteristics makes sense as it was often concerns about poor educational achievement and poor communication that led caregivers to seek help for their children. Caregivers also observed that their children employed various strategies such as memorization, word prediction, and pictures in order to manage their reading difficulty. As Mr. and Mrs. J discovered, their son was so competent at memorization and word guessing that he was able to temporarily hide his reading difficulty from both his teacher and his parents. However, when a child is struggling with a skill as essential as reading, it is bound to become a noticeable problem.

### **A Problem Versus Not a Problem**

Considering the challenges that the caregivers’ children faced, it is not surprising that several of the caregivers described their child’s language related disorder as a problem. The word *problem* was used several times in the caregivers’ discourse when discussing their child, “her problem started when” or “the problem was.” In addition to using the term *problem*,

caregivers also demonstrated a tendency to speak in absolute language using words like *never* and *always* to emphasize the severity of their child's issue:

“It was no sentences no nothing.” (Mrs. B)

“He has just always struggled when it comes to letter recognition.” (Mrs. D)

“She could not focus, she could not sit still, she could not do anything.” (Mrs. E)

In acknowledging their child's disorder as a problem, several caregivers also acknowledged their need for help, as it was a problem they were not equipped to cope with on their own. Mrs. G shared how she tried everything she knew to try, but nothing seemed to work:

We tried everything else we knew to do. We've tried after school, studying, tutors. Everything we could look up on the internet, games and we had exhausted all of my known resources, and I felt like I know enough to know I don't know everything, and it was time to call in somebody else to help.

Mrs. V shared a similar experience, noting the ongoing struggle of uncertainty:

As we've gone through the years and struggled through school then it was like you know we've got to have something to figure out what's going [on] here because it got to the point where it's like you know we're really struggling and something's going [on] here we need to figure out what it is so we can figure out how to work with it.

Another issue that was addressed by several of the caregivers was concern regarding their child's social interaction. Mrs. B explained that she worried about how often her son was separated from his peers:

I'm afraid you know he doesn't have that many friends and he gets pulled out...It seems like a lot of his friends are you know some of them are the ones that get pulled out too with him you know. So it's like I understand you know that point but it seemed like in kindergarten he had a lot more friends and I think it's a social I want to say social status kind of thing.

Mrs. N shared how she initially avoided seeking special education services for her daughter because she did not want her daughter to be the “new kid,” and in special education classes, “She was having trouble adapting. She was in middle school. The last thing I wanted to do was stick her in special ed.” Instead, she tried working with her daughter's school to make

adaptations in K's classroom environment. Her daughter continued to struggle though. During our follow-up conversation, Mrs. N shared that per her daughter's request, she had signed the paperwork initiating a special education assessment for her daughter. She noted that her daughter had settled in well at her school, and had several friends, many of whom were aware of her daughter's difficulties. Knowing that her daughter was not feeling a social stigma helped her feel more comfortable moving forward with the request for special education services.

### **Not a problem**

While all of the caregivers acknowledged that their child's disorder presented challenges, some of the caregivers, expressed minimal concern regarding their child's issues. Mr. J said about his son's language delays, "he was slow to speak and then it seemed like when he wanted to start talking he started talking pretty good." Mr. J recognized that some tasks were more difficult for his son, but he also believed that with the proper treatment, his son would be fine, "I didn't think anything really alarming was found [referring to the speech-language evaluation]. They needed to work on some things."

For Mrs. C and Ms. I, their focus was on turning the potential problem into a solution for their daughters. After learning that her daughter had dyslexia, Mrs. C used the diagnosis to encourage her daughter, explaining to her daughter what dyslexia was and how it made reading hard. Mrs. C believed it was important for her daughter to understand that she was not the problem, and that there was a perfectly logical explanation for her reading struggles. Ms. I expressed a similar belief and shared how much more confident her daughter was following her diagnosis, "and her confidence that was the main thing...that's what her teachers were always telling me I can't believe how much more confident she is... She's excited to go to school now which is nice...She knows what she has and she can get through anything now." Having knowledge was a powerful tool in shaping caregiver and child perception.

## **Influenced By Previous Experiences/Knowledge**

The meaning caregivers attributed to their child's language impairment was often influenced by a variety of individual factors, primarily related to life experiences. Some of the most commonly mentioned influences included: previous experiences with disorders or SLPs, knowledge gained through personal experiences, and, research and learning over time related to their child's disorder.

### **Previous disorder or/SLP experiences**

Several of the caregivers mentioned previous experiences with a sibling's, or a spouse's disorder. Mrs. K for example, was her brother's guardian. She expressed her familiarity with health care practitioners in general saying, "I've raised my brother and I work in the disability field." She also talked about attending numerous IEP meetings over the years, several of which had included conversations with her brother's SLP.

Some of the caregivers understood that the reading and learning difficulties might run in the family. Mrs. D shared that her son's father had struggled in school, "School was very easy to me. His dad on the other hand, he struggled a lot in school and he had a lot of the same problems with like spelling and reading and all that stuff." Ms. I shared that she had experienced learning difficulties similar to her daughter's, "I invert words and letters all the time so it's probably [from family], and her brother on her dad's side her little brother, they think he's dyslexic too. So she might be getting it from both sides."

While previous experiences with language and reading disorders might have helped some of the caregivers have a better understanding of their child's difficulty, some experiences may have also had a contradictory effect. Mr. J, one of the caregivers who struggled early on to acknowledge that his son might have a disability, talked about why he was not concerned, "At



that time I probably wasn't very worried, because you know some people that have kids had said that when they're ready to speak they'll speak."

### **Personal Knowledge**

For some of the caregivers, their understanding of their child's disorder was influenced by personal knowledge that they had gained through career, education, or other life experiences. Mrs. C, for example, was studying to become a teacher. She explained how her experiences as a student influenced how she viewed her daughter's disorder:

I am taking a different look at it then I would if I wasn't getting my degree, like right now I'm in a reading and language arts class where we are looking at those things. So she is kind of like a test dummy to me.

Mrs. C went on to share, that she was sometimes frustrated when the strategies she learned in her class did not work with her daughter, but it helped her to appreciate the complexity of the disorder and the lack of easy solutions.

Mrs. A shared how having other children highlighted her oldest daughter's delays, increasing her understanding of her daughter's limitations. "Cause I have my middle child who is a year, 17 months behind her, and is 2 to 3 grade levels reading above, and so I mean we [her and her husband] know what we are dealing with."

### **Changes over time**

Finally, the role of time was also noted by some of the caregivers, especially those who had been dealing with their child's language disorder for several years. Some of the children had been given multiple diagnoses over the years; giving the caregivers new labels to interpret and reconcile. Children with speech delays became children with possible apraxia, a learning disorder, or dyslexia. Mrs. A shared some of her daughter's diagnoses over the years, "They were saying at that point that they thought she had speech apraxia...She has a language processing disorder...She has severe dyslexia...And supposedly ADD/ADHD."

The behaviors changed over time as well. Difficulty with speech sound production, became difficulty with identifying letter and sight words. Then as a child progressed in school, reading and writing issues became apparent. Mrs. A talked about how she had come to understand different aspects of her child's disorder over time, particularly as her daughter developed and new facets of her daughter's disorder emerged. One example, she shared illustrated how she learned new information when new assessments were completed:

I had brought in a bunch of paper work too and showed them what I was seeing, but watching the test was kind of cool and listening to them explain 'well this is - we're checking her processing,' it was like something I had never thought about.

Mrs. A also shared that she began seeking additional information about her daughter's speech-language impairment and possible intervention options on her own in an effort to better understand her daughter's needs, "through some of my facebook pages and stuff that I'm on, I got these ideas of well they can start working on that in speech." She believed her own research helped empower her to engage in important conversations with her daughter's SLPs about possible treatment options and goals.

As a whole, the caregivers who participated in this study had a variety of both disorder and non-disorder related experiences that influenced their perception of their child's disorder. As their experiences evolved over time, so did some of the caregivers' interpretations of their children's disorder. For the most part, caregivers believed that they had gained a better understanding of the child's language and reading difficulties over time, though there were still areas of question. One area in particular that caregivers sought to better understand about their child's disorder was how their child's disorder would influence him/her as an adult.

### **The future**

The question "How will this affect my child in the future?" weighed on every caregiver's mind. As noted earlier in regard to the topic of long-term outcomes, the lack of perceived

information from professionals regarding long-term outcomes did not equal a lack of caregiver contemplation on the topic. For example, Mr. and Mrs. B talked about possible future jobs for their son, Mr. B started, “I still don’t see him book writing, a author.” Mrs. B agreed, “Yes or something that is going to require tons of reading, no doctor you know something like that kind of profession.” Mr. B continued, “I could see him being more hands on, hands on creative.” Overall, many of the caregivers were hopeful and talked about opportunities their child would have, tools that they were trying to put into their child’s hands. However, most of the caregivers also expressed concern for their child’s future, particularly in regard to their child’s reading and how poor reading skills may hold their children back.

### **Hopeful Expectations**

While many of the caregivers like Mr. and Mrs. B did not expect their children to seek out careers that involved heavy reading and writing, many were hopeful that their children would continue to make improvements and find enough success academically to have multiple career and college options:

“He has always said I’m going to go into what my dad is at. He’s said I’m going to do biomed in tech so I was like he would probably rock that or you know some type of service field like that. He would do well in.” (Mrs. B)

“Long-term I think I expect her to graduate college and go on ‘cause with all the tools that she’s getting.” (Ms. I)

Other caregivers were more focused on specific academic goals. Mr. J expressed the hope that his son would reach a point where reading and writing were not so hard for him:

I would like him to be able - to see him able to read. Be able to read well, be able to be handed a math story problem and be able to read through the math story, be able to go through the English of the story problem and then figure out how to work - you know just to understand the English, his English better, and be able to write, so that that’s my goal.

Mrs. A shared how the improvement she had seen so far in her daughter kept her feeling hopeful:

We have seen a huge improvement just from the time that she's been here of asking more questions, so we do hope that we are hoping that slowly she will progress. It's going to be slow, slow and steady is what we're hoping.

### **Worry**

Even though the caregivers expressed a lot of hope for their children, concern for their future always underlined that hope. Mrs. J's concerns plainly illustrated the practical day to day issues that can arise for adults that are poor readers:

You know in the future like I am concerned he'll receive say something like this [held up sheet of paper with small print filling entire page], because he would freak out if he saw this like, 'Oh my god you want me to read that mom.' You know, there's too many words, and I'm afraid he'll receive something really important one day and he'll just either set it aside because it's too much, or he won't ask someone, say 'hey can you look this over.' So I guess my concern is like, I'm not there, his dad's not there, who's going to protect him from people that'll take advantage of him, because he didn't understand what he signed.

In addition to worrying about her son finding himself in a difficult situation due to his struggle with reading, Mrs. J also worried about her son's happiness and satisfaction in life. She noted that he already feels a great deal of frustration with anything reading related and she worried that as an adult he may choose unhealthy ways to cope, "K has grown up around alcohol his whole life, and my other concern is it'll be a coping mechanism for him."

Overall, each of the caregivers expressed a mixture of both hope and fear regarding their children's future. Notably, as illustrated in Figure 3, the children diagnosed with dyslexia tended to have more optimistic caregivers, who generally believed that with appropriate tools, their children would have the same opportunities as their peers. Some of the caregivers referred to examples of people they knew or celebrities who had dyslexia and were successful. In contrast, the caregivers of the children with more complex language diagnoses presented as less optimistic

caregivers, expressing greater concerns about their children's future education and career options. As a whole, the children with dyslexia did present as less severe impairments than the children identified with a mixed reading disability, suggesting that caregivers had good reason for their optimism or their concern. However, caregiver optimism in regards to the dyslexia diagnosis could also relate to caregiver belief that he/she understood and knew how to deal with dyslexia. In contrast, a diagnosis of mixed reading disability appeared more vague and potentially more uncertain to the caregivers.

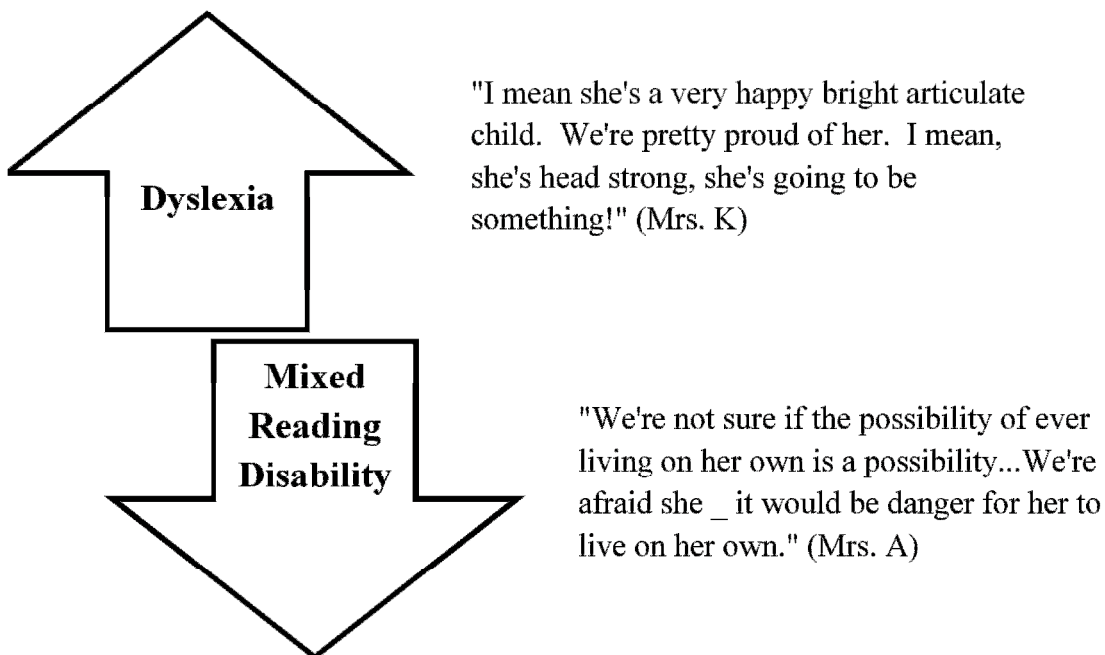


Figure 3. Graphic illustrating two conflicting future expectations expressed by caregivers, one of a child with dyslexia, the other of a child with a mixed reading disability.

### **Difficult to Understand**

Finally, in regards to defining their child's disorder, some of the caregivers talked about how difficult it was for them to understand their child's diagnoses, particularly to understand what it was like for their child to have a particular disorder. Mrs. C tried to explain, "I don't understand dyslexia, I just, I don't have it. I mean I get the gist of it, but when we're sitting down doing it (homework) in the back of my mind I'm just like why can't you do this? This is

easy, you sound it out.” Mrs. D expressed a similar sentiment, trying to explain how hard she found it to help her son:

When he was little I would always try to [help], but I’m not - I don’t know, the way I learn and the way he learns is way different. For example, just like spelling words when I was his age. If I needed to learn my spelling words I would just write them 10 times or something. It’s like when he writes them he’s writing them, but he’s not going through the letters together...He could write them 100 times, but if I asked him how to spell it he still wouldn’t get it right.

The difficulty some caregivers have in understanding their child’s disorder may connect to each caregiver’s personal learning experiences. Both Mrs. C and Mrs. D noted that they did not experience the academic struggles that their children have experienced. In contrast, Ms. I shared, that she “inverts words and letters all the time,” adding “that’s probably why I was more in tune [to her daughter’s academic struggles].” Overall all though, even though many of the caregivers viewed their child’s disorder as complex and challenging to understand, the caregivers expressed a desire to try to understand their child’s disorder and find ways to assist their child through its associated difficulties.

### **Summary of How Caregivers View Their Child’s Language Delays/Disorders**

The second part of Research Question 1 focused on how caregivers viewed their child’s language delay or disorder. For many caregivers, the meaning they attributed to their child’s disorder was multi-faceted and very complicated. First of all, caregivers placed a great deal of significance on the diagnostic label, often viewing it as the necessary solution they had been searching for. Having a diagnosis meant having a plan of action to address the problem. While the diagnosis was important, caregivers were also very aware of the various characteristics of the disorder that presented in their children. Educational and communication difficulties were commonly noted, especially in relation to reading/writing and comprehensible communication.

Some caregivers also observed their children's ability to find strategies and methods of coping with their disability such as using pictures or contextual cues when reading.

Another common view focused on the disorder as a problem or not a problem. Given the focus on finding a solution and the multitude of educational and communication difficulties associated with each child's disorder, it was clear that all of the caregivers viewed their child's disorder as a problem to some extent. However, several of the caregivers, particularly after finding their solution (the diagnosis), expressed certainty that the disorder was not an insurmountable problem for their child, but rather an explanation for why certain tasks were more challenging than others.

Previous experiences also played a role in influencing caregiver perceptions. Some of the caregivers reported previous experiences with SLPs or children/siblings with disorders that influenced how they responded to their child's language impairment, either positively or negatively. Several noted that their family, educational and career experiences also influenced their understanding and interpretations of their child's disorder. Having knowledge of other individuals with disorders that had met intervention goals or achieved success as adults gave caregivers hope for their child's future. However, that hope was almost always tempered by concern regarding their child's limitations.

Overall, trying to understand their child's language based disorder was a complicated task for caregivers. Despite their many efforts, several of the caregivers found that trying to understand their child's disorder was a constant struggle, especially when they were seeking to figure out what tools or strategies would help their child. Therefore, further information to better understand their child's disorder was often a primary goal of caregivers when scheduling a speech-language evaluation for their child.

## **Summary of Caregiver Perceptions of SLP Communication and Language Disorders**

The findings for Research Question 1 explored caregiver perceptions of the information SLPs communicated with them, and caregivers' perceptions of their child's language disorder. The findings indicate that caregivers tended to perceive SLP communication in terms of information received and information not received. In fact, caregiver satisfaction or dissatisfaction with SLP communication was closely linked with the quality of information that was perceived to be shared, particularly in regard to a clear and understandable diagnosis versus an unclear or unstated diagnosis. A strong desire for a diagnosis was further reflected in the caregiver responses as to their understanding of their children's language disorder. Overall, caregivers tended to view their child's undiagnosed disorder as a problem that interfered with their child's educational success and was very challenging for caregivers to understand. In contrast, several of the caregivers perceived the diagnosis as the answer or solution to the problem, something that would give them direction in helping their child. Thus, caregiver perceptions of SLP communication were influenced by their desire to find answers and better understand their child's language delay or disorder.

### **Findings for Question 2: Helpful Versus Unhelpful SLP Practices to Enhance Caregiver Knowledge and Collaboration**

Caregiver knowledge and caregiver collaboration both play an important role in how caregivers perceive SLP communication. As discussed in the literature review (Chapter 2), clients/caregivers who feel well informed are more likely to be satisfied with their health care provider and follow through on recommendations (Wanzer et. al, 2004). Additionally, clients/caregivers who believe they have some control over the intervention process are more likely to engage in positive collaboration with their health care provide. As Donovan et al. (2005) noted, health care providers can best help clients/caregivers feel in control by educating



them about the health related concern. In addition to increasing caregiver knowledge, ASHA emphasizes the importance of including the caregiver in the assessment and intervention process (ASHA 2006; 2008). Caregiver cooperation and participation is essential to meeting the needs of the whole child and ensuring positive intervention outcomes (Crais et al., 2006a; Hidecker et al., 2009).

Therefore, it is important for SLPs to make sure that in addition to working with the child, they are providing appropriate information and resources to the child's caregiver. Furthermore, SLPs must establish ongoing and productive relationships with the caregivers with whom they work. To accomplish both goals, SLPs must be attentive to their communication practices, recognizing which practices may be perceived as helpful and which practices may be perceived as unhelpful. Research Question 2 focused on what communication practices caregivers perceived as helpful versus what communication practices were unhelpful both to increasing caregiver knowledge and increasing caregiver collaboration. Research Question 2 was:

- What SLP communication practices do caregivers of children with language related disorders identify as effective or non-effective in building the therapeutic relationship?
- a. What SLP communication practices or resources do caregivers perceive to be helpful or unhelpful in increasing caregiver knowledge of language disorders?
  - b. What SLP communication practices or resources do caregivers perceive to be helpful or unhelpful in increasing caregiver involvement/collaboration?

While these questions were initially considered separately, it became apparent as the interviews were analyzed that for the caregivers, knowledge and collaboration were intertwined. Both knowledge and collaboration are key components to building an effective therapeutic relationship. I focused on the importance of caregiver knowledge in this study since caregivers must understand the disorder in order to effectively communicate with the SLP about the disorder. I also focused on caregiver involvement or collaboration with the SLP through the

evaluation and intervention process since caregiver and SLP collaboration is a key element of evidence based practice. However, examination of the transcripts indicated that caregivers frequently and consistently connected knowledge and collaboration as a dual concept rather than two individual concepts. For caregivers, the level of collaboration that occurred was influenced by their perception of understanding their children’s disorder and the intervention process. As illustrated in Figure 4, the level of knowledge influenced the level of collaboration and vice versa. Caregivers who were confident in their knowledge were more comfortable collaborating, and had more opportunities to increase their knowledge. Conversely, caregivers who considered themselves less knowledgeable about their child’s disorder and the intervention process were less comfortable collaborating. As a consequence, the two parts of this question were analyzed jointly.

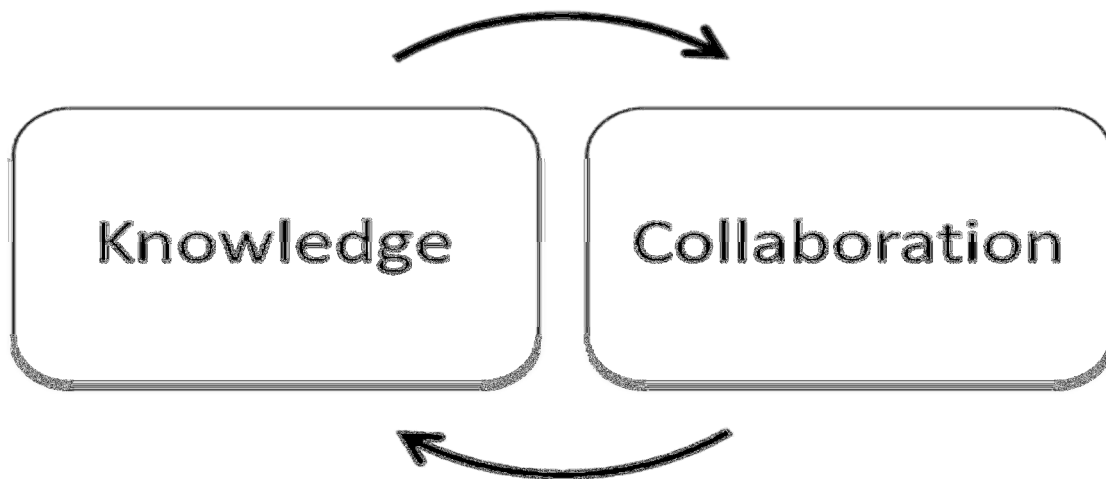


Figure 4. Graphic Illustrating the Interconnected Relationship Between Caregiver Knowledge and Caregiver Collaboration.

The following themes emerged from caregiver perceptions of therapeutic relationship building, with a focus on what communication practices were helpful versus what communication practices were not. Overall, 10 distinct themes emerged including: the

resources professionals provide, the manner in which professionals share information, the timing associated with information sharing, the presence or lack of follow-up information, the perception of open and honest communication, the perception of responsiveness to caregiver concerns, the perception of needs being met, the clarification of professional and caregiver roles, the whole family approach, and the knowledge caregivers have of SLPs as professionals.

### **Resources Professionals Provide: Information/ Homework/Intervention**

The resources provided by an SLP can take on a variety of forms, and could include almost any object or action designed to assist the caregiver in better understanding or helping their child. When asked about the resources that had been meaningful to them, caregivers focused primarily on information, homework, and intervention. The first and most referred to resource was information based resources. Information based resources included any resource that provided caregivers with further information about their child's disorder. Caregivers referred to written reports, websites, handouts, home intervention strategies, and other professional referrals when describing informational resources that had been helpful to them:

“They had given me other places I could go to if I needed.” (Mrs. E)

“They did send home a packet of stuff of like what they were working on.” (Mrs. B)

Several of the examples that caregivers provided of helpful informational resources, were resources that they had received after the evaluation. As Mrs. B noted, when explaining what she had liked about one of her son's SLPs, the ongoing contact was at least as meaningful as the information.

She would actually send home like here's a website. Here's this that you know some kids benefit from this...I mean she actually reached out to us more than I feel like the other ones did to give us the extra little boost...I felt like she helped out a lot.

While Mrs. B could not recall details regarding the websites, she had not forgotten how she appreciated the contact that sharing the information facilitated.

In addition to information based resources, several of the caregivers discussed various home work assignments or learning tools that had been provided for their child:

“They left flash like little flashcards out at the house to go like over what they were doing.” (Mrs. B)

“She also tried to give us different things to do.” (Mrs. E)

“They gave us little activities to do, and every time we went they got different vowel cards.” (Ms. I)

It gave caregivers a sense of knowledge and purpose when they understood what helped their child and could participate in using the helpful strategies:

Learning to break everything down for her to understand I think that learning how to do that was very helpful and trying to help her I guess decode the meaning you know. Also I know looking at the pictures you shouldn't rely on that, but they told me you know it's ok. Looking at the pictures kind of helps her you know see the word. (Mrs. E)

“I liked being able to watch his sessions ‘cause it helped me to think about stuff I could do at home with him.” (Mrs. J)

Finally, several of the caregivers referred to the availability of speech-language services as an important resource.

“I was concerned like when school was over last year I thought what am I going to do, and then that's when they mentioned that they had the summer program.” (Mrs. E)

“Just getting therapy here and that they would provide it...that was one of the biggest resources.” (Mrs. A)

“Mostly I just recall the programs that the clinic offers summer and during the school.” (Mrs. C)

Overall, during the interviews, caregivers focused on resources they had received. One caregiver, Mrs. B, however, pointed out that she had not received a referral for a support group, “No support groups, I mean we never talked to anybody else, no other parents that were going through the same things.” Mrs. B was the only caregiver to mention support groups in this study. As several of the caregivers noted, having access to appropriate resources provided opportunities to increase their knowledge about their child's needs, and in particular, intervention strategies

that helped their child. Having that knowledge, caregivers were better able to carryover strategies and recommendations in the home environment, thus establishing a productive collaborative relationship between the caregiver and the SLP.

### **Methods of Information Sharing**

Information sharing was consistently mentioned by the caregivers as a significant factor in the success or failure of the assessment and intervention process. While information can be shared in a variety of ways, three primary methods of information sharing stood out in the transcripts as most memorable and important to caregivers. First, caregivers spoke frequently of watching the evaluation or intervention session(s). They valued this experience, both the visual aspect of being able to see what their child was working on and the verbal aspect of having a clinician explain the assessment or intervention process. Second, caregivers noted the importance of having a “wrap-up” conversation with the clinician/s following the evaluation or intervention session. The significance of the “wrap-up” conversation was that it typically took place immediately following an evaluation or intervention session meaning caregivers did not have to wait for information. Finally, caregivers consistently referred to the written report. The evaluation report was discussed most frequently, but caregivers also noted receiving progress or intervention reports.

#### **Watching the session**

When asked what they found the most helpful or from what they had learned the most, caregivers consistently mentioned being able to watch the evaluation or intervention services. While the option of watching a speech-language session was only available at the university clinic and the early intervention setting, all of the caregivers had been given at least one opportunity to observe either an evaluation or intervention session. Watching the assessment or intervention session gave caregivers multiple opportunities to gain knowledge through watching

the activities as they occurred. Additionally, watching the sessions provided a crucial opportunity for collaboration, since it allowed both parties to question and discuss the activities as they were happening. Several of the caregivers specifically recalled the SLP explaining the purpose of various activities or tests while they were being administered:

“Watching the test was kind of cool and listening to them explain...they explained exactly what they were doing and why.” (Mrs. A)

I was in this room that I could see K through and as they went through these different reading tests with her the other lady the actual speech-language pathologist was in there and as they went through the test she would explain ok they're having her do this because (Mrs. F)

Then they let me watch the test being administered and everything so and the first part of the test was on a computer. They actually put the book in front of me that kind of followed the test that he was doing and then Dr. A and or the college student would explain to me what it was looking for and things (Mrs. J)

Having the opportunity to observe and have the assessment explained while it was occurring helped caregivers to have a better understanding of the process. Mrs. C noted that watching her daughter's evaluation helped her better understand the results provided in the written report. She explained that after watching the evaluation, she was able to better match the strengths and weaknesses described in the written report with actual test activities she had observed her daughter carrying out:

I really appreciated being able to watch it 'cause I've never had the opportunity to do that, and like I said because of G [son] I've sat through lots of these but it's a lot easier to understand after the fact when you're kind of having that regroup as to where the information is coming from.

She also appreciated being able to actually see her daughter's strengths in action; “I knew there was strength in oral comprehension but I did not see the drastic remarkable differences you know in those benchmark scores, and I mean it was just like undeniable to me at that point.” Mrs. D learned about her daughter's weakness and felt like she was better able to help her daughter with her new understanding:

They'd read a little sentence then ask what that meant; or if they gave her a simple word and asked her to describe that, well it was very hard for her to describe it, and I remember thinking, I guess I just kind of took for granted that she knew, that if I would say something or read something I guess I just always took for granted that she would know what I was talking about and she didn't. I think that kind of opened my mind up a little bit so when I we would come home and do homework with her it kind of helped me out a little bit more to know that this a weakness of hers. That what I took for granted she knew she really didn't know and I think that's what... I think it helped her but it helped me out too to kind of understand how her mind was working.

Mrs. D explained that watching her daughter's sessions not only increased her knowledge of her daughter's weaknesses, but also helped her feel more capable of helping her child. Mrs. J was one of the caregivers that regularly watched the intervention sessions as well. She appreciated how the clinicians always talked with her afterwards, and sought her input. She also felt like she got ideas to carryover at home:

They always let us watch and view. You know they wanted to make sure that what they were seeing was normal and typical. I liked being able to watch his sessions and 'cause it helped me to think about stuff I could do at home with him.

Mrs. B, one of the caregivers who did not initially mention watching, brought up her lack of ability to watch when I asked her if there was anything that would make her feel more involved in her son's intervention:

With our hours that we [her and her husband] work, it's hard to be down there with him. That would probably be the only negative thing I would say. A lot of times it was our niece dropping him off and then picking him up...so I mean it was just hard to try to work that schedule in.

Overall, the caregivers appreciated the benefits of being able to watch their children's sessions and voiced regret when it was not possible. They regarded watching as an opportunity to stay informed about and involved in their child's speech-language intervention. Additionally, watching the sessions provided a natural and convenient opportunity for consistent collaboration between the caregiver and the SLP. As some of the caregivers mentioned, it was easy to discuss

progress, concerns, and options when the child's performance during an intervention session was fresh in both the caregiver's and SLP's mind.

### **Having the wrap-up conversation**

In addition to watching the evaluation or intervention session, several of the caregivers also referred to the importance of the wrap-up conversation. The wrap-up conversation was defined by caregivers as the conversation that occurs between the caregiver and the SLP immediately after an evaluation or an intervention session. Most of the caregiver comments focused on the importance of the wrap-up conversation following the speech-language evaluation.

The wrap-up conversation after the evaluation served primarily to give caregivers an informal summary of how the evaluation had gone and to preview the diagnosis and recommendations that would appear in the written report. It also gave caregivers an opportunity to ask questions and provide feedback regarding what further services they might be interested in receiving for their children. Caregivers who received information about a probable diagnosis and likely intervention services were generally more satisfied than those who were told they would have to wait for the report. As noted earlier in the findings, caregivers placed a high level of value on receiving a diagnosis for their child, and often were satisfied or unsatisfied with their clinical experience based on whether or not they received diagnostic information in a timely manner. As Mrs. G shared, having a timely conversation about the diagnosis and future steps was very important to her:

I can't say that they went real in depth with me like the report did, but just knowing you know. Are they ok? Is it something we can fix? How treatable is it you know? I didn't need a five hour meeting on it I just need to know is there something going, is there not, and what do we do next?



She went on to discuss how the SLPs had included her in the conversation. She explained that they had provided recommendations, but also asked her how she wanted to proceed. Mrs. G noted that in the end, it was her suggestion that was followed:

The plan that was originally presented was apples and oranges. You can either come to the clinic or the school is free and you can do the...they might do it different than us they might do it exactly the same we don't know 'cause we can't speak for them but you have apples and you have oranges was more the way it was addressed to me, and I said well why can't we make a fruit salad...So my thoughts were well can't we complement each other...They didn't say no you know, they didn't. It seemed like they were very whatever's best for the child and the more we talked about that the more that approach seemed appropriate.

As Mrs. G described, having the wrap-up conversation allowed and encouraged her to take an active role in planning her daughter's intervention process. Mrs. G shared during our interview that she left the evaluation feeling knowledgeable regarding how the intervention process would proceed and prepared to facilitate teamwork between herself, her daughter's teachers, and the SLPs at the university clinic.

One challenge associated with having a wrap-up conversation immediately following an evaluation, was the inability of the SLP/s to score and thoroughly review evaluation results prior to sharing them with the caregiver. Several of the caregivers acknowledged that they were cautioned by the SLP that the information given during the wrap-up conversation may be incomplete as thorough evaluation of the data was not complete. For example, Ms. I shared, "They [SLP team] said that the way it was looking now, but they hadn't crunched the numbers, it does look like she was dyslexic but they needed to make sure and read over the test to make sure it was." The lack of certainty led some SLPs to wait until a later time to share information with the caregiver rather than providing a tentative diagnosis immediately after the evaluation. However, the lack of an informative wrap-up meeting typically resulted in caregivers like Mrs. N feeling frustrated:

They did not offer a diagnosis... That was the part where I feel like they shared a little bit with me, but it was more we're going to go through this as a group, we're going to evaluate it, talk together, figure it out, and then we will contact you, but then I got the report in the mail, but I never heard from them again.

She continued, saying she would have preferred to have heard something before leaving;

At the time I kind of wish they would have said you know this is what we're thinking. We think that maybe she has this and we're going to discuss it and see what we can come up with to help that. I'm sure they didn't want to say something when they weren't one hundred percent sure that's what they were going to suggest, but a little more concrete information would have been - would've made me feel better.

Thus, for Mrs. N, the lack of a wrap-up meeting also meant the lack of clarification regarding her daughter's diagnosis, and the lack of an opportunity for Mrs. N to ask questions and be involved in the recommendation making process. During our interview, Mrs. N shared that she had not fully understand the information shared in the report and she would have been grateful for some assistance in communicating her daughter's needs to her daughter's school.

While information sharing and collaboration can happen at other times and in other manners, the immediacy and the face-to-face nature of the wrap-up conversation presented as an effective way for SLPs to set a tone of collaboration and open information sharing from the beginning. When this opportunity was missed, these caregivers felt not only less knowledgeable, but less capable of active collaboration with their child's SLP.

### **The written report**

The final manner of communication noted frequently by the caregivers was the written report. The report typically contained a diagnosis, details about testing results such as test scores, and recommendations regarding future services, and provided caregivers with a written record that they could access at any time and share with other professionals or family members:

I got the paperwork and saying you know this is the level she's at which I really liked seeing because we knew she was low but at least we had it documented, because we have family members that aren't accepting this whole thing, and so it's black and white (Mrs. A)

It was a two page report that they sent me and it did have it [the diagnosis], and then they explained what she got or they did the percentage, like how many she got right to how many questions there were, and then versus when she's writing on paper and reading out loud versus what she got right, they broke it down to each section and told - said you know, then they broke it down afterwards and wrote their diagnosis afterwards (Ms. I)

Unlike the other two methods of information sharing, the written report on its own did not necessarily facilitate collaboration between the caregiver and the SLP. For example, Mrs. N noted that she struggled to understand the report, "I don't feel like I understand the report as good as I should. I should've sat down and read them more." She went to say that she could have called and asked for assistance, but she never followed through, "I don't know what was going on in our lives that I didn't get that done." However, as some caregivers shared, the SLP can use the report as a tool to encourage collaboration by following up on it with the caregiver. Mrs. C, for example, shared how the SLP had called her after mailing the report, keeping the lines of communication open. "Having a phone call just double checking that I got it, if I had questions, different options, and stuff to look at and where to go from there." Through following up on the report after it was sent, the SLP continued to involve the caregiver in the process and attempted to ensure that the caregiver understood and was satisfied with the information they had received.

### **Timing of Information Matters**

The timing of when information was provided or received was very relevant for the caregivers. Several of the caregivers, when asked what could have been better about their experience, expressed wishes related to timing. Specifically, caregivers often noted that they wished they had received certain information sooner. Additionally, several of the caregivers described how the lack of timely information had interfered with the collaboration process, particularly their ability to ask pertinent questions.

## Knowing Sooner

The most commonly mentioned issue in regards to recent evaluation experiences was the desire to receive the report or the diagnosis sooner. Caregivers were often working against a deadline themselves that required the documentation that a written report provided:

**I WISH** we could have gotten it a little sooner, and that's just because it came right at the end of the school year and I knew I was switching schools and I really kind of wanted a 504 in place, and I know, I was pretty sure I could have gotten it had we had more time there to go through their process. (Mrs. C)

Overall, getting the report sooner was treated in a light-hearted manner by the caregivers during the interview process, possibly due to the fact that caregivers were aware of my connection to the university clinic as a clinical supervisor. The phrase, *I wish* was used frequently by caregivers during our interviews, particularly in reference to the timing of information. Several of the caregivers laughed and declared that they did understand completing a written report took time. However, some of the examples of delayed information spanned significantly more time than a few weeks:

**"I WISH** that they [the SLP team] would have [shared more about her daughter's language], because knowing where we are at now and knowing how severe her language understanding is - that she doesn't have it." (Mrs. A)

**"I WISH** they [the SLP team] would have started working on the memory stuff back then." (Mrs. A)

**"I WISH** I would have pushed a little bit harder before then to get it [speech-language assessment] sooner." (Mrs. H)

**"I WISH** they [SLP team] would have shared with me more that you know this could be a long-term thing." (Mrs. J)

The words cloud in Figure 5 illustrates the words caregivers used when talking about receiving information and the frequency at which those words were used. Besides the term *I wish*, other notable words like *know*, *knowing*, *gotten*, and *sooner* were expressed frequently with regard to the timing of receiving information.



brought him after realizing that his communication was delayed. Due to his diagnosed delay he was also able to receive intervention services through his local public school. After driving for over an hour, multiple times a week for almost a year, Mrs. J decided that the local services would be enough for her son. Looking back now though, she wonders if she had all the information she needed: “So he was getting services through the school here and really I thought he was getting what he needed until this year we discovered he probably hadn’t been.” What she had believed to be a minor speech and language delay, turned out to be significantly more complex and long-lasting. As a health care professional herself, she knows health care professionals cannot predict the future – “maybe they [the SLP team] didn’t even know at the time since, we were just mainly there for the speech” – but she wishes she and her husband had known what to look for sooner.

Receiving timely information about their child was very important to caregivers. While they could laugh about their impatience regarding the length of time it took to write a report, many of the caregivers recognized the potential lost opportunities for their child when information regarding a diagnosis or long-term needs was not forthcoming. As caregivers relied on and expected the SLP to provide them with the information they needed, poor timing of information sharing could also negatively influence the SLP and caregiver collaborative relationship. Caregivers also expressed concerns about not always knowing if they were missing important information. As caregivers felt strongly about needing information in order to effectively collaborate with SLPs, the lack of timely information could interfere with caregivers’ willingness and confidence in communicating with their child’s SLP. As several of the caregivers shared, without the information, they did not know what questions they needed to ask.

## **Not Asking Questions**

Both Mrs. A and Mrs. J were satisfied with the information they had received from their children's SLPs initially. They only realized later that there were questions they should have asked. Having professional knowledge regarding language and reading impairments, SLPs have a responsibility to anticipate what information may be important for caregivers to know and seek to share that information with caregivers. As Mrs. J shared, SLPs need to be cautious of taking caregiver knowledge for granted:

He went to kindergarten and then he would've had to be reevaluated, and I just figured it was something the school did, so you know dumb me. So, he didn't have services and kindergarten went by and we just kind of thought of it's kindergarten, and then first grade is when I requested that he be evaluated for special ed.

Additionally, caregivers may not always ask the questions in their minds. Mrs. E shared her initial confusion regarding how her daughter's intervention was proceeding. She explained during the interview that she had not asked the SLP about her daughter's intervention because she believed it was her problem and she did not want to appear to be questioning the professional's methods:

You know at first when she went there I kept thinking why are they doing that? You know at first I was like ok this is just not - I don't understand why you're doing this and then like towards the middle to the end like then it allowed me I could process oh well you need to start this way to kind of build it up...I think I guess that was my problem I didn't understand at first.

Mrs. E went on to say that one of the SLPs did eventually explain her daughter's intervention process to her in more detail, and she now believed that she understood. However, she never did ask for the explanation. Mrs. E's hesitancy to ask questions illustrates the importance of including caregivers in the intervention discussion from the beginning and checking for understanding. Even though Mrs. E had watched her daughter's evaluation, regularly watched her daughter's intervention sessions, and regularly communicated with her daughter's SLP, there

were still missing pieces of information to fill in. In Mrs. E's case, more timely information focused specifically on her daughter's intervention plan could have improved the collaborative process.

Mrs. E was not the only caregiver who kept her frustrations to herself. In discussing her opportunities to observe her daughter, Mrs. A noted that there was one time she was very upset. She had been observing what she referred to as a summer re-evaluation and she noticed that the clinician was leading her daughter on:

Because we know C can't rhyme and so she would uh she was asking her to rhyme just like and so she was kind I felt leading her into where she would answer correctly. And I felt like that wasn't a good thing because it wasn't a fair assessment because I know what level she's at and I know she can't rhyme and so for like I said I felt like she was trying to make it where C wasn't as severe as she is.

Mrs. A did not share these feelings with the clinician and she did not indicate ever receiving a further explanation regarding the assessment.

These examples illustrate the need for SLPs to continue sharing and checking for understanding after the initial evaluation. Caregivers may not always feel comfortable questioning the professional or they may be unsure regarding how to frame their questions. Opportunities for providing caregivers information and encouraging collaboration may be missed if SLPs take silence or a lack of questions as an indication that all is understood.

### **Follow-Up**

Caregivers expressed a strong need for follow-up information and follow-up conversations with their child's SLP after the evaluation and during the intervention period. First of all, follow-up after the evaluation was essential to check for understanding. Caregivers often required further information and further explanations after having an opportunity to review and consider the information they had received during the evaluation. Secondly, follow-up was essential for encouraging ongoing caregiver involvement and collaboration with the intervention



process over time. Caregivers, however, often relied on the SLP to initiate these follow-up conversations and keep the communication lines open. Finally, follow-up was important for keeping information current in the caregiver's mind. Caregivers routinely struggled to recall information they had received during the initial evaluation. Caregivers would frequently say they "thought" something was mentioned or discussed, but they could not remember specifically what the SLP had shared.

### **After the evaluation**

Typically, caregivers noted receiving a written report a certain number of weeks following the evaluation. For many this was the first follow-up information they were provided. However, caregivers were not satisfied with a written report alone, especially if they had remaining concerns or questions. Mrs. F explained that she had expected further communication following her daughter's evaluation at the university clinic; "I kind of expected to go back, sit down with them, go over what you know what was going on and what we could do to make it better." She indicated that she received the report but never a follow-up phone call. Mrs. F shared the report with her daughter's school, but admitted that she had not fully understood the diagnosis and recommendations in the report. Even though she had questions, she did not initiate further contact with the university clinic, saying simply "I didn't get that [calling the university clinic] done."

In contrast, caregivers who had received a follow up phone call or conference reported feeling significantly more satisfied with the information they had received and their understanding of that information. For example, Ms. I shared: "Yeah they explained all the little different things and when we came back, 'cause we came back for a consultation, and they explained it in greater detail." Ms. I credited her confidence in understanding her daughter's

diagnosis to the follow-up conference with her daughter's SLP and noted that it was the first of an ongoing pattern of communication between her and her daughter's SLP.

Follow-up after the evaluation was important to helping caregivers solidify their understanding of their child's diagnosis. Caregivers frequently had new questions or concerns following the evaluation that they had not thought of before, or they needed further information regarding the information provided in the written report. Following-up after the evaluation was also important to building the collaborative relationship. While initial steps may have been taken by the SLP during the evaluation to establish a positive relationship, there was often a significant gap in time between the evaluation and the written report being received by the caregiver. By following-up and initiating further communication after the report was received, SLPs opened the lines of communication and set the stage for ongoing communication.

### **Ongoing communication**

While the follow-up shortly after the evaluation was important to setting a positive precedent, caregivers also expressed the need to have regular opportunities for communication. Mrs. E appreciated the ease in which she was able to communicate with the SLPs at the university clinic:

They were always willing. I could email them with any questions I had, call them with any concerns I had, there was always an open communication like if I ever had anything you know, they always made sure to call us you would always get this printed handout of what they did throughout the day and if I had any questions about it, but I know even last year when I would take her, after every class you know we would go through what she did. Whatever their concerns whatever they found they would always somehow get in touch with us which was very nice.

Like Mrs. E, several of the caregivers had opportunities to discuss their children with the SLP after intervention sessions:

“Oh they would always give updates...and anytime I picked him up if they wanted to share something they did.” (Mrs. J)

After every time they went we went up there they would um come out and we would talk about the sessions and see what homework she needed to do and stuff. So they just - it was a constant communication which was a good thing. (Ms. I)

While the university clinic setting assisted in encouraging follow-up conversations following sessions, regular communication and follow-up after sessions could also occur in other settings.

Mrs. A shared how her daughter's school SLP habitually conversed with her when she dropped off and picked up her daughter from the school.

Although having regular conversations was important and appreciated by the caregivers as a method of information sharing and keeping them involved in their child's intervention process, caregivers rarely initiated these conversations on their own. Mrs. D for example expressed how she had wanted a follow-up conversation:

I was just wondering if like they felt like they made progress and maybe that had been in the report like I said it was emailed to me. I probably read it, but like I think even just talking to somebody like a follow up call after that and then maybe with that teacher and I could've said ok so after working with him did you see a lot of progress with him? Or you know what do we need to do to keep moving forward or something like that. Looking back, the person that was working with him, I think it would have been beneficial to like have a little bit of communication with her just on what they were doing.

As she continued, Mrs. D shed some light on why she might not have initiated a conversation herself. Aside from being a busy working mother, she also worried about imposing:

Which I know that's asking a lot of somebody but I don't know you know just like a preschool teacher they'll tell you what they're doing for the week or whatever and then that way if I would've had any questions because I don't - I can't say that I would've even known how to contact the person that was working with him. I don't remember ever getting that information. And my son is not good about sharing.

Mrs. D's concern that she may not have been able to contact the individual working with her child was echoed by other caregivers as well. Mrs. J expressed frustration over having to leave a message and not always having her messages returned. Ms. G explained that she was willing to call, but she never thought about it until after business hours:

So I should've called two or three weeks earlier and instigated and life just tends to - gets in the way. Every time I call they're closed, I never get [anyone] because I never think about it during their business hours, so it's always Friday at four thirty when I remember you know it's never when you're [the clinic] open.

Overall, caregivers expressed a reliance on SLPs to initiate the follow-up conversations either through providing periodic opportunities for contact or reaching out to them on a consistent basis. As ongoing communication is essential to SLP and caregiver collaboration, it is important that it not only be initiated but maintained. The findings suggest that caregivers are open to the collaborative process, but may need some encouragement initially. Providing the necessary information on an ongoing basis and making sure that the caregiver has access (e.g., contact information) can help build caregiver confidence and strengthen the collaborative relationship.

### **Keeping Information Current**

Caregivers did not directly express a need for information to be restated and refreshed on a regular basis. However, throughout the interviews caregivers demonstrated a noticeable difficulty in recalling and restating important diagnostic information regarding their children. Furthermore, none of the caregivers mentioned having further conversations about their child's diagnosis and the implications of the diagnosis following the end of the evaluation and the beginning of the intervention period. When asked if the SLP had talked with her more recently about how her daughter's reading and language difficulties are connected, Mrs. A responded "no, not anything more." Follow-up conversations focused on reviewing previously stated information and checking for continued caregiver understanding could better ensure that caregivers retain important information and continue to be able to collaborate successfully. As expressed earlier in the findings, caregivers often struggled to recall key information provided at the initial evaluation, and caregivers do not always understand why certain intervention tasks are

chosen for their child. Since caregivers view knowledge as a significant part of the collaborative process, caregivers may be less likely to collaborate effectively with SLPs if they do not feel like they have a strong understanding of their child's needs and the purpose of the intervention process they are being asked to participate in.

Follow-up communication from the SLP stood out as one of the most important and beneficial behaviors to encouraging caregiver knowledge and establishing a collaborative relationship. Caregivers expected follow-up communication, but were sometime hesitant to ask for it, so when it was provided, it was perceived very positively by the caregivers. Additionally, while caregivers often recognized their need for ongoing communication, they often relied on the SLP to provide some level of guidance regarding what information they may find beneficial and what kinds of questions they should be asking.

### **Open and Honest Communication**

In addition to appreciating regular follow-up communication, caregivers appreciated what they viewed as forthright and open conversation. As Mr. B expressed, “no run around.” Mr. and Mrs. B compared and contrasted their experiences with professionals at their son's school versus their son's pediatrician. Mrs. B shared, “I was always questioning like there's got to be something else going on and they're [the IEP team] like oh no no no he's fine”. She continued saying that when they asked for a referral they were turned away: “the school would not refer us any place else because they said we cannot have anything to do with that ...they're like well they won't do anything else rather than what we're doing in here.” In contrast both Mr. and Mrs. B spoke very highly of their son's doctor. Mrs. B said:

He's been a good doctor for us...with B's migraines he was like I can't do anything more for you... so he sent us you know [to a specialist], he wasn't going to beat around the bush or anything...It feels like he was a very proactive doctor.

Mrs. A expressed similar sentiments noting that she really appreciated the vision therapist who had delivered the unpleasant news about her daughter's reading ability:

The biggest thing that we got out of the diagnosis and the talk with the therapist was that she has it pretty severe, to the point of that she may never be capable of reading or if she is, she is going to be way below grade level, several grades behind, so that was interesting for us 'cause we were hoping we could eventually get her past that, and so that was a little frustrating but it was good to know.

Mrs. G also talked about appreciating directness in regards to discussing service options, cost of services, and choosing the approach that was best for her child.

They were very thorough on the services that they [her children] would need, the services that they had to offer, we talked about you know we do have insurance, there would be cost, we discussed IEPs and where do we go from here, and what's best for the child and that was my bottom line was what's best for my kid, what's going to get them past this bump in the road fastest and most effectively.

Mr. J emphasized the importance of the SLPs being direct regarding what they needed from the caregiver. He shared how after an evaluation he was contacted and asked to facilitate communication between the SLP and his son's school. He indicated that he had been happy to do so, but wondered why it had taken so long: "that could have been helpful if I was told that when I had the meeting [after evaluation wrap-up], that you're going to need to keep the ball rolling on this, 'cause you know we lost probably six months there." As discussed earlier, timing was very important to the caregivers and direct communication was viewed as communication that did not waste time.

The caregivers consistently expressed their desire for open and candid information. Often, the caregivers expressed awareness that some of the information regarding their child might be difficult to hear and understand. However, caregivers perceived a lack of information or avoidance of difficult discussions as essentially dishonest. In seeking to establish a trusting and collaborative relationship, caregivers emphasized that it was important for the health care

professional to be willing to engage in difficult conversations and willing to acknowledge when they did not have the answers.

### **Responsiveness to Caregiver's Concerns**

Caregivers often reached out to health care professionals or entered an evaluation session with specific concerns in mind, specific information that they were seeking to obtain. Caregivers who perceived the health care provider as attentive to their concerns were more open to ongoing interaction and following through on the health care provider's suggestions. Two overall concerns stood out during the interviews. First, caregivers wanted to be listened to and have their opinions valued and second, caregivers wanted the SLP to work hard for their child.

#### **Listening versus not listening**

Caregivers' perceptions of the professional listening to what they had to say was important to developing a positive SLP-caregiver relationship which impacted their ability to collaborate effectively. Several caregivers noted examples of both SLPs and other health professionals not listening to them. When asked to explain how they knew if someone was listening or not listening, the answer boiled down to SLP verbal responses and actions. Mrs. A talked about how her daughter's school SLP added assessments and goals in response to her input. "I think that it's been very helpful and I think that they the school does pretty good, like the therapist working up there, taking my ideas and running with it and being like that's a good idea and doing that." In contrast, Mrs. A shared an earlier experience with one of her daughter's SLPs where she interpreted their words and actions as unresponsive to her needs:

I know I remember talking to them [SLP team] and saying I didn't feel like it was working, that I felt like we needed a change up and they said that we needed to give it more time. And that she was you know she was getting there and you know we told them that we didn't feel like she was and they just wouldn't really *listen* so and we didn't feel like she was getting enough services either. We asked them to increase it and they wouldn't do that either. They said that she was too young and that there wasn't - she didn't need that much.

In another example, Mr. and Mrs. B shared how several members of their son's IEP team would only discuss pull-out service options, even though Mr. and Mrs. B wanted to discuss classroom based options. Mrs. B explained, "I kind of wish the school would've listened a little bit more. Even after we voiced our concerns it just didn't feel like we got heard at all. I mean that's how I felt I just felt like they just blew us off." However, one IEP member stood out to them. In recalling her, Mrs. B said, "she [the school psychologist] was always on B's side more for him rather than the teachers were." When asked to explain further how the school psychologist was on B's side, Mrs. B recalled that the school psychologist had actively encouraged the IEP team to provide some of B's services in his classroom as Mr. and Mrs. B had requested.

Including caregivers in the evaluation and intervention process requires that SLPs listen to and address their concerns. When possible, following through on caregiver suggestions can build trust and encourage continued caregiver participation. The most important thing though, according to Mrs. C is just being heard:

I think the biggest thing is feeling heard, feeling as though I have a valuable information to bring to the table that my own observations are of value. I think a lot of times parents are asked questions about maybe a teacher, what they've said what they've seen, or another type of professional but it's not what do *you* see as issues or strengths.

### **Working hard for their child**

Caregivers also appreciated when they perceived the SLP to be working hard for their child. As Mrs. A said, "the speech teacher was awesome. She worked really good and hard with her [daughter]." When asked to elaborate on how appreciation for their child was shown, caregivers shared that it meant working with their child consistently, moving their child forward, acting as an advocate for their child, not giving up, establishing rapport with their child, and including their child in the conversation:



“Just continuing to work with her and getting her more along where she should be... It was very consistent.” (Mrs. A)

“They were so nice and always wanting to make sure that J was okay.” (Mrs. E)

“They [SLP team] talked a lot to her [daughter] personally, and that was my thing as well is you know that she’s an integral part of this. It’s going to succeed or fail with her blessing so she needed to be a big part and she really was.” (Mrs. G)

Caregivers also identified times when they believed professionals were not working for their child. When asked to describe what constituted professionals not working for their child, caregivers gave examples of professionals who they perceived as not wanting to deal with their child, not going the extra mile for their child, or not being patient and helpful to their child:

“It seems like she [child’s teacher] doesn’t want him in the classroom.” (Mrs. B)

“We saw absolutely no difference and we were getting frustrated because we said you know, obviously you guys aren’t working with her or not doing what she needs and so we finally pulled her from it and they were really mad.” (Mrs. A)

To facilitate caregiver collaboration, it is important for the professional to first acknowledge and be responsive to the concerns presented by the caregiver (e.g., Fitzpatrick et al., 2008; D. Luterman & Kurtzer-White, 1999a). Through acknowledging this basic need, SLPs can facilitate the building of mutual respect between caregiver and provider, as well as make certain that helpful information is shared and they collaborate with each other effectively.

### **Meeting Caregiver Needs**

In addition to the need of having their concerns acknowledged and responded to, caregivers also expressed some specific needs related to their evaluation and intervention experiences, primarily focused around their child. The three needs most frequently mentioned by caregivers included: receiving care and validation regarding their child, seeing their child make progress, and SLPs sharing their children’s positive attributes.

## **Validation and acceptance**

Along with their desire for information, caregivers had a strong desire for validation and acceptance from their child's SLP. In some cases, caregivers like Mrs. J had sought out clinical services for her son only after dealing with resistance at home. She appreciated the reassurance that her concerns had been valid, "I liked the fact that they were actually reassuring, what I had told them is what they were seeing too." Mrs. A expressed a similar sentiment, "It was very reassuring. It also helped us knowing that they were seeing what we saw. That I'm not totally crazy. That it was very real. So yeah that was very reassuring to me that they were like you're not crazy." The importance of the validation may have stemmed from other non-supportive experiences. Mrs. J had initially been discouraged by family members from bringing her son in for an evaluation. Ms. I shared that at least one of her daughter's teachers had "literally told me that I was being an over reactive mother and there was nothing wrong with my child." Mrs. A recalled a resource teacher that dismissed her concerns, "my issue was that she sometimes treated me dumb, because I'm the parent and I didn't know, oh I did have a degree but not the highest degree."

In addition to receiving validation, caregivers also expressed their appreciation of SLPs who were understanding, accepting, and welcoming toward them and their children. Several caregivers shared examples of being accepted. As Mrs. E shared, this feeling often started with their child:

It was like even through the testing everyone was always so welcome and they were so nice and always wanting to make sure that J was okay. You know 'cause during the testing they're [the child] by themselves but they [SLP] always made sure that she was okay.

Mrs. J recalled the patience exercised with her son, "They were really great with him...K was extremely shy. Still is extremely shy so until he warmed up it was kind of a slow process...they were really supportive though."

The show of support and acceptance was particularly appreciated when the caregiver was concerned about judgment. Following an unpleasant early intervention experience, Mrs. A waited until the family moved (approximately a year) before seeking out further speech-language services for her daughter. “They didn’t make us feel stupid for not getting the help that she needed, but it was we need to get this help going and we need it *now* it’s - we’re not waiting. So, it was very positive.” As illustrated in these caregiver comments, validation and acceptance are particularly important during the evaluation and the early stages of intervention. As the relationship and the intervention period progressed, caregivers desired to see their child progress.

### **Making progress**

Progress was important to all the caregivers; it was a sign to them that the interventions were helping. However, it was notable that caregivers did not just talk about progress in relation to improved percentages on their goals; rather they primarily talked about progress in terms of the changes in their children’s attitude and confidence.

Mrs. C noted that the most encouraging improvement she saw in her daughter was her daughter trying to read. “The difference I see in M is she’s willing to read now. Outside of school she wants to take a book to bed and read it on her own, whereas before she was so turned off. She’s developing that love to read.” Mrs. B made a similar comment about her son actually being willing to pick up a book, an activity in which she insisted she had never seen him willingly to engage:

He actually was like he wanted that book you know. He picked it up and started reading. I mean granted it was a thicker book probably not his word you know or grade level or what not but I was like hey you know what if you want to read it I will help you with the words that you know you can’t... I’d never seen him want to read.

In addition to seeing positive changes in their children's reading habits, some of the caregivers also observed positive changes in their children's self confidence. Ms. I described a significant change in her daughter's manner and confidence after a short period of intervention:

She will tell people ... I got held back....people are like aren't you ashamed to say it, she goes there is nothing to be ashamed of, and I'm like...there *is nothing to be ashamed* of. At least she knows what she has and she can get through anything now.

Ms. I went on to share how her daughter was now her own advocate at home and at school, letting her teachers and her mother know what she needed. Ms. I was confident that with her daughter's growing self confidence and "all the tools that she's getting," her daughter would someday be an independent young adult, "and have a career that she wants." For many of the caregivers, independence and choices in life were primary goals for the future. They wanted their children to have options in their future education and career choices that were not defined by their disability. Notable progress, especially progress that was functional and visible in their child's day to day routines, encouraged caregiver collaboration because it allowed the caregivers to see the value of the intervention process to their child. Furthermore, caregivers who were involved in the intervention process were able to learn which tools and strategies were most beneficial to their child and encourage the continued use of those tools and strategies over time.

### **Sharing the positives/strengths**

Caregivers often came to the evaluation focused on their child's weaknesses. However, SLPs that focused on sharing strengths as well as weaknesses provided a constructive reminder for caregivers to keep their child's abilities in mind. As Mrs. C shared, it is nice to be reminded of their child's strengths, "I do appreciate being asked the strengths because that lets me know that they care and it makes me refocus on the positives about my child rather than just maybe shortfalls of where there's - why we're here I guess." Mrs. E also appreciated the positive focus,

especially as it was shared directly with her daughter, “after every session they told us what she worked on, but they would also praise her on the things that she did well.”

Both the evaluation and intervention process can be stressful for the caregiver, forcing them to focus on and deal with their child’s weakness. Encouraging the caregiver to also recognize the strengths in their child and find ways to build upon those strengths can encourage positive intervention strategies and serve to build up the confidence of both the child and caregiver. As caregiver confidence increases he/she can feel more capable of helping their child be successful and potentially more easily recognize their valuable contributions to the collaboration team.

### **Clarifying Roles**

Caregiver knowledge and collaboration are key components to a successful evaluation and intervention process (ASHA 2004, Ferguson & Armstrong, 2004; Walsh, 2007). Therefore SLPSs engaged in best practices will seek to educate caregivers about their children’s disorders and involve them in the decision making process. As a whole, the caregivers who participated in this study expressed a desire and willingness to be involved in their child’s intervention process. However, they also noted the importance of maintaining their primary role as a parent to their child rather than solely focusing on the identified problem.

#### **I’m a Caregiver First**

In sharing information and seeking to involve the caregiver, one of the challenges that SLPs face is finding the right balance. The appropriate balance was different for each caregiver and depended on a variety of personal, educational, professional, and family factors. Mr. J for example did not perceive himself as capable teacher, “I’m not a professional educator so I stay out and let people that know how to do it do it.” He believed providing his son with professionals who knew what they were doing was the best way he could help his son. As Mrs.

D and Mrs. H explained there were practical benefits to keeping their involvement at a minimum, noting that for their sons working with *Mom* was more frustrating than helpful:

“He has no problems getting mad at me but if it’s somebody else asking him to do something he’s not going to get mad he’ll do it.” (Mrs. D)

He gets so frustrated with mom sometimes and the two of us just really butt heads at this age. It’s not that I can’t help him and try to explain to him it’s sometimes he just doesn’t want to listen to mom. That’s why somebody else working with him he’d probably do better with because he probably wouldn’t argue with them as much as he does me. (Mrs. H)

As Mrs. G shared, her priority in scheduling a speech-language evaluation was to find answers for her daughter. She was not as concerned with how the answers were obtained:

So as far as understanding exactly what the tests were, it was a little fuzzy but it didn’t matter because my goal was to get her tested, so I really could’ve cared less, I mean as long as she was safe, she wasn’t being harmed, then what\_ how you tested her was irrelevant to me.

Even though understanding the tests was not her priority, Mrs. G noted that she did appreciate receiving a description of the tests being administered to her daughter, “that was nice, that was helpful, because I had no idea what was we were doing, but I figured there was a reason.”

In a further discussion regarding finding the right balance Mrs. G explained that being a parent was not something that could be turned off. As an example she shared:

“I see her sitting in the chair with her legs curled and her feet on the chair and I keep thinking *she has chicken poop on her shoes!* This is why parents can’t be in the room and maybe shouldn’t watch, they have parent lenses not therapist lenses and this isn’t going to change.”

Overall, there was a theme expressed by the caregivers of trusting the professionals to do their job as well as an implied desire for the SLP to trust the caregivers to do their job, understanding that *their job* was to be a parent first. Desiring to be a caregiver first did not mean that caregivers were unwilling to collaborate with their child’s SLP. Rather for effective collaboration to occur, caregivers needed SLPs to recognize their role as caregiver and the unique responsibility and perspective that accompanied the role. Caregivers did not want to be

their child's at home SLP, but they were willing and interested in contributing as their child's caregiver.

### **Professionals are Experts**

The implied trust and willingness to defer to the recommendations the SLP and other professionals made stemmed from a general belief on the part of the caregivers that the SLP or any professional should be an expert. As Mrs. G explained, "I had exhausted all my resources and I was here to hand them [her children] off to you [the SLP] to figure it out." Throughout the interviews, caregivers consistently brought up the idea of professional expertise. In some cases, the caregivers expressed disappointment, because they had expected more from experts. Mrs. B shared her frustration with her son's school after they declined to take action despite her concerns:

"I mean that's what their job is that's what you rely on...you count on them to because they're the ones that are with your child during their learning you know. That's their field. They're supposed to be the experts."

Some of the caregivers expressed the view that as the expert, the SLP should lead the intervention, the collaboration, and any action:

"I would as soon take him to the people that know how to do it, instead of I guess a do it yourself program." (Mr. J)

I don't know if you would call it follow up or after care to kind of coordinate maybe their suggestions to the school. That would be best because they're the professionals, and they could advise them of what should be done to help her, not me being the go between. (Mrs. F)

In regards to the SLP taking the lead, Mr. J also expressed the need for his son's SLP to be explicit in requesting his assistance when it was needed, noting that he did not understand the process well enough to initiate potentially important activities or conversations on his own. In particular he referenced the need for his involvement in facilitating the collaboration between his son's SLP at the university clinic and his son's school. Like Mrs. F, he expected the SLP to take

the lead in establishing the collaborative relationship, and expressed some frustration that the SLP had not more clearly defined his role by telling him, “you need to stay active and keep rolling this ball so it can happen.”

Overall, several of the caregivers expressed the view that the SLP was the expert and therefore needed to take the lead in information sharing and setting the tone for the collaborative relationship. One of the challenges for SLPs with this perspective was that the expectations were high and not always stated. In addition to having high expectations of the SLP, caregivers also wanted to know early on what the SLP expectations were of them. Thus, the findings suggest that clear and direct communication about both the SLPs’ and caregivers’ expectations of each other is important to facilitating a positive and effective collaborative relationship between the two unique roles of caregiver and SLP.

#### **Acknowledging the caregiver and child as a contributor**

While the caregivers expressed a desire for the SLPs to take the lead in establishing the collaborative relationship, they also expressed the desire to contribute in some way to their child’s success. Caregivers felt empowered when they perceived themselves to be knowledgeable regarding their child’s needs, and were appreciative when their child’s SLP treated them as a valuable informant. Several of the caregivers recalled being asked to provide important information about their child. Mrs. D, for example, recalled sharing key information regarding her son’s previous testing experiences, “I had given them all the testing that the school had done as well, just to give them you know, that way you guys [the SLP team] weren’t doing the same testing.” Mrs. G also recalled sharing information about her child at the time of the evaluation, “I remember they basically asked us some background information. You know the stuff on history and we went over the basics and what our concerns were.”



While the interview questions that several of the caregivers recalled answering may have been basic, Mrs. C pointed out that they were still meaningful and provided the caregiver with an important opportunity to share his or her concerns, “I think a lot of times parents are asked questions about maybe a teacher, what they’ve [the teachers] said what they’ve [the teachers] seen or another type of professional but it’s not what do *you* [the parent] see as issues.”

Some of the caregivers also brought up the importance of being consulted in the decision making process following the evaluation. Mrs. G in particular shared how the clinicians had not only asked her opinion about what treatment options would be best for her daughter, but they had also agreed with her choice as the best option for proceeding, “I think that was a really important thing. I kind of just said well how about this, and they seemed very respectful... ‘we [the SLP team] hadn’t thought about it but why not,’ they didn’t say no.”

Finally, in addition to being given the opportunity to be heard, several caregivers also emphasized the importance of having their children be heard. Mrs. J brought up how challenging the evaluation can be for a child, “It’s just, it’s so frustrating for kids you know. I don’t think people understand how frustrating and difficult, and you know they have pride too and it’s like oh gosh mom I gotta get evaluated again.” Both Mrs. G and Ms. I stated that the overall experience can be less frustrating for the child by making them an integral part of it. Mrs. G shared how her daughter had been included in the evaluation and treatment discussion. “They talked a lot to her personally, and that was my thing as well is you know that she’s an integral part of this. It’s going to succeed or fail with her blessing so she needed to be a big part and she really was.” Ms. I shared how the SLP had made sure her daughter understood the results of her evaluation, “they detailed it really good for us so she could understand along with me because she wanted to be a part of it too because it’s for her.”

It may not be possible to make the evaluation experience a completely enjoyable experience for the child. However, by treating the child as a valuable informant and contributor to their evaluation process, the SLP can potentially reduce the child's feelings of frustration and helplessness. Thus increasing the caregiver's trust in the SLP and furthering a therapeutic alliance that includes both the caregiver and the child. Particularly with older children, the caregiver may take a secondary role to the child in the collaboration process, encouraging the child to take an active role in making intervention decisions.

### **Whole Family Approach**

Finding a balance among the many demands of family life was an important theme across the caregivers who were interviewed. As discussed earlier, caregivers wanted to be involved, but needed to prioritize their role as a parent. As shown in the participant table provided in chapter three, all of the caregivers had more than one child and many had spouses, significant others, or siblings who lived in their home. Additionally, some of the caregivers had more than one dependent with a diagnosed disability. Therefore, a common theme throughout the interviews was the struggle faced by caregivers in balancing their responsibilities across their whole family and the unique needs presented by their child with the language/reading disability. Overall, caregivers described three categories of family related experiences that influenced how they chose to interact with the SLP and involve themselves in the evaluation and intervention process; family and life related stressors, family member opinions, and other SLP experiences within the family history.

### **Other Stressors**

As with many families, the caregivers in this study were frequently contending with multiple issues at home. Problems ranged from work and scheduling issues to resistive family members who did not offer support. Mrs. H shared her struggled to find a helpful balance for her

son. As a high school student, he wanted to participate in sports, but sports often conflicted with possible speech therapy times at the university clinic.

I'm afraid if I say well we've got to go over [to the clinic] and do this [speech therapy] so you can't do track then he's going to lose interest in being in school, because it's going to be so focused on this [speech therapy], and if he really wants to enjoy doing an extracurricular activity I think he really needs to do it, but I also think the reading needs to be there, but I think there needs to be a balance to keep the interest in school.

Her son is receiving services from his public school to address his learning disability, and Mrs. H hopes that will be enough. She worries if she does not give him some control he will drop out of school. As Mrs. H's story illustrates, sometimes being a parent first means making difficult choices about what to prioritize.

Finding time for everything was a common dilemma for caregivers. Several mentioned the difficulty of balancing a busy after school schedule. Mrs. B noted, "with our hours that we work it's hard to be down there with him." Mrs. G recalled the challenge of identifying an open time slot for intervention in her daughter's busy schedule. "I remember saying well he [son] has boy scouts on Monday she [daughter] has girl scouts on Thursday. They both have religion on Wednesday and then they have big brother and big sisters and sports and soccer and all these other things."

For Mr. and Mrs. J, separate but shared custody provided a unique issue in this sample. Mrs. J worried about any home program being consistent across her and her ex-husband, "Well it can't be at home, because he (her son) lives in two different households it wouldn't be consistent." Communication misunderstandings had also occurred due to providers not realizing that Mr. and Mrs. J were divorced. Mrs. J explained that sometimes they would call her husband, but not her:

I was a little disappointed with the follow-up on that and then same with this one you know they contacted him first and I'm not sure why. I mean yeah he's his

dad so it's fine but you know it's usually the [mom] that follows through with stuff.

Balancing multiple stressors at home and work can make it challenging for caregivers to find the time for effective collaboration with their children's SLPs. Caregivers may also make choices or set priorities based on family needs that are in conflict with SLP recommendations, potentially leading to misunderstandings. Thus, emphasizing the importance of ongoing and open communication between caregivers and SLPs regarding intervention options that are not only helpful but also manageable for the client, caregiver, and family.

### **Family Member Opinions**

In addition to busy family schedules, disagreements or differences of opinion between family members was also a source of stress. One example of a family disagreement was shared by Mrs. J in reference to herself and her ex-husband. Mrs. J explained that she was always more concerned than her ex-husband and his family about their son's speech and language development, "it was really hard because with my husband at the time and his parents they didn't see there was an issue." Mr. J (who was interviewed separately) agreed with Mrs. J, "my wife at the time was probably more concerned than I was about that [son's delayed speech]." As Mrs. J went on to explain, the lack of support from family caused her to waver and question her instincts regarding her son saying, "I was kind of maybe a little hesitant in some cases to push."

In contrast, some caregivers described receiving a great deal of support from their spouses, sisters, cousins, and other family members, especially in helping them identify options and resources:

"My sister might've said the children's center does these screenings for more or less everything." (Mrs. B)

"My sister-in-law also, she's a teacher, and she does a lot of with the special ed kids. So we kind of talked with her a little bit you know." (Mrs. E)

As a whole, other family members often played an integral role in either encouraging or discouraging caregivers who were seeking services for their child. Thus, caregiver willingness to collaborate with their child's SLP, and follow through on activities at home, could be strongly influenced by the support or lack of support they feel at home. Additionally, as the caregivers who had support at home expressed, they also had the benefit of knowledge shared with them from friends and family, and confidence in their choice to pursue services for their child.

### **Other Speech-Language Experiences**

Previous family related experiences with SLPs and other health care professionals also influenced how some caregivers approached the evaluation/intervention process. One example of other SLP experiences included other children in speech therapy. Mr. B referred to his oldest son's experience, "I think also our thing to come back to is our oldest son, when he first started school he had speech. Mrs. C shared information about her son's SLP, "My son's diagnosed with Autism, and quite frankly I was not pleased even with where I was - what I was getting with my son, I would say my confidence level in her [SLP] is very low." Mrs. G had previous experiences with SLPs and other professionals as the caretaker to her disabled brother, who received special education services all through his school enrollment, "I have cared for my brother...I was seven when he was born and he has been with us for 20 years, I am his legal guardian and care provider."

As illustrated in Mrs. C's comment regarding her experience with her son, some previous experiences have the potential to negatively influence a caregiver's perception. Due to her negative perception of her son's SLP, Mrs. C did not desire to collaborate with her son's SLP and would not have considered her a knowledgeable source of information regarding her daughter's difficulties. Therefore previous experiences that call a professional's competence or expertise into question could potentially derail effective collaboration between the caregiver and

the SLP. In contrast, Mrs. G and Mr. B both expressed more neutral to positive feelings regarding their previous experiences with SLPs. Mrs. G simply noted that she had several previous experiences with SLPs as well as other health and educational professionals while caring for her brother and felt knowledgeable about the general special education process. Mr. B recalled that his oldest son had experienced fast progress and dismissal, so the interaction had been minimal. However, neither Mrs. G or Mr. B expressed concerns about engaging in collaboration with their child's SLP. In fact Mrs. G expressed some confidence in being able to navigate "the system" due to her previous experiences. For SLPs, having an awareness of previous caregiver experiences and expectations can facilitate an understanding of the caregiver's perspective and current levels of knowledge, as well as assist the SLP in determining how best to engage the caregiver in the current service provision process.

### **Caregiver Knowledge of SLP Service Options**

Even with previous experiences, several of the caregivers acknowledged significant gaps in their knowledge regarding SLP services. For the most part, caregiver knowledge regarding SLP services focused on the provision of speech sound intervention. Mrs. C, having a son with autism, was aware of some of the language based services that SLPs could provide, but she was not aware that speech-language services could address her daughter's reading difficulty.

Overall, the caregivers who participated in this study were knowledgeable and well educated individuals with all of them having some level of college education. Additionally, each of them had taken the initiative to seek out additional services for their children beyond what was provided in the school system. Mrs. A, for example, did not hesitate to seek out an early intervention service program when she realized her daughter's communication was regressing. Mr. and Mrs. B also reached out for early intervention services when they became worried about their son's lack of speech. Mrs. J brought her son directly to the university speech-language and

hearing clinic, recalling it from her time as a student at the university. Each of these families knew early on that something was wrong with their young child's communication and they promptly sought out speech-language services to address their children's needs because they knew they needed assistance. However, in spite of this level of awareness, when their children began to experience academic, particularly reading issues, all three families acknowledged that it never occurred to them to ask their child's SLP about their children's reading issues.

In fact, several of the caregivers sought a speech and language evaluation for their child only after a referral from their child's doctor. Mrs. F shared how her daughter's doctor referred her, "she [daughter's doctor] sees her monthly and as we visited with her she was concerned about dyslexia... and told us we should be evaluated at the university clinic." Ms. I shared that it was one of her daughter's teachers who "saw the signs and recommended us to call."

Others, like Mrs. H, started asking around and searching the internet until she found a place that provided reading evaluations:

I was looking for somebody that dealt with the reading and development and stuff and somebody I can't remember who it was mentioned the HC, so I went online and obviously looked it up and read about it and said well I can start with them and see what's going to happen.

Overall, there was a general consensus among the caregivers that there was a lack of awareness that SLPs could help with what parents saw only as a "reading issue." Even the caregivers who had some familiarity with SLPs saw them as "speech" professionals only. Mrs. A said: "We knew it was an issue at home, but we didn't know that speech-language could do that" referring to her daughter's complex memory and language issues. Not realizing that her daughter's SLP might be able to assist with her daughter's memory and language issues, Mrs. A did not communicate with her daughter's SLP regarding her concerns. The lack of information sharing in this example, illustrates the difficulty of engaging in collaboration when both parties

lack important knowledge; Mrs. A that her daughter's SLP may be able to provide assistance with her concern, the SLP that Mrs. A had unspoken concerns regarding her daughter.

In order for effective collaboration to occur, it is important that caregivers be provided with knowledge and information about not only their child's diagnosed disorder, but also about interrelated communication areas (e.g., language, fluency, voice, etc.) and the various speech-language service options available. Caregivers, like Mrs. A may not initially recognize that non-speech production information could be applicable to her daughter's intervention plan. A strong collaborative relationship that encourages an open dialogue can encourage the sharing of important knowledge that can make a difference in a child's treatment plan. Furthermore, the lack of awareness among caregivers stresses the need for SLPs to actively educate not only their clients but the local community regarding services that they can provide.

### **Summary of Caregiver Knowledge and Collaboration**

Research Question 2 explored SLP behaviors that caregivers perceived as helpful or unhelpful in increasing caregiver knowledge and collaboration. As noted in the introduction, the caregivers frequently wove together the concept of knowledge and collaboration in their responses, noting that knowledge was essential to the collaboration process and that the collaboration process worked to increase knowledge. Therefore all of the themes presented in this section related to both increasing caregiver knowledge and engaging caregivers in the collaboration process.

The first three themes, resources professionals provide, methods of information sharing, and timing of information, all focused on caregivers' ongoing needs for information to be shared in a clear and relatable manner. Caregivers discussed the importance of receiving informative resources and access to diagnostic and intervention information in a timely manner. In particular, caregivers emphasized the benefit of being able to watch an evaluation or intervention



session, noting that being able to observe their child assisted them in understanding the evaluation or intervention and helping their child at home.

The next three themes, follow-up, open and honest communication, and responsiveness to caregiver concerns, concentrated on caregiver comments regarding how SLPs needed to communicate with them in order to share information and encourage collaboration. Overall, caregivers emphasized the importance of SLPs initiating follow-up conversations following the evaluation and over the course of intervention, SLPs keeping their communication clear and forthright, rather than avoiding or glossing over challenging topics, and SLPs demonstrating that they are listening to caregivers through their actions.

The next three themes, meeting caregivers' needs, clarifying roles, and whole family approach, highlighted several caregiver expectations and challenges in regard to the intervention and collaboration process. First of all, caregivers discussed the importance of seeing evidence of progress in their child and evidence of caring from the SLP. Caregivers were more comfortable collaborating when they saw positive outcomes from the intervention process and when they believed that the SLP genuinely cared about their child. Secondly, caregivers expressed several expectations in regards to roles. They expected the SLPs to be experts in their field, and capable of helping their child. Generally, caregivers wanted to contribute and be involved in the evaluation and intervention process, but they were wary of taking on any responsibilities that they perceived as contradicting their primary role as caregiver. Finally, as a primary caregiver, caregivers noted that they faced many challenges in engaging in collaboration with their child's SLPs. Busy schedules, other children's needs, and unsupportive family member were just a few of the challenges they faced.

Finally, the last theme, caregiver knowledge of SLP service options, stands on its own, though it was somewhat interwoven throughout the caregiver discussions regarding knowledge

and collaboration. Consistently throughout the discussions, caregivers noted that they had minimal knowledge regarding the full scope of SLP practice, thus limiting several of the caregivers in the services that they sought for their child early on.

Overall, the findings from Research Question 2 suggest that caregivers are open to collaborating with SLPs but they have specific expectations regarding SLP communication practices. Specifically, caregivers emphasized the importance of having timely information about their child's disorder, as well as ongoing opportunities to communicate with their child's SLP. Furthermore, as caregivers often felt uncertain about their own contributions to the collaborative process, SLP initiation of follow-up communication was identified as an important first step to building a collaborative partnership between caregivers and SLPs. Caregivers also noted the importance of open and honest communication (such as acknowledging the severity of the disorder), practices that were responsive to caregiver concerns (such as active listening and follow-through on caregiver requests), and practices that value caregiver contributions (such as asking the caregiver to share their observations ), while acknowledging the challenges caregivers may face in seeking to collaborate (such as busy schedules, other family member's needs).

### **Summary of Findings**

In summary the findings from this study provide information regarding caregiver perceptions of SLP communication about child language delays and disorders. Across both Research Questions 1 and 2, twenty unique, yet connected themes emerged. In particular caregivers shared their perceptions regarding SLP information giving, their interpretations of their child's language related disorder, and their perceptions of effective and ineffective SLP communication practices in regard to encouraging increased caregiver knowledge and collaboration.

## CHAPTER 5: DISCUSSION

The focus on caregiver perceptions of SLP communication regarding child language disorders offers a unique addition to both the health communication and communication sciences and disorders literature. First, this study furthers the relationship between health communication theories focused on doctor-patient communication and their application to SLP-client/caregiver communication, adding an additional healthcare provider and patient relationship to the health communication literature. Secondly, the focus on language delay and disorder from a caregiver perspective is distinctive. While there is a great deal of literature regarding child language impairments and a growing body of literature regarding the importance of family centered speech-language services, this study takes the step of obtaining caregiver views of their children's language impairment and their communication with SLPs. Finally, this study furthers the application and use of qualitative methodology in the field of communication sciences and disorders. The use of a collective case study approach and semi-structured interviews for data collection allowed the researcher to explore a relatively new topic and make connections between caregiver perspectives and what is currently known in the literature.

Several of the themes identified through examining the caregiver transcripts provide relevant and practical insights into caregiver perspectives of SLP communication. This chapter reviews the key findings from the study, discusses what they add to the current literature, and the practical implications for SLPs. The discussion will be organized in relation to the literature review, discussing the findings for Research Questions 1 and 2 in connection with health communication, SLP and client/family centered practices, childhood disorders and qualitative research.

## Review of Findings

Research Question 1 was analyzed as two separate sections, with the first section focusing on information caregivers described receiving from the SLP and the second section focusing on caregiver interpretations of the disorder.

1. How do caregivers of children with language related disorders perceive SLP communication with them regarding language delay and disorders?
    - a. What information do caregivers describe receiving from SLPs regarding language delays and disorders?
    - b. How do caregivers describe their understanding of language delays and disorders?
- In total, five themes emerged from the first part of research question one, addressing

caregiver perceptions of SLPs as information givers. Table 7 provides a brief description of each theme associated with the SLP information giving. As a whole, caregiver perceptions of SLP

Table 7. Themes related to SLP information giving

Theme	Description
The Diagnosis	Receiving a clearly defined diagnosis was important to caregivers. Some diagnoses such as Dyslexia were easier for the caregiver to understand and recall.
Incomplete Information	Caregivers believed that some informational topics were not adequately addressed or made clear to them. In particular, caregivers reported receiving minimal information about the connection between language and reading, and long term consequences.
Services Provided	Generally, caregivers believed that they had received substantial information regarding their children’s goals and objectives for speech-language services, what service options their children had access to, and what activities or interventions took place during the therapy time.
Memory	Caregivers struggled to recall important information they had received from the SLP regarding their child’s language/reading disorder.
Quality of Experience	Caregivers connected the quality of their experience with the quality of the information they believed they received from the SLP.

information giving focused on the types of information they received or did not receive, as well as the clarity and understandability of the information they received. Based on the findings presented, caregivers placed a high value on receiving clear and concrete diagnostic information, but often had difficulty recalling important details. Since caregivers had difficulty recalling some

of the information they had received, it is likely that they did not share all of the pertinent information they received. However, their lack of memory is significant in itself, as information that is not retained cannot serve to assist the caregiver in understanding their child’s disorder and collaborating with the SLP.

The second part of Research Question 1 examined the multiple interpretations and feelings caregivers expressed in describing their child’s language delay/disorder. Considering the complexity associated with language disorders, it was not surprising that caregivers talked about their child’s language impairment in a variety of different ways and through a variety of different lenses. Overall, six distinct themes emerged (see Table 8). Some common associations

Table 8. Themes related to Understanding Language Delays/Disorders

Theme	Description
Diagnostic Labels Equal Solutions	Caregivers often associated having a diagnosis for their child with having a solution for helping their child.
Characteristics/ Behaviors	Caregivers associated several of their children’s characteristics/ behaviors with their language/reading disability; particularly educational difficulties and speech/communication difficulties. Caregivers also recognized coping strategies their children utilized.
Problem Versus No Problem	Several caregivers referred to their child’s language/reading disorder as a problem that they needed help addressing. However, some caregivers did not recognize the disorder as problem or expressed the belief that the disorder had ceased to be a current problem.
Previous experiences/knowledge	Previous life, personal, and family experiences influenced how caregivers talked about and understood their child’s language/reading disorder.
The Future	Caregivers worried about their children’s future, especially future jobs and educational opportunities that required proficient language and reading skills.
Difficult to Understand	Understanding how their child’s disorder influenced their learning was a challenge for all of the caregivers, especially caregivers who had been successful in school.

that caregivers made included relating the disorder to a problem that had to be solved and relating the diagnostic label to an answer or a solution to the problem. Caregivers also

interpreted their child's disorder based on past experiences, both good and bad; and future expectations for their child, both positive and negative. Generally, caregivers expressed high levels of awareness of their children's difficulties. Frequently caregivers were able to describe in detail some of their children's struggles. However, describing their child's struggles was not the same as understanding why their child struggled and how to help their child overcome their struggle. As a whole, the findings suggested that while caregivers had many ways to describe their child's language related disorder, they still struggled to understand their child's disorder in a way that was meaningful to them and their child.

Research Question 2 focused on caregiver perceptions of how SLPs worked to increase caregiver knowledge and establish collaborative relationships with caregivers.

2. What SLP communication practices do caregivers of children with language related disorders identify as effective or non-effective in building the therapeutic relationship?
  - a. What SLP communication practices or resources do caregivers perceive to be helpful or unhelpful in increasing caregiver knowledge of language disorders?
  - b. What SLP communication practices or resources do caregivers perceive to be helpful or unhelpful in increasing caregiver involvement/collaboration?

Based on the findings across transcripts, caregiver knowledge and caregiver collaboration were examined as a unified concept rather than as separate goals. Ten distinctive themes related to both knowledge and collaboration were identified (see Table 9).

All of the themes focused on concepts or communication behaviors that caregivers believed were important to increasing their knowledge and preparedness to collaborate. In particular, caregivers talked about the importance of SLPs providing informational resources in a timely manner, providing consistent follow-up that met caregivers' needs, communicating in an open and honest manner, being responsive to caregiver concerns, clearly defining caregiver and SLP role expectations, and understanding caregiver challenges to collaboration.

Recognizing the importance of key communication practices can help SLPs be more effective in

Table 9. Themes Related to Caregiver Knowledge and Collaboration

Theme	Description
Resources Professionals Provide	Caregivers appreciated resources being provided to them by SLPs. They particularly valued informational resources about their child’s disorder, activity resources that provided at home practice, and intervention resources in the form of direct speech-language service provision.
Information Sharing Method	Caregivers described three primary methods of information sharing that they perceived to be helpful; watching, the wrap-up, and the written report.
Timing of Information	The timing of information received was very important to caregivers. They always wanted it as soon as possible and not having information in a timely manner interfered with their ability to effectively understand their child’s needs and collaborate with professionals.
Follow-Up	Caregivers described times where they received good follow-up information and times where they felt like they never received further information. Poor follow-up experiences led to caregivers feeling dissatisfied and confused.
Open and Honest Communication	Caregivers appreciated straightforward and open lines of communication. They felt ignored and disrespected when professionals “beat around the bush” or were perceived as hard to communicate with.
Responsiveness to Caregiver’s Concerns	Caregivers came to the speech-language evaluations with very specific concerns they expected to be addressed. SLPs that listened to them and were responsive to those concerns were perceived positively.
Meeting Caregiver Needs	Caregivers described several needs that were met through the evaluation and intervention experience. Three that stood out were, seeing progress in their children, being validated that they were right about their child, and being reminded of the positives of their child.
Clarifying Roles	Caregivers often referred to the expertise they expected to see from professionals. They expected the experts to know what they were doing, and perform the necessary tasks to help their child. Caregivers also wanted to be acknowledged in their role. They didn’t want to be the experts, but they wanted to be respected for their contributions.
Whole Family Approach	Caregivers referred frequently to the multiple competing responsibilities and challenges they faced as a caregiver that influenced how they interacted with the SLP.
Caregiver Knowledge of SLP Service Options	Caregivers had varying levels of knowledge about speech and language development and SLP professionals. However, their knowledge regarding the SLPs role in assisting with language and reading based issues was limited.

sharing clinical information regarding language disorders and encouraging caregiver collaboration during the intervention process.

## **Health Communication**

The caregivers in this study attached a significant level of value to the information they received from SLPs. In fact, caregivers strongly associated their quality of experience with the level of information they believed they had received. Several of the behaviors that caregivers in the current study identified as important to SLP communication were comparable to PCC behaviors that have been identified previous health communication studies (van Zanten et al., 2007; Melissa Bekelja Wanzer, Wojtaszczyk, & Kelly, 2009). Caregivers who participated in the current study emphasized the importance of SLPs providing clear and complete information (Findings for Research Question 1), and SLPs being listening and caring professionals (Findings for Research Questions 2). Additionally, the findings related to caregivers' understanding of their child's disorder (Research Question 1), and their perceived challenges to collaborating with SLPs (Research Question 2) add to our knowledge regarding the application of family systems theory to SLP service provision (Broderick, 1993; Hare et al., 1989; Pecchioni & Keeley, 2011; Segrin & Flora, 2005).

### **Clarity and Completeness of Information**

Deciding when and how much information to share can be a challenge. SLPs must often determine what the most critical pieces of information are to share initially, as well as how much information needs to be shared and possibly re-visited over time. Hand (2006) found that SLPs did not always provide clear and complete information to caregivers who were unfamiliar with the evaluation process. The findings in the current study pointed to three key subjects that caregivers perceived to be incomplete and unclear, and these included, a focus on speech only concerns, the language-reading connection, and long-term consequences.

An almost exclusive focus on speech sound production was also noted in the findings in relation to the focus of services and the information shared. Three of the children represented in



this study, who currently presented with language based disorders, had previously received speech-language services. However, per the caregivers' reports, the services had exclusively focused on speech. For children with multiple issues to be addressed, the SLP may have initially chosen to focus on one primary area. Alternatively, it is possible that the SLPs who worked with the children in this study did attempt to communicate concerns regarding other areas such as language but the caregivers did not recall or attach importance to these other areas. Rather they consistently shared that "speech" was being addressed by their child's SLP. Therefore, even if speech was considered the critical issue that needed to be addressed at the time of the initial evaluation, not addressing other issues may suggest to caregivers that other issues do not exist.

Another topic that stood out in the findings related to SLP information sharing as not being well understood by caregivers was the nature of the language and reading connection. While some caregivers appeared to understand the connection between language and reading better than others did, overall, the knowledge that caregivers expressed regarding the subject was limited and did not suggest a full understanding. In particular, caregivers appeared to struggle with expressing an understanding of the language component and how it was connected with reading. Mrs. J, for example, understood that her son had trouble "processing" what he read, but did not appear to further connect his language difficulties with his reading difficulties. Considering the important role that language plays in reading development and how closely a given reading diagnosis is tied to a child's language ability, it is important that SLPs strive to address this area of incomplete information. It may not be necessary for caregivers to fully understand every aspect of the reading and language connection in order to assist and understand their child. However, having a general understanding of the reasons behind their child's struggle to read may help caregivers to better understand their child's disorder at a functional level and improve their ability to offer appropriate accommodations and assistance.

Finally, one particular topic of information that stood out in the findings of this study as information that in hindsight caregivers wish they had known or understood better was the reality of long-term consequences related to their child's disorder. While a positive prognosis can keep caregivers hopeful, it may also lull caregivers into believing that their child's speech delay is "no big deal". However, the research suggests that even children who appear to catch up on their speech skills, are at increased risk of having future academic issues (Paul, 1996). These children often continue to lag behind their peers on standardized testing measures (Rescorla & Schwartz, 1990). Through sharing possible risk factors with caregivers, SLP can potentially motivate caregivers to engage in positive and on-going prevention activities. The research suggests that early intervention can significantly reduce the future complications associated with speech-language impairments (Kruse, Spencer, Olszewski, & Goldstein, 2015; Wilcox & Woods, 2011). Additionally, if the SLP shares knowledge regarding prognostic indicators, knowledgeable caregivers can be more alert to the signs of risk in their child and take steps to reduce potentially negative consequences by being prepared and taking action before their child falls behind in school.

### **Listening and Caring Professionals**

Two of the themes related to increasing caregiver knowledge and collaboration were *responsiveness to caregiver concerns* and *meeting caregiver needs*. In particular, caregivers discussed the importance of responsive listening and showing care and concern for their child and their child's family unit. Listening and empathetic behaviors such as showing care and concern are identified as important PCC behaviors in the health communication literature (Nuutila & Salanter, 2006; Propp et al., 2010; M. B. Wanzer et al., 2004). Caregivers, who participated in Lutterman's (1999) study, also identified empathy as an important quality for professionals to possess. The participants in the current study provided examples of what they

perceived to be effective listening and caring behaviors for establishing a positive therapeutic relationship.

First of all, caregivers emphasized the need for SLPs to demonstrate that they were listening to and valuing caregiver input by being responsive to the concerns the caregivers raised. Caregivers were appreciative of SLPs and other health care professionals who made noticeable changes to service delivery, offered appropriate resources, and encouraged ongoing and mutual discussions regarding caregiver concerns. Caregivers also felt validated when they believed their concerns were listened to. As noted in the findings, one of the needs caregivers had when seeking help for their child was to receive support and reassurance that their concerns were valid. In contrast, caregivers described their frustration when they did not feel that their concerns were being heard or validated. Caregivers often became noticeably perturbed when describing incidents where they perceived their concerns to have been “blown off”. The primary examples caregivers provided of “not listening” behaviors included, refusing to address a concern voiced by the caregiver (e.g., only willing to discuss pull-out services when the caregiver requested classroom services) or contradicting caregiver concerns by suggesting that the child was “fine” or “just needed more time”. Collaborative relationships depend on both parties sharing information. However, caregivers will be hesitant to share their concerns if they do not believe that the SLP will listen and be responsive to them.

In addition to listening, caregivers in the current study also talked about the importance of showing care and concern, especially for their child. This finding is similar to Nuutila’s (2006) finding that professionals showing obvious care for the child promoted positive family coping. Caregivers in the current study focused on SLPs showing care through consistently working hard for their child and taking the time to build a positive relationship with their child. Caregivers recognized the importance of their child’s role in the intervention process and their

perception of the professional often mirrored their child's attitude or responsiveness toward the professional. Caregivers were more receptive to building a therapeutic relationship with their child's SLP when they saw that their child already had a positive and supportive relationship with their SLP.

### **Caregiver Understanding of Language Delays/Disorders**

The findings of this study offer additional perspective regarding how caregivers reach an understanding of their child's language disorder (Hidecker et al., 2009). Caregivers as a whole expressed the view that their understanding of their child's language disorder was complicated, influenced by their history, and constantly evolving over time and new experiences. The dynamic and variable understanding that caregivers had of their child's disorder reflects key concepts noted in family systems theory, particularly in regard to family coping (Hare et al., 1989; Manning et al., 2011; McCubbin et al., 1983; McCubbin et al., 1993). Family coping models, such as the Double ABCX model described in Chapter 2, suggest that caregiver understanding of an event or disorder is influenced by a variety of factors and can play a key role in how a family moves forward after receiving a diagnosis.

Caregivers in the current study drew their understanding of their child's disorder from a variety of sources including past experiences with disorders, educational knowledge, and general life experiences. However, information received from their child's SLP was viewed as particularly meaningful. Caregivers often looked to SLPs to provide them with a starting place for defining their child's language impairment. Prior to receiving a diagnosis, caregivers frequently referred to their child's disorder as their child's problem. As knowledgeable individuals who knew their children, the caregiver typically knew something was wrong, but often struggled to describe to other caregivers, doctors, and teachers exactly what was wrong. Some of the caregivers became adept at describing and categorizing their child's difficulties,

especially in terms of educational difficulties and speech production difficulties, but they struggled to understand the “why”.

The “why” was an important piece to caregiver understanding. For many caregivers the answer or the explanation for the “why” was a diagnosis. In other words, caregivers viewed having a clear diagnosis for their child as having the solution to their child’s problem. While some caregivers did express the desire for a ‘quick fix’ based on having a solution, several of the caregivers were simply happy to know that their child’s impairment could be addressed and that there was a reason or an explanation for their child’s difficulties. Following a diagnosis, many of the caregivers were able to focus on the tools and accommodations that helped their child rather than focusing on their child’s problem. As caregivers considered the diagnosis to be a solution, caregivers could now focus on dealing with the new issue at hand, how to help their child move on with their life as a child with a specified disorder. The shift from problem to solution focus suggests a positive change in the caregiver’s definition of the disorder, and may be significant in helping the caregiver begin to establish a shared meaning of the diagnosis and shared goals for their child (McCubbin et al., 1983). This change in focus was reflected to varying degrees in all of the caregiver interviews. It was most evident in the interviews of the caregivers who believed they had an understandable diagnosis. However, even the caregivers who felt less sure of their child’s diagnosis had reached a point in their child’s intervention process where they could point to some positive changes. Having a diagnosis appears to facilitate the shift from problem focus to solution focus, but not having a diagnosis does not necessarily prevent it.

### **Caregiver Perceived Challenges**

Overall, caregivers expressed a desire to be collaborative partners with the SLPs, but also acknowledged several challenges to the development of a truly collaborative relationship.

Caregivers who participated in this study highlighted the following challenges in their

interviews: finding balance between meeting the specific needs of their child with a disability and meeting the needs of others, not believing themselves to be knowledgeable enough to make a difference for their child, not feeling comfortable initiating the collaboration process with SLPs, and the ongoing process of making sense of their role as a caregiver of a child with a disability in light of their previous and current life experiences.

The findings presented in this study offer a unique perspective regarding how caregivers of children with language impairments view the collaborative process with SLPs. The findings also add a distinctive component to the patient/family centered communication model and family systems theory. As noted in the literature review, family systems theory acknowledges the many interconnected layers between an individual, their family, and their family's external systems and recommends that health care providers consider the whole family in their assessment and intervention process (Broderick, 1993; Galvin, Dickson, & Marrow, 2006). As expressed in the findings of this study (*whole family approach*); the caregivers faced many challenges balancing the needs of the child receiving speech-language services, the needs of other children in the family, the needs of their spouses/significant others, the needs of their employers, and many other responsibilities. Therefore, while caregivers expressed a desire, to collaborate with their child's SLP, they also expressed the need to be "caregiver first" which meant balancing many responsibilities at once. Results from a previous study that examined barriers to caregiver implemented shared reading interventions support this finding. Justice, Logan, and Damschroder (2015) identified multiple key barriers to caregiver collaboration including the issue of time pressures.

Another barrier Justice et al. (2015) identified was the lack of awareness of benefits. Caregivers in this study emphasized the importance of feeling knowledgeable and aware of the purpose of the intervention. In fact, one of the practices that caregivers found the most helpful to

the collaboration process was gaining knowledge regarding their child's needs and understanding the strategies, accommodations, and interventions that helped their child. In other words, caregivers were much more likely to assist with generalization at home if they felt confident in their knowledge to perform a task and the benefits to their child in performing that task. For SLPs, family centered communication practices need to include an awareness of the many challenges caregivers face and a willingness to be flexible in establishing opportunities for caregiver involvement.

### **SLP Client/Family Centered Practices**

The importance of family centered practices are acknowledged in the communication sciences and disorders literature and form a key component of evidence based SLP practices (e.g., ASHA, 2008; Crais, 1991; Crais, Roy, & Free, 2006b). The findings from the current study support previous research that stresses the importance of the timing of information sharing and the need for clear and concrete information sharing, particularly in regards to diagnostic labels (Hand, 2006; D. Luterman & Kurtzer-White, 1999b). Additionally, the findings from this current study add to the current literature by further examining caregiver perceptions of when information should be shared (Research Question 2), and how caregivers view and understand SLP diagnostic labels (Research Question 1).

### **Timing & Ongoing Presentation of Information**

As noted in Chapter 4, caregiver descriptions of the information they received from SLPs primarily focused on the initial evaluation appointment. The focus on information shared during the initial evaluation may have been due to caregiver perceptions of the evaluation as the point at which they had received the most significant information and possibly the point at which they expected to receive the most significant information. In fact, all of the caregivers expressed their desire for immediate or fast information at the time of the evaluation. In particular, caregivers

wanted to know their child's diagnosis as soon as possible. Lutterman and Kurtzer-White (1999) also found that immediate information was important to caregivers of children with a hearing loss, with 83% of the caregivers in their study saying "yes"; given the choice, they would have wanted to know that their baby was deaf at birth (pg. 3). For caregivers it was the information they received that determined if the evaluation was a positive experience. In contrast, caregivers were quickly disappointed in their experiences when they believed that key information that they wanted to receive was not included (e.g., a diagnosis or a treatment plan).

Caregivers may also have focused on the initial evaluation appointment if they felt that follow-up information was lacking. Consistent and informative follow-up communication also stood out in this study as a key factor in encouraging an effective therapeutic relationship. While caregivers placed a high value on receiving diagnostic and service option information at the time of the evaluation, they also acknowledged that they struggled to recall a great deal of the information they had initially received (e.g., details regarding the diagnosis, prognostic information, descriptions of the intervention process) and valued receiving follow-up information from the SLP. Lutterman (2001) notes, there are several reasons why caregivers may struggle to recall the majority of the information provided to them at an initial evaluation including an inability to cognitively process and retain rational information while in an emotionally overwhelmed state. Furthermore, even if the caregivers believed they understood the information at the time it was presented, without regular communication and follow up the information tended to be forgotten.

A caregiver not recalling information does not mean it was not shared, but it does suggest that the information may not have been well enough understood to be retained long-term. SLPs need to be aware that even if a caregiver claims understanding at the time of the evaluation, the caregiver may not retain the given information and understanding of the information over time.



Rather than feeling frustrated at having to repeat information, SLPs should consider information sharing an ongoing process over the course of the relationship, not a stagnant event.

Furthermore, periodic checks for caregiver understanding should be considered part of a typical routine in the process of maintaining a productive relationship with a caregiver.

Overall, the topic of reading and language presents as a challenging topic to address with caregivers in a meaningful manner. Ensuring caregiver understanding may require the provision of background information regarding both language and reading independently prior to discussing the relationship between them. Furthermore, multiple conversations may be necessary, as opposed to one at the time of the evaluation, to ensure true understanding. Sharing information later on requires that follow-up communication occurs and that the evaluation appointment not be the only setting in which SLPs share information. Follow-up communication over time can also be important to being sure that caregivers are receiving and understanding all the information they need to advocate for their children over time. The importance of follow-up communication between the health care provider and caregiver has not been examined closely in the health communication literature, most likely due to the different nature of doctor-patient relationships. SLPs like other allied health care professionals (e.g., physical therapists) frequently provide monthly, weekly and even bi-weekly intervention services to their clients (Blackstone et al., 2011). Thus, the regularity of the contact between SLPs and their clients distinguishes them from health care providers like doctors who primarily provide evaluation services (e.g., annual physical, illness, specialized procedure) on an as needed bases and do not typically provide ongoing intervention appointments.

Lutterman (1999) explains that caregivers may not initially be ready to hear and take all of the necessary information in. He suggests that in some cases, SLPs must learn to wait and share key information later on when the caregiver expresses a readiness to hear and discuss

further information. The findings from the current study suggest that there are benefits to waiting to share some information, as caregivers may have trouble recalling information beyond the diagnostic label. However, caregivers further indicated in their responses concerning positive SLP communication that they appreciated SLPs initiating follow-up communication. This finding suggests that caregivers may be hesitant or unlikely to express their need for further information without some level of encouragement from the SLP. Therefore, the caregiver emphasis in this study on the importance of the SLP initiating follow-up communication to provide ongoing information is a noteworthy addition to the literature.

### **Health Literacy Challenges Related to SLP Diagnostic Labels**

The findings suggest that caregivers often struggled to clearly understand speech-language diagnoses and the implications of those diagnoses. For this study, caregiver understanding was particularly in doubt when the label given to their child was unfamiliar to them or inconsistent with their expectations. It was notable in the findings that caregivers did not always perceive speech-language labels as a diagnosis, referring to a label such as speech or language delay as a description rather than a diagnosis.

### **Diagnostic Label Confusion**

Previous research has pointed to the difficulties associated with the lack of a clear and consistently used label in identifying children with language based disorders (D. V. M. Bishop, 2014; Reilly et al., 2014). While the findings in this study did not specifically address what label should or should not be used, they did clearly indicate, that consistent and clear label use among SLPs is important to helping caregivers understand their child's diagnosis. As caregivers explained, they often sought an evaluation for the purpose of getting an expert opinion and a documented diagnostic label.

One issue among practicing SLPs is the different labels used to describe language related disorders as well as a hesitancy at times to even use a diagnostic label, particularly in early intervention and school settings (Schuele & Hadley, 1999). Clinicians may feel uncertain of the appropriate label themselves or believe that describing a child's strengths and weaknesses is enough. New clinicians are frequently warned to avoid technical terms or jargon when communicating with a client or caregiver, especially when providing diagnostic information that may be challenging for someone not in the field (e.g., Haynes & Pindzola 2012). Some health care professionals, including SLPs may also avoid using technical diagnostic terms, believing that a diagnostic label will not change the treatment course and may take the focus off the functional needs of the client (Schuele & Hadley, 1999). However, while technical terms alone can be confusing, avoiding them completely may actually lead to significant misunderstandings between the caregiver and the SLP. One of the difficulties with completely avoiding technical terms, including diagnoses, was illustrated in caregiver responses regarding their child's "non" diagnosis of speech-language delay. As expressed in the themes related to SLP information giving, several of the caregivers did not view their children's early label of speech-language delay as a "true" diagnosis. Rather, caregivers referred to their child's speech delay as a general description that had been provided to them. Viewing the term as a general description rather than a diagnostic term, caregivers may have interpreted the word "delay" to indicate that their child would outgrow their temporary condition. This interpretation may have contributed to the general positive prognosis that caregivers associated with their late talking children, a prognosis that does not acknowledge the potential risk for later language and reading issues (Johnson et al., 2010; L. Justice et al., 2013; McCardle et al., 2001)

Difficulty in recognizing a diagnosis was also evident in examining the discussions regarding diagnoses associated with language and reading. As noted in the findings, caregivers

typically understood a diagnosis of “dyslexia” but did not always clearly interpret other labels as diagnostic labels. For example, caregivers in this study viewed both “mixed reading disorder” and “reading comprehension deficit,” as general descriptions rather than diagnostic labels. One reason for this misunderstanding may be the lack of continuity in labeling language and reading disorders (C. Dollaghan, Nelson N. W., & Scott, C., 2012). Another factor may be the lack of formality associated with the diagnosis even in the written report. In many speech-language evaluation reports, the diagnosis is written in sentence format and is not paired with its diagnostic code number; a code caregivers may be familiar with seeing on documentation from their physician. Additionally, caregivers may not be as familiar with language and reading disorder terms beyond the well-publicized label of dyslexia. As Schuele and Hadley (1999) note, it may be important for SLPs to carefully choose key diagnostic terms in order to appropriately inform caregivers. It is not necessarily the technical term that will confuse caregivers, but the lack of an explanation of that term. Therefore, by providing a clear diagnostic label along with an appropriate description of the meaning and implications of that diagnostic label, SLPs can more fully inform caregivers and potentially avoid misunderstanding related to diagnosis and outcomes. More fully informing caregivers may include providing caregivers with educational materials about speech-language labels and possibly comparing and contrasting the relationship between labels, particularly if caregivers are struggling to understand the difference between dyslexia and a mixed reading disorder.

In providing additional caregiver education, SLPs must also recognize some of the potential barriers that caregivers must overcome in understanding and accepting an unfamiliar diagnosis or coming to a new understanding of a diagnosis they thought they understood. For some of the caregivers in this study, one of the key challenges may have been re-examining their assumptions about their child’s disorder.

## **Confirmation Bias**

Caregivers frequently arrived at the evaluation with certain expectations or biases regarding the evaluation outcomes. SLPs need to be aware of and prepared to deal with confirmation bias, which is preferring evidence that supports our beliefs and ignoring evidence that questions our beliefs (Finn, 2006). Several of the caregivers who participated in this study overwhelmingly sought out the speech-language evaluation based on a belief that their child might have dyslexia. In looking for confirmation of their belief, some caregivers were not open to other diagnoses. For example, one caregiver, Mrs. F expressed certainty that her daughter had received a diagnosis of dyslexia from the university clinic even though the written report indicated a language comprehension disorder, not dyslexia. The idea of dyslexia had been suggested to her by her daughter's doctor, who recommended that Mrs. F bring her daughter to the university for a dyslexia evaluation. Another caregiver, Mrs. A did not dispute the mixed reading disorder diagnosis the university gave her daughter, but she continued to refer primarily to the dyslexia diagnosis given to her by her daughter's optometrist. Optometrists are not licensed to diagnosis dyslexia, but they can diagnosis visual perception disorder, a disorder commonly associated with dyslexia (Hogan & Bridges, 2008).

SLPs are likely to experience confirmation bias with other disorders as well, particularly disorders that are "well known" to the general population. For example, in my personal experience working in schools, caregivers would request an evaluation for their child because they believed their child had autism. This belief typically was present because someone they knew, maybe a teacher, sister, or friend had suggested it. If the evaluation did not result in a diagnosis of autism though, the caregivers would often refuse to accept the presented evidence.

Repetition over time may be necessary when a caregiver struggles to understand a diagnosis, especially when their preconceived notion is not confirmed by the evaluation process.

Whether caregivers are having difficulty perceiving their child's diagnosis as the "real" concern or difficulty accepting a different diagnosis, it may be helpful for the SLP to consistently revisit the assessment process, keeping in mind that for most caregivers the diagnosis is new and unfamiliar territory. SLPs generally do not expect children to learn a new concept with one repetition; neither should they expect it of the child's caregiver. Rather, SLPs should remember that explaining and discussing the implications of a diagnosis is not a one-time event.

### **Childhood Language Disorders**

As discussed in the literature review, childhood language disorders are complex and variable in how they present in a child. Several components of disorder could potentially be observed including difficulties with vocabulary, morphology, syntax, pragmatics, narrative, reading and phonology (L.B. Leonard, 2014). SLPs may or may not describe all aspects of a language impairment to a caregiver, depending on the specific strengths and weaknesses presenting in a child. Additionally, while SLI is the preferred term in the research literature, it is rarely used in the school and clinical setting (D. V. M. Bishop, 2014; Schuele & Hadley, 1999). In fact, several children who present with language disorders are never directly identified as having a language impairment, particularly in the school setting (C. Dollaghan, Nelson N. W., & Scott, C., 2012; J. Tomblin et al., 1997). Therefore it is not surprising that caregivers in the current study never used the term SLI to describe their child. The findings from Research Question 1, related to caregiver descriptions of their child's services (*Services Provided*) and their child's disorder (*Characteristics/Behaviors*), suggest that caregivers primarily focused on their child's educational difficulties and their child's difficulty communicating due to unclear speech and language. Both categories described by caregivers in these findings included aspects of language impairment, suggesting that caregivers had some awareness of their child's language status, but may not have had concrete terms or ways of expressing their understanding.

## **Language Characteristics/Behaviors Described by Caregivers**

Caregiver descriptions of their child's language status were inconsistent across cases and minimal in the amount of information provided. While all of the children who were discussed in the current study had a language-related disorder and recent language assessments in their files, the caregivers as a whole were primarily focused on their child's reading and educational difficulties, and had variable levels of understanding regarding the connection between language and reading. It is possible that the caregiver focus on reading obscured caregiver knowledge in regard to the characteristics of their child's language impairment. However, even though the findings were variable, some of the caregivers did provide descriptions of their child's language abilities in relation to either their vocabulary, syntax, narrative, and phonology abilities. Overall though, caregivers did not use formal terms such as those listed above, but rather referred to their child's "word use", "sentence making", "story telling", "recall", "following directions", and "speech" abilities.

As noted in the findings, caregivers tended to describe their child's speech and language in relation to their "talking". For example, Mrs. A described her daughter's speech as "garbled", Mrs. B talked about her son having "no words", and Mrs. G expressed that her daughter had always used "words that were too big for her". Mr. J also noted that his son had difficulty putting words together to make sentences and Mrs. E mentioned that her daughter had trouble retelling stories she had read. Overall, their comments suggest a focus on expressive language, particularly how clearly their children expressed themselves. A few of the caregivers also spoke about difficulties with writing, particularly spelling issues, and reversing letters. While the caregivers did not directly speak of vocabulary issues, or syntactic issues, they appeared to have some understanding of their children's limitations in using language.

The findings presented a few examples of caregivers commenting on their child's receptive language ability. In particular, four of the caregivers of the children diagnosed with dyslexia specifically recalled being told that their child's comprehension was a strength. Knowing that their child had good comprehension appeared to be important to these caregivers, possibly because they associated strong comprehension abilities with intelligence. In general, the caregivers of the children with good comprehension skill believed their children were smart and resourceful students, capable of learning strategies to deal with their reading impairment. In contrast, the findings presented at least one example of a caregiver, Mrs. A, noting her daughter's difficulty with comprehension. Mrs. A specifically referred to her daughter's "memory" and "language processing" ability being impaired. She did appear to understand that issues with recalling and processing language impacted her daughter's reading ability.

Overall, the findings related specifically to SLI and the nature of the children's language impairment were not discussed in detail by the caregivers. The lack of comprehensive information from caregivers regarding different aspects of their children's language related impairment could be attributed to a variety of reasons. First, as noted in the findings, caregiver memory was an issue. It is possible that caregivers were given more concrete terms and descriptions of their child's language that they did not recall. Secondly, as noted in the literature, there is variability in how language disorders present themselves and how SLPs talk about language disorders (C. Dollaghan, Nelson N. W., & Scott, C., 2012; Schuele & Hadley, 1999). Finally, caregivers may simply not have given much consideration to describing their child's language or what the SLP said about their child's language weaknesses, when their focus was on their child's reading abilities. Further discussion that was focused on language or the presentation of key terms related to childhood language disorders could have yielded more



caregiver discussion regarding terms that they understood or recalled their child's SLP sharing with them.

### **SLP Advocacy**

One of the themes that emerged in the findings that was not directly addressed in the literature review was the importance of SLPs educating caregivers about their scope of practice. In particular, the findings from Research Question 2 suggested that lack of caregiver awareness of the SLP's scope of practice presents a serious barrier to SLP service provision, especially the SLP's ability to collaborate with caregivers. Professional advocacy, in particular educating other health care professionals and caregivers about speech-language disorders is addressed in the literature and practice standards as an important aspect of SLP service provision (e.g., ASHA, 2004; Harrison, Dannhardt, & Roush, 1996; J. B. Stoner et al., 2006; van Kleeck, 2013). As is indicated in the themes associated with helpful SLP communication (Research Question 2), caregivers were frequently unaware of the breadth of SLP service provision. Thus, in addition to educating other professionals and caregivers about language and reading disorders, SLPs need to educate other professionals and caregivers about their scope of practice. While not necessarily surprising, the findings from this study reiterate the lack of awareness regarding the assessment and intervention options that SLPs can provide. Several of the caregivers who participated in this study knew of the SLP as a health care professional, however, overwhelmingly the caregivers associated SLP service provision with speech sound production services only. Likely, the focus on speech sound production services that many of the caregivers received from early intervention and school based providers further solidified this expectation. In fact, several of the caregivers indicated that they had never thought about coming to an SLP for their child's language/reading issues until some other professional or caregiver with an experience had referred them.

One caregiver, Mrs. C, shared that she knew SLPs worked with social language issues, due to her son with Autism having received speech-language services, but she never would have thought of SLPs providing literacy or reading services. When her daughter began having difficulties, she reached out to many people, but never to her son's SLP, noting that talking to her son's SLP never occurred to her. As a student in a university education department, she reached out to one of her professors and it was through her professor's recommendation that she brought her daughter in for a speech and language evaluation. Other caregivers shared similar stories saying that they had received a recommendation to seek out a speech-language evaluation from a particular teacher, friend, or doctor who knew from previous experiences that an SLP could assess reading. A few caregivers shared that they had sought out SLP services at the university clinic after searching the internet for places that did "reading evaluations". While all of the caregivers who participated in this study have learned more about SLP services, several of the caregivers also expressed frustration over the length of time that had passed before they knew about the "other" services that SLPs could provide. "I wish I knew sooner" was a common refrain among several of the caregivers.

The reasons for limited caregiver awareness of SLP service provision especially in regard to language and reading issues are probably varied and complex. One simple reason to consider is that SLP involvement with language and reading disorders is still considered relatively new to the profession (ASHA, 2001) and not all SLPs may address language and reading disorders depending on the nature of their work setting<sup>12</sup>. Furthermore, our professional knowledge regarding the connection between language and reading is still in the process of developing, so it may not be surprising that parents have even less understanding. When possible though, it is

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<sup>12</sup> The lack of caregiver awareness regarding the scope of SLP services could be particular to the region where this study was conducted. The typical SLP load in this region is composed almost exclusively of children with speech sound production issues and children with secondary language issues. Additionally, children with primary language disorders can be difficult to identify and may be going undiagnosed (J. Tomblin et al., 1997).

important that the SLPs seek to provide caregivers with knowledge regarding service options even if language or reading based services do not appear applicable at the time.

### **Qualitative Research**

This study examined caregiver experiences and perceptions of communicating with SLPs regarding language delays and disorders using a qualitative approach. In particular, through a semi-structured interview format, composed of interview questions guided by the known theoretical literature available in health communication and communication sciences and disorders fields, the researcher offered caregivers an opportunity to reflect upon and share their experiences communicating with SLPs. The use of a qualitative methodological approach allowed the caregivers to share complex and detailed narratives regarding their experiences communicating with SLPs. This approach resulted in a rich and extensive data set. The focus on caregiver perspectives allowed caregivers to share the aspects of the communication experience that were most significant to them, and these included the aspects they understood and appreciated, the aspects they felt were missing or difficult to understand, and the aspects they felt led to better knowledge and collaboration between them and the SLP.

One unique aspect to this study was the 100% participation by participants. As noted in the methods, potential caregivers were initially approached by the SLP who supervised their child's evaluation and or intervention at the university clinic. Caregivers, who indicated they were willing, spoke with the researcher for further information. Every caregiver who was approached agreed to participate in the study, and every caregiver who agreed to participate followed through on scheduling and participating in the interview. The high percentage of participation likely resulted from a participant pool that was friendly toward the university and happy to participate in a study that only required them to talk about their child. Additionally, contributing to the study gave the participating caregivers the opportunity to be heard as experts

on their children and their experiences, likely a unique and satisfying opportunity. The percentage of participants who participated in the brief follow-up interview was also high with 9 out of 11 caregivers participating. As the follow-up interview was important to checking the validity of the study, the willingness of the majority of caregivers to make time for a follow-up interview strengthened the results of the study.

### **Implications For SLP Communication Practices**

The findings from the current study suggest several practical implications regarding SLP communication practices in sharing information with caregivers and developing collaborative relationships with caregivers. First of all, the importance of the speech-language diagnosis being clearly stated and a mutual understanding of the diagnosis being established between the caregiver and the SLP was highlighted throughout the interviews. Secondly, the need for SLPs to initiate collaboration opportunities and follow-up communication with caregivers was emphasized. Finally, the lack of caregiver awareness of the role that SLPs can play in assisting children with language and reading disorders suggests a need to educate caregivers about the SLP scope of practice and the services SLPs can provide.

### **Importance of Establishing Shared Meaning of the Diagnosis**

To communicate effectively with caregivers, it is helpful for SLPs to understand how caregivers understand or define their children's disorders and what caregivers are hoping to gain from a diagnosis and the intervention process. Having an understanding of a caregiver's perception of his or her child's diagnosis can help the SLP respond appropriately to the caregiver's needs and expectations, and provide appropriate resources to fill in the information gaps. If an SLP had a significantly different expectation for the child than the caregiver, the divergence of expectations may result in miscommunications and fractured relationships. For example, a caregiver may not understand why a particular intervention strategy is chosen and

may become frustrated because he or she does not see how the intervention is going to help the child (e.g., the caregiver perceives the child to have a ‘reading problem’ and wonders why the SLP spends time working with the child on understanding and identifying story grammar elements). Similarly, if a caregiver expects a diagnosis to lead to a solution that will “fix” their child, he or she may become frustrated when months pass and their child continues to struggle. A shared understanding of the diagnosis and prognostic factors can help caregivers and SLPs truly collaborate on service and intervention decisions. It can also help caregivers to have a realistic view of how the SLP can help their child.

While prognostic information is usually considered a “best guess,” as opposed to a definite outcome, especially when looking years ahead, it is important that SLPs and caregivers discuss the possibilities. Caregivers are often thinking about their child’s future, especially in relation to their education and career options. Having an accurate understanding of what their child’s potential strengths and weaknesses are and how those characteristics can influence their child’s future, can help caregivers advocate for their child early on and set realistic expectations for their child’s future. As the findings indicated, it is possible for caregivers to have hope while still being realistic about the challenges ahead. Furthermore, increased awareness could potentially decrease both caregiver and child frustrations over time and possibly lessen the impact of long-term issues related to language impairments.

### **Initiating and Following Through with Collaboration**

Finding the right balance of SLP initiation and client initiation in collaboration can also be a challenge. While all of the caregivers expressed a desire to receive ongoing information and follow-up communication from their child’s SLP, almost all of the caregivers also admitted to expecting the SLP to initiate the desired communication. SLPs need to keep in mind that part of their role, especially early on in the relationship, may be to initiate the follow-up conversations

with the caregiver and provide regular opportunities and encouragement for the caregivers to ask questions and develop their own skills in assisting their children. Over time as the caregiver becomes more comfortable in the collaborative relationship, the SLP may find that the caregiver is more willing to initiate, but the relationship may not reach that stage of trust without someone initially taking the lead.

SLPs also need to be cognizant of the manner in which past experiences influence future experiences for caregivers. Every caregiver has different life experiences and it may be impossible for SLPs to even begin to understand what factors are influencing a particular caregiver and family without asking and seeking to understand them on an individual basis. Many case histories and intake forms do ask a few initial questions about family history, family education, and the general make-up of the family. It is important that SLPs follow-up on “family” information and seek to understand how the family history (e.g., child abuse, divorce, caregiver with a disability, other children/siblings with a disability) as well as the current family dynamics (e.g., single parent responsibilities, demanding jobs, communication issues between divorced caregivers, custody issues, health concerns, education level) influences a caregiver’s knowledge, and desire for collaboration.

SLPs also need to seek out opportunities for collaboration with caregivers across all evaluation and intervention settings (e.g., schools, university clinic, early intervention programs, and private practice clinics). This may require finding creative ways to communicate with caregivers who cannot be present during sessions. Several of the caregivers found the opportunity to observe speech-language intervention sessions and talk with the SLP during or after sessions to be very helpful in increasing their knowledge and ability to collaborate with the SLP. However, in many ways, watching was a unique opportunity not available in all settings where speech-language assessment and intervention is provided. For example, speech-language

services that are provided in the school system are not typically set up to encourage caregiver observation, and even if they were, many caregivers would not be able to take advantage due to work or other responsibilities (L. Justice, Schmitt, Tambyraja, & Farquharson, 2014). School based SLPs are often frustrated with how difficult it can be to communicate with caregivers and to get caregivers involved in their children's intervention (Joseph, 2010; Talladay & Harten, 2013). However, the importance of having the visual example and face-to-face explanations really stood out for the caregivers in this study. Even though regular observations may not always be possible, finding ways to "show" caregivers what is happening in the therapy room may have benefits to helping caregivers better understand an intervention and feel more capable of being involved. Of course, watching is not the only way to effectively share information. As noted, earlier, perhaps the most important aspect to increasing caregiver collaboration in any setting is an SLP who is willing to consistently reach out and initiate the communication process. The collaboration process between the SLP and caregiver may also be benefitted by setting up regular opportunities specified for parent education and training. As several of the caregivers in this study noted, knowledge is a very powerful and necessary tool in the collaboration process. Additionally, previous research has shown that well informed caregivers who are given the opportunity to learn through consultation and hands on practice with the SLP are more successful and comfortable carrying over interventions at home (Kirk, Moore, & Schley, 2011).

### **Caregiver Education and SLP Advocacy**

One practical manner of addressing the lack of awareness regarding SLP services may be for SLPs to provide materials that list their services and to make a point of discussing all aspects of speech-language service provision early on, when services are being initiated. Additionally, a full speech-language evaluation should address all areas of speech-language (e.g. speech sound production, oral motor function, language components, voice, fluency), providing SLPs an

excellent opportunity when reviewing evaluation results to not only share information about the area of primary concern, but also to address other areas related to speech rather than glossing over areas that did not represent an immediate concern (ASHA, 2004). Furthermore, SLPs may want to consider providing additional written materials about language and literacy and how early language development patterns can point to later language and literacy abilities. Finally, there may be opportunities for further advocacy in mass media outlets at the state level through professional SLP state organizations and at the national level through ASHA. For caregivers in this study at least, the connection between language and literacy represented a significant gap in their knowledge that needs to be addressed.

### **Limitations and Future Studies**

As with any research endeavor, there are limitations to this study and the potential for future research to expand upon the current findings. First, the overall sample of participants lacked diversity. All of the caregivers were Caucasian and spoke English as their first language. Caregivers from more diverse backgrounds, particularly caregivers whose first language was not English, may have presented with different concerns regarding the information sharing process. Caregivers from more diverse backgrounds may also have expressed a very different understanding of language impairments and placed a different value on a diagnosis depending on their unique cultural beliefs and experiences. Additionally, the information from this study represents one limited region within one state. Caregivers living in other states and even other cities/regional areas may have access to different service options, and SLPs in other regions or states may approach language/reading disorders differently than in the region where this study was conducted. Future studies should seek to include caregivers from a broader cultural and regional background, thereby creating a more diverse and generalizable participant pool.



There was also limited diversity among participants in regards to their educational background and their evaluation experiences. All of the caregivers who participated in this study were reasonably well educated and had sought out additional services for their child at the university clinic. As education and background knowledge appeared to play a role in influencing caregiver perceptions and understanding of their child's language impairment, caregivers with less educational experiences may offer a different perspective as well as different experiences in regard to SLP communication. SLPs would also benefit from a better understanding of what motivates caregivers to seek out additional speech-language services or not. Are there significant differences between caregivers who seek out university clinic services for their child and those who do not? Do caregivers who do not seek out additional services have knowledge of other options? Several of the caregivers in this study indicated that they had not initially known they had other options. Through expanding the diversity of participant education and primary evaluation/service experiences (e.g. public schools, private practices, and early intervention agencies), future research could allow for more varied experiences and opinions across different segments of the population, adding to our overall knowledge of caregiver perceptions.

Another limitation to the study was the timing of the interview relative to the evaluation. All of the caregivers had difficulty recalling details from their conversations with SLPs. The difficulty with recall suggests that caregivers were likely given information or resources that they did not recall or possibly even recalled being given information that was not actually given (Loftus, 2004). Future studies of this nature might benefit from conducting multiple interviews at different times including an interview within a few days of the initial evaluation. Following the initial interview, follow-up interviews could be conducted at predetermined points of time (e.g., 3 months after intervention services have started, 6 months later with ongoing services, 12 months later with ongoing, changing, or concluding services). Follow-up interviews would give

the caregiver more opportunities to share information regarding “recent” communication with the SLP, as well as opportunities to note changes that may occur in the communication.

Additionally, further examination of communication methods (e.g. viewing a therapy session, giving caregivers informational pamphlets) and best practices in follow-up conversations (e.g., how frequently should they occur) may be helpful in better understanding ways to encourage caregiver retention of knowledge that SLPs believe to be essential.

The open-ended nature of the semi-structured interview approach also presents some limitations. As the focus of this study was on caregiver perspectives of SLP communication and caregiver understanding of their child’s language disorder, the open-ended approach was most conducive to encouraging caregivers to share what was most relevant and important to them. However, a more structured approach that provided caregivers with examples of commonly used speech-language terms (e.g., utterance length, narratives, grammatical structures), and diagnoses (e.g., SLI, late delayed speech, expressive language impairment) and more specifically questioned caregivers regarding the meaning of those terms/diagnoses and how they related to their child, would have potentially given the caregivers the opportunity to demonstrate more knowledge and awareness of various speech-language terms than they did in this study. Future studies may benefit from adding additional procedures to the interview process that add structure and follow-up on content either not fully discussed or introduced by the caregiver. For example, after conducting an open-ended interview, the researcher could consider following up with more focused questions, possibly in a survey format, designed to elicit further caregiver knowledge regarding speech-language terms and content.

In addition, a lack of comprehensive speech-language files for the children in the study and a lack of SLP perspectives on their communication with the caregivers who participated in the study, presented as a limitation. While the diagnosis from the university clinic files was verified

for every participant, most of the early intervention information and school setting information could not be verified, since only a few of the caregivers had provided the university clinic with previous early intervention/school reports. Having documented information (e.g. written speech-language reports, IEPs) regarding those services could have assisted the researcher in better understanding and asking follow-up questions regarding early intervention and school experiences with SLPs. Seeking caregiver permission for further access may assist in gathering more verifiable information in the future. Furthermore, while the researcher had some knowledge of what had occurred during a few of the university evaluations due to her participatory role as clinical supervisor, the clinicians who participated in the university evaluations were not interviewed. Additionally, the clinicians who worked with the caregivers' children outside of the university evaluation setting were not interviewed. Therefore, all information gained in this study is solely from the perspective of the caregiver. While the purpose and design of this study was to focus on the caregiver's perspective, future research would benefit from the ability to compare and contrast the perspectives of both the SLP and the caregiver, and to identify areas of communication success and communication breakdown.

Finally, as some of the caregivers with late elementary, middle school, and high school children noted, their children were as much involved if not more involved in the evaluation process as they were. Like their caregivers, the children frequently engaged in communication and collaboration with the SLP. This study did not seek to include children's perspectives of their language related impairment, or perspectives of SLP communication with themselves or their caregivers. Future studies should include older children (late elementary, middle school, high school) as participants in the interview process in order to gain their perspective on the evaluation process and their experiences communicating with SLPs regarding their language impairment.

## Conclusion

The purpose of this study was to examine how caregivers of children with language related communication disorders perceive their communication experiences with SLPs. While the literature contains studies that have examined the process of health care provider communication (Ok et al., 2008; M. B. Wanzer et al., 2004), and the importance of collaboration between health care providers and their patients/clients (Donovan et al., 2005; Melissa Bekelja Wanzer et al., 2009), no studies to date have examined the process of communication between SLPs and the caregivers they serve. This study also focused on the caregivers' perspective of the communication process. As such, the results from this study contribute a great deal to our understanding of caregiver perceptions of SLP information sharing, caregiver perceptions of language related disorders, and caregiver perceptions of the SLP and caregiver collaboration process.

Communicating with caregivers regarding communication impairments in a manner that supports client/caregiver understanding is a key component of the SLP's roles and responsibilities. However, sharing information effectively is dependent on the listener's understanding and retention of information. The first key finding was the importance that caregivers placed on receiving clear and concrete diagnostic information. The pertinent themes that emerged in regard to SLP information sharing included: the *diagnosis*, *incomplete information*, *services provide*, *memory*, and *quality of experience*. Overall, these themes stressed the importance of complete information giving, particularly in regard to the child's diagnosis. The findings also indicated the need for SLPs to consistently review information and check for understanding as caregivers often struggled to remember details, and they did not always fully understand the given diagnosis and its implications.

Another key finding of the current study was that while caregivers described their child's language disorder in many ways, they all struggled to understand how to help their child. Themes related to caregiver understanding of their child's disorder included: *diagnostic labels equal solutions, characteristics/behaviors, problems versus no problem, previous experience/knowledge, the future, and difficult to understand*. As suggested in the varying themes, caregivers' understanding of their child's disorder was complicated and constantly evolving. As a whole, caregivers sought solutions for the problem aspect of their child's disorder, expressed worry about and hope for their child's future, and sought to understand the "why" of their child's difficulties.

Finally, one of the unique aspects of this study was the opportunity for caregivers to openly express their perspectives regarding SLP communication practices that were beneficial to increasing their knowledge and ability to collaborate. The following themes emerged: *resources professionals provide, methods of information sharing, timing of information matters, follow-up, open and honest communication, responsiveness to caregiver's concerns, meeting caregiver needs, clarifying roles, whole family approach, and caregiver knowledge of SLP services*. Overall, the themes revolved around how and when SLPs provided informational resources and encouraged communication opportunities. As a whole, caregivers stressed the importance of receiving information as soon as possible, the SLP initiating follow-up communication, the SLP being a caring and proactive professional, and the SLP appreciating caregivers' contributions as caregivers. Having an awareness of the type of communication practices that are important to caregivers can assist SLPs in more effectively communicating with caregivers and avoiding missed opportunities due to misunderstandings regarding expectations and roles.

The results from the caregiver cases presented in this study provide clinicians with important topics to consider when talking with caregivers about their children's language related

communication disorders. The findings also further our professional understanding of SLP communication practices in relation to enhancing caregiver knowledge and encouraging collaboration, both essential components of effective evidence based service provision. Studies that further explore SLP communication and caregiver perceptions are necessary to continue enriching our knowledge as a profession regarding best practices to engage clients and caregivers in successful therapeutic relationships and ongoing collaborations.

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## APPENDIX A: PROPOSED SEMI-STRUCTURED INTERVIEW QUESTIONS

### Introduction:

1. Introduce self to participants
2. Review the purpose of the study with the participants.
3. Ask them to provide as many specific details and real examples as possible when responding to questions.

### Questions:

\* Probes will be used throughout the interview to encourage further details

\* Certain questions will have key points that need to be addressed

1. Let's start at the beginning... Tell me a little about *Name*? (Get them comfortable and talking about a relatively safe topic)
2. Tell me about *Name*'s current services, why is he/she coming to the H. Clinic?
  - a. Probes: How would you define or describe *Name*'s difficulty?
  - b. If not addressed: Encourage them to describe reading and/or language concern
3. Tell me about *Name*'s early development; talking, walking, learning?
  - a. Probes: Tell me more about... *concerns or red flags that are mentioned.*
  - b. If not addressed: What did you notice that caused you to seek services? (Something was wrong?)
4. Tell me about what actions you took when you first became concerned that *Name* may have some difficulty with *concern as identified by caregiver*?
  - a. Probes: Who did you talk with about these concerns? (*family, professions, neighbors*)
  - b. Probes: Did you talk with an SLP at that time...why or why not?
5. Let's talk about the first conversation you recall having with an SLP regarding *Name*.
  - a. If not addressed: Tell me what led to the conversation....*seeking information, evaluation process, referral?*
6. Let's talk some more about the conversations you recall having with *SLP's name*. Tell me what you remember about the first few or early conversations you had, include as many details as you can recall.
  - a. If not addressed: Tell me about when in the process (prior to or during an evaluation) the conversation took place?
  - b. Probes: Tell me more about... *any topics that relate to language or reading/ stand out as significant to the conversation.*

7. Ok, let's talk about other conversations you had with *SLP's name*. Tell me what you recall about other conversations, try to recall to the best of your ability about \*when (after the evaluation but before therapy, half-way through therapy sessions, etc...) the conversations occurred.

(Possible probes that may be asked after Question 6 or 7 depending on caregiver responses)

- a. Probe: How did *SLP's name* describe Name's difficulty to you?
  - b. Probe: Tell me what name or diagnosis *SLP's name* gave to your child's concern?
  - c. Probe: Tell me more about the kind of information or resources that were you given regarding the cause or reason for *Name's* concern?
8. Many children with reading difficulties also have difficulties with understanding or expressing language, tell me about any conversations you may have had with *SLP's name* regarding language disorders.
- a. Probe: Tell me more about what *SLP's name* said about Name's language abilities
  - b. Probe: Tell me more about how *SLP's name* described language disorders to you?
    - i. If not addressed: Did *SLP's name* use or refer to any possible diagnosis during the evaluation process or during therapy?
    - ii. If not addressed: What characteristics of language delays or disorder did *SLP's name* discuss with you?
  - c. Probe: Tell me more about how *SLP's name* described the relationship between reading and language.
  - d. Probe: Tell me more about how *SLP's name* described the long-term consequences associated with Name's concern.
  - e. Probe: Tell me more about the background information *SLP's name* gathered from you.
    - i. Was family history and/or genetics discussed?
  - f. Probe: Tell me about any conversations you have had with *SLP's name* regarding change over time? Things to watch for or prepare for? Future challenges?
9. Looking back over the conversations that you recall, how do you feel about **when** the SLP shared information with you?

- a. Probe: Was the timing appropriate?
  - b. Probe: Anything you wish had been shared earlier, later, or multiple times?
10. Tell me about the types of resources related to language delays or disorders that were given to you by *SLP's name*?
- a. Probe: Can you give me an example?
  - b. Probe: What did you like or dislike about one or more of these resources?
11. Tell me about resources you found on your own?
- a. If not addressed: How did you get them?
12. Overall, looking back over all of the conversations, what were some of the things *SLP's name* said or did or offered that you found the most helpful?
- a. Probe: Can you give me an example?
13. What are some of the things you wish *SLP's name* had said or done or offered?
- a. Probe: Can you give me an example?
14. What are some of the things that *SLP's name* said or did or offered that were not helpful?
- a. Probe: Can you give me an example?
15. Overall, how would you describe your relationship with *SLP's name*?
- a. Probe: Give me an example of time you collaborated with *SLP's name*.
  - b. Probe: Give me an example of a time you felt left out of the process.

Repeat questions 6-14 as needed for each various SLPs/locations of service the caregiver has worked with (the caregiver will not be encouraged to recall conversations with every single SLP or SLP student they have encountered, but rather to focus on the significant conversations or interactions.

16. Tell me about your long-term expectations for NAME'S progress?
- a. Probe: Tell me how capable you feel of helping Name continue to progress?
  - b. Probe: Tell me how confident you feel that you understand Name's difficulty?
  - c. Probes: Thoughts on future reading ability, careers, independence, academic, long-term issues, continued therapy.

17. Is there anything else that you would like to share that I haven't asked about.

Wrap-up:

1. Thank the participants for coming in.
2. Remind participants that I would like to follow up with them after I have had a chance to review and evaluate all the interviews in order to confirm my interpretations of the information they have shared. Verify contact information for follow-up.

## APPENDIX B: TRANSCRIPTION CONVENTIONS

1. Open the designated audio file from the f drive and rename it based on the following criteria:
  - a. Participant number
  - b. Date
  - c. Pass number
  - d. Transcriber's initials

Example: A transcript for participant MA2, obtained on October 10, 2014, having the first pass completed on it by JH would be save as follows;

MA2\_OCT\_10\_2014\_firstpass\_JH

2. Use headphones and a foot-pedal to increase your accuracy.
3. For a first pass; follow the provided transcription conventions and transcribe the interview as accurately as possible, including pauses and interjections.
4. For a second pass; follow the provided transcription conventions and review the provided transcript, checking it for accuracy and attempting to clarify any unintelligible utterance. Make any changes in red type; double check and provide time or repetitions for any pauses or interjections.
5. For a third pass; follow the provided transcription conventions and review the provided transcript for accuracy, paying particular attention to any areas of disagreement between pass one and two
6. Save regularly.
7. After completion of a transcript. Be sure to save in the appropriate F drive file, then email research group to notify that transcript is ready.

Transcription Conventions- Modified from Standard SALT Conventions (Miller & Iglesias, 2012)

1. Transcript Format. Each entry begins with one of the following symbols. If an entry is longer than one line, continue it on the next line.
  - \$ Identifies the speakers in the transcript; generally the first line of the transcript. Example: \$ Child, Interviewer
  - C Child/Client utterance. The actual character used depends on the \$ speaker line.
  - I Interviewer utterance. The actual character used depends on the \$ speaker line.
  - + Typically used for identifying information such as name, age, and context. Example of current age: + CA: 5;7
  - Time marker. Example of two-minute marker: - 2:00
  - : Pause between utterances of different speakers. Example: five-second pause: : :05
  - ; Pause between utterances of same speaker. Example of three-second pause: ; :03
  - = Comment line. This information is not analyzed in any way, but is used for transcriber comments.
  - Revisions, interviewee revised or rephrased their statement
  - < > When utterances overlap, one speaker begins before the other ends or utterances are made at the same time. For example <in the summer>. This can co-occur with *interrupted* utterances where the speaker does not complete their thoughts.

2. End of Utterance Punctuation. Every utterance must end with one of these six punctuation symbols. See following page.

. Statement, comment. Do not use a period for abbreviations.

! Surprise, exclamation.

? Question.

~ Intonation prompt. Example: E And then you have to~

^ Interrupted utterance. The speaker is interrupted and does not complete his/her thought/utterance.

> Abandoned utterance. The speaker does not complete his/her thought/utterance but has not been interrupted.

< > overlapped utterances, see above for further information

3. { } Comments within an utterance. Example: C Look it {C points to box}.  
Nonverbal utterances of communicative intent are placed in braces. Example: C {nods}.

4. Unintelligible Segments. X is used to mark unintelligible sections of an utterance. Use X for an unintelligible word, XX for an unintelligible segment of unspecified length, and XXX for an unintelligible utterance.

Example 1: C Give me the X. Example 2: C He XX today. Example 3: C XXX.

5. Mazes. Filled pauses, false starts, repetitions, reformulations, and interjections.

( ) Surrounds the words/part-words that fall into these categories. Example: C And (then um) then (h\*) he left.

6. Spelling Conventions.

- Filled pause words: AH, EH, ER, HM, UH, UM, and any word with the code [FP]
- Yes words: OK, AHA, MHM, UHHUH, YEAH, YEP, YES
- No words: NO, AHAH, MHMH, UHUH, NAH, NOPE
- I don't know (*intoned*): IDK
- Concatenatives: BETCHA, GONNA, GOTTA, HAFTA, LIKETA, OUGHTA, SPOSTA, TRYNTA, USETA, WANNA, WHATCHA
- Numbers (*examples*): 21 or TWENTYONE
- Other English spellings:

AIN'T	HMM	NOONE	OH, OOH
ALOT	HUH	NOPE	UHOH
ATTA	LOOKIT	OOP, OOPS, OOPSY	LET'S



## APPENDIX C: CODE BOOK

### Research Question 1- Part 1

How do caregivers of children with language related disorders perceive SLP communication with them regarding language delay and disorders?

- c. What information do caregivers describe receiving from SLPs regarding language delays and disorders?

*5 Themes related to the information caregivers recall and describe receiving from SLPs regarding language delays and disorders.*

#### 1. The Diagnosis

Caregivers' descriptions of the diagnosis they did or did not receive from the SLP, and caregivers' descriptions of how well they understood the diagnosis, or how clearly it was explained to them. Caregivers' descriptions of dyslexia as the diagnosis they received or sought an evaluation for should also be noted.

<b>Code</b>	<b>ID</b>	<b>Definition</b>	<b>Examples</b>
<b>Given a Label</b>	<b>1GL</b>	Descriptions of being given a diagnosis.	<p>“They [SLP team] said that the way it was looking...it does look like she was dyslexic”</p> <p>“She has a language processing disorder”</p>
<b>Not Given a Label</b>	<b>1NG</b>	Descriptions of not being given a diagnosis.	<p>“I think I had asked if maybe he did have like a form of dyslexia or something and I can't remember if anyone ever specifically said yes or no”</p> <p>“I think they [SLPs] had a hard time like labeling her”</p>
<b>Clarity of Label</b>	<b>1CL</b>	Comments related to how clear a diagnosis was to the caregiver versus how vague or unsure the caregiver was of the diagnosis.	<p>“I thought it was pretty good detail”</p> <p>“There was never I don't think any - and I still don't know that I know for sure what”</p> <p>“No I don't think he was diagnosed with anything at the time, just a delay in speech and language”</p>
<b>Dyslexia</b>	<b>1DY</b>	Comments related to dyslexia.	<p>“I know there's something in there about the dyslexia”</p> <p>“No I don't think he was diagnosed with anything at the time... I think the HC told us one time that they did not believe that he had dyslexia”</p>

## 2. Incomplete Information

Caregivers' descriptions or statements indicating that certain information was lacking or deficient, particularly information regarding the connection between language and reading, what they could expect long-term, and the prognosis for late talkers.

Code	ID	Definition	Examples
<b>Language-Reading Connection</b>	<b>2LR</b>	Discussion of the connection between language and reading or other language based issues; key words language, reading.	“Nothing has really been said about her reading”  “ I think at the time it was just his language was lacking his and his ability to form sentences”
<b>Long-Term outcomes</b>	<b>2LT</b>	Discussion of SLPs talking or not talking about the long-term issues associated with their child's disorder, or caregiver comments about long-term outcomes.	“I wish they [SLP team] would have shared with me more that you know this could be a long-term thing”
<b>Late-Talkers Prognosis</b>	<b>2PP</b>	Discussion about their personal beliefs about their late talking children's prognosis, and what the SLPs told them about their late talking children's prognosis.	“I mean they just told us, get him started and surely you know a lot of kids you know overcome it you know by the time they're in kindergarten”

## 3. What My Child is Working on in Therapy

Caregivers' descriptions of information they received regarding their children's goals and objectives for speech-language services, what service options their children had access to, and descriptions of what activities or interventions took place during the therapy time.

Code	ID	Definition	Examples
<b>Goals-Objectives</b>	<b>3GO</b>	Descriptions of their child's goals and objectives and/or their progress towards them in therapy/intervention.	“We have went through IEPs.. I think that they do that about once a year and they set a goal for the next year”
<b>Services Options</b>	<b>3SO</b>	Descriptions of the SLP service options they were offered or provided (e.g., timing of services, location of services, frequency of services, etc.)	“They were very thorough on the services that SHE would need, the services that they [the clinic] had to offer”
<b>SLP Therapy</b>	<b>3SP</b>	Descriptions of the activities their children engaged in during interventions (e.g., reading, playing, word games)	“Working with her on the three step directions...her /t/'s it's something with her tongue not moving right...and then the memory recalling”
<b>Focus on Speech</b>	<b>3FS</b>	Descriptions or responses to questions from the interviewer indicating that the focus of therapy was working on speech related issues as opposed to language or reading issues.	“The /th/, making /th/ sound, getting the /th/ that sound out...that's what they worked with throughout”

#### 4. Information Given Influences Experience Quality

Caregivers' comments expressing satisfaction or dissatisfaction regarding their clinical experience and connecting it to the amount of information they received or felt they had access too.

<b>Code</b>	<b>ID</b>	<b>Definition</b>	<b>Examples</b>
<b>Satisfactory Experience</b>	<b>4SE</b>	Comments connecting caregivers' feelings or impressions about their clinical experience to the level of information they received or have.	"It was very reassuring that...they were seeing what we saw"
<b>Unsatisfactory Experience</b>	<b>4UE</b>	Comments expressing unhappiness or frustration over information that caregivers did not receive	"It was a very bad experience. They didn't explain things"

#### 5. Memory

Caregivers' comments expressing difficulty remembering what information they received during an evaluation or intervention period, either in response to an interview question about whether something happened or whether certain information was received, or while describing an event or interaction but not recalling details.

<b>Code</b>	<b>ID</b>	<b>Definition</b>	<b>Examples</b>
<b>Poor Memory</b>	<b>5PM</b>	Reports of not recalling something that happened or that may have been shared.	"I can't hardly remember, I think they would read a book or something"  "No, I don't remember"

Research Question 1- Part 2

d. How do caregivers describe their understanding of language delays and disorders?

*6 Themes related to how caregivers talk about their understanding or interpretation of their child's language delay or disorder.*

1. Diagnostic Labels Equals Solutions

Caregivers' use of specific diagnostic labels to describe their child and caregivers' comments regarding the connection between having a label and having a solution.

Code	ID	Definition	Example/s
<b>The Label</b>	<b>1GD</b>	Descriptions including specific labels that identify a diagnosis that is present or not present (e.g., ADD, ADHD, Dyslexia, Mixed Reading Disorder, Language Processing Disorder).	<p>“they actually labeled him as being dyslexia”</p> <p>“it said in black and white it was dyslexia”</p>
<b>The Solution</b>	<b>1TS</b>	Comments expressing belief that the diagnosis is the solution or the beginning of the solution to the problem.	<p>“Now we have something to look at, this is his problem...this is what we are going to do_ work on, here's the solution you know, more dedicated stuff to his problem, that has been proven to help with those issues”</p>

2. How “this” Affects my child/Characteristics

Caregivers' descriptions of how the disorder has affected their child's education and communication abilities, as well as how their child copes with the challenges.

Code	ID	Definition	Example/s
<b>Educational Difficulties</b>	<b>2ED</b>	Educational based characteristics or behaviors that caregivers attribute to their child's disorder (e.g., difficulty writing, reading, and spelling).	<p>“it's just when he writes you can't, you can't follow him on paper”</p> <p>“it always seems like he's about a year behind on the grade level on his reading”</p>
<b>Unclear Speech &amp; Language</b>	<b>2UC</b>	Speech-Language based characteristics or behaviors that caregivers attribute to their child's disorder (e.g., unclear speech, poor word finding, stuttering, inability to put a sentence together).	<p>“the words started coming back, but they were still very garbled and not always clear</p> <p>“she only had like one word sentences”</p>
<b>Strategies for Coping</b>	<b>2SC</b>	Any strategies, tools, or behaviors that caregivers describe as helpful to their child in dealing with their disorder (e.g., looking at pictures, using spell-check).	<p>“If he reads it, his comprehension is way down, but if somebody else reads it to him it's all very good”</p> <p>“We found out then too K was really good at memorizing things and that's kind of how he's survived through school so far”</p>

### 3. A Problem vs. Not a Problem

Caregivers' comments about their child's *problem* when describing the disorder including descriptions of the problem being absolute, of the problem causing them to need help for their child, and of the problem leading to a social barrier for their child. Additionally, contrasting remarks are present, caregiver's comments expressing that their child's disorder is not a problem.

Code	ID	Definition	Example/s
<b>Absolutes</b>	<b>3AB</b>	Descriptions of the disorder as something that is extremely off. Use of absolute terms such as; <u>never</u> talk, <u>no</u> words, <u>can't</u> spell or problem focused terms such as; something <u>wrong</u> , or her <u>problem</u> .	"I kept telling them that there was something more that I felt was wrong."  "her speech completely stopped"
<b>Need Help</b>	<b>3NH</b>	Descriptions of the disorder as something that needs to be fixed or something they need help addressing.	"I was like you know we have to do something"  "it was time to call in somebody else to help"
<b>Social Barrier</b>	<b>3SB</b>	Descriptions of the disorder as something that causes negative emotions, or creates barriers (e.g., social, educational).	" it seems like a lot of his friends are you know some of them are the ones that get pulled out too with him you know"
<b>It's Not a Problem</b>	<b>3NP</b>	Descriptions of the disorder as minor issue, not something to be concerned about.	"it seemed like when he wanted to start talking he started talking pretty good"  "I thought oh this is just a minor thing we're just going to blow-over. He'll get over it"

### 4. Influenced by Previous Experiences & Knowledge

Caregivers' descriptions of experiences influencing how they perceive their child's current diagnosis, including their experiences with other family members with disorders, their continuing learning and research over time, and their other personal experiences that have contributed to their knowledge about their child and their child's disorder.

Code	ID	Definition	Examples
<b>Learning over Time</b>	<b>4LO</b>	Descriptions of how their understanding of their child's disorder has changed over time.	"we didn't know that speech-language could do that kind of stuff, but through some of my facebook pages and stuff that I'm on, I got these ideas of well they can start working on that in speech"
<b>Previous Child/Sibling Disorder Experiences</b>	<b>4PD</b>	Descriptions of how their understanding of their child's disorder was influenced by previous child or sibling experiences.	"I think also our thing to come back to is our oldest son. When he first started school he had speech...So he just went down had a few extra you know half hour of help and then was back, and then he got out of it right away"
<b>Previous Personal Knowledge</b>	<b>4PP</b>	Descriptions of how their understanding of their child's disorder was influenced by previous personal knowledge or experiences.	"Cause I have, my middle child who is a year - 17 months behind her, and is 2-3 grade levels reading above. And so I mean we know what we are dealing with"

## 5. The Future

Caregivers' comments regarding their child's future, including expectations of where they see their child in the coming years, hope for their child's success and worry for potential pitfalls.

Code	ID	Definition	Examples
<b>Expectations</b>	<b>5EX</b>	Descriptions of their future expectations for their child related to school, work, independence, etc.	"I still don't see him in a book writing, or something that is going to require tons of reading, no doctor you know something like that kind of profession. I could see him being more hands on. He's going to be a hands on guy, hands on creative."
<b>Worry</b>	<b>5WO</b>	Descriptions of their worry and concern for their child, especially in regard to living independently and being successful in school and work.	"as immature as she is we're not sure if that if the possibility of ever living on her own is a possibility"  "I feel like he's no matter how much help he's he gets I think he's just he's always going to struggle"
<b>Hope</b>	<b>5HO</b>	Descriptions of their hopes and dreams for their child, the best case scenarios, how they hope their child will be in the future.	"I just hope that there's always another resource out for her to reach toward"  "She always says she wants to be a nurse and she may very well be a nurse but she's kind of more of a hopefully she will be a teacher to cause she does that too but she's such a caring person she may very well end up being a nurse but I don't know"

## 6. Easy vs. Hard to Understand

Caregivers' comments regarding how well the disorder was explained to them or how well they feel like they understand the disorder.

Code	ID	Definition	Examples
<b>Understanding</b>	<b>6UN</b>	Descriptions of the disorder that indicate the caregiver does understand the disorder. Personal declarations of understanding.	"they explained all the little different things; and when we came back ...for a consultation, they explained it in greater detail"
<b>Not Understanding</b>	<b>6NU</b>	Descriptions of the disorder that indicate the caregiver does not understand the disorder. Personal declarations of not understanding.	"I don't understand dyslexia, I just, I don't have it"  "I don't feel like I understand the reports"

### Research Question 2

What SLP communication practices do caregivers of children with language related disorders identify as effective or non-effective in building the therapeutic relationship?

- a. What SLP communication practices or resources do caregivers perceive to be helpful or unhelpful in increasing caregiver knowledge of language disorders?

- b. What SLP communication practices or resources do caregivers perceive to be helpful or unhelpful in increasing caregiver involvement/collaboration?

*10 Themes related to effective versus non-effective communication practices for building SLP-Caregiver Relationships*

1. Resources Professions Provide

Caregivers' descriptions of the resources that were given or not given to them by an SLP or other professionals, including information based resources, homework or assignment based resources, therapy or intervention based resources, or other non-categorized resources.

<b>Code</b>	<b>ID</b>	<b>Definition</b>	<b>Example/s</b>
<b>Information Resources</b>	<b>1IR</b>	Descriptions of being given informational resources, including verbal information, written reports, informational websites, informational brochures/fact sheets, referrals, or any other informational sources.	<p>“Learning to break everything down for her to understand”</p> <p>“They had given me other places I could go to if I needed”</p>
<b>Homework Resources</b>	<b>1HR</b>	Descriptions of being given things to work on at home, activities, activity websites, picture cards, etc.	<p>“They left flash like little flashcards out at the house to go like over what they were doing”</p> <p>“They always gave me exercises to do at home, practices to work with her on”</p>
<b>Therapy Resources</b>	<b>1TR</b>	Descriptions of <i>intervention</i> or services being a resource or something that is helpful.	<p>“Just getting therapy here and that they would provide it”</p> <p>“ the programs that the HC offers summer and during the school”</p>
<b>Other Resources</b>	<b>1OR</b>	Anything that a caregiver identifies as <i>a resource</i> that does not fit into the other categories.	<p>“No support groups I mean we never talked to any anybody else no other parents that was going through the same things”</p> <p>“They came out to my house and tested her out there. Which made it nice”</p>
<b>No Resources</b>	<b>1NR</b>	Descriptions of things they were not given or anything that a caregiver specifically states was <i>not provided</i> .	<p>“No support groups I mean we never talked to any anybody else no other parents that was going through the same things”</p> <p>“they never gave us at that point in time, never really gave us anything”</p>

## 2. Methods of Information Sharing

Caregivers' descriptions of the manner in which information was shared with them, including watching the evaluation/intervention, having a wrap-up conversation with the SLP, and receiving the written report.

Code	ID	Definition	Example/s
<b>Watching the Session</b>	<b>2WS</b>	Descriptions of <i>watching</i> the evaluation/intervention.	"They always let us like watch and view you know they wanted to make sure that what they were seeing was normal"
<b>Wrap-up Conversation</b>	<b>2WU</b>	Descriptions of what the clinicians shared with them after an evaluation or intervention session.	"they said that the way it looking now but they hadn't crunched the numbers it does um look like she was dyslexic but they needed to make sure"
<b>The Written Report</b>	<b>2TR</b>	Descriptions of getting the report and information they received in the report.	"I remember getting the letter in the mail, more of the evaluation"

## 3. Timing of Information Matters

Caregivers' comments related to the timing of information received, including when information was received, and how lack of information influenced question asking.

Code	ID	Definition	Example/s
<b>Sooner is Better</b>	<b>3SB</b>	Descriptions of receiving information later than expected (e.g., late reports, late diagnosis, late therapy, late prognostic information).	"I wish we could have gotten it a little sooner, and that's just because it came right at the end of the school year" "I wish they would have started working on the memory stuff back then"
<b>Not Asking Questions</b>	<b>3NA</b>	Descriptions of times they didn't understand something or didn't know what questions to ask.	"I never thought about that." "I just figured it was something the school did, so you know dumb me"

## 4. Follow-Up

Caregivers' descriptions of the follow-up information they did and did not receive, as well as the ongoing communication access they felt they did or did not have with the SLP.

Code	ID	Definition	Example/s
<b>Good Follow-Up</b>	<b>4GF</b>	Descriptions of being given further information after the initial evaluation or consultation, (e.g., being given a refresher).	"Oh they would always give updates, and anytime I picked him up if they wanted to share something they did"  "having a phone call, just double checking that I got it"



<b>Lack of Follow-Up</b>	<b>4LF</b>	Descriptions of the lack of follow-up, lack of ongoing communication, lack of professional availability.	“I think it would have been beneficial to like have a little bit of communication with her just on what they were doing”
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### 5. Open and Honest Communication

Caregivers’ descriptions of professional communication that they perceived as straightforward and open; communication that did not *beat around the bush*.

<b>Code</b>	<b>ID</b>	<b>Definition</b>	<b>Examples</b>
<b>Clear / Helpful Communication</b>	<b>5CC</b>	Descriptions of information that was clear, honest, and complete regarding any aspect of the communication disorder (e.g., descriptions of services, evaluations, tests, diagnosis).	<p>“we talked about you know we do have insurance, there would be cost, we discussed IEPs and where do we go from here”</p> <p>“he was like I can’t do anything more for you... so he sent us you know [to a specialist], he wasn’t going to beat around the bush”</p>
<b>Unclear /Unhelpful Communication</b>	<b>5UC</b>	Descriptions of information that was vague, unclear, or unspoken regarding the communication disorder (e.g., descriptions of services, evaluations, tests, diagnosis).	<p>“they’re [the IEP team] like oh no no no he’s fine”</p> <p>“the school would not refer us any place else because they said we cannot have anything to do with that”</p>

### 6. Responsiveness to Caregiver’s Concerns

Caregivers’ descriptions of SLP or other professional actions that they perceived as responsive and positive, including listening and acting on caregiver requests and noticeably working hard for their child.

<b>Code</b>	<b>ID</b>	<b>Definition</b>	<b>Example/s</b>
<b>Listening</b>	<b>6LI</b>	Comments regarding professionals, especially SLPs, listening and responding to requests.	“the school does pretty good, like the therapist working up there, taking my ideas and running with it and being like that’s a good idea and doing that”
<b>Not Listening</b>	<b>6NL</b>	Comments regarding professionals, especially SLPs, not listening or responding to requests.	“I kind of wish the school would’ve listened a little bit more. Even after we voiced our concerns it just didn’t feel like we got heard at all”
<b>Working Hard for Their Child</b>	<b>6WH</b>	Descriptions of professionals providing more, being consistent, showing care for their child, continuing to work. Any kind of positive description of the professional treating the child well.	<p>“ just continuing to work with her and getting her more along where she should be speaking, and teaching her words and things like that”</p> <p>“they were so nice and always wanting to make sure that J was okay”</p>

### 7. Meeting Caregiver Needs

Caregivers' descriptions of needs that were met through the evaluation and intervention experience, including seeing progress in their child, being validated that they were right, and being reminded of the positives of their child.

Code	ID	Definition	Examples
<b>Making Progress</b>	<b>7PR</b>	Descriptions of their child making progress either in the therapy room, on tests, in school, or in activities at home (e.g., reading or homework).	<p>“Outside of school she wants to take a book to bed and read it on her own UM whereas before she I think was so turned off”</p> <p>“I think certain things are coming I mean clicking for him”</p>
<b>Care &amp; Validation</b>	<b>7CV</b>	Flexible, positive professional actions that demonstrated care, acceptance and welcome. Descriptions of the caregiver feeling validated or treated well by the professional.	<p>“It’s nice to be able to see those two points correlating with, and it helps when they [SLP] can see and you’re like oh god I’m not crazy”</p> <p>“they [SLP] didn’t make us feel stupid for not getting the help that she needed”</p>
<b>Sharing the Positive</b>	<b>7SP</b>	Comments about professionals sharing their child’s positives/strengths.	<p>“they would praise her on the things that she did well”</p> <p>“ I do appreciate being asked the strengths cause that lets me know that they care and it makes me refocus on the positives about my child rather than just maybe shortfalls”</p>

### 8. Clarifying Roles

Caregivers' comments regarding their belief that professional should be experts, as well as comments regarding how caregivers perceive their role in the evaluation/intervention process.

Code	ID	Definition	Examples
<b>Professional Experts</b>	<b>8PE</b>	Descriptions of professionals as experts or individuals who can do something caregivers cannot do.	<p>“that’s what their job is that’s what you rely on”</p> <p>“I had exhausted all my resources and I was here to hand them off to you to figure it out”</p>
<b>Caregiver’s Contributions</b>	<b>8CC</b>	Comments regarding their knowledge, roles and contributions to their child’s evaluation or intervention. Either comments about what they did or wanted to do or comments about what the SLP did or should have done to include them.	<p>“I think the biggest thing is feeling heard, feeling as though I have a valuable information to bring to the table that my own observations are of value”</p> <p>“I kind of think I am taking a different look at it then I would if I wasn’t getting my degree, like right now I’m in a reading and language arts class”</p>

			“they always let us like watch and view you know they wanted to make sure that what they were seeing was normal”
<b>I’m a Caregiver First</b>	<b>8CF</b>	Comments regarding their role as a caregiver versus the expert. Comments that illustrate they care about the intervention, but they are a parent first.	“so as far as understanding exactly what the tests were, it was a little fuzzy but it didn’t matter because my goal was to get her tested, so I really could’ve cared less I mean as long as she was safe she wasn’t being harmed, then what_ how you tested her was irrelevant to me”

### 9. Whole Family Approach

Caregivers’ descriptions of other stressors, family members, or previous experiences with SLPs influencing their current choices about their child’s intervention, the way they interact with the SLP, and how they relate to and involve themselves in the process.

<b>Code</b>	<b>ID</b>	<b>Definition</b>	<b>Examples</b>
<b>Other Stressors</b>	<b>9WF</b>	Discussions of other stressors in the family influencing their choices related to intervention, their interactions with SLPs, and their perceptions of the process.	<p>“I said well it can’t be at home, because he lives in two different households it wouldn’t be consistent”</p> <p>“if he really wants to enjoy doing an extracurricular activity I think he really needs to do it, but I also think the reading needs to be there, but I think there needs to be a balance”</p>
<b>Family Member Opinions</b>	<b>9OF</b>	Discussion of other family member or family issues influencing their choices related to intervention, their interactions with SLPs, and their perceptions of the process.	<p>“he didn’t speak soon enough, my wife at the time was probably more concerned than I was about that”</p> <p>“it was really hard because with my husband at the time and his parents they didn’t see there was an issue”</p>
<b>Other SLP Related Experiences</b>	<b>9OE</b>	Discussion of previous experiences related to speech-language issues influencing their choices related to intervention, their interactions with SLPs, and their perceptions of the process.	<p>“My son’s diagnosed with Autism, and quite frankly I was not pleased even with where I was what I was getting with my son, I would say my confidence level in her [SLP] is very low”</p> <p>“I knew knowing that I had dyslexia that that was something to pay attention to”</p>

### 10. SLP Advocacy

Caregivers' descriptions of what they know about SLPs as professionals and their expectations regarding what an SLP can do for their child, as well as reasons why caregivers choose seek out professional services for their child, and how they ended up bring their child to an SLP.

<b>Code</b>	<b>ID</b>	<b>Definition</b>	<b>Examples</b>
<b>Seeking Services</b>	<b>10SS</b>	Descriptions of why and how they chose to seek professional services for their child. Any descriptions of getting a referral, making an appointment, or asking a teacher.	<p>“it went from clear to completely babble to where we couldn’t understand a word she was saying”</p> <p>“They [doctor] just said that they [SLP] would probably do some testing to see what J was needing the extra help in or what her struggles were”</p>
<b>Caregiver Knowledge of SLPs</b>	<b>10CK</b>	Descriptions of what they know about professionals, especially SLPs. Comments about what they expected from an SLP or speech-language evaluation.	<p>“We knew it was an issue at home, but we didn’t know that speech-language could do that”</p> <p>“I didn’t think of speech-language pathologists as being the profession that I would go to for a reading issue I think of more like stuttering issues, losing speech”</p>

## APPENDIX D: IRB APPROVALS

### ACTION ON PROTOCOL APPROVAL REQUEST



Institutional Review Board  
Dr. Dennis Landin, Chair  
130 David Boyd Hall  
Baton Rouge, LA 70803  
P: 225.578.8692  
F: 225.578.5983  
[irb@lsu.edu](mailto:irb@lsu.edu) | [lsu.edu/irb](http://lsu.edu/irb)

**TO:** Janna Oetting  
COMD

**FROM:** Dennis Landin  
Chair, Institutional Review Board

**DATE:** September 16, 2014  
**RE:** IRB# 3519

**TITLE:** Caregiver Perceptions of Speech Language Pathologist (SLP) Communication: Examining How SLPS Talk with Caregivers about Child Language Disorders

**New Protocol/Modification/Continuation:** New Protocol

**Review type:** Full  Expedited  **Review date:** 9/16/2014

**Risk Factor:** Minimal  Uncertain  Greater Than Minimal

**Approved**  **Disapproved**

**Approval Date:** 9/16/2014 **Approval Expiration Date:** 9/15/2015

**Re-review frequency:** (annual unless otherwise stated)

**Number of subjects approved:** 15

**LSU Proposal Number (if applicable):** \_\_\_\_\_

**Protocol Matches Scope of Work in Grant proposal: (if applicable)** \_\_\_\_\_

**By:** Dennis Landin, Chairman  \_\_\_\_\_

**PRINCIPAL INVESTIGATOR: PLEASE READ THE FOLLOWING –**  
**Continuing approval is CONDITIONAL on:**

1. Adherence to the approved protocol, familiarity with, and adherence to the ethical standards of the Belmont Report, and LSU's Assurance of Compliance with DHHS regulations for the protection of human subjects\*
2. Prior approval of a change in protocol, including revision of the consent documents or an increase in the number of subjects over that approved.
3. Obtaining renewed approval (or submittal of a termination report), prior to the approval expiration date, upon request by the IRB office (irrespective of when the project actually begins); notification of project termination.
4. Retention of documentation of informed consent and study records for at least 3 years after the study ends.
5. Continuing attention to the physical and psychological well-being and informed consent of the individual participants, including notification of new information that might affect consent.
6. A prompt report to the IRB of any adverse event affecting a participant potentially arising from the study.
7. Notification of the IRB of a serious compliance failure.
8. SPECIAL NOTE:

*\*All investigators and support staff have access to copies of the Belmont Report, LSU's Assurance with DHHS, DHHS (45 CFR 46) and FDA regulations governing use of human subjects, and other relevant documents in print in this office or on our World Wide Web site at <http://www.lsu.edu/irb>*

## Project Report and Continuation Application

(Complete and return to IRB, 130 David Boyd Hall.  
Direct questions to IRB Chairman Dennis Landin, 578-8692.)



Institutional Review Board  
Dr. Dennis Landin, Chair  
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IRB#: 3519 Your Current Approval Expires On: 9/15/2015

Review type: Expedited Risk Factor: Minimal Date Sent: 7/23/2015

PI: Janna Oetting Dept: COMD

Student/Co-Investigator: Karmen Porter

Project Title: Caregiver Perceptions of Speech Language Pathologist (SLP) Communication: Examining How SLPS Talk with Caregivers about Child Language Disorders

Number of Subjects Authorized: 15

Please read the entire application. Missing information will delay approval!

I. PROJECT FUNDED BY: NA LSU proposal # ?

II. PROJECT STATUS: Check the appropriate blank(s); and complete the following:

- 1. Active, subject enrollment continuing
- 2. Active, subject enrollment complete
- 3. Active, subject enrollment complete; work with subjects continues.
- 4. Active, work with subjects complete; data analysis in progress.
- 5. Project start postponed
- 6. Project complete; end date / /
- 7. Project cancelled: no human subjects used.

III. PROTOCOL: (Check one).

- Protocol continues as previously approved
- Changes are requested\*
  - List (on separate sheet) any changes to approved protocol.

IV. PARTICIPANT ENROLLMENT

- Number of participants enrolled 11

V. UNEXPECTED PROBLEMS: (did anything occur that increased risks to participants):

- State number of events since study inception: 0 since last report: 0
- If such events occurred, describe them and how they affect risks in your study.
- Have there been any **previously unreported** events? Y/N N?  
(if YES, attach report describing event and any corrective action).

VI. CONSENT FORM AND RISK/BENEFIT RATIO:

- Do new knowledge or adverse events change the risk/benefit ratio? Y/N N;
- Is a corresponding change in the consent form needed? Y/N N

VII. ATTACH A BRIEF, FACTUAL SUMMARY of project progress/results to show continued participation of subjects is justified; or to provide a final report on project findings.

-Data collection from participants is complete, analysis of interview data is currently being completed. Plan is to defend dissertation by December, 2015.

VIII. ATTACH CURRENT CONSENT FORM (only if subject enrollment is continuing); and check the appropriate blank:

- 1. Form is unchanged since last approved
- 2. Approval of revision requested herewith: (identify changes)

Signature of Principal Investigator: \_\_\_\_\_

Date: 7/23/15



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**OFFICE OF SCHOLARSHIP AND SPONSORED PROJECTS**

DATE: September 22, 2014

TO: Karmen Porter  
FROM: Fort Hays State University IRB

STUDY TITLE: [631689-1] CAREGIVER PERCEPTIONS OF SPEECH LANGUAGE  
PATHOLOGIST (SLP) COMMUNICATION: AN EXPLORATORY STUDY  
EXAMINING HOW SLPS TALK WITH CAREGIVERS ABOUT CHILD  
LANGUAGE DISORDERS

IRB REFERENCE #: 15-007  
SUBMISSION TYPE: New Project

ACTION: APPROVED  
APPROVAL DATE: September 18, 2014  
EXPIRATION DATE: September 18, 2015  
REVIEW TYPE: Full Committee Review

Thank you for your submission of New Project materials for this research study. Fort Hays State University IRB has APPROVED your submission. This approval is based on an appropriate risk/benefit ratio and a study design wherein the risks have been minimized. All research must be conducted in accordance with this approved submission.

This submission has received Full Committee Review based on the applicable federal regulation.

Please remember that informed consent is a process beginning with a description of the study and insurance of participant understanding followed by a signed consent form unless documentation of consent has been waived by the IRB. Informed consent must continue throughout the study via a dialogue between the researcher and research participant. Federal regulations require each participant receive a copy of the signed consent document. The IRB-approved consent document must be used.

Please note that any revision to previously approved materials must be approved by this office prior to initiation. Please use the appropriate revision forms for this procedure.

All SERIOUS and UNEXPECTED adverse events must be reported to this office. Please use the appropriate adverse event forms for this procedure. All FDA and sponsor reporting requirements should also be followed.

Please report all NON-COMPLIANCE issues or COMPLAINTS regarding this study to this office.

Please note that all research records must be retained for a minimum of three years.

Based on the risks, this project requires Continuing Review by this office on an annual basis. Please use the appropriate renewal forms for this procedure.

If you have any questions, please contact Leslie Paige at 785-628-4349 or [lp Paige@fhsu.edu](mailto:lp Paige@fhsu.edu). Please include your study title and reference number in all correspondence with this office.





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**OFFICE OF SCHOLARSHIP AND SPONSORED PROJECTS**

DATE: September 18, 2015

TO: Karmen Porter  
FROM: Fort Hays State University IRB

STUDY TITLE: [631689-2] CAREGIVER PERCEPTIONS OF SPEECH LANGUAGE  
PATHOLOGIST (SLP) COMMUNICATION: AN EXPLORATORY STUDY  
EXAMINING HOW SLPS TALK WITH CAREGIVERS ABOUT CHILD  
LANGUAGE DISORDERS

IRB REFERENCE #: 15-007  
SUBMISSION TYPE: Continuing Review/Progress Report

ACTION: APPROVED  
APPROVAL DATE: September 17, 2015  
EXPIRATION DATE: September 16, 2016  
REVIEW TYPE: Full Committee Review

Thank you for your submission of Continuing Review/Progress Report materials for this research study. Fort Hays State University IRB has APPROVED your submission. This approval is based on an appropriate risk/benefit ratio and a study design wherein the risks have been minimized. All research must be conducted in accordance with this approved submission.

This submission has received Full Committee Review based on the applicable federal regulation.

Please remember that informed consent is a process beginning with a description of the study and insurance of participant understanding followed by a signed consent form unless documentation of consent has been waived by the IRB. Informed consent must continue throughout the study via a dialogue between the researcher and research participant. Federal regulations require each participant receive a copy of the signed consent document. The IRB-approved consent document must be used.

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Please note that all research records must be retained for a minimum of three years.

Based on the risks, this project requires Continuing Review by this office on an annual basis. Please use the appropriate renewal forms for this procedure.

If you have any questions, please contact Leslie Paige at 785-628-4349 or [lp Paige@fhsu.edu](mailto:lp Paige@fhsu.edu). Please include your study title and reference number in all correspondence with this office.

## VITA

Karmen Porter received her undergraduate degree in communication sciences and disorders from Abilene Christian University. She pursued her Master of Arts from Louisiana State University graduating in 2005 after completing her thesis entitled, *Strategies and Beliefs about conflict Resolution: Comparing children with Language-Learning Disorders to Children with Typical Language Development*. Her CF experience was in early intervention with Garrity Speech and Language Associates in Baton Rouge, followed by serving as a school based SLP for EBS Healthcare in Texas. In 2009, she returned to Louisiana State University for doctoral work under the direction of Janna Oetting, Ph.D, as a graduate research assistant in the Language Development and Disorders Lab. While in the Language Development and Disorders Lab at LSU, she worked on an NIH grant investigating the grammars of nonmainstream English-speaking children with specific language impairment. In 2012 she joined the faculty at Fort Hays State University in Hays, Kansas, where she is currently a member of the American Speech-Language-Hearing Association, holding the Certificate of Clinical Competence in Speech-Language Pathology, and the Kansas Speech-Language-Hearing Association. Her current research and teaching interests include language development in diverse populations, fluency, counseling, and collaboration between SLPs and caregivers. Upon completing her Ph.D., Karmen will continue to work at Fort Hays State University as an Assistant Professor.