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A Qualitative Analysis of Parent Observations of Children Diagnosed with a Developmental Speech Delay

Diana Patrick

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**A Qualitative Analysis of Parent Observations of
Children Diagnosed with a Developmental Speech Delay**

Diana Patrick

a thesis submitted in partial fulfillment
of the requirements for the degree of

MASTER OF SCIENCE, SPEECH-LANGUAGE PATHOLOGY

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Abstract

The present study used qualitative (phenomenological) research methodology to obtain and analyze the “personal stories” of mothers of children with had received a diagnosis of either developmental apraxia of speech (DAS) or developmental phonological disorder (DPD). Using a semi-structured interview, six mothers of children with DAS and five mothers of children with DPD were asked to reflect on specific aspects of the development of their child over time, with emphasis on communication development and communication challenges. In addition to providing rich descriptions of performance, the present study addressed the proposition that DPD and DAS are separate disorders by examining the distinctiveness of the narratives obtained from the two parent groups. Developmental “threads” (e.g., motor development, behavior, characteristics of verbal output) were followed across three early developmental stages: the baby stage (infancy to age 2;0), the toddler stage (ages 2;1 to 3;11), and the preschool stage (ages 4;0 to 6;11). The results of the present study provide support for the perspective that the two diagnoses describe different sets of children. This difference can best be captured as *additional deficits* more commonly reported in DAS rather than problems that are unique to each subtype. That is, children who receive these diagnoses share many characteristics, particularly when young. However, for children considered to have DAS, additional problems, many outside of speech, are reported more frequently by mothers.

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1. Review of the Literature

Developmental speech delay (DSD) is a speech production disorder of uncertain etiology that affects approximately 8% of children in the preschool and early school-aged years. At the most general level, children who receive this diagnosis are those who present with age-inappropriate speech production (pronunciation) errors and reduced speech intelligibility relative to their age. Children who receive the DSD label are not, however, homogeneous with respect to clinical presentation, prognosis, and presumed etiology.

At present, three clinical subgroups of DSD have been identified in the literature. The largest subgroup, sometimes referred to as the “residual errors” group, consists of children who appear to have a “pure” *articulation disorder*. These children maintain errors on a small set of commonly misarticulated speech sounds (e.g., /r/, /l/, or /s/) beyond the time when most of their peers have mastered these phonemes. Otherwise, the phonology, language, and academic performance of these children is similar to peers without a speech disorder history.

Children belonging to the second subgroup receive a clinical diagnosis of *developmental phonological disorder (DPD)*. These children display speech that is characterized by multiple omissions or substitution errors that can often be described using error pattern categories (e.g., substituting all fricative sounds with stop consonants). The speech intelligibility of children with DPD is reduced relative to their peers and these children have been found to be at risk for concomitant problems in expressive language, phonological awareness, and

reading achievement (Felsenfeld, Broen, & McGue, 1992; Lewis, Freebairn, & Taylor, 2000; Shriberg & Kwiatkowski, 1988).

The third subgroup, *developmental apraxia of speech (DAS)*¹, is the smallest and most controversial of the three DSD classifications, affecting only about one to two children per thousand (Shriberg, Aram, & Kwiatkowski, 1997a). Speech-language pathologists (SLPs) and specialists in the field continue to struggle with the identification and treatment of this subtype, and some even question whether DAS exists as an entity that is qualitatively distinct from severe DPD (Dollaghan, 2003; Velleman, 2003a). Despite the controversy that surrounds it, the DAS diagnosis continues to be applied to children, and the prevalence appears to be on the rise. According to Campbell (2003), the number of diagnosed cases of DAS has increased by 30-40% over the past five years, for reasons he believes have more to do with “a lack of clear definition of the disorder” rather than an increase in the number of children who are symptomatic.

Origin of DAS

A small number of research studies have been conducted on the etiology and the defining characteristics of DAS; however, these issues continue to be a source of disagreement among researchers and clinical specialists in the field (Hall, 2000b; Nijland, Maassen, & Meulen, 2003). One hypothesis regarding the cause of DAS is that it is essentially a motor-programming disorder of speech, which reflects the inability of the brain to sequence the movements of the articulators for correct productions of phonemes (Campbell, 2003; Hall, 2000b;

¹ Some researchers prefer the term childhood apraxia of speech (CAS) to describe this subgroup. In the present manuscript, I have elected to use the more conventional diagnosis of developmental apraxia of speech, or DAS.

Nijland, Maassen, & Meulen, 2003; Velleman, 2003b). Although most proponents of a motor-based etiology for DAS emphasize that the motor programming deficits exhibited by these children are specific to the speech production mechanisms (the phonation, resonance, and articulatory systems), other investigators have suggested that children with DAS may have more widespread motor impairments (Bradford & Dodd, 1996; Hodge, 2003; Velleman, 2003). Hodge (2003), for example, has noted the parallels between the clinical profiles of children diagnosed with DAS and those diagnosed with a more generalized *developmental coordination disorder*, (*DCD*) a diagnosis recognized and described in the DSM-IV manual (1994). Hodge argues that, because many children diagnosed with DAS display concomitant gross and fine motor deficits, the DAS diagnosis should perhaps be renamed *developmental speech coordination disorder* (*DSCD*), to emphasize its clinical and perhaps etiological similarities to DCD.

If the etiology of DAS is neuro-motor, it may be assumed that specific neurological deficits would be identifiable, either through brain imaging or by assessing “soft” signs in clinical tests of motor functioning. However, to date, no imaging or clinical studies have consistently identified structural or functional anomalies in the brains of children with developmental disorders of speech (Hall, 2000b), although the number of such studies available in the literature is still quite small.

Of interest, however, are the recent findings obtained from a group of researchers in England who performed brain imaging studies with members of a

three-generational family (the “KE” family), in which 15 of 31 members were diagnosed with a complex speech and language disorder, whose symptoms were considered similar to DAS (Vargha-Khadem, Watkins, Price, Ashburner, Alcock, Connelly, Frackowiak, Friston, Pembrey, Mishkin, Gadian, & Passingham, 1998). Affected individuals in this family were diagnosed either through direct testing or, when that was not possible, through informal report. By using PET and MRI scans, brain imaging of members of the family diagnosed with the complex DAS phenotype and those used as controls (no diagnosis of abnormal speech or language reported) were examined. Vargha-Khadem et al. (1998) concluded there was a correlation between abnormal development of several brain areas and the speech diagnosis (DAS versus control). Specifically, relative to the controls, the subjects with DAS displayed less grey matter in the left and right caudate nuclei, the left supplementary motor area, and the left inferior frontal cortex (Vargha-Khadem, 2003). Although preliminary, these findings do support the possibility that subtle neurological anomalies exist in some individuals diagnosed with DAS, and may contribute to its etiology.

The one speech behavior that has received the most attention as a potential diagnostic marker for DAS is abnormal prosody, specifically lexical stress and intonation (Campbell, 2003; Hall, 2000a; Munson, Bjorum, & Windsor, 2003; Shriberg, Aram, & Kwiatkowski, 1997b). Munson and colleagues (2003), for example, studied five children diagnosed with DAS and five children diagnosed with DPD. The children repeated nonwords modeled by a phonetically trained adult. Acoustic measures of lexical stress were compared

using Cool Edit Pro software and Pratt signal processing software, and trained listeners were asked to distinguish stress patterns in the subject's productions. The findings revealed that children with DAS were judged by listeners to be "less accurate in producing stress" than were children with DPD, although the group differences on the acoustic measures were small and were not statistically significant. In interpreting these findings, Munson et al. concluded that although they had found "some support for the hypothesis that production of linguistic stress is impaired in children with suspected DAS," future research was needed to replicate these findings.

Velleman (2003b) has provided an interesting alternative hypothesis to explain the prosodic deficits seen in some children with suspected DAS. Noting that inappropriate stress patterns tend to be observed in older rather than younger children with DAS, Velleman argues that these deficits may in fact be iatrogenic (resulting from treatment) rather than intrinsic to the disorder. To support this alternative explanation, Velleman points out that many treatment approaches used with children with DAS rely heavily on segmentation activities, which break words and sentences down into motorically manageable segments but also distort normal prosody and stress patterns. Until this confound is resolved, Velleman argues, researchers and clinicians should be cautious about using abnormal prosody as a primary diagnostic marker for this condition.

Origin of DPD

Across several decades, isolated causal correlate studies of children with both pure articulation and phonological disorders have been performed to

determine if variables can be identified that are strongly correlated with the disorder's occurrence (see Bernthal & Bankson, 2004 for a review). These studies have found that a small percentage of children diagnosed with DPD have known accompanying causal conditions, such as impairments in hearing, speech, or cognitive mechanisms. However, the larger percentage of children diagnosed with DPD do not have obvious impairments in mechanisms which are known to affect speech.

Beginning in the late 1960's, several descriptive and correlational studies were performed to identify variables that were significantly associated with the presence of articulation and phonological disorders in otherwise normally developing children. The types of variables that have been examined is wide ranging, and includes socioeconomic status, birth order, parenting style, speech sound discrimination ability, minor structural variations of the speech mechanism, hearing and middle ear functioning, oral sensory function, verbal and nonverbal intelligence, oral-motor performance, language production and comprehension, and psychosocial functioning (Bernthal and Bankson, 2004; Shriberg & Kwiatkowski, 1994).

In their comprehensive study of 178 children diagnosed with moderate to severe DPD, Shriberg and Kwiatkowski (1994) examined 169 variables (they called them causal correlates) that were potential etiological contributors to this disorder. Across this large number of variables, many individual items were found to be present in some of the case histories of children with DPD; however, the investigators chose to highlight only those variables that occurred for a majority

of the subjects. Three variables were ultimately judged to be of greatest potential etiological significance: a) expressive language deficits, which occurred in about 75% of the children; b) a sensitive temperament (feelings easily hurt), which was reported for 67% of the children; and c) a positive family history of speech and language problems, which was found for 56% of the cases. They concluded that, although some variables do occur more frequently among children with DPD than would be expected by chance, no single variable can be considered as a primary “cause” of DPD. As such, they described DPD as a complex developmental disorder whose etiology or etiologies remain unknown.

In summarizing their extensive review of the etiological literature for DPD and “pure” articulation disorders, Bernthal and Bankson (2004) provide the following statements, with which most investigators would agree:

“Despite the large body of literature reflecting investigations of a wide variety of variables potentially related to articulation [and phonological] impairments, many questions remain unanswered. One truth that emerges from the literature, however, is the absence of any one-to-one correspondence between the presence of a particular etiological factor and the precise nature of most individuals’ phonologic status.” (pg. 192)

Differential diagnosis of DAS versus DPD

In a recent paper, Williams (2002) asked five clinicians specializing in articulation and phonology to describe the assessment battery they typically used for young children referred for assessment because of concerns about poor intelligibility. These experts were in good agreement about the essential elements of this diagnostic battery. All indicated that they would administer at least portions of a standardized test of articulation or phonology and would use the normative information available to guide their interpretation of the severity of

the problem. In addition, all of the experts indicated that they would take a case history, would perform a hearing screening, would screen oral-motor functioning, would administer a language screening instrument, would collect a sample of conversational speech, and would perform stimulability of some error sounds. The experts were split about the remaining analyses they would perform. Hodson, Scherz, & Stratman (2002), for example, indicated that she would include a test of phonological awareness in her assessment battery, which was not included routinely in the batteries of the other investigators.

For children who are suspected of being apraxic following this initial assessment or for other reasons (e.g. diagnosis by the referring parent, another SLP, or infrequently a referring physician), additional assessment measures may be employed to supplement the standard battery and “confirm” the suspected DAS diagnosis. Most often, the supplementary assessments involve the administration of one or more informal diagnostic checklists or “apraxia tests” that have been developed and marketed for this purpose. (c.f. The Apraxia Profile, Hickman, 1997). These tools are designed to be completed by SLPs following some period of observation and/or formal testing. Portions of these tools are completed in consultation with a parent (usually the mother) who is asked to provide speech and developmental information.

The existing tools ask clinicians to determine if certain behaviors and symptoms that have been associated with DAS in the literature or through anecdotal reports are present for a given case. Children who are judged to display “multiple” DAS symptoms are more likely to be classified as DAS than

children who exhibit few(er) DAS characteristics on these checklists. Although useful for organizing clinical observations, the number and types of symptoms required for a positive DAS diagnosis have not been empirically established for any of the commonly used “tests” or checklists, which limits their diagnostic utility.

The first “symptom checklist” that was developed to facilitate this differential diagnosis was published by Rosenbek and Wertz in 1972. In this now classic paper, these investigators identified several “salient speech characteristics” that they believed defined the DAS subtype and distinguished it from other developmental disorders of speech. These indicators are presented in Table 1, as cited in Duffy (2003).

Table 1. Speech Characteristics for DAS Proposed by Rosenbek & Wertz (1972)

- Prominent phonemic errors; omissions, substitutions, distortions, additions, repetitions, prolongations
- Frequent metathetic errors
- Errors increase as words increase in length
- Repetition of isolated sounds are often adequate
- Connected speech is more unintelligible than single words
- More frequent errors on fricatives, affricates, clusters
- Vowel errors
- Errors are inconsistent
- Prosody is abnormal (e.g., slow rate, even stress)
- Groping, trial-and-error behavior

Since that time, several additional symptom checklists for DAS have been proposed (Campbell, 2003; Forrest, 2003; Hall, 2000a; Shriberg, 2003; Strand, 2003), all of which are essentially variants of the Rosenbeck and Wertz criteria. Despite their small differences, these more current checklists continue to focus on a detailed analysis of speech characteristics, although some investigators argue that children who are suspected of being apraxic should also be assessed in non-speech (e.g., motor or language) areas (Ball, Bernthal, & Beukelman, 2002; Hodge, 2003).

In a published “letter” to the parents of children diagnosed with DAS, Hall (2000a) provided a non-technical description of the variables she believed were the most likely to discriminate between children with DAS and those with DPD, based upon a review of the existing literature. Hall concluded that, compared with children who were diagnosed with DPD, children with DAS were more likely to: display inconsistent speech errors, have more difficulty sequencing sounds and syllables in conditions of increasing motor complexity, produce more voicing and vowel errors, have abnormal prosody, display more groping/silent posturing of the oral articulators, and have intermittent hypernasality. In addition, Hall noted that children with DAS appeared to be more likely than children with DPD to develop elaborate gestural systems to communicate.

Strand (2003) and Campbell (2003) recently published their own versions of diagnostic checklists for suspected childhood apraxia of speech. The specific markers they included in their lists are provided in Table 2. As can be seen,

these lists are quite similar to each other and to the original list published by Rosenbek and Wertz in 1972.

Table 2. Clinical Markers for DAS Proposed by Strand (2003) and Campbell (2003)

<u>Strand's (2003) Criteria</u>	<u>Campbell's (2003) Criteria</u>
<ul style="list-style-type: none"> • Difficulty achieving and maintaining articulatory configurations • Presence of vowel distortions • Limited consonant and vowel repertoire • Use of simple syllable shapes • Difficulty completing a movement gesture for a phoneme in longer or more complex phonetic contexts 	<ul style="list-style-type: none"> • Difficulty with the sequential and temporal ordering of articulatory movements • Slow articulatory movements-increased consonant and vowel durations • Halting and staccato-like transitions between sounds and syllables • Abnormal prosodic characteristics • Reduced speech intelligibility • Articulatory errors consisting primarily of substitutions and deletions • Vowel errors • Inconsistent speech errors • Articulatory groping • Phonologic and other linguistic deficits

Finally, in a recent investigation, Forrest (2003) developed a DAS checklist by asking 75 practicing SLPs to provide the three “top” characteristics that they believed were critical for a DAS diagnosis. Somewhat unexpectedly, a total of fifty different symptoms were identified when these responses were reviewed. Forrest subsequently reduced this symptom number by focusing on the six criteria that were the most frequently endorsed. These “top six” symptoms

were: inconsistent productions (32), groping/effortful productions (18), general oral-motor difficulties (21), inability to imitate sounds (17), increasing difficulty with sound production as the utterance length increased (15), and poor sequencing of sounds (14). Interestingly, even these frequently mentioned behaviors accounted for only 52% of the total number of responses obtained. Perhaps more than any previous study, these findings highlight the diversity of behaviors that are considered to be diagnostically “essential” for a DAS diagnosis across current practitioners.

During the most recent National ASHA Convention, the Committee on Motor Speech Disorders in Adults and Children discussed the criteria used to diagnose a child with suspected DAS (Goldberg, Vargha-Khadem, Forrest, Strand, & Ozanne, 2004). Multiple studies and their findings were reviewed during this presentation, including the Forrest (2003) study. As part of the presentation, panel members questioned the appropriateness of several traditional indicators of DAS. These included the presence of general oral-motor difficulties, the occurrence of groping/effortful productions, increasing difficulty with sound production as the utterance length increased, and poor sequencing of sounds. Interestingly, these were four of the six most endorsed characteristics identified in the Forrest (2003) study.

This Committee suggested that an alternate list of indicators may be more appropriate for diagnosing this disorder and differentiating it from other developmental speech disorders. The five indicators that they preferred were: inconsistent productions, inability to repeat (i.e. to vocally imitate), vowel errors,

prosodic errors, and poor sound sequencing. However, even for these indicators, considered to be the most robust by this expert panel, caution was still advised. In their concluding statements, the Committee stressed that more research is required before any given symptom can be considered “essential” for a DAS diagnosis.

Using Parents as Diagnostic Informants

Although SLPs have a clear role to play in describing the nature and clinical features of both DAS and DPD, alternative sources of information are needed to broaden our current understanding of these elusive conditions. One important “voice” that has been notably absent from our knowledge base is the voice of parents of children who have been diagnosed with these conditions. Compared to a clinical practitioner (SLP), who has limited experience with the child, it can reasonably be argued that parents are the true experts when it comes to their child’s skills and development. Clinicians and researchers bring their own biases to the task of characterizing these disorders. Because of their background and interests, it is natural for specialists in speech-language pathology to focus on speech characteristics when attempting to define and differentiate DAS and DPD, potentially to the exclusion of other relevant observations. Parents, on the other hand, may enhance these careful but potentially narrow observations by widening the lens beyond the speech domain. The value of including a parent’s perspective in child health and behavior research was highlighted by Richters (1992) who wrote:

“Psychologists have long relied on mothers as a principal source of information about their children’s’ functioning. Not only are

mothers...willing and able...to participate in the research enterprise, but through their traditional role as primary caregivers they typically become the chief archivists and historians of their young child's developmental milestones and behavior patterns. Teachers, peers, trained observers, and mental health workers can provide important information about children's' behavior, particularly in situations not accessible to mothers. Nonetheless, mothers are often in a unique position to sample their children's' behavior more frequently, across a greater variety of situations, and over more extended periods of time than other informants." (pg. 485).

Several options are available for obtaining descriptive information from parents (hereafter, mothers), including using written checklists, performing observational studies of natural interactions between parent and child (ethnographic studies), and engaging mothers in focused interviews (phenomenological studies). Each of these methods is potentially appropriate and can provide valuable information; usually, the decision about which method to use depends upon the research design and the questions being posed.

One straight-forward method for obtaining maternal data involves asking mothers to complete case history forms, investigator-developed checklists, or published scales or behavioral inventories. The advantages of this method include ease of completion, time efficiency, and, in some cases, the availability of external norms against which study children can be compared. For studies that require very large sample sizes, checklists that can be completed efficiently over the telephone or in writing are often the most practical way to obtain information. The primary disadvantage of these assessment tools is their superficiality. Typically, mothers are asked to review a pre-generated list of symptoms or behaviors (e.g., drooling, vowel errors), and are asked to indicate for each if that symptom or behavior is "present" or "absent" for their child. In some cases, the

parent may be asked to judge the frequency or severity of symptoms on a rating scale (e.g., 1=never observed; 5=observed very frequently). The type of data generated from these measures is particularly useful for studies where quantitative (numeric) data with subsequent statistical tests and group comparisons are desired. Alternatively, it is important to recognize that this method of data collection significantly limits the depth and flexibility of information that can be obtained, and, importantly, precludes the detailed explanation of each individual item or phenomenon.

An alternative strategy for obtaining maternal data is to engage a small number of subjects in extended interviews that focus on a theme of interest to the researcher. These types of investigations, sometimes termed phenomenological studies (Camic, Rhodes, & Yardley, 2003), are particularly useful when the investigator wants to obtain “rich” or “deep” information about a phenomenon for which there is limited existing information. As noted by Finn and Felsenfeld (2004), phenomenological approaches are particularly useful for organizing complex and dynamic data into themes, models, or stages that reflect the common experiences expressed by members of a group. In this type of study, the investigator approaches the topic under study without a firm preconception about what variables will be important or what themes will emerge. Instead, the themes are “allowed” to develop in a dynamic way as the data are examined. Phenomenological studies generally involve fewer subjects than do most quantitative investigations. Statistical methods are rarely applied, although, where appropriate, the strength of themes or trends can be expressed with

reference to the percentage of respondents who were members of given thematic categories

The primary strength of phenomenological studies is their flexibility, and the depth of coverage that they are designed to elicit. However, when using these designs, it is important to recognize their inherent limitations. Because samples are small and may not be representative of all members of a group, generalization to all members may not be appropriate. Unlike quantitative studies, qualitative studies rely more upon nuanced interpretation rather than statistical significance for identifying “important” findings. This places a large burden on the investigator(s), who must ensure that their own biases do not compromise the rigor of their analysis or interpretation. Finally, phenomenological studies are inappropriate to answer certain types of research questions (e.g., identifying cause-effect relationships). They are most appropriate for addressing questions of “subjective meaning,” that is, for uncovering the way people “structure and narrate the important personal stories of their lives” (Finn & Felsenfeld, 2004). The outcome of many phenomenological studies is the creation of heuristics (models, analogies, stages) that capture and describe the prototypic experiences expressed by members of a group, such as parents of children with speech disorders. From these shared stories, insights about personal phenomena may be mined and hypotheses can be generated that can be tested, if desired, using mixed (qualitative and quantitative) methodologies.

In comparison to other clinical fields, relatively little information has been obtained from parents of children with speech and language disorders using

phenomenological approaches. In perhaps the first study of its kind, Rannard, Lyons, and Glenn (2004) interviewed caregivers of 40 children between the ages of 6;10 and 16;9 years of age who were diagnosed with specific language impairment (SLI) to obtain insight about the child's performance and the families' experiences. Of the 40 caregivers who were interviewed, 38 included either mothers or mothers and fathers. In one case, the father was the only informant, and in another case, the informant was the child's grandmother. A chronological approach was used to elicit the mother's descriptions of the development of these children prior to their enrollment in a self-contained language unit classroom. Per the caregivers' reports, between eight and eighteen months of age, these children either produced no speech sounds or they produced speech that was described as "strange" or "unrecognizable." At approximately two years of age, the children reportedly began to produce single words, but at the age of two and a half, most of the children's speech was still described as "unrecognizable" (i.e., unintelligible). Interestingly, many of the caregivers of children in this group reported that the child's sibling(s) were able to understand the SLI child more easily than others, including the parents, at this time. Most of the children were described by their caregivers as having average or above average receptive language skills; it appeared that these children mainly experienced deficits in expressive language.

According to the caregiver narratives, many of these children began to have temper tantrums between the ages of twelve months and approximately two years. The caregivers reported that they believed that these tantrums were

directly connected to their child's poor intelligibility, and reflected frustration at their inability to communicate. However, because many of these children behaved badly at this time, caregivers often reported that they avoided taking their child out in public and exposing them to social situations.

In addition to obtaining descriptions of the children's language and behavior, Rannard and colleagues obtained and examined information pertaining to the caregivers' emotional and physical involvement in the care of their SLI child. Some caregivers indicated that they felt guilt and frustration because of their inability to understand their child's communication attempts. Moreover, although many of the caregivers revealed that they recognized a problem early on, many did not seek intervention right away; reportedly, the caregivers waited an average of two years between the time of initial concern and the time when speech and language services were sought.

In terms of their perceptions of the effectiveness of speech therapy, the responses of the parents were decidedly mixed. Most of the caregivers reported that they believed that both the mainstreamed classrooms and "pull-out" speech therapy had limited effect on their child's expressive language abilities. In contrast, most of the caregivers reported that they believed the language unit classroom was therapeutically effective and facilitated language growth. However, despite their generally positive appraisal of the language unit, many caregivers indicated that they disliked the fact that their child had been labeled as a "special education student."

In a similar qualitative study, Glogowska & Campbell (2000) interviewed 16 parents, 14 of which were mothers, of preschool children (unknown diagnoses) who were receiving speech and language therapy (SLT). Through the use of interviews, the researchers gathered information specifically pertaining to the parental views of and involvement in SLT. Through the parents' descriptions, three phases of involvement in SLT emerged: "getting in," "getting on," and "getting there."

According to Glogowska and Campbell, the commencement of speech therapy, the "getting in" phase, engendered mixed emotions among the parents. In this phase, some parents reported that they felt relieved that their child would be receiving services. Other parents, however, indicated that they were still coping with the recognition that their child had a problem, and, for these parents, they were still grieving this loss when therapy began. Interestingly, many of the parents who participated in this study reported entering therapy with high hopes for a "quick fix." When this did not happen, some of the parents reported feeling discouraged, confused, and/or distraught.

In the second phase, the researchers discussed a variety of emotions felt by the parents regarding the SLT process. Several parents reported feeling content that something was being done to help their child both in therapy and at home. A smaller number of parents, however, reported that they remained dissatisfied with the therapy their child was receiving. These parents perceived that the therapy was not (rapidly) helping, and began to believe that it was a waste of time. The final phase, "getting there," was characterized by both

acceptance that the disorder would not simply disappear and concern and uncertainty regarding the child's future. During this phase, parents expressed both hopes for and concerns about the long-term outcomes in education and beyond that their child would experience. This investigation is unique in that it is the first study to use phenomenological methods to identify a testable heuristic (their three-phase model) that parents of children with speech/language disorders may be expected to move through as they recognize and cope with their child's disability.

To date only two unpublished reports posted on the "Apraxia-Kids" website (www.apraxia-kids.org) have reported data obtained from parents of children with a developmental speech disorder, specifically DAS. One of these reports (Lohmann, 2004) was based upon a volunteer sample recruited from a solicitation posted on the Apraxia-Kids Listserv. The second investigation (Garn-Nunn, 2004) was performed by analyzing the spontaneous Listserv postings generated by parents during a one-month period. Both of these informal studies reached similar conclusions. First, both surveys highlighted the residual confusion among parents about the criteria for diagnosing DAS, and about the utility of the DAS label. Like professionals in the field, parents are uncertain about whether DAS can be definitively diagnosed, and how or by whom such diagnoses should be rendered. A second recurring theme extracted from these surveys was the presence of comorbid deficits among the children with DAS. Many parents described non-speech issues they faced with their child with DAS, including gross and fine motor deficits, sensory integration deficits, hypotonicity,

and learning and academic problems. Many of the participating parents questioned the traditional belief that DAS was confined to speech, and wondered if DAS might be part of a more generalized “developmental syndrome.” Finally, a frequent area of discussion for parents involved issues surrounding speech therapy. These issues were wide-ranging, but often involved finding problems associated with finding experienced SLPs, obtaining insurance reimbursement for speech services, and finding the most optimal therapy approach for their child. Although informal, the findings from these surveys highlight the practical concerns expressed by parents of children with DAS, and provide insight into the types of issues that motivated parents of children with DAS discuss among themselves in a public (internet) forum.

Purpose of this Study

The present study was the first to use qualitative (phenomenological) research methodology to obtain and analyze the “personal stories” of a small number of parents of children who have received a diagnosis of either DAS or DPD. The primary purpose of the present study was to ask parents to reflect in detail on specific aspects of the development of their child with a DSD over time, with special emphasis on communication development and communication challenges. In addition to providing rich descriptions of performance, the present study addressed the proposition that DPD and DAS are separate disorders by examining the distinctiveness of the narratives obtained from the respective parent groups. As part of this analysis, “exhaustive descriptions” of the communication development of a prototypical child with DAS and a prototypical

child with DPD were generated by synthesizing the comments derived from the narratives of both parent groups. Two primary and related questions were posed:

- 1) How do parents of children diagnosed with DAS and parents of children diagnosed with DPD describe in narrative fashion the performance of their child over time, with particular reference to emerging and changing communication behaviors?
- 2) To what extent are the observations and experiences of parents of children diagnosed with DAS similar to those reported by parents of children diagnosed with DPD?

2. Methods

2.0. Overview of analysis approach

Preparation and analysis of the interview data followed the guidelines for qualitative analyses outlined by Boyatzis (1998) and Kearney (2001). The primary analytical objective was to identify and to consider the extensive list of individual experiences that were extracted from the transcripts of all of the participants, and to then determine how the individual experiences could be combined into broader recurring themes that captured the “shared pathways” of the DAS or DPD narratives. The narratives were analyzed to find data that reflected the child’s development as a “holistic picture.” The pictures reflected in each narrative were used to find common trends within and across the diagnostic groups of children with DAS and those with DPD.

Following one of the analysis models proposed by Kearney (2001), a chronological approach was used to organize the narratives. Specifically, three age epochs were established after the data were collected and reviewed (birth to age 2, ages 2 to 3, and ages 4 to 6, the oldest age in our sample). The narratives were examined within and then across these developmental stages. This analysis method allowed us to use *time passage* as the principal method of organization for consolidating the large amount of data.

2.1. Participants

Parents were selected as potential study participants. To be considered for participation, the parent (all were mothers) had to have a child between the ages of 3;6 and 7;6 who had received a primary diagnosis from a speech-

language pathologist of either DAS or moderate to profound DPD. No attempt was made to verify these diagnosis by obtaining clinical or medical records or through direct assessment of the child. Rather, in this study, the opinions of practicing clinicians (for the DAS subgroup ad at the Duquesne University Pediatric Articulation and Phonology Clinic staff) were accepted. If the parent reported that their child was diagnosed with any co-occurring neurological, oral-structural, cognitive, hearing, or severe social-emotional conditions, they were excluded from further study participation.²

2.2 Participant Recruitment

The recruitment process for parents of children diagnosed with DAS began prior to and during the “Apraxia-Kids Parent Conference” held at Duquesne University in July, 2004. To inform parents of this study, a solicitation was posted on the Apraxia-Kids website (<http://www.apraxia-kids.org>) prior to the Conference (Appendix A). The Apraxia-kids website receives over 110,000 hits monthly, and is considered the most comprehensive source of information on DAS for parents and professionals presently in existence (Shriberg & Campbell, 2003). The Apraxia-Kids Parent Conference was attended by approximately 425 parents of children who were diagnosed with DAS, drawn from across the nation and Canada. The events at the conference included both research papers and round-table discussions that focused on various etiological, diagnostic, and treatment issues of interest to this group. Parents who were potentially interested in participating in our study were asked to contact the principal

² . One parent of a child with a comorbid neurological condition was interviewed, but these data were not included in the analyses reported here.

investigator prior to or while attending the Conference to learn more about the study, to read the consent form, and to determine if they met eligibility criteria. Those who chose to participate were contacted to arrange a convenient meeting time and location for the study interview. Interviews were completed at the Duquesne University Speech-Language-Hearing Clinic and at locations within local hotels (where participating parents were staying).

Parents of children diagnosed with moderate to severe DPD were recruited from among current and former clients of the Pediatric Articulation and Phonology Specialty Clinic of the Duquesne University Speech-Language-Hearing Clinic. Children in this subgroup had to be diagnosed with a moderate to profound phonological disorder by clinical personnel, based upon the results of the established assessment protocol used in this specialty clinic. In addition, these two clinical specialists (Felsenfeld and Staltari) had to agree that the child was negative for suspected apraxia of speech. Clients who were judged to be potentially appropriate were contacted by the Program Director (Felsenfeld) or the Clinical Instructor associated with this specialty clinic (Staltari).

For children in the DPD subgroup, initial contact occurred during regularly scheduled therapy visits or by telephone for clients who no longer attended regularly scheduled treatment sessions. Potential participants were initially provided with a verbal and written summary of the study, the consent form, and the principal investigator's contact information. For parents who agreed to participate, the principal investigator (Patrick) contacted the participant via telephone to schedule a convenient meeting time and location for the interview.

These interviews occurred either at the Duquesne University Speech-Language-Hearing Clinic or at the subject's home.

2.3 Sample composition

The final participants in this study included six mothers of children diagnosed with DAS and five mothers of children diagnosed with DPD. In both cases, these could be considered “convenience samples” as opposed to random samples of parents with speech-delayed children; as such, they may not be representative of all such parents in the population. To obtain some descriptive information about the socio-economic composition of the present study group, mothers were asked to provide selected demographic information during the initial portion of the interview. Eight of the eleven mothers described themselves as Caucasian, with two of the mothers in the DPD group identified as African-American, and one mother in the DPD group as Native American. Most mothers reported that they resided in city or suburban, middle-class neighborhoods, some with mixed ethnicity and others primarily Caucasian. When discussing occupations, most participants described the occupations of both parents as “professional.” Some of the mothers described themselves as “stay-at-home moms,” with a few mothers describing themselves or their husbands as unemployed. A visual inspection of these variables suggested that the two groups are comparable with respect to socio-economic factors. Both groups can be described as middle or upper-middle class families with generally well-educated professional parents.

In addition, it is important to note that the participants in this study probably represent parents who are more than typically motivated with respect to seeking services for their target child. All of the participating parents reported that they noticed the speech problem early and sought out evaluations and sometimes multiple therapists for their child. The parents in the DAS subgroup had taken time away from their schedules to attend a national conference on this topic. As such, it is important to recognize that the parents included in this study probably represent an atypically well-informed and motivated subset of parents of children with DSDs.

2.4 .Interview procedure

Each of the eleven participants individually completed one interview designed to elicit information regarding their child's development, focusing on communication. The interviews were un-timed and lasted between 60 and 90 minutes. Each interview was conducted by the principal investigator and was audio taped using a high-quality audio recorder. To assure confidentiality, the interviews were assigned participant numbers.

The semi-structured interview included five grand tour, or broad context, questions with both planned and unplanned prompts (Appendix C). The interview questions were derived from a combination of clinical intuition and published data regarding differential criteria used to diagnose DAS. To assure that the most effective questions were asked, two professionals reviewed the interview questions with the principal investigator: (a) a Professor of Qualitative Research at Duquesne University (Stern) reviewed the interview with the

principal investigator and (b) the Clinical Instructor in the Pediatric Articulation and Phonology Specialty Clinic at Duquesne University (Staltari) completed a mock interview with the principal investigator. Based on the suggestions made by the two professionals, changes were incorporated into the final draft of the interview.

The five “grand tour” questions asked parents to reflect on the following experiences: (a) their child’s early development (six to twenty-four months) with particular focus on emerging social and communication behaviors; (b) the ease and naturalness of communication between parent and child in the past and presently; (c) changes in communication performance over time; (d) the impact that DAS/DPD has had on the family; and (e) the parent’s experiences with the DAS/DPD label. Planned and unplanned prompts were integrated into the interview to gather more information from the parents. A planned prompt was asked to elicit more specific information pertaining to a grand tour question (e.g., “can you paint a picture of how he communicates?”). These prompts were used only if expected information was not obtained from the grand tour question. Unplanned prompts were used to clarify a spoken message or to retrieve additional information (e.g., “tell me more”) in cases where the principal investigator felt additional information or detail would be helpful in interpreting a response. To focus on the child’s communication development, only responses to questions (a) through (c) were analyzed secondary to the extensive amount of information obtained during the interviews and the limited time period available for completing the thesis.

2.5. *Data analysis*

Each audio taped interview was transcribed verbatim and typed by the principal investigator or another trained graduate student in speech-language pathology at Duquesne University. A standard word processing program (Microsoft WORD) was used. Interjections, verbatim false starts, and word or phrase repetitions were omitted during transcription³. The principal investigator then read through each transcript multiple times and highlighted all quotes that were “information rich.” To be considered “information rich,” a quote had to pertain to the development of the child and had to describe the child’s communication or related performance. These quotes were then transferred onto color-coded (blue for DAS, white for DPD) index cards, one quote per card. Quotes were written on the index cards using different ink color based on the child’s gender (red ink was used for males and black ink was used for females). The participant number, grand tour question identifier, and the page number of the transcription were placed onto each index card to facilitate referencing of the transcript when necessary.

Following this, the index cards for each grand tour question were sorted by using a staged process. First, the cards were sorted into preliminary clusters of recurring information, which we called emerging thematic categories. The thematic categories were derived primarily from the data cards themselves and on occasion, guided by past research. After reviewing the initial sorting, the clusters of index cards were reorganized into broader thematic codes. This step

³ To assure confidentiality, the interview transcripts will be kept at Duquesne University and will be available by contacting Dr. Susan Felsenfeld via email (felsenfeld@duq.edu).

had the effect of reducing the number of categories by allowing like clusters to be grouped into the most superordinate category the data would allow. For example, the superordinate thematic code of “motor development” was developed by subsuming several original categories including, “gross and fine motor delay,” “hypotonicity,” and “oral motor dysfunction.” Following this step, the final thematic codes were reviewed and reorganized to ensure that all of the raw material was properly placed. At this final stage, multiple index cards which did not pertain to the information sorted were discarded. Data were first analyzed for all of the DAS subjects. Following this, data from the DPD subjects were examined. Subjects remained identifiable by card color throughout the analysis procedures.

As previously noted, *time passage* was used as the principal organization method during the analysis. For each group, experiences were placed into one of three age groups: birth to age 2; ages 2 to 3; and ages 4 to 6. These age divisions were not developed initially. Instead, the idea of following various developmental threads across time emerged as a useful organizing strategy during the data analysis process. For example, we discovered that discussions of motor development often occurred at various times throughout the interview, as reports of delayed early motor milestones, low muscle tone as babies, clumsiness as toddlers, poor fine motor control during coloring activities in preschool, and so forth. Rather than “forcing” the data into one of the initial grand tour questions, this strategy “allowed” the data to fall into its natural

developmental place, and permitted revealing quasi-longitudinal child portraits to emerge.

In a secondary analysis, a frequency count of specific symptoms mentioned by parents was obtained for all parents combined and for the two diagnostic groups separately. This analysis was completed by reviewing all of the final index cards and identifying key words or phrases contained in each (e.g., “drooled” “shy,” “sensitive to touch.”). After these key words were identified, they were tallied for each group; that is, the number of parents who reported this behavior was obtained. A percentage of occurrence for each symptom was computed by dividing the number of reported occurrences for that symptom by the number of parents in that subgroup, and then multiplying this value by 100. These data were compared against two current DAS checklists to determine if our results corroborated or failed to corroborate symptoms that have been identified as diagnostically discriminating in past research.

The final analysis involved the development of two exhaustive descriptions (i.e., prototypic case narratives) that captured the experience of raising a child with DAS and DPD. These descriptions were generated by synthesizing the comments derived from the narratives of participants from both parent groups.

2.6. Credibility

To enhance the trustworthiness of the data, both member checking and peer debriefing were employed. For the member checking procedure, six of the eleven participants were asked to review their own written transcripts and a written summary of the transcript generated by the principal investigator (see

Appendix D for an example). These participants were selected randomly and were equally distributed between the two diagnostic groups. Via email, participants were asked to review the written material to ensure that the principal investigator captured and interpreted their narratives appropriately, from their perspective. Five of the six parents who were sent the summaries responded with minor changes regarding wording differences and a few age differences of developed characteristics; such input from this procedure was incorporated into the final analysis. Thus, the results of the member checking procedure indicate that the investigator accurately recorded and interpreted these narratives, as judged by the participating parents.

To determine the reliability of thematic codes and the placement of the index cards, another graduate student in speech-language pathology (a peer debriefer) who was blinded to group membership was asked to sort a mixed set of randomly selected index cards (65) containing key words and phrases into their respective superordinate categories. Results revealed highly acceptable inter-rater agreement; 59 of the 65 sample index cards were sorted into the same thematic codes derived by the principal investigator.

3. Results

The primary purpose of this study was to increase our understanding of the development of children diagnosed with DAS or DPD through the viewpoint of eleven parents. The first level of analysis involved extracting individual experiences from the narratives provided by the participants. These experiences, or core symptoms, were then synthesized into thematic codes based upon a chronological analysis of three developmental levels: (1) *infants to age 2;0*, (2) *ages 2;1 to 3;11*, and (3) *ages 4;0 to 6;11*.

3.0. Characteristics of target children

Although not direct subjects of this study, information about the target children was collected from the mother at the time of interview. This information is summarized below in Table 3.

Table 3. DEMOGRAPHICS OF THE CHILDREN

	<i>Gender, age</i>	<i>Diagnosis</i>	<i>Age of treatment initiation</i>	<i>Receiving speech therapy</i>	<i>Family history</i>	<i>Parental occupations Mother/Father</i>
C01	Female, age 5	DAS	2;0	Yes	No	Physical Therapist/ Multimedia graphic designer
C02	Female, age 5	DAS	3;0	Yes	No	Monitor of drug research studies/Sales
C03	Male, age 5	DAS	2;6	Yes	Yes	Sales/Business Owner
C04	Male, age 4	DAS	1;6 to 2;0	Yes	Yes	Owner of company/electrician
C05	Male, age 3	DAS	2;0	Yes	Yes	Stay-at-home mom/Researcher
C06	Male, age 6	DAS	2;0	Yes	Yes	Telemarketer/Quality Engineer
C07	Female, age 4	DPD	1;6	Yes	Yes	Stay-at-home mom/ Homicide Detective
C08	Male, age 5	DPD	2;0	Yes	Yes	Emergency Medical Technician
C09	Female, age 4	DPD	3;9	Yes	Yes	Stay-at-home mom/ Currently unemployed
C10	Male, age 5	DPD	Unknown	Yes	Yes	Student/Retired cook
C11	Male, age 5	DPD	2;0 to 3;0	No	No	Substitute teacher/Professor

As can be seen, a larger proportion of the children in this sample were males (67% for the DAS group and 60% for the DPD group). Children ranged in age from three to six years at the time the interview was completed, with a modal age of five years in both groups. All of the children had received speech therapy in the past, and all but one child in the DPD group were still receiving speech therapy at the time this interview was completed. Most children were first enrolled in speech therapy between the ages of two and three years, although one child from both groups reportedly began therapy between one and a half and two years of age. All of the children were enrolled in therapy before their fourth birthday, with one parent in the DPD group unable to recall the specific age when her child's therapy began. Finally, as has been frequently reported, parents reported a positive family history of speech or language problems at a very high rate; specifically, 67% of the DAS children and 80% of the DPD children were reported to have other relatives with these problems. These findings suggest that, in many ways, (age, gender, therapy history, family history, parental occupations) these two groups of children were highly comparable.

Primary qualitative findings

3.1. Infants to age 2;0

When analyzing information related to this stage of development, four recurring themes emerged from the parent's narrative description from both groups. These themes were: (a) early characteristics of verbal output, (b) desire to communicate, (c) motor development, and (d) sensory hypersensitivity.

3.1.1. *Early characteristics of verbal output in infancy to age two*

During this period of development, the two groups of parents discussed multiple aspects of early verbal output. A major recurring symptom reported was the limited verbal output that the infants produced and how quiet they were between six months to one year of age. This symptom was reported in five of the six children diagnosed with DAS and in all of the children diagnosed with DPD. One parent of a child with DAS describes her child's verbal output close to one year of age.

P02⁴ "She was pretty quiet... as far as producing sounds, it was not, not often."

Another parent of a child with DPD discussed her child's verbal output as an infant.

P11 "He never did that [babbling]. He was always pretty quiet."

Two parents of children diagnosed with DAS reported that the children produced babbling as an infant, but then lost the ability to produce such output. These parents also reported that as infants, their children were quiet.

P02 "...she kind of lost interest in that in maybe [babbling]."

P04 " And then he lost speech at around eleven months."

"...he was very, very, very quiet."

Another aspect of early verbal output was the few words that children with both diagnoses were able to communicate by their second birthdays. Most parents of children with both diagnoses reported the very limited number of

⁴ Bolded participant numbers represent the DAS subgroup

words or different sounds that their child was producing. One parent of a child with DAS described her child's use of few words around two years of age.

P06 "So he had like less than five words at that time... even if he did have those words, he didn't use them functionally."

One parent of a child diagnosed with DPD explained her child's use of words at the same time period. This parent also reports the limited number of consonants produced by her child.

P07 "...two months prior to her second birthday, I'm gonna say she had maybe 10 words at that point."

"I don't think that there was much variety in terms of consonant sound production..."

During early communication development, the participants also reported the poor intelligibility of their children's limited verbal output. Parents of children with DAS and parents of children with DPD describe their child's poor intelligibility in similar ways.

P01 "I'd say maybe [others] could understand 10-25% of what she was trying to say..."

P08 "First and second birthdays, still a lot of gibber gabber."

Finally, during early communication development, characteristics of verbal output were described as abnormal in prosody or quality. This characteristic was reported more often among parents of children diagnosed with DAS; five of the six children were described as having some type of abnormal prosody or vocal

quality. Only one of the five children diagnosed with DPD were described as such.

P01 "...I can't say that... [there was] a lot of fluctuation in her voice, in the tone of her voice..."

P10 "Seemed like his sounds were always in the throat."

3.1.2. Desire to communicate in infancy to age two

Participants also indicated that their children appeared to have a desire to communicate with others. These children attempted a variety of forms of communication to effectively relay their message. All eleven participants reported that their children were able to comprehend what others were communicating.

P03 "He understood you completely, he just couldn't communicate."

P07 "I always felt that she was able to understand everything that was being said to her, but just couldn't get it out."

These children also appeared interested in communicating with others. When asked if their children were interested in communicating, most participants reported that their children appeared to want to communicate.

P05 "He was more interested in expressing himself..."

P08 "No one understood anything he was saying... he was trying to express it but it just wasn't comin out clear..."

Even with the desire to communicate and the ability to understand others, children in both diagnostic groups were not able to repeat. It was reported that ten of the eleven attempted to do so, but were unsuccessful at imitating. When

asked if their child was able to imitate speech, parents commonly stated, “no.” Reportedly, one child with DAS was able to imitate sounds heard in the environment (e.g., ambulance siren).

All of the eleven parents reported that their child developed nonverbal communication strategies to express his/her wants and needs. To communicate, each child independently created and used multiple nonverbal strategies. One parent of a child diagnosed with DAS described her child’s ability to communicate using such strategies.

P01 “She could get her point across to almost anybody by gesturing.”

P05 “...he did kind of the equivalent of bringing you to and kind of gesturing... So he was really I feel inventive and creative at getting his message across.”

P11 “He was really good at grunting and pointing when he want[ed] something...”

3.1.3. Motor development in infancy to age two

Although motor development is not directly linked to communication, a delay in motor development continually was mentioned by the participants. Delays in both fine and gross motor skills were discussed during some of the interviews. All six of the parents of children with DAS mentioned fine motor delay as part of their child’s development; there was no mention of a delay in fine motor by the parents of children with DPD.

P02 “It was delayed as well... gross motor and definitely fine motor.”

Parents also reported receiving therapy for muscle tone issues. Five of the six parents of children diagnosed with DAS reported that their children were hypotonic; there was no discussion of hypotonicity in children with DPD.

P05 "...his big problems seem to be the rolling... it's the trunkal part... he simply could not pull up."

Four of the six parents of children with DAS also reported a delay in gross motor. Three of five parents of children with DPD also reported gross motor delay. The children considered to have a gross motor delay walked late and were also described as clumsy.

P01 "She took her first step on her first birthday and then didn't walk again until she was fifteen months old..."

P06 "...I know crawling, walking, everything gross motor, he did late."

P05 "...[he] is somewhat clumsy and uncoordinated with fine and gross motor..."

P09 "...she is little miss booboo queen...she's always falling...she'll drop things moreso than my other daughters ever did."

Another aspect of motor development discussed by the participants was oral-motor dysfunction. Only two of the five parents of children with DPD mentioned such difficulties; however, all six of the children with DAS reportedly experienced some type of oral-motor involvement. Parents often indicated that their child had an excessive amount of drooling.

P02 "... a lot of drooling, definitely."

P04 "...drooling, not all the time, but frequently. He would never also notice that he was drooling and wipe."

Additionally, parents of children with DAS reported that their children had some difficulties with volitional oral-motor movements. Per one parent's report, her child could not blow out her first birthday candles.

P01 "...she couldn't pucker her lips to blow and she couldn't suck out of a straw."

Another parent reports that her child with DPD needed occupational therapy to address weak oral musculature.

P07 "...she needed OT for the oral-motor, because the muscles around her mouth were weak..."

3.1.4. Sensory hypersensitivity in infancy to age two

Another aspect of development usually not directly related to speech development is sensory hypersensitivity. Whether diagnosed by a professional or noticed by the parent, sensory hypersensitivity to sound, touch, light, or a combination of the three was reported. Six of the six parents of children with DAS reported some type of sensory hypersensitivity during their child's development; three of the five parents of children with DPD reported the same.

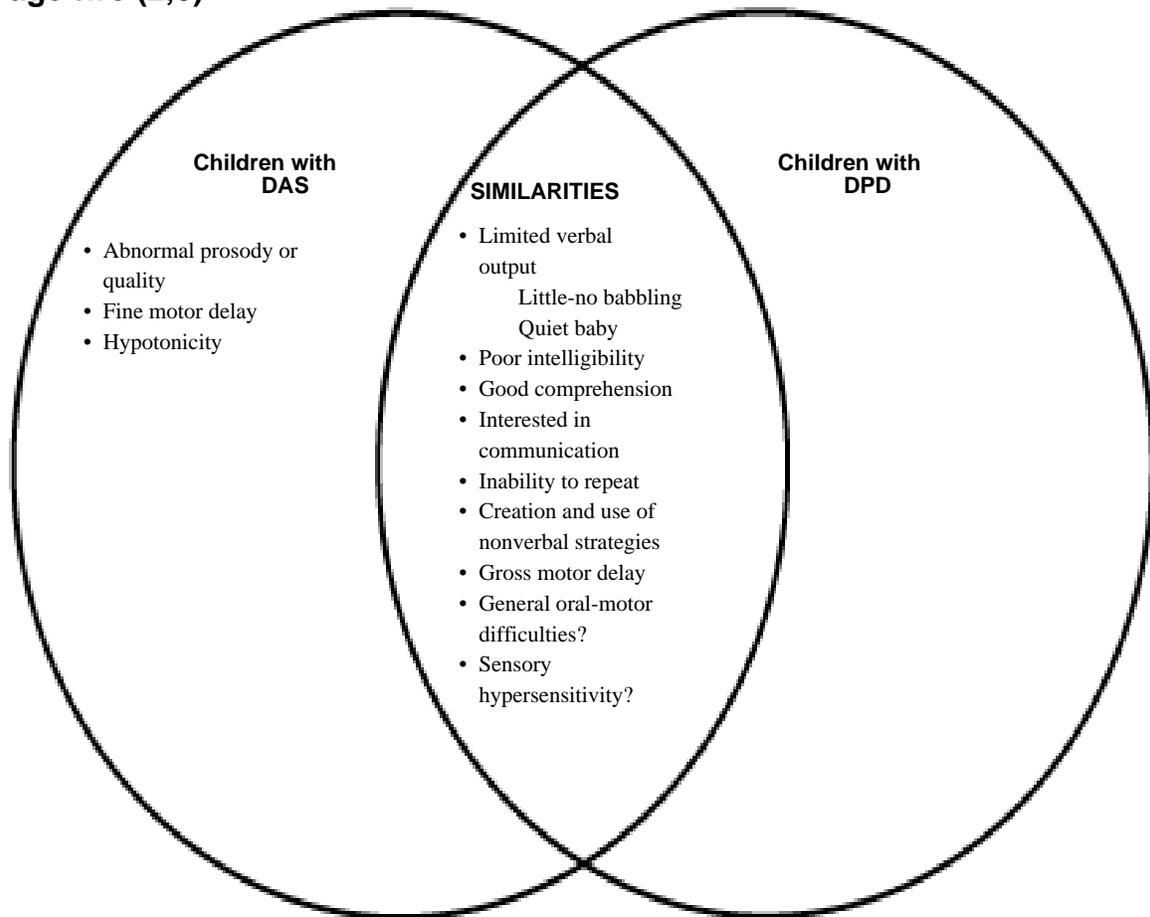
P01 "...he gets overloaded with visual."

P03 "He did have some sensitivity to touch..."

P10 "...[loud noises are] extremely irritating to him and he would kind of flick at his ears."

Figure 1 below is a Venn diagram that illustrates visually both the overlapping and the distinguishing observations reported by parents from the first chronological age group (infancy to age 2). As can be seen in Figure 1, many of the observations overlap at this age. For children diagnosed with DAS, a set of additional indicators (primarily motor and sensory) are identified. No additional, distinctive indicators were consistently reported for the DPD children. Similar diagrams are presented for the other two age groups after each is discussed in the text.

Figure 1. Venn diagram of symptoms reported at first age group: Infancy to age two (2;0)



3.2. *Ages two to three years*

Between two and three years of age, common themes became apparent through the parents' descriptions. Characteristics of verbal output and an increase in awareness of communication abilities and frustration were two themes which emerged during this period of time.

3.2.1. *Characteristics of verbal output between two and three years*

By the age of three, it appeared that the verbal output produced by the children began to diverge somewhat as a function of subgroup. Children with DPD increased their verbal communication in comparison to the children with DAS. Overall, these children began acquiring more words, simple word combinations, and/or short phrases.

P07 "...she had maybe ten words [22 months of age]..."

P08 "...he would answer at this time, probably two to three word phrases..."

The children with DAS continued to attempt verbal production; however, their speech continued to be characterized by open syllables and approximations. Some children were able to produce a limited number of words.

P02 "...it sounded like she was six months again...it was a lot of just the babbling, kinda incoherent cooing..."

P05 "...he was speaking in syllables at that point... he started combining..."

For example, "... he couldn't say 'baby Anna;' it would be '[bi n^].'"

Another aspect of verbal output discussed was the unnatural sounding speech the children produced. Most parents reported that between the ages of two and three years, their child's speech did not sound natural.

P05 "It was kind of like a verbal extension of grunting...it was choppy...[teachers would] say consistently that...'it takes two or three days for me to get his tone."

P09 "It sounded like she was talking like a much younger child than what she was."

Yet another symptom which emerged was the minimal intelligibility of the children's verbal productions. In both the children with DAS and those with DPD, limited intelligibility seemed to be a common thread. Many parents report that their families, or familiar communication partners, had a better understanding of the child's speech; therefore, others would look to them to translate what was being said.

P04 "No one else could understand him but us."

P11 "[His brother] translated for me... we all relied on [him] to translate..."

Because of the limited verbal output, the unnatural speech, and the limited intelligibility produced, the parents of the children with DAS and the parents of the children with DPD reported the limited amount of conversation they were able to have with their children.

P06 "...I do remember sitting down and him communicating back to me what he wanted and I communicated to him what I wanted, but there wasn't really... not a true conversation."

P09 "I could talk to her and she could talk to me, but for a true understanding of what she was saying, I couldn't."

3.2.2. Awareness and frustration between two and three years

Between two and three years of age, it seemed that both the children with DAS and the children with DPD became more aware of their difficulty communicating verbally. Many of the parents reported that during this time, their children realized how limited their verbal output was and how little others understood.

P01 "...she would definitely look for someone else to translate...didn't wanna be out of a close family member's eyesight."

P02 "...she was becoming more and more aware of her lack of communication..."

P11 "...he was coming to the realization that people couldn't understand him."

It also appeared that even though verbal communication was difficult, both the children with DAS and the children with DPD were interested in communicating with others. Therefore, these children continued to create and to use nonverbal communication strategies to relay information to their communication partners.

P02 “She would come and get our finger and then pull us to whatever she wanted to see, do, things like that.”

P06 “It was still not a lot of words, more signs and pointing and gesturing.”

P08 “...[he would] try to give me hints by pointin to somethin on television...try to find things around him and relate what he was talkin about.”

With the desire to communicate came frustration and occasional externalizing problems. These parents reported that the children in both diagnostic groups expressed frustration and became behaviorally challenging as their awareness of their verbal communication problems increased.

P04 “...he'd have a tantrum if you didn't understand him...”

P06 “...there was a lot of frustration when he couldn't communicate what he wanted. He would whine and cry.”

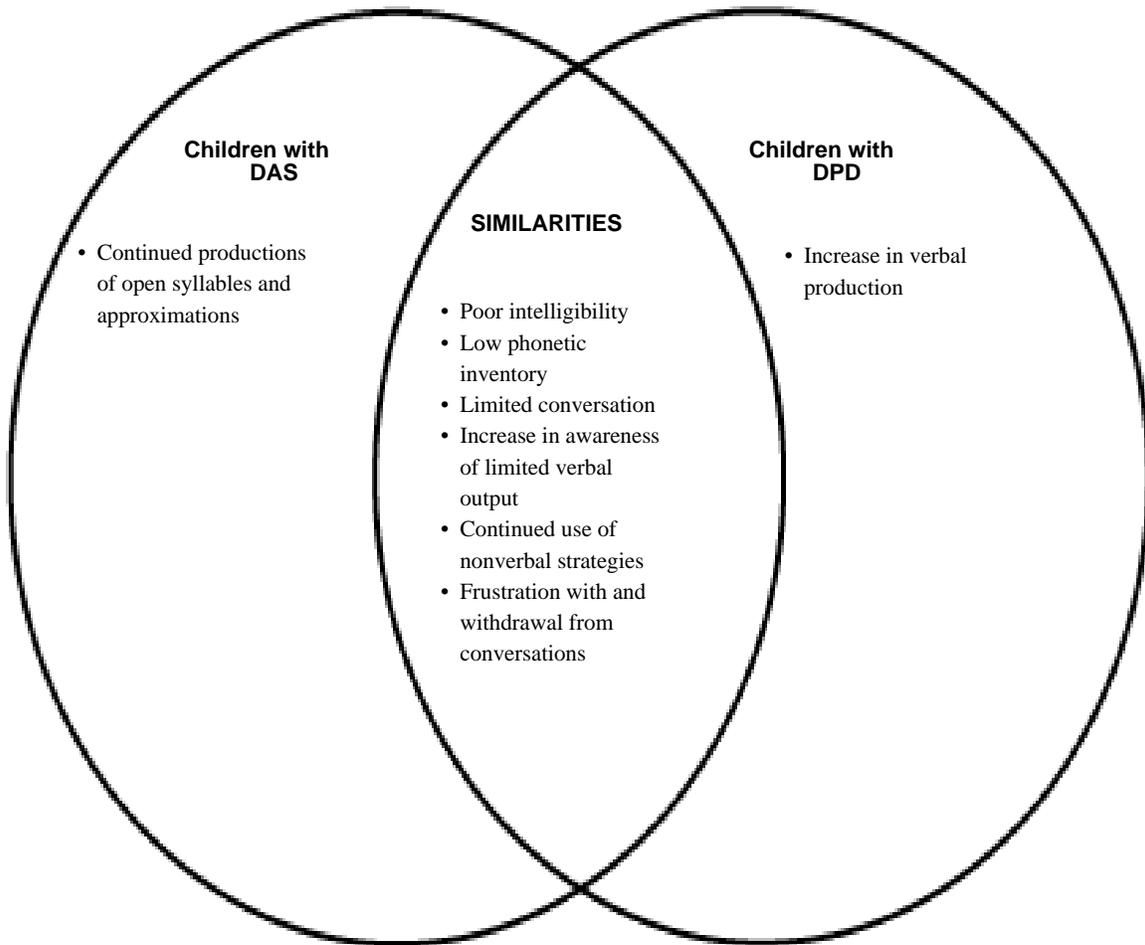
P09 “I know she struggled... you could see the frustration...”

Parents also reported that children with DAS and children with DPD withdrew from social interactions at times based upon their awareness of limited verbal output.

P02 “She would hug the kids when she would get there and then as the day...as that time progressed you could see her face would become more blank. She would try and communicate less...”

P10 “But when he got truly frustrated after he stopped havin the tantrums, he would just say ‘I say nothing mom...’”

Figure 2. Venn diagram of symptoms reported at second age group: Ages two to three years (2;1 to 3;11)



3.3. Ages four to six years

When analyzing the children's communication between the ages of 4;0 to 6;11, the narratives became significantly more variable. Specifically, although some of the children in this age group were still identified as disordered, a small number were described as resolved or nearly resolved. Despite this variability, three themes emerged, particularly among children who continued to display problems (the incomplete resolvers). These themes were: (a) continued and

additional expressive language difficulties, (b) increase in awareness of communication problems with associated frustration, and (c) continuing motor impairments.

3.3.1. Continued and additional expressive language difficulties at ages four to six years

One apparent theme which emerged was the additional expressive language difficulties some of the children were experiencing. Three of the six children diagnosed with DAS and three of the five children diagnosed with DPD reportedly still had articulation errors. Parents reported that their child continued to have difficulty producing some sounds, although many of the residual errors (e.g., with liquids) were considered developmentally appropriate.

P01 “The only things that are still left that aren’t age-appropriate substitutions like she can’t do the letter ‘r’...she’s having a hard time with ‘sh...’ she’s got some articulation problems still.”

P11 “[His communication] is really great. He still has a few little words, but I think based on his age, it’s the typical ‘l’s’ and ‘r’s...’”

Two of the six parents of children with DAS reported that their child continued to produce vowel distortions during speech.

P01 “...she’s working on fine-tuning a short, a vowel /a/.”

P05 “Some vowel distortions... Says /ʌ/, the schwa.”

The parents also reported that their children displayed difficulties with grammar use in conversation. Five of six parents of children with DAS and three

of five children with DPD reported that their child had difficulty with grammatical rules of language.

P05 “‘Let I go,’ instead of ‘let me go’... The ‘I’ and ‘me’ was something that was hard at the beginning and it’s kind of now dragging.”

P06 “He doesn’t have great sentence structure...”

P09 “I know there’s a tense issue, of using her verbiage... the past tenses.”

These children also appeared to have difficulty finding words at times. This theme was reported by two of six parents with children with DAS and two of five parents of children with DPD.

P03 “...he would be tryin to tell me things, and he would say a few words, and then he’d stop... and he would say, ‘mommy what that word?’”

P07 “...I began to wonder about the word finding because it seemed like as she got words to use, she still had trouble identifying things... And she would describe them... she couldn’t remember the word.”

3.3.2. Increase in awareness of communication abilities and frustration at four to six years

Between the ages of four and six years, awareness, self-consciousness, and frustration about impaired communication became a prominent characteristic of children in both groups. The children continued to feel frustrated with their productions of verbal output in both conversational and therapy activities. On occasion, this frustration displayed itself in the form of behavioral problems.

P04 “They’re teachin him how to deal with his frustrations and work solutions out rather than hitting or screaming or actin out...”

P09 “Repeating sentences and some of that is hard for her... she is really frustrated with. And you can see by the end of the session, that she’s just truly had enough.”

This frustration seemed to be directly linked to verbal communication ability; it appeared that as time passed and these children began to verbally communicate more effectively their frustration level decreased somewhat.

P02 “...since she is able to find success in...communication, her frustration level decreases.”

P08 “...him controlling when he’s not able to get something across to someone, he doesn’t get frustrated...He’s grown a lot in that area.”

Parents also reported that their children’s awareness of their ability to produce more intelligible speech increased. The children with DAS and the children with DPD realized that others were able to understand more of their speech during conversation.

P02 “...she is initiating a lot more sounds. She’s realizing that she can say a lot of things...”

P11 “[He felt] very frustrated. Because once he started speech [therapy]... and started developing things he just took off with talking.”

These children were also described as self-conscious or intimidated to speak to other people, even though their verbal output was becoming more intelligible.

P01 "...not only is she very self-conscious about her speech, but she's very self-conscious about anything at all that's is gonna involve her having to be on a team..."

P07 "[She] is usually very shy when you first meet her, with new people. I mean, she will just crawl up my leg..."

3.3.3. Motor development at ages four to six years

Another theme which emerged during the early development, infants to age 2;0, was motor development. This theme also re-emerged when discussing the children between the ages of 4;0 to 6;11. It appeared that many of the children began "to catch up" with other children their age in motor development. However, some of the children with DAS continued to have deficits in gross and fine motor skills.

P04 "...I was really concerned with his grapho-skills."

P05 "...the sensory stuff and the gross motor stuff started seeming worse."

It appeared that children with DAS also continued to be described as hypotonic.

P02 "[OT] says she's hypotonic and hypertonic in some areas..."

P06 "He gets OT and PT still for his fine motor... his muscle tone and strength is the big thing..."

As in the early stages of development, some of the parents of the children with DAS further reported that oral-motor difficulties were still an issue between the ages of 4;0 to 6;11.

P01 “She still has some oral apraxia... she’s having a tough time in swim lessons, because she’s gotta know not to breath when she’s down under the water.”

Figure 3. Venn diagram of symptoms reported at third age epoch: Ages four to six years (4;0 to 6;11)



3.4. Secondary analysis

For this analysis, a frequency count of specific symptoms mentioned by parents was obtained for all parents combined, and for the two diagnostic groups separately. These data were compared against two current DAS checklists to determine if our results corroborated or failed to corroborate symptoms that have been identified as diagnostically discriminating between DAS and DPD in past research. The results of this analysis are presented in Table 4 below. For readability, symptoms that are judged to be generally comparable and highly endorsed (60% or more) in both groups are bolded. Symptoms that appear to significantly discriminate the two groups (more than 40% difference) are italicized. Results of the current study are compared with the top six diagnostic indicators of DAS identified in the Forrest (2003) study, and are then compared with the diagnostic criteria for DAS proposed during the 2004 ASHA convention. Following this, additional findings of interest obtained in the current study are identified and coded similarly.

Table 4. SYMPTOMS REPORTED BY PARENTS

SYMPTOMS CHECKLIST	CHILDREN WITH DAS	CHILDREN WITH DPD	FREQUENCY	
			DAS (6)	DPD (5)
Forrest (2003) checklist				
Inconsistent productions	1 5		2/6 (33%)	0%
General oral-motor difficulties	1 2 4 5 6	7 8 10	5/6 (83%)	3/5 (60%)
Groping			0%	0%
Unable to imitate sounds	1 2 3 4 5 6	7 8 10 11	6/6 (100%)	4/5 (80%)
Increase errors with increase utterance length	5		1/6 (16%)	0%
Poor sequencing			0%	0%
ASHA Convention (2004)				
Inconsistent productions	1 5		2/6 (33%)	0%
Inability to repeat	1 2 3 4 5 6	7 8 10 11	6/6 (100%)	4/5 (80%)
Vowel errors	1 5		2/6 (33%)	0%
<i>Impaired prosody</i>	<i>1 3 4 5 6</i>	<i>10</i>	<i>5/6 (83%)</i>	<i>1/5 (20%)</i>
Poor sound sequencing			0%	0%
	CHILDREN WITH DAS	CHILDREN WITH DPD	FREQUENCY	
Symptoms from current study				
Little-no babbling/quiet baby	1 2 3 4 5 6	7 8 9 10 11	6/6 (100%)	5/5 (100%)
Vocal to "lost speech" (as infant)	1 4		2/6 (33%)	0%
Nonverbal strategies	1 2 3 4 5 6	7 8 9 10 11	6/6 (100%)	5/5 (100%)
Good comprehension	1 2 3 4 5 6	7 8 9 10 11	6/6 (100%)	5/5 (100%)
Poor intelligibility	1 2 3 4 5 6	7 8 9 10 11	6/6 (100%)	5/5 (100%)
Gross motor delay/late walker/clumsy	1 2 5 6	7 8 9	4/6 (66%)	3/5 (60%)
Sensory hypersensitivities	1 2 3 4 5 6	7 10 11	6/6 (100%)	3/5 (60%)
<i>Hypotonic</i>	<i>1 2 4 5 6</i>		<i>5/6 (83%)</i>	<i>0%</i>
<i>Fine motor delay</i>	<i>1 2 3 4 5 6</i>		<i>6/6 (100%)</i>	<i>0%</i>
Awareness with frustration, age 2+	2 3 4 5 6	7 8 9 10 11	5/6 (83%)	5/5 (100%)
Low phonetic inventory, age 2-3	1 2 3 4 5 6	7 10 11	6/6 (100%)	3/5 (60%)
<i>Persistent open syllables, age 2-3</i>	<i>1 2 3 4 5 6</i>	<i>11</i>	<i>6/6 (100%)</i>	<i>1/5 (20%)</i>
<i>Increase in verbal production, age 2-3</i>		<i>7 8 9 10 11</i>	<i>0%</i>	<i>5/5 (100%)</i>
Grammatical errors, age 4-6	1 3 4 5 6	7 9 10	5/6 (83%)	3/5 (60%)
Outgoing/social, age 4-6	1 2 4 5 6	8 9 10 11	5/6 (83%)	4/5 (80%)
<i>Sensitive/emotional, age 4-6</i>	<i>1 3 4 5 6</i>	<i>7</i>	<i>5/6 (83%)</i>	<i>1/5 (20%)</i>
<i>Perfectionist/obsessive, age 4-6</i>	<i>1 3 5 6</i>	<i>9</i>	<i>4/6 (66%)</i>	<i>1/5 (20%)</i>
<i>Imaginative/creative/artsy, age 4-6</i>	<i>1 6</i>	<i>7 8 9</i>	<i>2/6 (33%)</i>	<i>3/5 (60%)</i>
<i>Active/sports, age 4-6</i>	<i>2 3 4</i>	<i>7 9 10 11</i>	<i>3/6 (50%)</i>	<i>4/5 (80%)</i>

3.5. Exhaustive Descriptions

Prototypical child diagnosed with DAS (“Joey”)

In infancy, Joey has little to no babbling and is described as a very quiet baby. He seems to be interested in communicating with others, and appears as though he does understand what others are saying. He has oral-motor and oropharyngeal difficulties (e.g., difficulty breastfeeding secondary to inability to suck appropriately and “choking” episodes secondary to weak oropharyngeal musculature).

Between his first and second birthdays, Joey begins to develop nonverbal strategies to communicate. These strategies include using facial expressions and body language, pointing, and grunting. Joey’s family attempts to establish effective means of communication with him at this time by having him try to imitate words, which he usually has little success doing, or by giving him choices he can respond to non-verbally. By his second birthday, Joey tries to communicate verbally by producing a limited number of word approximations (open syllables that mostly likely have a consonant-vowel formation) which he uses to label multiple people/items. He has very few real words that he uses consistently.

At age two, Joey displays delays in both gross and fine motor skills, and he receives both physical and occupational therapy to address these issues. He is described by his mother as low in muscle tone and clumsy. Sometimes he still drools. Joey displays sensory hypersensitivity involving both sound and light. Bright lights and loud sounds often trigger a startle response and may cause Joey to cry and cover his eyes/ears.

Between the ages of two and three years, Joey’s speech output is still characterized by approximations, open-ended syllables (with minimal combining of syllables), and possibly a few words. Verbal output (expressive language) is still limited. At this age, Joey is evaluated by a speech-language pathologist and begins to receive speech therapy.

By age three years, Joey appears to become more aware of his inability to verbally communicate. His parents report that at this time Joey is demonstrating an increase in frustration level. They perceive that Joey’s frustration is directly related to his lack of verbal communication; as the ability to verbally communicate increases, Joey’s frustration level decreases. Around this time, Joey is described as shy around new people, but very social with people he knows. Initially, Joey avoids unfamiliar communication interactions, and others still rely on his familiar communication partners to translate his message. In terms of personality, Joey is described as sensitive and emotional and a bit of a “perfectionist.” As Joey enters kindergarten, he continues to have some articulation,

prosodic, vowel, and grammatical errors, although overall intelligibility improves. He begins to “catch up” with his peers in many ways, but still does not function at age-appropriate levels in speech, language, pre-academic and motor areas.

Prototypical child diagnosed with DPD (“Chloe”)

During infancy, Chloe is described as a quiet baby who produces little to no babbling. However, she appears to understand what others are saying and is interested in what is being said to her. She is late to walk, and as a baby is described as clumsy. Between her first and second birthdays, Chloe begins to develop nonverbal communication strategies to communicate. During this time, she attempts to communicate verbally, but her output and phonemic inventory are limited and her early verbal attempts are not understandable to most others. Her family attempts to establish effective means of communication by having Chloe try to imitate, which she usually has little success doing. By age two, Chloe begins to use gestures to communicate and often points or leads her communication partner to the desired item. With the exception of speech, Chloe is developing normally. Her gross motor skills are in the low-average range for her age, and her fine motor skills are average. Chloe does, however, display some sensory hypersensitivity, involving touch. She reportedly doesn’t like to wear “rough” materials and gets agitated if dirt, glue, or other substances get on her hands.

Between the ages of two and three years, Chloe’s language output jumps, although her speech is still moderately unintelligible to most listeners. She is able to produce more words and phrases at this point in time. She is, however, beginning to display frustration when her utterances are not understood. At times, she will refuse to talk and occasionally cries or throws things when she can’t get her message across. Despite these intermittent expressions of temper, Chloe is described as a socially outgoing and affectionate child. She has a good sense of humor and is sensitive to the feelings of others. Chloe has a few close friends with whom she interacts appropriately.

As she enters kindergarten, Chloe continues to have some articulation and phonological errors, and has some continuing deficits in expressive morphology (e.g., pronoun and verb tense errors). At this time, her motor skills are much improved, and she performs well in her dance class. With these exceptions, Chloe appears to be catching up with her peers and is clearly on the road to resolving her residual speech and language deficits.

4. Discussion

The primary purpose of this study was to discover, from the parents' perspectives, trends or themes that may help us to better understand the communication development of children diagnosed with DAS and those diagnosed with DPD. To do this, eleven mothers of children who had previously been diagnosed as either having DPD (5) or DAS (6) completed a semi-structured interview that focused on their child's development over time. Using phenomenological analysis procedures, information-rich quotations were extracted, evaluated, classified, and re-classified into a set of coherent themes. For the present study, these themes were all "child-focused," that is, they reflected the mothers' descriptions of their child. Throughout the interview, other important information emerged or was solicited: for example, information about the mothers' feelings and concerns, the child's therapy history and experiences, and the effects of the disorder on the family. These data, although rich and important, are beyond the scope of this thesis and will not be described herein.

The unique contribution of this study was its methodology and its sample. In the past, virtually all empirical information about characteristics of DPD and DAS has been obtained from descriptive studies completed by researchers or speech-language pathologists. These audiences have either limited interactions with each child they observe, and/or they have a priori theories or beliefs about the nature of the disorders that may influence the information they choose to assess. In general, the descriptions of these have focused in a "microscopic" way on the particulars of speech production; again, this likely reflects the interests

and biases of the professional observers. In the present study, a “zoom lens” was substituted for the microscope. The informants for this study were mothers of children with speech disorders, not professionals, and, as such, they offered a wider perspective on the development and performance of their child. This more free-ranging discussion of each child uncovered interesting behaviors, some outside of the realm of speech, which may be appropriate for further study using both qualitative and quantitative methodologies.

After examining the information provided by the mothers who participated in this study, a chronological approach was adopted to organize the large amount of data that was obtained. Several developmental “threads” (e.g., motor behavior, ease of communication, communication strategies) were followed across three early developmental epochs to examine what changed or emerged across these important developmental periods.

The Baby: Infancy to age 2;0

During this developmental period, parents of the children in the two diagnostic groups reported more similarities than differences in communication development. One of the most important observations to emerge in this developmental period was the observation made by all eleven parents that their child was a “quiet baby,” who produced little or no babbling as an infant. The significance of “low babbling” as a predictor of later language development is still unclear (Oller, Eilers, Neal, & Schwartz, 1999; Stoel-Gammon, 1985), and certainly, the absence of babbling by itself cannot be used as a predictor of subsequent speech or language delay. However, the fact that all of the parents in

this investigation recalled and discussed the virtual absence of babbling and vocal play is intriguing, and suggests that this may be an early marker of problems that warrants further study. Although expressively quiet, infants and babies in both diagnostic groups were reported by all parents to be interested in communication. All of the children were described as socially interactive and all appeared to understand speech.

The overwhelming communication problems that appeared to emerge in this early epoch related to efforts to produce verbal or vocal output. Because output was not easy and natural for these children, and because these children desired connection and communication with others, all eleven children reportedly developed nonverbal communication systems on their own to express their wants and needs. These systems sometimes involved primitive vocal behaviors (“grunting”) but more often were nonverbal (“pointing,” “gesturing”). In addition, both sets of parents discussed difficulties their child had with vocal imitation. Many of the parents indicated that they tried to encourage their child to repeat simple words during this time, but each who did so described the difficulty their child had in performing even simple vocal imitation tasks. These latter observations are interesting because both of these behaviors, the development of gestural systems to communicate and difficulty with vocal/verbal imitation, have been regarded in the literature as indicative of DAS but not necessarily DPD (Hall, 2000a).

The presence of early oral-motor difficulties was ambiguous in this sample. Although many (83%) of the mothers of the DAS children reported that

their child with DAS had some difficulty with oral-motor functioning (e.g., problems excessive drooling, inability to blow out birthday candles, choking episodes), a large number of parents of DPD children (60%) reported similar difficulties at this early age. Thus, the results of this study suggest that this particular indicator may not be highly discriminating, but is potentially important from a clinical perspective.

One final similarity worth noting during this age was the report of sensory hypersensitivity, whether it be to sound, to light, or to touch. One or more of these hypersensitivities was mentioned by all six of the parents in the DAS group, and by three of the five children in the DPD group. This finding has never been reported in published studies of DAS or DPD, although it is interesting to note that problems with hypersensitivity have been mentioned repeatedly on the Apraxia-kids website. At the very least, these results suggest that a more rigorous examination of the frequency of these problems in all speech delayed children is warranted, as it suggests that both DAS and DPD may involve more widespread neuromotor or neurosensory systems than has been previously appreciated.

Finally, it is interesting to note that all of the parents reported that, at this time, they and their child began to work together to develop effective dyadic communication strategies. As children approached the upper end of this epoch (around age two), most of the parents indicated that they were concerned about communication development, and many sought professional advice at this time.

During this time period, two salient differences were also identified that appeared to differentiate the two diagnostic groups. Compared to children who later went on to be diagnosed with DPD, more of the children in the DAS subgroup (83%) than the DPD subgroup (20%) were reported to display abnormal prosody and voice quality, even at this early age. Although not universal within the DAS group, and not exclusive to that group, the trends that we found may provide support for the hypothesis that prosodic difficulties are more frequently seen in children who are later diagnosed with DAS than those who are considered to have DPD (Munson, et al., 2003; Hall, 2000a; Forrest, 2003; ASHA Convention, 2004).

The second potentially important difference that was observed involved reports regarding the early motor integrity and performance of these children. These reported deficits occurred primarily in the DAS sample, and involved fine motor development, general muscle tone, and, as previously discussed, possibly oral-motor development. All of these indicators were very frequently reported in the DAS sample, and fine motor problems and hypotonicity appeared to be highly discriminating. All of our mothers of children with DAS (100%) reported that their children had notable or clinically diagnosed fine motor deficits that appeared by age two, compared with none of the mothers of children with DPD. Similarly, 83% of the mothers in the DAS subgroup described their young child as “hypotonic.” None of the mothers in the DPD subgroup mentioned that their child had low muscle tone. This finding is quite striking, and offers some support for

Hodge's (2003) contention that children with suspected DAS may be more appropriately viewed as having a generalized motor coordination deficit.

The Toddler: Ages 2;1 to 3;11

In the toddler years, parents of children with DAS and those with DPD continued to describe their children in very similar ways. In general, most of the children in both diagnostic groups were described as having poor intelligibility of speech, and consequently all had difficulty engaging in successful conversations with others. During this time period, all of the children were reported to experience an increase in their awareness of their communication abilities, and, reportedly, associated frustration and some externalizing (tantruming) were observed. During the toddler period, all of the children continued to create and to use sophisticated nonverbal communication strategies. These findings appeared to be a continuation and elaboration of characteristics observed by parents during the baby stage. It is interesting to note that, in many respects, both the verbal and behavioral descriptions of these toddlers are quite similar to the descriptions provided by parents of two-year old children with SLI, as reported by Rannard, Lyons, and Glenn (2004). This finding suggests that, at this developmental stage, children who are later diagnosed with DPD, DAS, or SLI may strongly resemble one another. In future studies, it would be interesting to compare all three of these diagnostically ambiguous groups over time to determine more precisely when distinctive clinical profiles begin to emerge.

The most salient difference between the DAS and DPD groups during the toddler period involved the amount of verbal output the respective children

produced. Whereas toddler children with DPD appeared to experience a “verbal expansion” during their twos, the children with DAS remained at a verbal plateau. This report was again very striking. All of the mothers in the DPD subgroup reported that their child began to produce more real words and/or word combinations between the ages of 2;1 to 3;11. None of the mothers of children with DAS described this phenomenon. Rather, the mothers of children with DAS continued to describe the struggle that their child was experiencing when attempting to produce speech output. Within the DAS group, some of the mothers did report that their child attempted to produce more words during this time; however, these productions were characterized as being primitive word approximations and continued use of open syllables (e.g., they were consonant-vowel constructions, such as “ba” or “muh.”). In contrast, the output of the children with DPD, though still unintelligible to most listeners, was universally described as more connected and lengthy than it previously had been. This vivid difference of deficits in both the quality and the quantity of output in the DAS group is consistent with several recent descriptions of the speech of children with DAS (Campbell, 2003; Strand, 2003) and supports the hypothesis that some aspects of production may distinguish the groups at this age. In fact, the finding that DAS children universally demonstrate a “verbal plateau” between the ages of 2;1 and 3;11, whereas children with DPD universally expand verbally during this time may be one of the most significant findings of the present study.

The Preschool and Kindergarten Child: Ages 4;0 to 6;11

When children were between four and six years of age, a different set of developmental issues became more salient for both groups. During this time, the mothers began to focus on issues beyond speech production, although concerns about residual or occasional problems with speech intelligibility remained a common theme. As before, both marked similarities and significant group differences were observed. Somewhat surprisingly, many parents in both groups (50% of the DAS group and 40% of the DPD group) reported that their child no longer had significant articulation or phonological errors at ages four to six. This degree of improvement in segmental articulation was unexpected, and perhaps reflects the positive effects of the therapy that all of these children had received.

Interestingly, for both groups, concerns about mild to moderate deficits in expressive language were reported to be of more concern during this time than were problems with speech production. Among mothers of the children with DAS, 83% indicated that their child had grammatical deficits, and one-third indicated that their child had problems retrieving words. Similar difficulties were expressed by many mothers of the children with DPD: 60% of these mothers reported that their child's grammatical development was not age-appropriate, and 40% indicated that their child had significant word-finding problems. These findings compare favorably with the findings reported by Shriberg & Kwiatkowski (1994), who found that about 75% of children referred to a University clinic because of poor intelligibility displayed concomitant problems with expressive language. (It is worth noting that their study sample included primarily subjects who were

diagnosed with DPD, but may have also included some DAS subjects). In the present study, more children with DAS than DPD were reported to have expressive language problems, although the group differences were modest. Thus, it may be most appropriate to conclude that expressive language problems are mentioned frequently by mothers of both groups of children, and therefore expressive language involvement in the preschool years does not appear to discriminate these groups. Because these children were still young at the time of interview, it was not possible to determine if pre-academic problems were emerging. However, several parents in both groups indicated that they were concerned that these problems awaited them (c.f., Glogowska & Campbell, 2000).

A second area that achieved prominence during this age epoch involved discussions of the child's personality and/or temperament. As they became more intelligible, all of the children were reported to show a decrease in externalizing behaviors, such as tantrums. In general, all of the children were described by their mother as generally well-adjusted, social, and pleasant. In fact, a majority of preschool children in both groups (83% for DAS and 80% for DPD) were described by their parent as "outgoing" and "social," particularly around familiar people, which was a somewhat surprising finding, given their recent history as poor communicators. However, children who were diagnosed with DAS were reported to display some temperament differences when compared with the DPD children. A majority of mothers of children with DAS (83%) described their child as overly sensitive and emotional, in comparison to only 20% of the mothers of

children with DPD. Possession of an overly sensitive temperament was described by Shriberg & Kwiatkowski (1994), who found that 67% of their children with intelligibility deficits were described as somewhat or very sensitive. Taken together, these findings suggest that a sensitive temperament may be characteristic of many children with speech delay. However, because no normally developing comparison groups were included in either this study or the study by Shriberg and Kwiatkowski, this observation requires further study before it can be properly interpreted.

Interestingly, four of the five DAS children who were described as “sensitive/emotional” were also described as “perfectionistic/obsessive” by their mother (66%). A “perfectionistic/obsessive” personality was described by only one parent of a child with DPD (20%). At present, it is not known whether children with DAS are more likely than control children to display clinically diagnosed OCD or other types of personality disorder as they mature. However, this preliminary parental observation suggests that this question may be appropriate to ask in future epidemiological studies of DAS subjects.

One important difference that distinguished the diagnostic groups re-emerged during this period of development. Parents of children within the DPD group rarely mentioned either fine or gross motor problems when describing their preschool children; in fact, 80% of the children in the DPD group were reported as being “active in sports.” In contrast, several of the children with DAS were still described as being hypotonic and/or as having continued fine motor delays. Thus, the “soft” motor problems that were first identified in the DAS group in

infancy continued to be noted as salient problem areas for many children through the preschool period.

Comparison with DAS checklists

Results of the secondary analysis, or the frequency count of symptoms mentioned, revealed the following trends. First, it is interesting to note that, of the six criteria identified in the Forrest (2003) study, only one symptom (unable to imitate sounds) was spontaneously reported by a large number of parents. Interestingly, although usually considered a diagnostic indicator for DAS, the present study found that this item was reported by over 80% of parents in *both* groups. One additional item, general oral-motor difficulties, was endorsed by a majority of parents (80%) of the children with DAS, and a somewhat smaller but still sizeable number of children with DPD. Included in such oral-motor deficits were possible hypotonicity of the oral musculature, drooling, and swallowing difficulties. If not reported as a “core symptom,” it is possible that oral-motor difficulties may be present in the children, but did not seem to meet the mean parental threshold to comment on such a deficit. Equally interesting is the observation that three of the six core diagnostic variables from this checklist, inconsistent productions, groping, and poor sequencing were never or almost never mentioned by any of our parents.

A similar pattern of findings is observed when the results of the current study are compared against the diagnostic criteria for DAS proposed by the 2004 ASHA convention’s expert panel. Of the five core criteria recommended by this group, only one, inability to repeat, was mentioned by a majority of parents in

both groups. One of the other indicators, impaired prosody, was highly endorsed by parents in the DAS group (80%), but was mentioned much less often by parents of children with DPD (20%). The other indicators identified by this group- inconsistent productions, vowel errors, difficulty with sequencing- were mentioned by between 0% and 33% of parents in both groups.

When parents were free to discuss all behaviors that were of concern, several interesting observations emerged across participants in the present study. Table 5 below highlights the items that best discriminated the children diagnosed with DAS from those who were diagnosed with DPD. As can be seen, several of the most discriminating observations obtained from parents involved observations about behaviors other than speech. In particular, parents of children with DAS described several motor indicators, sensory abnormalities, and temperament characteristics as areas of concern, in addition to some indicators relating directly to speech (impaired prosody, open syllables).

Table 5. Parent Observations that Best Differentiated Children with DAS from Children with DPD

Sensitive/emotional temperament
Perfectionist/obsessive temperament
Hypotonic
Fine motor delay
Impaired prosody
Plateau in verbal production between ages 2 and 3
Persistent open syllables

One group or two?

One of the primary objectives of this study was to compare the profiles of children diagnosed with DAS with those diagnosed with DPD to determine if the results suggested one disordered group or two. Clearly, the methodology used in the present study cannot definitively determine if these two diagnoses represent children who are intrinsically (e.g., genetically or neurologically) different from one another. However, using a qualitative research methodology the results of the present study provide some support for the perspective that the two diagnoses describe two different sets of children. This difference can best be captured as *additional deficits* more commonly reported in DAS, rather than problems that are unique to each subtype. That is, children who receive these diagnoses share many if not most characteristics, particularly when young. However, for children considered DAS, additional problems, many outside of speech, are reported more frequently by mothers. At the very least, the results of this study suggest that children who are considered to have DAS should be assessed broadly rather than narrowly in future research studies, as it appears that at least some children with DAS may have motor, sensory, and/or psychosocial (temperament) deficits that reflect more than just speech (Hodge, 2003).

Limitations

It is important to recognize that the data collected, by design, were based solely upon the mothers' perspective. No direct attempt was made to verify the parents' narrative descriptions through direct testing of the children or by

obtaining clinical or medical reports. Thus, it can be argued that the mothers were providing information that was systematically biased, incomplete, or inaccurate. In addition, because this interview asked mothers to discuss their children as infants, there may have been behaviors or events that occurred during early development that the parents had difficulty recalling or that were recalled inaccurately. However, given that the target children were still relatively young at the time of the interview (the oldest children were 6 years of age), the reliability of the retrospective reports would presumably be enhanced, particularly in this highly educated and motivated parent sample.

Another possible limitation of this study may be that the sample of parents of children with both diagnoses is unique; these parents may not be a representative sample of parents, especially of the children with DAS. All of the eleven participants were motivated to seek intervention and to bring their child to speech therapy. The parents in the DAS group were familiar with the Apraxia-kids website, and had traveled to a specialty conference on DAS. As such, it can be argued that these parents are likely to be more sophisticated and perhaps more motivated than the typical parent of a speech-delayed child. While this particular limitation may reduce the generalizability of the present findings, the unique sample may have enhanced the quality of the data that were obtained. Because these mothers were generally well educated and very concerned about their target child, they were likely to have been perceptive observers. All of the mothers were able to express themselves articulately, and appeared to be motivated to provide information that was accurate and detailed. Thus, at this

preliminary stage, our atypical convenience samples may actually have been highly appropriate for hypothesis generation due to the richness of the narratives we obtained.

Another possible caveat of this study was that parents may have been reporting what is known about the disorder rather than what they personally had experienced. This potential confound is particularly likely for parents of the children with DAS, all of whom had sought information about the disorder from a variety of sources. In fact, it was noted that many of the parents of children with DAS used “professional jargon,” during the interview. However, in analyzing the content of the reports, it became clear that the DAS parents were not simply reporting that their child possessed the “top six” symptoms that they learned about through the media. In reality, many of the symptoms reported as “most characteristic” of DAS on the websites (e.g., articulatory groping, difficulty sequencing) were rarely reported by this subset of parents. This argues somewhat against the potential criticism that mothers were merely “telling what they knew” about the disorder rather than “telling what they lived.”

A final study caveat worth mentioning is the inherent circularity of relying upon prior diagnoses to segregate the groups. Presently, it is acknowledged that the accurate differentiation of these two groups is problematic, and it is possible that the children in both groups were “mis-classified.” However, absent a “gold (or even a “tin”) standard” to differentially diagnose these conditions, expert opinion is considered our only and best alternative (Dollaghan, 2003). Interestingly, the present results suggest that the various speech-language

pathologists who diagnosed these children may have done an adequate job, as systematic and coherent group differences did emerge when these prior diagnoses were accepted.

Future Research

Although this study provided useful and descriptive information, a number of additional studies and additional analyses of this data set are possible. For example, parents in this study were asked to reflect on their experiences raising a child with a DSD. Throughout the interview, mothers reported an extensive amount of information regarding the impact the DSD has had on themselves and on their families, and many reported that they and their families passed through several “stages” on their way toward accepting their child’s disability, which perhaps would be similar to the phases described by Glogowska and Campbell (2000) for mothers of SLI children. As was the case for the SLI study, this information would potentially be very valuable in helping parents of children with speech-delay realize that many of the feelings and concerns they experience are shared by others.

Additionally, a gender analysis of the two diagnostic groups may also be an interesting investigation to complete. A cursory inspection of the data that were collected suggested that there may be interesting differences between boys and girls who are diagnosed with a DSD. To date, no studies have examined characteristics of boys with speech-delay versus girls with speech-delay, and this information would have both interesting theoretical as well as practical value.

In addition, it would be very interesting to extend this study by interviewing these same parents over time. Because interesting longitudinal changes were observed in the children's early years, it would be interesting to see if the groups continue to diverge through the middle childhood years. This type of study may help us determine how children with DAS and DPD fare in school and socially as they mature. A longitudinal study may also give us important information about the relationship between treatment variables (e.g., orientation of treatment, type of treatment, length of treatment, and outcome of treatment) for ages of 6;0 to 12;11 years. Additionally, some of the intriguing non-speech variables that were identified in this study, for example sensory hypersensitivities, concomitant motor development delays, and high-risk temperaments, could be tracked to determine if they resolve (or are maintained) over time.

Finally, it would be very interesting to include additional informants in future studies of children with DSDs. In particular, it would be potentially informative to interview teachers of these subjects. Teachers have a unique perspective, and can often provide insights about specific patterns of strength and weakness in academic areas, as well as insights about social functioning and behavior. This "third voice" may serve to expand even further our holistic knowledge about both of these puzzling yet fascinating clinical groups.

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APPENDIX A

Recruitment Paragraph for Apraxia-Kids Website and Conference Materials

My name is Diana Patrick. I am a graduate student in Speech-Language Pathology at Duquesne University and am interested in completing a Master's Thesis pertaining to parent observations of children diagnosed with developmental apraxia of speech. I am looking for volunteers who would like to discuss with me their child's development over time. This meeting would involve discussing such aspects as your child's early communication behaviors, your child's ease and naturalness of communication, and changes in your child's communication over time. This discussion will take about 90 minutes during the Apraxia-Kids Parent Conference being held at Duquesne University on July 15th, 16th, and 17th, 2004. I would also appreciate if you could bring a video-tape of your child when he/she was approximately two years of age, collected at home or in another natural environment. If you would be interested in discussing observations of your child's development to contribute to our field's growing knowledge of apraxia or if you have any questions regarding the study, please email me at **dm_patrick@comcast.net** before the conference. Hope to be in touch soon! Thank you for your consideration and time.

Recruitment Paragraph for Children with Phonological Disorders

My name is Diana Patrick. I am a graduate student in Speech-Language Pathology at Duquesne University and am interested in completing a Master's Thesis pertaining to parent observations of children diagnosed with phonological disorders. I am looking for volunteers who would like to discuss with me their child's development over time. This meeting would involve discussing such aspects as your child's early communication behaviors, your child's ease and naturalness of communication, and changes in your child's communication over time. This discussion will take about 90 minutes and can be scheduled at a time and location that is convenient for you. I would also appreciate if you could bring a video-tape of your child when he/she was approximately two years of age, collected at home or in another natural environment. If you would be interested in discussing observations of your child's development to contribute to our field's growing knowledge of speech disorders or if you have any questions regarding the study, please email me at **dm_patrick@comcast.net** Hope to be in touch soon! Thank you for your consideration and time.

APPENDIX B

CONSENT TO PARTICIPATE IN A RESEARCH PROJECT

Title: “A *Qualitative Analysis of Parent Observations of Children Diagnosed with a Severe Developmental Speech Delay*”

Investigator: Diana Patrick, B.S.H.S., Principal Investigator
Graduate Student in Speech-Language Pathology
Duquesne University
5922-2 Nicholson St. Pittsburgh, PA 15217
(724) 971-1498

Advisor: Susan Felsenfeld, Ph.D., CCC-SLP, Co-Investigator
Assistant Professor
Department of Speech-Language Pathology
Duquesne University
Rangos School of Health Sciences
(412) 396 – 4205

SOURCE OF SUPPORT:

This study is being performed as partial fulfillment of the requirements for the Masters degree in Speech-Language Pathology at Duquesne University.

PURPOSE:

I understand that I have been asked to participate in a research project to discuss my perception of my child’s early and current speech and language performance. I understand that all of the participants in this study are parents of children diagnosed with a speech disorder and this is why I have been selected. If I choose to participate, I understand that I will be asked to complete a single interview session lasting approximately 90 minutes, either at Duquesne University or at an alternate location that is convenient for me. During this interview, I will be asked to answer questions in the following general areas: a) my child’s early development, with particular focus on emerging social and communication behaviors; (b) the ease and naturalness of

communication between myself and my child; (c) changes in my child's communication performance over time; (d) the impact that my child's speech problem had had on our family; and (e) my knowledge about my child's speech problem. I understand that my responses will be audio taped and later transcribed by the investigator. I also understand that I have been asked to voluntarily furnish a video-tape of my child when he/she was approximately two years of age, collected at home or in another natural environment. However, if I do not choose to submit this video, I understand that I can still participate in the interview process. Finally, I understand that the investigator may contact me again during the next few months so that I may review the transcription of my personal interview for accuracy.

RISKS AND BENEFITS:

There are no risks involved in this study. By participating, I will have contributed to the understanding and knowledge of speech disorders affecting children.

COMPENSATION:

There will be no cost associated with participation in this study. Also, no monetary compensation will be provided.

CONFIDENTIALITY:

I understand that any information obtained about me from this research, including my audio-tape, my child's video-tape, and the transcription of the interview, will be coded by subject number and will be kept confidential. This identifying information will not be released to anyone without my written consent. Information and audio and video tapes will be kept in locked file cabinets that will be accessible only to the co-investigators. All written documents, audio and video tapes, and subject identifiers will be destroyed within five years of the testing date. I understand that my identity will not be revealed in any description or publication of this research. Therefore, I consent to such publication for scientific purposes.

RIGHT TO WITHDRAW:

I understand that I may refuse to participate in this study or withdraw my consent at any time. In addition, I understand that I may ask to have the tape recorder turned off at any time during the interview, and can request that portions of the written transcript be obliterated.

VOLUNTARY CONSENT:

I certify that I have read the above statements, or that Ms. Patrick or Dr. Felsenfeld have explained all of the above to me and have answered my questions. I understand that any future questions I have about his research can be answered by Ms. Patrick whom I may call at (724) 971-1498 or Dr. Felsenfeld whom I may call at (412) 396-4205. I

understand that should I have any further questions about my participation in this study, I may call Dr. Paul Richer, Chair of the Duquesne University Institutional Review Board (412-396-6326). Also, I understand that my participation is voluntary and that I am free to withdraw my consent at any time, for any reason. On these terms, I certify that I am willing to participate in this research project.

Parent's signature

Date

INVESTIGATOR'S CERTIFICATION:

I certify that I have explained to the above individual the nature and purpose, the potential benefits and possible risks associated with participating in this research study, have answered any questions that have been raised, and have witnessed the above signature.

Investigator's signature

Date

APPENDIX C

Interview Draft

Interview Opening

Introduce self

Obtain signature on consent form

Begin recording and obtain assent for audio-taping

“I would like to begin by asking you a few general questions about your family.”

Family size and structure (# of siblings and birth order)

Mother’s occupation

Father’s occupation

Briefly describe your current neighborhood. (city, rural, suburban, etc)

Can you tell me about the background of the families in your neighborhood
(professional/non, ethnicity, etc)

Family history of speech or language problems?

- Describe for each affected family member. Include immediate and extended relatives.

Grand Tour Question #1: *Early communication*

“I’d like you to tell me about _____’s early communication development. Think back to when _____ was 6 months old. Can you describe how _____ communicated as a baby and toddler?”

- Describe _____’s vocal behavior before s/he began to use real words (babbling stage)
 - For example, a “big babbler” or very quiet?
 - Interested in communicating with others (e.g., played peek-a-boo)?
- What was _____’s communication like around his/her first birthday?
 - Used real words? If so, describe
 - Comprehended speech?
 - Imitated your speech?
 - Were you concerned about speech development at this time?
- What as _____’s communication like between his/her first and second birthdays?
 - Used real words?
 - Combined words?
 - Produced different consonant sounds?
 - Was understandable by most others?
- How did _____ make his/her wants and needs known to you between his/her first and second birthday?
 - Gestured extensively?
 - Pointed?
 - Grunted or screamed?
- Were any strategies developed to facilitate _____’s communication during this time? If so, please describe.

- What were your thoughts regarding _____'s speech development during this time (e.g. concerned)?
- How was _____'s overall motor development progressing during this time?
 - Problems with swallowing?
 - Problems with chewing?
 - Excessive drooling?
 - Late walker?
 - Clumsy?
- How was _____'s general health during this period of development?
 - Any recurring health issues?
- Did _____ have any particular sensitivity to touch (e.g., clothing tags, shoes) during this or any period of development? If so, please describe. How did you come to notice that?
- Is there anything else you would like to tell me about _____ and his or her early communication development? Have I missed something that was of concern to you?

Grand Tour Question #2: *Ease and naturalness of communication*

“I would like you now to think about _____ when s/he was between 2 and 3 years of age. What was it like to communicate with him/her during this time?”

- Were you able to have a conversation with _____?
- During this time, did _____ develop strategies to communicate? Can you describe these?
- Say _____ wanted to tell you something, but was having difficulty getting his/her point across. What would s/he do in order to make you understand?
- What were _____'s conversations like with others? Did they rely upon you or other family members to “translate?” If so, please describe.
- What were your conversations like with _____? Did you sometimes avoid talking to _____ because it was so difficult to communicate with him/her?
- Did _____'s speech sound natural to you at this time? If not, can you tell me what made it seem unnatural?
- What do you think _____ felt like when communicating with others (e.g. frustrated, not concerned)?
- Tell me about _____'s personality/temperament.
 - Shy, outgoing?
 - Difficult temperament?
 - Anxious or fearful?
 - Has personality changed or remained relatively stable? If it has changed, what do you think contributed to that?
- What were your thoughts regarding _____'s speech development during this time (e.g. concerned)?
 - Did you seek advice or intervention? If so, from whom (physician, SLP).
 - Did you share your concerns with others? What response did you receive?

Grand Tour Question #3: *Changes in communication over time*

“I would now like you to concentrate on _____’s current communication abilities. In general, how does _____ communicate? What are the most significant changes you have seen?”

- Can you paint a picture of how _____ communicates today?
- Greatest improvements?
- Most significant remaining challenges?
- Tell me briefly about the speech intervention that _____ has received, both in the past and currently.
 - Helpful or not?
 - Can you describe what is happening in therapy right now (if applicable)

- Tell me about _____’s interactions with peers?
 - Many friends or more of a loner?
 - Difficulty communicating with peers?
 - Excluded from social gatherings (e.g., birthday parties)?
 - Looks forward to going to preschool/school in the morning?

- Tell me how _____ is doing in preschool/school.
 - Learning problems?
 - Pre-reading/reading skills?
 - Enjoys sports? Well coordinated?
 - Favorite activities/school subjects?

- Besides speech, does _____ currently have other chronic health problems or other problems for which he/she is receiving special services (e.g., OT, PT, reading specialist, psychologist, nutritionist)? What kinds of things are they working on with _____?

Grand Tour Question #4: *Family impact*

“Now let’s shift to your family’s reaction to _____’s communication. Can you describe for me the impact, if any, that _____’s overall communication has had on your family?”

- Perceived stresses on family dynamics/interactions (greatest challenges)?
- Any positives associated with the disorder (unexpected benefits or joys)?
- Do you believe your life would have been different if _____ had always had normal speech development? How?
- Do you think that _____’s speech problem has had an affect on his/her ability to form a strong bond or attachment with others within the family?

Grand Tour Question #5: *Impact of diagnostic label*

“Can you tell me the circumstances surrounded your first encounter with the term apraxia (or phonological disorder)?

- Has learning this label made a difference? In what ways?
- Have you used this label to try to research your child’s problem?
 - If so, where have you searched or whom have you consulted? (internet, physicians, SLP, etc.)?
 - Results of search attempts (provided comfort, created more confusion?)
- What do you know about developmental apraxia of speech (DAS) / developmental phonological disorder (DPD)? Would you like to know more? If so, what would you like more information on?
- Do you participate in parent support groups for DAS/DPD, either face-to-face or via the internet? If so, please describe.

Interview Termination

“Our interview is nearly complete. Before we wrap up, is there anything else about _____ that you feel I should know that we haven’t already covered? Do you feel I have obtained a reasonably complete picture of _____, particularly his/her speech development and challenges?

“If you think of anything you would like to add to your personal story after today, please feel free to contact me, either by email or phone. As you know, all of our correspondence will be kept confidential.”

Member checking reminder

Thank participant for time and effort and close appropriately.

APPENDIX D

EMAIL FOR MEMBER CHECKING

Dear [Participant],

I have been working on my thesis entitled “A Qualitative Analysis of Parent Observations of Children Diagnosed with a Severe Developmental Speech Delay,” in which I interviewed you this summer at the Apraxia-Kids Parent Conference. As you may remember, we discussed part of the research process called ‘member-checking’ to ensure that I have recorded and interpreted your interview accurately. I have attached the following information:

1. *The transcript.* For the transcript, I have listened to our recorded interview and typed exactly what I have heard.
2. *A summary.* For the summary, I have included the beginning version of my interpretation or thoughts of the main points of the interview.

Please review this information for any inaccuracies and corrections you would like to make. If you could email me back by July 10th, I would greatly appreciate it, as my thesis is coming to an end shortly thereafter – July 29th!

Thank you for cooperation and time. I look forward to hearing back from you soon.

Sincerely,
Diana Patrick

TRANSCRIPTION: Participant 2

C02 - child with DAS

Diana – So, I also wanted to begin by making sure it's ok to be audio-taped.

P02 – absolutely

D – Ok, and, just kinda talk a little about your general questions about your family. Um, maybe the family size and the structure of your family.

2 – Ok, um, it's just [my husband] and I, we're both, uh, we both, work full time. Uh, both uh graduated college, we both have bachelor's degrees. Uh, we have [C02] who's five and [her sister] is, uh, [C02]'s sister, who is two.

D – Ok, and you're occupation again.

2 – I know, it's kinda funny. I monitor drug research studies (ok) and [my husband] sells orthopedic surgical equipment.

D – Ok. And could you briefly describe your current neighborhood?

2 – Current neighborhood, it's uh a newer subdivision. There's probably, I think there's 160 houses in the subdivision, Um, middle class, maybe.

D – um, professionals, a lot of professionals?

2 – single-family homes. (ok) Yeah, professionals.

D – ok, um, ethnicity?

2 – mixed, yeah, it's mixed. Um... to being in Tuscan or the south, west. Um, there's Hispanic, Asian, um, white/Caucasian, there are some African Americans, I would say, it's it's fairly mixed, fairly mixed.

D – Ok, and is there a family history of speech or language problems?

2 – No. None on my side or [my husband]'s side.

D – ok. Now, we're gonna, kinda get into the interview and talk about [C02]'s early communication. So, I'd like you to tell me about her early communication development. Think back to when [C02] was 6 months old. Could you describe how she communicated as a baby or toddler?

2 – Um, she became pretty vocal, I think, um, you know normal development, it seemed like. You know, cause we, she was, she was quite premature. Um, and so she was being followed regularly through early intervention programs. Um, but even at six months when we went for that appointment, you know, things were, seemed to appear on target, you know, she was making cueing sound, or cooing sounds and and babbling, things like that.

D – ok, was she interested in communicating with others? Did she show an interest?

2 – Yeah, yeah she would, you know, try, you know, she would smile and you know, make the eye contact, and you know would make sounds for us to interact with her or would respond to sounds that we had made to her.

D – ok, and what was her communication like around her first birthday?

2 – She was pretty quiet. (laugh) Um, we didn't really, uh, in trying to figure that one out, we were, we were reviewing this video tape um to bring it here and at her first birthday party, outside of laughing, you know, she would laugh, she was very social, um, outside of laughing, she didn't have much sound. (really). So, I don't know what happened between six months and a year, you know, but, she, and she's had no medical problems, no infections, no anything that we can think of, you know. But so, about about, you know, her first year, uh when we did the follow-up clinic at that time, you know, we did start showing, expressing concern that she she wouldn't say momma, or she couldn't say dada, she, uh, kinda lost interested in in maybe that communication. Um, she, she would wanna be by you all the time, you know or laugh and giggle and things like that, but as far as um producing sounds it was not, not often (laugh).

D – ok. Could she comprehend speech?

2 – Yes. Yes. You know, if we would ask her to come, you know she would crawl over or you know if she wanted her bottle, you know, she would definitely you know kinda gesture for it, things like that, she she definitely has comprehension.

D – ok. And what about imitation of speech, was she able...?

2 – no, none, it was very rare.

D – Ok. Um, were you concerned, you said you were concerned, you started expressing some concerns, (um hum), ok.

2 – Yeah, to the follow-up clinic personnel, I think we were seeing a, I think she was an OT, PT person at the time.

D – Ok. And what was her, er, [C02]'s communication like around her first and second birthday, between there?

2 – um, a lot of um, I think probably eighteen months we still had no, no real sounds out of her. Um, closer to her second birthday we were getting the general /a/, [ʌ, ʌ], a lot of /ʌ/'s, a lot of grunting, maybe some beginning grunting. Um, a lot of pulling your finger to go show you whatever she needed. Um, pointing, things like that.

D – Ok. Was there a lot of gestures used, did she kinda?

2 – A few, a few. Like I said, pointing maybe. Um, you know, we were trying to get her to say drink. I do remember that you know um she was kinda using a little bit of a sign

for drink or /d^d^/ maybe some simple, you know simple sounds, like that, but it was pretty limited, pretty limited.

D – Um, were any strategies developed to facilitate her communication during this time?

2 – Not yet, uh, not before she was two, no even around her two year old birthday. Uh the, the follow-up clinic kept, you know, saying you know she's just a little delayed, it'll come, just, you know, give it time. Um, pediatrician wasn't really concerned again. She just thought it was you know she was just delayed. Um, so you know as far as like introducing like a picture board or sign language, that was never um suggested, I guess.

D – Ok, did you as a family kinda come up with any, um, strategies.

2 – I don't think so, you know just uh let her you know let her continue to try and pull us wherever she needed or you know you do whatever you can to help facilitate your child you know from getting frustrated you know so you just kinda play, I guess, we played multiple, we called it multiple guess all the time you know. Did you want the ball, did you want this, do you want that? Um maybe we played multiple choice with her until she kinda nodded her head or you know showed an interest in what we were talking about.

D – ok. Um, what were your thoughts regarding her speech development during this time?

2 – getting more concerned, definitely. Um, you know again we expressed concern that you know she doesn't, she didn't repeat sounds really, she never initiated sound, um, besides the giggling and the laughing. Um, but it was, you know, she was pretty much quiet. She was very quiet.

D – Ok, and how was her overall motor development progressing over this time?

2 – delayed. It was delayed as well. Um hum. Gross motor and definitely fine motor. (really?) um hum.

D – Ok, problems with chewing swallowing, drooling?

2 – Not with that part, but um, you know walking up stairs, walking down stairs, you know ability to hold a crayon, or a pencil was very tough. Um, you know, at least to scribble and things like that she would hold it like a fist. Um, you know, she, using a spoon, getting things like into her mouth without it falling off the spoon or fork were tough. Um, but she's never had a problem of eating. You know, she would eat anything, you know any texture, any any flavor of things.

D – Any excess drooling?

2 – Uh, yeah, a lot of drooling, definitely. And um everything went into her mouth. Um, whatever, anything, anything and everything. You know, if it wasn't food, it was shoes,

it was you know a piece of cloth on the floor, you know pillow, she was a big thumb sucker. Um, books, ate a lot of books. Lots of things in this mouth. (ok) That's continuing.

D – (laugh) Is it? (yes) Um, I know you said that she had some problems walking up and down steps, (uh hum) was she a late walker at all or?

2 – Um, let's see, she was probably not real late. Um, 18 months approximately. Um, it's a little bit delayed but not. I'm trying to think, yeah it was probably close to 18 months.

D – Ok. Um is she clumsy at all, a little?

2 – Yeah, she's termed clumsy, yeah, especially at 2, she would you know, sit on a chair, we'd have to certainly help her do that or she would, we couldn't let her, climb, you know, she would try to crawl up the stairs, but she was kinda unbalanced. Um, yeah, she would, she would slide off the couch quite a bit (laugh). Um, yeah, people thought she was clumsy.

D – ok, um, how was her general health during this period of development?

2 – very healthy. (ok) Um, she's probably, besides the check-ups, you know, which you go annually or at that time you go every 6 months, um, she's gone to the physician, I think twice. She has a, she gets a, like a, it's like a cold sore, it's a herpes simplex infection on her left middle finger every year about May. I don't know why, it just resurfaces. But, um, never had like ear infections, you know besides childhood colds, running noses, and cough. No fevers to speak of. Um, no drug allergies. So, no, very healthy.

D – Did she have any particularity, particular sensitivity to touch during this period of time?

2 – Not that I was aware of.

D – Ok, no clothing tags, shoes bothered her?

2 – uh uh uh, hm. Um, I think when, when we, she didn't like to be held, so maybe it was, maybe it was a tactile, we didn't really you know think about it at the time, um, she wasn't a real snuggler, you know as a 2 year old or infant would be you know just really want to be close to their mom. Whenever you would try to hug her or hold her on your lap and she would kinda squirm. (ok) So we wouldn't hold her real close.

D –Ok. What about, um, the playdough textures and stuff? Did she have any?

2 – Um, when she would get, you know, we did a lot of finger painting, you know, I'm I'm a big hands-on person, um, when we did finger painting, she didn't like it on her hands,

you know. Um, but it it would just be like she would shake her hands to try to get it off. But she didn't, like, cry, it didn't really, you know, affect her to the point where she wanted to stop. You know, um, she would just definitely shake her hands, but I would give her, like, a different color to use and she would be right back on it.

D – Ok. Um, is there anything else that you would like to tell me about [C02] during this period of development? Is there anything you think I've missed?

2 – Um, let me think. Just that she was, you know, even though she didn't communicate like verbally, um, she was still a, she was very social. Um, it also goes with having no fear, she has no fear. (laugh). Um, she was very expressive with her face, so she could communicate through lots of facial expressions. Um, so she, you know, she still got her point across I think a lot. She found other ways to communicate, that's for sure.

D – what kind of, what would she do, a little, to communicate? Like, the pointing you said, I think would she like pull you aside to take you to the place? Or

2 – Absolutely, yeah, there was a lot of it. She, she would come get our finger, that was kind of, I mean, it was something that we, just kind of um, taught her to do or she kinda learned to do herself. She would just come and get our finger and then pull us to whatever she wanted to see, do, things like that. Um, or it was just very, like I said, very facial expressive.

D – Ok, um, now I'd kind of like to talk about the ease and naturalness of [C02]'s communication. Um, I'd like you to think about when she was between 2 and 3 years of age. What was it like to communicate with her during this time?

2 – Got more and more frustrating. You know, um, it was easy for us to, you know, I mean she knew that, what we were saying. Um, but it got to be frustrating for her because, you know, if she would want something, she wouldn't say anything at all, you know. But, if we chose the wrong thing that we thought she wanted, then she would, um, really get frustrated. (OK) Definitely. Um, you know, she became more and more aware, you know, she was becoming more and more aware of her lack of communication maybe. So, you can tell that, yeah, by by her third year it was pretty frustrating.

D – Um, were you able to have a conversation with her in any way?

2 – where she would respond?

D – uh hum.

2 - No, no. Um, not that, I mean, not maybe she would respond with a few sounds, but not, not much. That I recall.

D – During this time, did you develop any more strategies to help facilitate communication?

2 – Um, huh uh, not before she was three. Uh uh. We were still just told that, she wa, you know, she was a little delayed, but, you know. She kept, maybe, I think, she was maybe making more sounds, but nothing constructive, nothing, um, of meaning. You know, so they sound, well she is making more sounds, and so she is on her way.

D – (laugh). On her way. Um, so say [C02] wanted to tell you something, but was having difficulty getting her point across. What would she do in order to make you understand?

2 – Um, she, I don't know, gosh, at three, let me think. She would probably just repeat the sound, make a sound, and if we didn't get it, it was just, um, she would turn into like a little tantrum. (really?) Um hum, um, hum. And then the tantrums just progressively got worse. So, but at three, it was, uh, yeah, you know just like a little two year old tantrum. She would fall to the floor and kick or you know crawl.. agh. (laugh).

D – Um, what were her conversations like with others?

2 – Um, just simple little sounds or there was none at all. You know, if um, trying to think if my sister came over, you know, she would go up and hug her and yeah grab her finger. It was always grabbing the finger. Come with me, come with me. Um, you know, or she just wouldn't say anything. Besides laughing. We like to laugh. She's very funny (laugh).

D – Did, um, they rely on you to understand what [C02] wanted?

2 – Did, did outside members, or friends and family? (Uh huh) Definitely, definitely. You know, trying, what does that mean, or what does she want? You know, cause we would just read her body language or maybe her gesturing or, or things like that. Yeah, everybody always said, what is she saying, what does she want? I don't know. Your guess is as good as mine. (laugh)

D – Um, what were your conversations like with her?

2 – Um, mostly one sided. You know, I would just, you know talk to her like she was responding, maybe or um answer my question that I asked for her, you know. Um, you know, [C02] how are you? You know, or do you feel good? You know, and would get no response. Oh yeah, you look really happy, you know. Just kinda have a, I would you know continue to talk to her, but, what, when she wouldn't respond, maybe just kinda read her language, body language a little bit and fill in the answer for her. You know, just, just keep going with it. You know or read books, you know, um. You know, doesn't

the puppy look happy? Or get the ball puppy, get the ball. You know, and she would just sit and listen, but not very often respond.

D – Ok, um, did you sometimes avoid talking to her because it was so difficult to communicate with her?

2 – Oh I'm sure I have, you know. Um, I'm sure there's a lot of things, yeah, I've avoided asking her questions, or or things like that. Because you know that she can't respond, or definitely um we found later you know by not giving her choices, you know we would just we would just say, you know, [C02] do you want the red one or the blue one? But that became more frustrating for her. You know and so there would be a lot of times we just avoided the choice and just given her, here's the red one, kind of thing.

D – And, did any of her speech sound natural to you at this time? Any of the little sounds that she had or?

2 – It sounded, um, you know, between like 2 and 3, it sounded like she was 6 months again. 6 or 8 months old again, 9 months. Well, um, it was a lot of just the babbling, you know, kinda incoherent cooing and babbling. So, it's like, it sounds natural but it sounds, like, you know, we should be doing much more than this by now. (Ok) It sounds like the early stages of language.

D – Ok, um, what did you think [C02] felt like while she was trying to communicate with others?

2 – Um, she, I think she felt like she was being social you know, by trying, trying to communicate. But like I said, when she couldn't, when she wanted something specific or when she was trying to get her point across and we couldn't quite understand what she was saying, it became very frustrating, very frustrating for her. And her behavior you know manifested into little tantrums or she would just sit down and not participate at all, um, run the other way out of frustration, tactics like that.

D – And, could you tell me about [C02]'s personality, a little?

2 – uh she (a lot... laugh). She's a spitfire. Um, she's very funny, no she's a very good little girl. Um, let's see. She's, she's extremely social. As I've said many times, extremely social. She has no fear. Um, very happy, loves to run and laugh, and you know giggle and and things like that. Um, but, in the sense, like, she she wants to be around people all the time. Um, little kids you know when we go to a playground, she's always done this since she could walk probably, um, go to the park and play on the jungle gym and immediately, if there's another little kid there or even a mom a dog a grandpa, it doesn't matter, she doesn't, you know she certainly doesn't discriminate, um,

she'll go up and she'll hug their leg, or she'll she'll wanna sit on their lap. Um, I recall, she was probably about a year and a half when we were in the airport flying, and she immediately went up to this older couple sitting, waiting for their airplane. It didn't matter, she went over and just kept play, playing with the guy's leg and the guy thank goodness was nice enough and he put her right on his lap and they were having a grand old time, you know. And you know [C02] would just, like I said just giggle and you know, facial expressions where her eyes just just light up. You can completely tell. Um, let's see, as far as like uh communicating with you know same thing with cousins or grandparents that come. She just wants to, she'll go and pull their finger or pull their hand. Come with me come with me. Always wants to be by them. Um, but then but then you know, once you, once she tried to get her point across and she couldn't be understood it was like... a lot of raspberries. (laugh) But.

D – um, has her personality changed or remained relatively stable?

2 – Um, when we put her in school at, we put her in her preschool at 3 and a half, um, it became increasingly difficult for her because she's got other sensory issues I think going on as far as um, she doesn't like to sit for long periods of time. I don't know if it's sensory or ADD or whatever. You know, you got all these terms that are now coming up as she gets older. Um, but, but interacting with other um, other kiddos in her preschool class or even a teacher, you know [C02] would sit circle time, teacher would be reading a book, and [C02] wanted to point out that there was a puppy in the book. Well, teacher couldn't understand her, so [C02] would just keep saying it, teacher couldn't understand her, or you know and so she would just get really frustrated. Um, so her behavior would you know she would act out, she would have a tantrum, very hard to recover. Um or the other classes that I've observed where the kids, [C02] wanted to go um play, you know ask another kid to play you could tell by her body language. You know, she would go up to the to the other little kid, do you want to play trucks with me or whatever the kid's playing with. Kid couldn't understand her, so [C02] would just take the truck. Well then the other child thought [C02] was being mean and taking the truck away. Um, and so, you know then she, he would go tell the teacher, [C02] took my truck, and [C02] would get yelled at because she took the truck. And, so you know she got blamed a lot for being, you know kinda being a bad kid, but it was just she couldn't be understood, from my observations. Of course being a parent you don't think your child does anything wrong, but. Um, and so she actually was only in the preschool for, August to November when we pulled her out because she would go and be good for like the first ten minutes.

Every day she would go like she's never seen these people again, you know before, nothing's wrong. You know, she would go and hug the teachers as soon as she got off the bus. She would hug the kids, you know, when she would get there and um and then as the day, it was only a two hour and fifteen minute class but as that time progressed you could just see her her face would become more blank, um you know she would she would try and communicate less and she would just go and take the truck instead of even asking at that point. Um, she would um, the teachers would, put her in time out a lot because um, because she took the truck or she hit the kid because you know the kid didn't want to give her the truck. So, she, a lot of these other you know behaviors would come out, um because she she couldn't be understood so she found her own way of, can't understand me, I'll just take the truck. (yeah) kinda thing and that happened a lot during, um, um the school time that she was there. That help, (yes it does), does that explain it? (laugh)

D - Yeah, um, what were your thoughts regarding her speech development during this time?

2 – We were very concerned. Um, very concerned and we were pushing more towards getting her evaluated. I mean at the same time even though the the teachers at the program you know were frustrated with [C02] they at least they were still a very good resource for us um you know and they kept you know they would recommend you know I really think that [C02] should see a speech therapist, I really think [C02] should go uh get evaluated. And so that's kinda where it um I'm trying to think. That kinda fell into place a little bit earlier too before school even started. Um, right at the end of the at three years old you get you graduate from the early intervention program. Um, the psychology analysis er psychology evaluation of [C02] was that she was very delayed, um, cognitively as far as speech. Um, her receptive seemed fairly good, like 74% or something like that I think it said. But um she couldn't get tested on verbal because she couldn't say anything. Um so they pushed us to go get [C02] evaluated by a speech therapist, by an occupational therapist and by this other group called Child's Find. Um, I guess they are the ones that also encouraged us to go into this Project Able Preschool and then the preschool teacher said she's pretty severe we don, you know I think maybe you should pursue other things and I think one of the speech therapists at that point is the one that diagnosed [C02] with the Apraxia.

D – Ok, um, did you seek any advice from physicians or?

2 – Yeah, definitely um talked to the pediatrician every visit, you know. Um, and al, probably by the third birthday, you know, we kept saying we're concerned, we're concerned, and she said she's just delayed. Um, and then since she knew we were being followed through the early intervention program, you know she didn't really recommend anything else because we're you know they had recommended the speech therapist already, they had recommended occupational therapy already um by her third birthday. And so, let's see after that, um, after her third birthday, I think the pediatrician you know was getting more concerned and you know definitely recommended a speech therapist, recommended [C02] saw a speech therapist on a regular basis, um, but that was about it.

D – Ok (I think). Um, did you share your concerns with others?

2 – Yeah, (laugh) and they concer, they shared obviously their concerns with us as well, you know. What are you going to do, what are they say about it? Um, yeah we we tried to talk to anybody, you know. That's why, like I said the school, um teachers, you know, have you ever seen other kids like this? what would you recommend? what've what have other parents done in the past? You know, we we would try to talk to anybody to see what what our options are you know this is new to us you know what do we do? What, where do we go? And try to see what other people have done.

D – Yeah, ok, Now I'd like to talk about, um, her changes in communication over time (OK). Ok, and I would like you to concentrate on [C02]'s current communication. In general, how does she communicate?

2 – Right now, being five, a lot of word approximations. Um, that's after a year and a half of therapy three days a week. Uh, so, a lot of word approximations, um, we do some sign language, um, she's not real interested in sign language, my two year old signs quite a bit (laugh). Um, all um it's still a lot um a lot of pulling you know come follow me, come, come with me. But if um, she tries she tries to tell us first you know um you know uh [m^ w^ wa] you know "mom, want water." Ok, you know, um, if we don't quite get that, you know then she'll try and do a sign, show us, you know, a drink, you know show us like she wants a drink. Or, she will just pull us over to the refrigerator and open the door and pull out the juice or whatever she wants. So, a lot of it is is still you know pointing, gesturing or just tagging us along. Come with me, (laugh) Ok, and we still do a lot of the multiple guess. You know, do you want do you want water, do you want juice, do you want something to eat, are you hungry? And usually you know she kinda affirms either with her face, yes, or or she'll say [ya] or you know something.

D – Ok, and what are the sig, most significant changes you've seen?

2 – In her, in her communication? (Uh huh). Um, I, I think mostly she's she is initiating a lot more sounds, she's realizing that she can say a lot of things, um, she definitely, we we're not always you know getting her to imitate a a sound as much, just to communicate, she's actually um, initiating a lot of the sounds on her own er, initiating conversation. Um, and she's now able to put 2, 3 4, word approximations together more into a sentence, or you know, if we slow her down her clarity is a little better. But, there's times where she just, you can tell she's saying a whole story, and you just you just kinda let her go and it's all it's just a whole sequence of sounds but nothing really intelligible. But I, at the same time, since she is able to find success in com, some of her communication, um her frustration level decreases. They're definitely you know inversely related (laugh).

D – um, what are the most significant remaining challenges you feel she has?

2 – Clarity, you know, continue to get her some clarity. Um, and continue to, er her challenges are just to still you know verbally communicate and make it intelligible. Um, I think, we were trying to think back, at three years old, I think we decided um we kinda came up with she had like 2 or 3 clear words. Um at 4 she probably had closer to 5 or 6 clear words, which isn't that many over a year's time. At 5, she probably has, you know, in the speech-language world, um words which means has the beginning consonant, end consonant, you know and the whole sounded appropriately, she probably has closer to 15 or 20 now. But at 4 she probably had 10 approximations where at 5 she probably has you know 100 approximations that she uses. So, it's definitely come a long way, um but still we're we're working off a lot of approximations and not a lot of words. So, people um that are around her all the time can understand at least the context of what she's speaking about or what she actually wants, um, probably understand you know 70-80%. If you're not around her very often, it's closer to 40, 45%. Which is great, you know, we're not playing interpreter as much. But still quite a bit because it's not clear. So our challenges are to gain approximations and definitely work on the clarity.

D – Um could you tell me briefly about the speech intervention that you have received?

2 – Yeah, (laugh), not been good. Um no, it's been good for the last year and a half but um, I think when we were voicing concerns, yeah I guess now that I'm bringing this up, um, voicing concerns at 2 years old, I think she was closer to 3 years old, um, they you know they recommended the early intervention program, recommended speech therapy, but it wasn't a very aggressive approach. Um, the therapist would come to the house,

um they would do home therapy an hour at a time, once a week or whenever we scheduled it. You know, um, so sometimes it was once a month, sometimes it was 2 or 3 times a month, um, and then you know we'd go on vacation or other things would come up and then we'd have like 3 months without any therapy. Um, and the, the we started off with a good therapist who really got [C02] engaged in activities and really had a chance to get [C02] kinda imitate sort of a sound. Um, I think her sound that they were working on at the time was [go], like just a, an /o/ sound, any kind of an /o/ sound. Um, and that therapist we had for about 4 months and at least got [C02] to do an /o/ sound kinda on command. Um, then we went to through a therapist, who, (laugh) who would come to the house, she was a peach, um, and really couldn't get [C02] engaged in anything. Um, would bring a laptop with her and through in. I know I get that same facial expression whenever I bring that up. Um, and cause we had the same facial expression. She brought her laptop with her and would put in like a CD ROM, child interactive CD ROM, and I just remember watching this and there'd be like a little bear going across the screen. However, out of the hour that she was there, 15 or 20 minutes was to get the laptop out, get the disk out, get it running, get the program going, and by the time the little bear kinda went across the screen, you know [C02] was, she wanted to push the buttons and things like that, and she the therapist kept saying no don't push the buttons, don't push the buttons. You know, just a minute, just a minute. Well, 15 minutes of telling, being told no and just a minute, [C02] got pretty frustrated and so basically was not interested in therapy at all or in interested in what uh she had to say. So, by that time, we were kinda like well what she's doing with [C02] we can do by ourselves, you know. We didn't, we weren't gaining anything in our opinion. Um, but then we met, you know then we got the the diagnosis of Apraxia and we, you know, were kinda encouraged to really find therapy for [C02]. Um, so then we went through 4 other therapists I think over the next year. Um, and the more we learned about apraxia, the more we were able to weed out some therapists. Um, the for example the other therapist that we went to twice (laugh), um these are all very clear (it's all coming back, laugh), it's coming back. We went to her twice. The first time you know was obviously just the evaluation, so she could see what [C02]'s like, blah blah blah. So, you know, pretty much no therapy, just kind of, just to see where [C02]'s at and what kind of program [C02] should be into. Second therapy session, um, [C02] sat at the table, [C02] would be 3 and ½ by this age, um, [C02] would sit at the table, therapy table and the therapist would be like um, [C02] say this, [C02] say this, and [C02] couldn't say it and

[C02] wanted to go get of this chair and go play with the teddy bear or something on the floor, I don't remember what was on the floor, but wanted something on the floor. And the therapist said, no you can't get down until you say this you know. Say this and was really kind of in her face. And um basically as you can see I ca, you know [C02]'s frustration levels was increasing, my frustration level (laugh) frustration level was was a little crazy at this point. Um and I just kinda picked [C02] up and said thanks for your time but this is not working. Um, you know from everything we've read about apraxia, you know the more you force her to do it or the more you you know get in her face and say do this, she can't and she's going to shut down even more. You know, um, so she was really kind of a an aggressive therapist but like too extreme, you know. You can't get down until you say this well [C02] couldn't say anything at this point, so that was pretty tough. Um, the other therapist had a student with her, um, and actually had gone to an apraxia conference, but had a student observing um the therapist at the time, and so there was two people in the room, myself and then [C02]. Um, and I usually kinda just sit back and let the therapist take over obviously. Well the one therapist, the main therapist um was trying to really get [C02] going. [C02] wasn't responding and so she was trying even harder. Well then the student decided to jump in and so they were both like [C02] do this, say this, do this, say this. And so, you know can you say uh, can you say uh, can you say oow, and so it was like this bombardment of therapy going on and and [C02] of course then went, you know, she just shut down at the same time. Um, and tried a second session, I try, try and give people the benefit of the doubt, tried the second session with her and it didn't get any better. It was um she couldn't get [C02] engaged in anything. Um, [C02] got pretty frustrated, so we didn't go to uh, to that one. Um so we went through a series of several. Um and finally we went to a conference with Dr. Strand last January, January of 2003. So [C02] would be 3 and a half, yeah 3 almost four at this point cause she turns four in april. Um and fortunately we met up with um the uh one of the coordinators of the conference who knew somebody in Tuscan who had a son and kinda networked a little bit that way and via email we kinda said you know hey who do you have as a therapist because their son had similar issues and that's how we found the therapist that we have now. Who is much better. Um, I, you know there's some things obviously I'd like to change about her, but at the same time, she's been great for [C02] because she, she feeds on [C02]'s successes and doesn't really promote the negative as much um. You know, and really builds on getting [C02] an approximation, at least. Or uses sign language, you know, she you know encouraged us

to maybe use sign language with [C02] or encouraged us more to use like a picture board and kinda just really given us helpful hints on how we can get [C02] successful communication. So, oh we've been doing that for a year and a half, three days a week. So I think, you know, by just increasing the amount of therapy, finding a therapist that [C02] enjoys going to and at least um is, isn't in [C02]'s face and kinda lets [C02] dictate maybe more play therapy, it's become more successful.

D – Ok, glad you finally found someone (laugh).

2 – Yes, oh me too, me too. Oh it's been, it was a lot you know. And we knew that that's what we needed you know from everything that we've read, we knew that we needed a therapy to [C02] and frequent, you know and step up the frequency but trying to find somebody that, well, A) was qualified or had worked with kids with apraxia. That's the other thing, we couldn't find anybody that worked with kids with with apraxia. Um, solely or just didn't know how to deal with her, you know. Because she she wouldn't say sound or her, you know she had a lot of sounds that weren't you know able to imitate what they were asking. So, it's kinda, kinda tough.

D – Yeah, um, I lost my. ??? Um, could you tell me about some of her interactions with peers now?

2 – still very social. Um, she's very domineering. You know, for not being able to communicate she certainly is right in people's faces. Um, where everything that we have been told, especially by our therapist now, and and other people that have evaluated [C02] is um that's very rare. Usually if they can't communicate a lot of times, they shut down, become isolated or you know kinda play by themselves. I've never seen that (laugh) ever, ever ever ever. Um, she is she wants to be the middle of the, you know, middle of the group and and she wants to be right next to the kid with the toy or whatever. She she will try and find anybody that will engage play with her. She's very social. Which is good. I guess it's a, it's a positive. I keep saying you know if she would just you know be a little bit friendly, you know a little just you know have a little fear and maybe not so dominant. I guess she gets that from her mom. (laugh).

D – that's a good thing, then (It's alright, we'll deal with it). Yeah, um, does she look forward, is is she in school now, in preschool?

2 – Um well I was taking her to a structured day-care center, um she goes to in-home day care, but basically my two children are the only ones there and um there's like another little boy er little girl that come infrequently, but every so often. Um, and so what I was trying to do to get her around other kiddos, you know, cause she, you know, she's

so social and things like that I wanted to get her around other kids, but the same thing was kinda happening as it was the year prior in the preschool setting, um so I was only taking her um I started to take her, this was about 3 months ago, um, like 2 days a week, Thursday and Friday, cause she had I was kinda tryin to do like a routine you know to keep her in a routine. Monday, Tuesday, Wednesday was speech therapy, and so then Thursday and Friday at the same time slot then we would go to the structured day care center. Um, um for a little bit longer, but um to get her around the other kids. Um, and it was going well. I would stay with her most of the time to kinda be play interpreter. Um and she she would be right in. She wanted she would as soon as she would show up you know the other kids would be like “[C02]” and she would go over and hug everybody and hug the teachers whatever you know and wanna go run and play with everybody. Um, but when it came time to come inside or you know um they played a lot outside, when it was time to come inside and play in like the the centers you know like like a lot of day care centers have the centers you know like the house center and the wood block center and whatever you know the different little things like that were it was kinda more contained and focused, and um [C02] would have to interact more on an intimate level trying to communicate, um, she couldn’t be understood by her peers and so again a lot of her frustration behavior would come out. Uh, she would hit, she would growl, she would do raspberries, she would scream, those types of things. So, if I wasn’t there to intervene, or the teacher wasn’t there to intervene, excuse me, um, you know it would get pretty frustrating. So, we did that for about three months and about about a month ago, we we just decided to phase that out, too.

D – Ok (so,) um, did she look forward to going there, was that like?

2 – uh huh, uh huh, absolutely. You know, I’d say we’re going to go play with the kids today and it was like oh ok, you could see in her face, you know, and as soon as we pulled in the parking, she was already unbuckling her seat belt, you know she was like couldn’t wait til I got the door open, she would run to the door, um, definitely. You know when it was time to leave, you know even if she’s had, even if she had like a bad time as far as like you know behavior wise, when it was time to leave, she still didn’t want to go, you know. It was like “no, no” I’m like well it’s time to go you know. Um, so yeah it could, she definitely wanted to go. Wanted to stay.

D – Yeah, didn’t want to go home. (laugh) Um, could you tell me about um do you notice any learning problems or pre-reading, her pre-reading skills, what are your?

2 – Um, I think you know we're kinda early in that, but at the same time I, um, it took us a long to get like letter recognition, we're still trying you know she has them all now, but like the alphabet, um there's definitely um it took us a long time. Even number recognition. Um, learning the alphabet, was, took a long time the whole alphabet, where, now that I have a a you know in a sense normal child to compare to maybe more on a daily basis, we can really see how much more delayed she was. Um, cause at 2 years old, you know my my uh [her sister], you know knows the alphabet can definitely recognize a lot of the letters you know. If we say where's the letter "b" she'll be able to point to it, where [C02] had a long time, um didn't know that for a long time. Um, it was probably closer to when she was 4 that she really was able to do letter recognition or say the alphabet. Um, saying the alphabet is even tough obviously cause she uses a lot of the same sound for different letters. Um, but you at least, there is at least is some sort of a sound change when she does the alphabet. Um, we're let's see, and and now when we do play we have the alphabet in front of us you know. Where is the letter "c" she can point to with a much more you know higher percent accuracy.

D – uh huh, ok. Um, does she enjoy sports?

2 – Any of them. Anything outdoors, anything running, anything. Yeah, um, we play baseball, you know to try and work on her you know coordination. Um, loves to play baseball, softball, um soccer, we have several soccer balls. Swimming is probably her favorite, um, but we do, yeah, we do just about anything. She gets a little frustrated with crochet, (laugh), cause she can't quite get that mallet, you know it's like I think it's like you know her some of her fine motor, gross motor delay that she can't quite get the, hold the mallet just right. But yeah we play just about anything with her.

D – So she still does have some of the coordination difficulties now?

2 – uh huh, yeah, definitely. Um, as far as like writing, you know, she has, she still holds the pen a lot of times with the the whole fist grab, uh unless I help her you know remind her you know you need to hold it with just your fingers. You know do a lot of more verbal you know reminders instead of actually going over and taking the pen and putting it in her hand properly. You know, we can just tell her a lot of times now and she can readjust. Um, but um yeah like writing, writing letters or handwriting is there's a lot of letters that she can't write. She can do about 5 of them right now and they're all stick letters besides the "o" she can do you know the "o". Um, but the stick letters, you know "a" and "h", "e, f, and i" are about the ones that she knows right now. So,

D – Um, her favorite activity, what would you say, or a sub, a school subject, you know I know she's not in school yet, but?

2 – Yeah, um, if it's a physical activity, definitely swimming or anything outside, playing on the you know jungle gym anything you know, climbing, running, re-occurring theme here too (laugh) Um, as far as like you know focused activity, um more like reading books, loves to read books, flip through pages and pages and pages of books. Um, um, coloring things like that, she doesn't have a lot of interest in, is just is not very successful for her, um building things, she loves, she loves to throw rocks (laugh) by the way, um, but she likes to take rocks and she'll build a pile, playing in the sand box, um, movies, of course every kid likes cartoons (yeah). Um, but that's about, you know, loves painting. Those types of things.

D – Ok, yeah (laugh). Um, besides speech does [C02] currently have any chronic health problems or other problems which she is, special, needs special services? I know you said, um, sensory

2 – Yeah sensory, sensory, sensory integration dysfunction. Um, loud noises, you know, not even loud noises, I shouldn't even say that. Um, like air conditioning turning on in our house, you know just that low fan rumble. Um, she like either covers her ears or she will like get up from whatever she's doing and she'll just run. Run the other way, like what the heck was that. Um, or a truck driving down the street, whatever the case may be. She um, any unexpected noise just kinda confuses her a little bit. Um, the occupational therapist says she's hypotonic and hypertonic in some areas. She's very um, like, um, in her torso she's very hypertonic, she's very tight. Um, she has um, um, some concerns or you know like climbing things, height, she gets a little you know more nervous about being off the ground. You know, anything that has a a height to it. It depends, you know, but at the same time she'll go jump on the couch for 10 minutes you know and not have a problem. Or, just is really kind of um funny in that sense, her little sensory issues. And then again, everything like I said still goes to the mouth. Um, everything (laugh, yeah), so we have like chewy things that she can definitely chew on now. Um, that are more appropriate, besides a shoe (laugh). Uh, then she may have ADD, may have ADHD, they're still trying to rule that out. They don't know if it's because she can't communicate that she loses focus really quickly or loses attention cause she can't engage, or is it from her sensory issues that she doesn't like sitting or things touching her for that long. You know they're still trying to rule some of these other things out still. But those are the other things that are being tossed around right now.

D – Ok, and um, now I'd like to shift to the family impact that her communication may have had. Um, lets shift to your family's reaction to [C02]'s communication. Can you describe for me the impact, if any, that her overall communication has had on your family?

2 – Um, immediate family or like extended family? Like grandparents, aunts and uncles or just like mom, dad, and sister?

D – Um, mom, dad, and sister, maybe right now.

2 – Maybe mom, dad, and sister? What's the impact? Um, her communication um, since it always leads to frustration has been very tough. Um, there's you know I wouldn't say we we avoid going to do things cause I don't I don't think I don't believe in really preventing her or not exposing her to things just because she can't communicate. Um, but there's you know we have to constantly be present, if we do go somewhere, for example to the park. You know at 5 years old you would expect to be able to take your child to the park. If they see other kids, you know um they would be able to just go ahead right and play. Um, but the other kids can't understand her and so a lot of times we have to always be present to kinda play interpreter. Um, if we're not present and the kids can't understand her then [C02]'s frustration level kinda goes, um you know gets a little high. Um, so then it's not a fun event for us. You know, so there's we definitely play a lot of preventive, use a lot of preventive measures to avoid some of that lack of communication frustration. Um, and as far as um other dynamics, you know, we're trying to take a sign language class, we're trying to learn sign language through books. Um, so it's taking, you know we're trying to learn whatever we can you know so that that takes extra time away from you know things that we would normally like to do maybe. Um, in commun, other communication issues upon the family. Um, you know the interaction between her and her sister you know can be kind of tough. You know just as it would when you know between peers. Um, sometimes [her sister], being 2, doesn't quite doesn't understand what [C02] wants, or, you know that's also, sis, you know do you play it off as lack of communication or do you play it off as sibling rivalry? We don't you know that you constantly play that game too. Is, can [her sister] not understand her or does [her sister] not want her to play with that book with her? You know, you you, it's kinda tough.

D – Yeah, um, do you think there's any positives associated with the disorder?

2 – Um, (that have come), I think you know [C02] has a lot of, more skills that a lot of kids have. You know, as far as, trying to being understood, um, you know she, with with

the sign language and and other things um I think her coping skills are becoming much better. Um, because if we can't be under, if we can't understand her through through verbal, you know then she'll move to a gesture. If we can't understand her through gesture, then she'll go to a sign language you know. And so it's like, uh you can't understand me? Well I'm gonna, darn it I'm going to find some way and you will, you know, you will be able to understand me. Um, you know where maybe if I compare her to her nephew who, my nephew who is, er her cousin that's the same age, you know he's much more demanding um, I want this, and if he can't get that, you know he's much quicker throw a tantrum because he's not getting what he wants. Where [C02], she's not getting what she wants because she can't be understood, you know. And so maybe she's like well, if I can't have that then she'll move on to something else. Can I have this? (laugh) You know, or something like that. So I think maybe she is her coping or her patience is is much better than some kids that have all the the skills.

D – Yeah, um, do you believe your life would have been different if [C02] had always had the typical speech development?

2 -... (switching to tape 2 – didn't begin taping at beginning). ...that lead or something. (uh hum) But again I think if um I think if [C02] was you know normal developing or had speech the entire time um and if it wasn't compounded by maybe some of her sensory issues, yeah. I I mean if I can comp, like I said I compare her to the my two year old who is has all of those things, how much easier my life would be, you know. (laugh) Cause it is, it's amazing how um how much preventive medicine that we play you know lets you know if we does this lets lets make sure we grab the chewies with us, make sure you know that we're going to be in an area where we can you know we can be around [C02] all the time so we can play interpreter. Um, you know we wanna make sure there's not too many kids around where she gets over stimulated or you know can't communicate. Um, you know so, we do a lot of a lot of preventive medicine I think, pre-planning. You know, it makes things more successful. Um, you know definitely the playing interpreter takes a lot of extra time because you know you always have to be there. You know even going to the grocery store she looks normal, she's five, you would expect her to know her name, you'd expect her to be able to respond to how old are you, you know, you know when strangers come up and say you know "hi, how are you?" You know, "how old are you?" And she can't say how old she is, you know then or she says you know she knows how old she is and she says some sound you know and then all of a sudden you get the funny look from the person that asked the question like, what did

she just say, you know. And so then once you explain, oh she's she's six, you know um and I think [C02] even is now becoming more aware of it. That's kind of frustrating for her to have us constantly talk over her all the time. You know, I think she's becoming aware of that, you know. "I said six" you know kinda thing but or five, you know "I said five." "Why do you have tell the people that?" Or they keep asking her her name "what's your name?" and she says "[esi]" and then go "what?" and they, she says "[esi]!" You know, and it gets louder, but doesn't get any clearer (laugh), you know. (aw) So, then she just kinda shuts up and goes on if they don't understand her after a while. So, D – Ok, um, do you think that [C02]'s speech problem has had an effect on her ability to form a strong bond or attachment with others within the family?

2 – Um, I I I would say so, I mean not not you know tremendous impact but definitely enough that um you know she she knows that there's some things that she can't say and so you can tell that she just doesn't. She just doesn't communicate at some point. Um, you know it's easier for her to just go help herself or go do it herself or just not even interact at all. You know it's it's pretty tough for her, I think, a little bit. To really feel, especially you know when there's a big conversation going on and my two year old's involved in it or you know if it's just even play or reading a book, um, and [C02] can't be understood, you know she just kinda feels like why try or you know she just doesn't participate at all. So, I think that could be you know, she may feel like a lack of a bond, I'm not sure.

D – um, now I'd like to kinda talk about the impact of the diagnostic label of apraxia. Um, can you tell me the circumstances surrounded your first encounter with the term apraxia?

2 – Um, she was just over three and she was, we were trying you know, figure out what was wrong with her so she was being evaluated by everybody and their sister, I think. Um, we, the time we got evaluated by the psychologist and then we got evaluated a different psychologist and then the occupational therapy, the speech therapy, uh speech therapist. I think there was like 6 of them total. And nobody could figure out what's going on and finally the one speech therapist, who I, uh, I hand her a lot of credit, you know said I really think [C02] has apraxia. She goes I don't have a lot of encounter, you know exposure to it, I just have read about it, I've learned about it, and I think this is probably what she has. And so she had um you know she said it's apraxia, this is what it is. She she nailed it right on the head that it's kind of a motor planning you know type of thing. She explained more as I've seen it in people with strokes, that type of thing. Um,

but she does not, you know, she was aware that there is a child apraxia. She did provide us with a website, which is why we're here today at apraxia-kids. Um, she said there is a lot of information at this website, you know I would encourage you to read the information. Um, and once we started to read that information on the website it was like, ah, this is [C02] all over, you know. Um, so that was pretty exciting. This is [my husband] calling, do you want to pause that for a second?

PAUSE

D – going to let this go for

2 – ok, so I'm sorry what was the question?

D – Make sure it works [tape recorder] (laugh). Um, we were discussing the encounter with apraxia and you said that you started (oh yes) reading up on the website and you said this is [C02]

2 - yeah, that was um once we kinda got the term you know the this is what she may have, the diagnosis or whatever you wanna call it, um, and once you know there's very limited about it unfortunately, um but once what we have read was definitely everything. (OK) Yeah, fit her to a tee. You know um it had mentioned you know maybe she has, you know the autism, maybe she has you know just speech delay you know, it was like all these things and nobody could really kinda come up with any particular thing until we got the term apraxia. It was like yes, this is it. It was like the light came on and you know we were able to now focus on what would be the best way to to help her or to treat this, you know. So it was it was it was it was very exciting for us. It was very exciting to you know to be diagnosed with some, something, instead of oh just wait, or you know. We had one lady that told us um at the insurance company, oh k, she's just lazy. Oh yeah that went over well as you can tell. Yeah, um, she's just lazy and um she had they she had told my husband that and [my husband] just went you know what, I'm done talking to you, you don't know my daughter, you have never met her before, she's three and a half, she is not lazy, you know, I can't believe you would even, you know, say that (yeah) without even knowing her (right). So, it was very offensive. (I'm sure). Um, but you know at the same time, and well, going back to the other question of would our life be different if [C02] was normal, um, yeah, there's um, a couple of, couple, two parents I know of that don't want their children to play with [C02] because they don't want them to talk like [C02], which is crazy. I, it's, but it's it's amazing how people think some times, you know. It's like, it's not a disease, it's not like you can catch this, you know. But they were afraid that their child was gonna revert back to talking like that or they weren't

gonna be encouraged to talk better or something. It's really strange. (yeah, sounds like it). I'm like, whatever. You know. You can't cure ignorance, so anyway. So, once we got the diagnosis it was very exciting.

D – And, um, what do you know about developmental apraxia of speech?

2 – What do I know about it, um? Boy, um, I do know that it is definitely a um an oral motor planning issue, um motor planning issue. Um, from my understanding of course that um [C02], this is how I explain it that um [C02] is completely receptive, she can understand everything but um it was it's the output that that gives her the trouble. Um, her brain can't send the signals to the muscles of her mouth to get them in the right formation at the right time to make the appropriate sound. That's how I explain it.

D –ok, pretty good explanation (laugh)

2 – you know you try and tell other people that don't know anything about it you know what it is um that that's my explanation, so.

D – uh huh. Would you like to know more?

2 – absolutely. I would always love to know more you know. I would like to see a lot more research done to you know to be able to fine tune therapy for kiddos that have this, so other people don't have to go through 8 therapists to try and find 1 person that works. You know, um I I would love to know more you know. Um, you know I can read you know I I understand the physiology and I understand the anatomy of it but at the same time I'd like to know a little more, know more details about what can we do to like I said the the the therapy or the treatment side of it or is there any prevention, is there any modes to to prove it in in a faster um, is it genetic, you know, I don't, I don't know if I really care so much about etiology cause I can't change that. I don't, I don't know you know why it happened, I don, it's not gonna change how I can treat it now maybe. So it's nice to know but every child is so different it's kinda hard to say well their's came from ?, their's came from you know an infection when they were young you know. We're all on the same boat still, we still need to know how to get forward. (right).

D – Um, this is kind of a a question about your other daughter, if you wouldn't mind answering, answering. Um, was she premature also or

2 – Um, no, but it was still a complicated pregnancy. Um, let's see, [C02] was, [C02] was 9 weeks premature, um due to wat, my water just breaking. Um, we tried to take preventive medicine, preventive measures so that if I got pregnant again it it wouldn't occur. Um, they never really found anything, but when I got pregnant with [her sister], um 4 months, I was 4 months pregnant and I was already 95% effaced and partially

dilated, (wow), so they did an emergency “cerclash”, put me in the hospital, the emergency “cerclash” is when they tie your cervix together, what looks like a twisty little thing (laugh) um, and then I was put on bed rest for the remainder of the pregnancy, so they um, cut the “cerclash” at 37 weeks and I had her at 38 weeks.

D – ok, sorry, just as a little side note for myself (no, it’s good to know), thank you (uh huh), thank you. Um and do you participate in any of the sup, parent support groups for apraxia?

2 – Um, no for the simple reason that I can’t, there’s none in Tuscan that I’m aware of, where we live. Um, since [C02] you know has these delays we she is you know enrolled in the department of developmental disabilities. Um, I have asked my case worker multiple times, you know, do you know of any other parents or do you know of any, I think we were looking more support groups for behavior because of all the behaviors that came out because of not being able to be understood. Um, and then I asked her about any other parents that have, you know, children that have apraxia, um and our case worker said, this is, this is um not verbatim but pretty darn close. Um, she said that she had about 300 cases, clients, casework, caseload, her case was about 300, um, and our daughter was the only one that had the diagnosis of apraxia without the separate diagnosis of autism, which she would be able to sup, you know provide lots of support groups for autism um or possibly asperger’s, um, but none just for verbal apraxia or oral apraxia. Um, she did ask a lot her other colleagues if they had any and um she said that there was maybe 1 other out of the other case workers (?), so there really isn’t much out there that were we found.

D – Any internet support?

2 – Not really, do you, now, the only, I I don’t do much internet. [my husband] doesn’t really either. We kinda use it for like, buy airline tickets or something (ha) But as far or to to research maybe the apraxia but as far as like online chatting that’s not something that I really pursued.

D – Ok, actually our interview is complete. (ok). Before we wrap up is there anything else you can think of to tell me about [C02] that you feel I should know, I haven’t covered?

2 – I think you got everything (laugh) pretty thorough. I guess that’s in my babbling ways of talking. I don’t think so.

D – do you feel I have a pretty complete picture of her and her development over time.

2 – I think so, I hope so.

D – uh huh. It seems like it, too. But if you would think of anything else that you maybe forgot or think I should know, feel free to contact me at any time. I know you have my email address and my phone number (yes, yes I do). So, in any way, I could be happy to answer any questions

2 – Ok, if you'd, you'd be more than happy to, this is, I don't know, I'd like it back at some point if it's not a problem (yeah) But this is when she is not quite a year, she's like 20 days shy of being a year until she's 2 and ½. (ok that's great thank you and we'll). So this might be the perfect time for you.

D – right. And I'll mail it back to you as soon as.

2 – and if you need anything before that or after I certainly have those.

D – Ok, thank you

2 – feel free to look at em. I don't think there's anything indecent on them (laugh) Hope not. Lots of birthday parties. (oh good)

D – It, I just want to remind you, if it would be ok if we did send back the transcription after it was complete so you can verify for accuracy and stuff.

2 – Yeah, that'd be great (if that's ok). Sure.

D – Ok, good, thank you.

2 – anything else? (no, thank you so much). I'll give you back your lab coat since it's so cold in here...

SUMMARY: Participant 2

A. Early communication development:

When discussing your child's early development, I gathered that she was premature, and around six months of age, her development appeared to be on target; she was cooing and babbling, was interested in communicating with others and understood others, and had no other medical concerns. Around her first birthday, it seemed as though your daughter became quiet and was unable to produce sounds. Between her first and second birthdays, it appeared that she began using strategies to compensate for her speech. She began grunting, pulling people what she wanted, pointing, and using her facial expressions. Your family also began using a "multiple guess" strategy to help her communicate and not become frustrated. Even though around two years of age your concerns were growing, the pediatrician did not appear as concerned.

When discussing gross and fine motor skills, it appeared that your daughter was delayed in both. She walked late (around 18 months) and could be termed "clumsy," had difficulty holding spoons, pencils, etc. in her hand, and drooled. She may also have a tactile sensitivity, in that she did not like to be held.

B. Ease and naturalness of communication:

By age three, your child seemed to still be happy, but to become more and more frustrated regarding her awareness to her lack of verbal communication. At this time, it appeared that she began having tantrums, which progressively became worse, when she was not understood. She was still a quiet child, but began repeating/making a few more sounds. Her speech, however, sounded like "...the early stages of language," characterized by a lot of incoherent cooing and babbling. Your daughter continued to use nonverbal strategies, such as pulling a finger, body language, or gesturing. Others

also relied on you to translate what she was trying to communicate. Although you tried to have one-sided conversations with her and read to her often, there were times when you may have avoided a communication interaction with her because of increasing frustration with communicating.

Your child appeared(s) to be a happy, social, active girl. At three when she entered preschool (which she only attended for a few months), she had difficulty sitting for long periods of time or would have tantrums or throw another's toy when not understood; however she really enjoyed being around the other children. Around age three, teachers, the pediatrician, and others began sharing your concerns regarding her communication. At this time, she was evaluated by speech and occupational therapists.

C. Current communication:

Around five years of age, your daughter developed 2-3 word approximations in a sequence, began using minimal sign language, and continued to pull people or point to what she wanted and to use her body language. She began initiating and repeating sounds and is successful at times in verbally communicating, which caused her frustration level to decrease. She also gained close to 100 word approximations and 15-consonant-vowel-consonant words. Challenges for her continued to be, 1) to become more intelligible to people close to her (70-80% intelligible at this time) and to others (40-45% intelligible at this time), and 2) gain more approximations. Speech therapy seemed to be a struggle for your family to find an appropriate therapist for her.

In the day-care setting, she continued to be a very social child, and seemed to enjoy going but when asked to do structured tasks, seemed to become frustrated when she could not be understood. It also took some time to develop number and letter recognition, but she enjoyed reading books. She also seemed to enjoy the outdoors and any type of sport; yet, she still had difficulty with fine and gross motor activity. The OT

discussed with you that she may be hypotonic and have sensory integration dysfunction regarding loud noises and oral sensory issues. At this time, it was noted that she may have ADD/ADHD.

D. Family Impact:

Since her communication leads to frustration, it has been somewhat difficult for you and your family. Although you did not avoid situations, you had adapted a way of preventing possibly tough situations because of your daughter's communication and sensory issues by being constantly available to interpret what she had said. Also, therapy and sign language classes may have taken you and your family away from things you would have liked to do. Possibly because of her difficulty with communication, she has developed more patience and a greater ability to cope with difficult situations. Although your family seems very close, your daughter may have felt a lack of bond between some family members because there are times where it may be easier for her to do something by herself.