DEAF AND AUTISM SPECTRUM DISORDER: THE IMPACT ON CHILD AND FAMILY

GAYLE M. GOLDSTEIN

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ABSTRACT

The goal of this study was to identify similarities and differences between individuals who are Deaf, who are hearing with ASD and those who are both Deaf and have ASD on measures of communication, behaviour, and social skills. In addition, information about parent/caregiver stress, coping, and empowerment was acquired to better understand the caregiver experience of these three groups. Results indicated a number of similarities between the Deaf-ASD and hearing ASD groups on measures of communication, social skills, and behaviour. Further, parents in the Deaf-ASD group identified experiences with stress and coping similar to parents in the hearing ASD group. In contrast, feelings of empowerment and decision making power in the Deaf-ASD group resembled that of parents in the Deaf group. While the similarities found within this study suggest that individuals in the Deaf-ASD group more closely resemble their hearing ASD counterparts, these results also indicate that Deafness may play a significant role in the presentation of the ASD features and the impact they have on caregivers, services, and diagnosis.

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DEDICATION

To my parents and brother, thank you for your constant support. Your love and encouragement has helped me to reach this goal.

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Deaf and Autism Spectrum Disorder: The Impact on Child and Family

In recent years, research in the area of Autism Spectrum Disorders (ASD)[±] has exploded. Much more is known about the prevalence rates, etiology, symptomatology and phenotypic characteristics of this population. Similarly, the research on deafness[†] has provided new information about the challenges that these individuals experience. While much of the literature on individuals who are Deaf is focused on communication and educational concerns, research on the social, emotional, and family impact is rapidly increasing. Further, for individuals who are Deaf *or* who have ASD, there seems to be an improved understanding of their development and deficits, in addition to more insight about family dynamics and the issues that these two groups of families encounter. Yet, despite the documentation of the co-occurrence of Deaf-ASD spanning 20 years of research (Malandraki & Okalidou, 2007), there continues to be little research providing information about the diagnostic process, intervention and parent support (Easterbrooks & Handley, 2006; Guardino, 2008) with this group to help inform parents and professionals.

The following literature review first examines the current research available on the prevalence rates, identification and diagnostic issues that impact individuals who are

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[±] The term Autism Spectrum Disorder (ASD), will be used to describe individuals who have the DSM-IV-TR diagnoses of Autistic Disorder (AD), Asperger's Disorder (Asperger's) or Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), which is more consistent with the newer DSM-5 terminology.

[†] For the purposes of this paper the term 'deaf' will be used to provide a clinical or medical description of a mild to profound hearing loss. A profound hearing loss refers to individuals with a 90dB or greater hearing loss and a moderate to severe loss refers to individuals with a hearing loss between 41dB and 90dB (Flexer, 1999). The term 'Deaf' will be used to encompass all Deaf individuals in hopes to make this study's findings applicable to all within that population However, the use of 'd' and 'D' is an evolving issue when referring to individuals who are d/Deaf, and it is recognized that there may be disagreement on the issue.

Deaf and have ASD. Next, Chapter One provides a review of the communication and social skills research provided for individuals who are Deaf and individuals who are hearing with ASD. A review of the limited research on the communication and social skills of individuals that are Deaf with ASD. In addition to individual characteristics, this study examines the family experience, which is presented in Chapter Two. In particular, parental stress, coping, and empowerment amongst parents who have a child who is Deaf, who has ASD or who is Deaf with ASD was examined.

Given that this study has two major goals, examining child information and examining parental information, each chapter will present the hypotheses that are associated with the goal of that chapter. Further, because there are multiple hypotheses within each chapter that examine a different aspect of functioning (e.g., language and ASD symptoms), the hypotheses are presented in connection to each of these areas of functioning.

Of the limited literature on the Deaf-ASD population, American prevalence rates estimated that, within the ASD population, 6.6 percent were also deaf (Stewart, 1978). However, this prevalence rate was based on 1977 American demographics by estimating the number of individuals who had a hearing loss or Autism from this information and combining these numbers to estimate the number of individuals with both diagnoses. The result of this equation was an estimated 6700 individuals in the US who were likely identified as deaf and had a diagnosis of ASD.

Identifying prevalence rates of ASD amongst individuals who are Deaf continues to be quite difficult because of the complications associated with simply identifying a child as deaf and diagnosing ASD. For example, Gillberg et al. (1990) as well as

Steffenburg (1991) found that, amongst individuals who met criteria for Autistic Disorder or Asperger Syndrome according to DSM-IV-TR criteria, 15 to 30 percent were also identified as deaf. The National Alliance for Autism Research (NAAR), however, reported that this estimate was between 30 to 50 percent. Previous research, conducted in both the United States and Europe, has shown that, amongst children with ASD, 33-46 percent also had a hearing loss that fell within the moderate to severe range (e.g., Hindley, 1997; Klin, 1993). In contrast, Rosenhall and colleagues (1999) estimated that approximately 3.5 percent of individuals with ASD have a mild to moderate hearing loss, and 5.3 percent of deaf individuals have ASD. To further add to the variability in reporting, a recent report from the Centre for Disease Control (Baio, 2014) indicated that, of demographic information shared by eight of the eleven states, none of them identified any children eight years or older who have ASD and who are also deaf.

The most recent Annual Survey of Deaf and Hard of Hearing Children and Youth conducted in 2009-2010 (Gallaudet University's Research Institute [GRI], 2010) reported that of 37,667 identified deaf and hard-of-hearing children in the United States, approximately 611 also had a diagnosis of an ASD under the DSM-IV-TR criteria and 1725 had a diagnosis of developmental delay. Szymanski, Brice, Lam, and Hotto (2012) used the information from the 2009-10 Annual Survey to estimate current prevalence rates of ASD amongst Deaf children and from the survey data, Szymanski and colleagues estimated that the prevalence rate of ASD in Deaf children that was reported by American schools was approximately 1 in 53. They also identified that, amongst 8-year-old Deaf children, this prevalence rate was approximately 1 in 59, which may be similar to prevalence rates in the hearing population of 1 in 68 children identified in 2010 (Baio, 2014). Consistent with prevalence rates in the hearing population, the gender ratios are approximately 3 males:1 female receiving ASD based services. Amongst Deaf-ASD students, 56 (9.2%) also were identified with a developmental delay.

Such wide variability in the reporting of prevalence estimates of ASD within the Deaf population may be a consequence of how individuals are reported based on what has been described as the primary or secondary diagnosis or identification. Consequently, individuals may be counted more than once as they are given each identification; or if a second identification has not been made they may not be included in the Deaf-ASD group count. Difficulties identifying individuals in this specific population as a result may impact the ability to collect important information about their development. Therefore, the number of individuals who are Deaf and have ASD could potentially be under-represented. Yet, it seems that with Early Hearing Detection and Intervention programs, although not mandatory in all areas, it has become easier for health professionals to identify and reduce the age at which children who are congenitally deaf are generally identified from 19-36 months to 3-6 months of age or at birth (Yoshinaga-Itano, 2006). As a result, it is easier to produce more accurate prevalence rates of co-occurring disorders in the Deaf population, as evidenced by the most recent GRI survey that examines prevalence rates and identifying features within the Deaf population.

To that end, the 2009-10 GRI (2011) survey examining information only of identified Deaf children in the United States provided information about identification and age of onset rates. Specifically, they indicated that approximately 41% of identified Deaf children were born deaf. Approximately 14.5% of children were born as hearing but became deaf and were identified as deaf before the age of 2, whereas 9.7% of children in this survey became deaf and were identified after the age of 2. In addition, for approximately 35% of children, the age at which the child became deaf was unknown. Yet, while the survey indicates that these numbers are for age of identification, it may be unknown for many of these children if it truly is age of onset or rather age that the child was identified as deaf.

Using the GRI (2011) data to learn more about the Deaf-ASD group reported, Szymanski and others (2012) found that, when compared with Deaf peers without ASD, mothers in the Deaf-ASD group were reported to have had a higher number of pregnancy complications (e.g., illness). Further, fewer genetic or heritable cases of deafness were identified in this group. Szymanski and colleagues (2012) also found that, amongst children with a profound hearing loss, there was a significantly higher percentage of ASD than for other degrees of deafness. This information may help in the diagnostic process when examining risk factors for the presence of ASD with a child who is deaf.

In recent years, the importance of detecting ASD at an early age and differentially diagnosing between another ASD or non- ASD disorders (e.g., communication disorders, non-verbal learning disorders, Attention Deficit Hyperactivity Disorder [ADHD]) has increased greatly. Research has also shown that the median age of first ASD identification has also decreased (Shattuck et al. 2009), and that a reliable diagnosis continues to be identified at approximately 24 months of age (Baron-Cohen, Allen, & Gillberg, 1992; Moore & Goodson, 2003).

Thus, similar to a deaf identification, when a child has ASD, parents often do not identify that there are problems with development until overt signs of disturbances in communication (Landa, 2007), behaviour, or socialization are evident. Difficulties with communication and social interaction have therefore become the hallmark in the identification of ASD. The DSM-5 (American Psychiatric Association, 2013) highlights that persistent deficits with social communication and social interaction in addition to the presence of stereotyped or repetitive interests and activities (APA, 2013) must be present for a diagnosis to be made. For many hearing children, these difficulties become clear when they enter a pre-school program. However, for other hearing children, these deficits may be milder in presentation and a diagnosis may result from persistent issues with social interactions and communication with others over a longer period of time.

When there is a previous diagnosis of ASD or identification that a child is deaf, the task of detecting if the other (i.e., deaf or ASD) is present can be quite difficult due to overlapping or masking markers of identification.   Further, given that communication difficulties are inherent to both children who are Deaf and those who have ASD, the ability to diagnose ASD in a child who is Deaf becomes much more difficult (Easterbrooks &Handley, 2006; Klin, 1993). As a result, diagnoses can be delayed and the initiation of intervention postponed. However, with Early Hearing Detection and Intervention programs, recent research has shown that, amongst children who are identified as deaf and diagnosed with ASD, they will most likely be identified as deaf first. Such findings were noted by Myck-Wayne, Robinson, and Henson (2011), who found that the four children in their study were first identified as deaf and then diagnosed with ASD. In fact, each child was first identified as deaf and it was not until Deaf and Hard-of-Hearing (D/HH) early intervention services did not improve development that further assessment was suggested, often by the D/HH service providers.

Interestingly, Myck-Wayne and colleagues (2011) of the four children reported in their study, the pediatricians involved in care tended to attribute the ASD symptoms that are often characteristic of hearing children with ASD at that age to the fact that the child is Deaf. Yet, parents reported warning signs such as delayed motor development, lack of eye contact, or difficulty imitating facial expressions, which are not characteristics that Deaf children without ASD demonstrate. Therefore, because health professionals may not be versed in both of these identifications and diagnoses, it likely contributes to the later identification of the ASD and makes an early identification more difficult to obtain.

Given that difficulties with communication are the hallmark in identifying deafness and a distinguishing criterion for ASD, a dual identification becomes much more problematic. Szymanski and Brice (2008) argue that when either the deafness is not identified the ASD remains un-diagnosed, or when they co-occur, the individual continues to lack sufficient communicative or social input and may become "linguistically, communicatively, emotionally, and socially isolated" (p.11). Therefore one of the goals of this study is to gain a better understanding of the communication development and difficulties that impact individuals who are Deaf and have ASD (Deaf-ASD).

Chapter One – A Review of Communication and Social Skill Development Within Deaf, ASD, and Deaf-ASD Groups

Communication and Social Skills of Deaf Individuals

While communication and social skill development are inter-dependent, they may have different developmental trajectories (Hill & Coufal, 2005). Yet, when there are deficits in one area (i.e., communication or social skills), the other can also be significantly impacted (e.g., Landa, 2007; Locke, 1997). Therefore, children who demonstrate problems with communication and/or social development can easily become marginalized by their peer group. Botting and Conti-Ramsden (1999) reported that children with pragmatic language concerns tend to have fewer socialization opportunities because of these communication deficits. As a result, these children are more likely to be excluded from social peer groups and tend to withdraw from social activities (Goodyer, 2000). Research examining communication and language development amongst individuals who are Deaf has certainly helped lead to a better understanding of the relationship between communication and social skills.

Communication development. As noted, Early Hearing Detection and Intervention programs have significantly improved the ability of professionals to identify if a child is deaf at a much early age. Despite the effectiveness of these programs, many children continue to go unidentified until approximately 2 to 3 years of age (Yoshinaga-Itano, 2006). As a result, they often miss out on accessing meaningful oral or visual language and communication that is found in their natural environment (Vernon & Andrews, 1990; Yoshinaga-Itano, 2006). In general, children who are Deaf or Hard-of-Hearing (HH) rely on the visual environment and their visual abilities to support their communication (Easterbrooks & Handley, 2005). Therefore, exposure to more accessible or visual forms of language such as Signed English or American Sign Language (ASL) may help to foster communication skills. For some children, intervention may focus on the development of their visual ‘listening’ skills and possibly integrate aural habilitation when the child is using hearing aids or cochlear implants to incorporate spoken language into their communication repertoire. For most children who are Deaf or HH, intervention that supports and improves their visual attention, peer interactions, and general communication skills (Calderon & Greenberg, 1997; Moeller, 2000; Myck-Wayne, Robinson, & Henson, 2011) is quite beneficial. Given that the linguistic and communication needs of children within the Deaf and HH population demand additional resources, basic communication skills may be acquired at a much later age than their hearing counterparts.

Approximately 96 percent of Deaf children are born to hearing or HH parents (Goldstein & Bebko, 2003; Mitchell & Karchmer, 2004). The course of language acquisition among Deaf children of hearing parents compared with Deaf children born to Deaf parents appears different and is often more arduous. Deaf children of Deaf parents acquire language generally following the same timeline as hearing children of hearing parents, although it is usually through manual communication (i.e., ASL) that is available in their natural environment. Conversely, Deaf children of hearing parents are more likely to be exposed to oral English or manual codes of English[†], because these forms are often more accessible for hearing parents with no experience of ASL. Further, linguistic intervention also tends to occur at later periods of development because of late

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[†] A system of hand signs in English order, with words like 'the' and 'of.' The signer often signs and speaks at the same time.

identification and/or insufficient linguistic stimulation at an early age (Goldstein & Bebko, 2003).

Vygotsky (1978) viewed the role of the parent as providing a model for language and therefore a foundation for the development of complex thought for the child by encouraging the child to perform beyond his/her current level of functioning. For hearing children of hearing parents, this is achieved by providing oral communication and language in the child's environment. For Deaf children of Deaf parents, language development is provided at a similar rate but through a visual modality. Yet for Deaf children of hearing parents, providing adequate models of language becomes more difficult for parents. For example, if hearing parents themselves are learning manual modes of language and communication at the same time as their deaf child, then they are most likely not the best communication role models because parents may not achieve a high level of fluency (Erting, 1992).

Overall, however, Meier and Newport (1990) reported that Deaf children who are exposed to accessible communication as early as possible exhibit the same language milestones as their hearing peers. Yet, results from Gregory, Bishop, and Sheldon's (1995) study suggest that many Deaf individuals who developed fluent language skills continue to exhibit some difficulties with the pragmatic aspects of communication. Those results suggest that pragmatic language development is not dependent on age of language exposure, but possibly more the type of language used, making it a cultural issue rather than a linguistic one. However, with ASD, given that difficulties with the pragmatic use of language are a core feature in identification, the diagnostic process may become more difficult for clinicians assessing Deaf individuals.

Peterson, Wellman, and Slaughter (2012) postulated that Deaf children of hearing parents, particularly those who are exposed to sign language later in life, experience more difficulties with social language and demonstrate delays with Theory of Mind (i.e., their ability to understand what other people know, think or feel), because of their restricted access to early language and social conversations in their immediate environment. To that end, Peterson and colleagues (2012) found that over half (56%) of their sample of young adults, who are Deaf children of hearing parents, experienced significant difficulties interpreting verbal humour and sarcasm, regardless of their communication modality (oral language, Signed English, British Sign Language). Moreover, they also found that Deaf children of hearing parents demonstrate delays in the development of Theory of Mind (ToM), which can significantly impact their capacity to interact with others in socially normative ways.

Rhys-Jones and Ellis (2000) argued that the difficulties with ToM amongst Deaf individuals resemble more of a delay than a deficit. Specifically, they found that in comparison to neuro-typical hearing adolescents and hearing adolescents with Asperger syndrome, the Deaf adolescents in their study appeared more similar to hearing neuro-typical adolescents than those with Asperger syndrome on measures of social awareness. However, individuals in the Deaf group tended to chronologically match a younger hearing neuro-typical age group. To that end, Russell et al. (1998) suggested that the delays of ToM found amongst individuals in the Deaf population, were due to the delay in language development rather than overall developmental. Therefore, Deaf children who have access to some form of language and communication (either oral or manual) from birth will develop better language fluency and have greater access to language that communicates social-emotional states. For Deaf individuals who are language deprived or are considered to have late language acquisition, there is an initial focus on learning functional language and therefore, there is not as much spontaneous sharing of inner thoughts and feelings (Peterson & Siegal, 1995). As a result, for these children, the ability to gain and adeptly interpret peer and other social feedback may also be delayed, thereby impacting their overall social-emotional development.

Vandell and George (1981) found that when young Deaf children interacted with other Deaf children they tended to use more gestures, facial expressions, and pointing along with vocalizations. When interacting with hearing children, however, young Deaf children were found to use more object-related strategies such as using an object or pointing to an object, as a frame of reference or to gain the attention of another. Similarly, Duncan (1999) found that, when young Deaf children were given opportunities to initiate social interactions, they were more likely to use strategies that used physical advances, such as touch or stamping their feet, than their hearing peers in an integrated academic setting. Vandell and George (1981) postulated that the ability of these children to adapt different strategies based on the potential communicative partner suggests that they are aware of their partners' communicative characteristics. This also supports evidence that young Deaf children who have early access to language and communicative interactions are able to develop ToM abilities at an early age.

Social Skills Development. A review of the literature conducted by Antia and Kreimeyer (1997) indicated that, in general, Deaf children demonstrate greater difficulties interacting with others than did their hearing counterparts. It is important to note that not all Deaf or HH children demonstrate social skill deficits. For children who do, these deficits appear to be more impactful in comparison to neuro-typical developing hearing children. Thus, while children who are Deaf may demonstrate ToM, they may experience problems engaging in sustained positive social interactions. Polat (2003) highlighted that, while the sensory issue of deafness can impact psychosocial development, it is certainly not the “cause” of social skill issues that may be seen amongst Deaf children. Instead, it becomes important to examine additional variables that may impact the social development of Deaf individuals. For example, parental hearing status and language fluency, communication modality, type of school, and teachers, are several variables that can play a significant role in the psychosocial adjustment of Deaf children.

A review of the literature on the social skills of Deaf children indicates that social difficulties of Deaf children are more associated with language ability and communication skills, rather than auditory status (i.e., hearing, Deaf, HH; e.g., Antia & Kreimeyer, 1997; Meadow, 1968; Polat, 2003; Weisel, Most & Efron, 2005). Further, language development and pragmatic familiarity is, in turn, associated with the frequency of communication that children experience (Spencer, Koester, & Meadow-Orlans, 1994). Therefore, Deaf children born to Deaf parents are more likely to have access to meaningful language and social communication at an earlier age than Deaf children born to hearing parents, who are more likely to miss out on early language opportunities Meadow (1968).

Meadow (1968) identified marked differences between the social and emotional experiences of Deaf children of Deaf parents and Deaf children of hearing parents. In particular, she found that Deaf children born to Deaf parents were more likely to demonstrate better maturity, responsibility, independence, and sociability than Deaf children born to hearing parents.

Meadow (1968) attributes some of this difference to the adjustment of the parents to having a Deaf child. In particular, Deaf parents were more likely to be accepting of their child being deaf and adjust more quickly than hearing parents. As a result, hearing status of parents can impact the communicative and modeling style that is used when promoting social interactions in young Deaf children.

Polat (2003) also found evidence to support previous research (e.g., Delgado, 1982; Hilburn, Marini, & Slate, 1997; Weisel, 1988) that parental hearing status impacted the psychosocial development of Deaf children. In particular, Deaf children of Deaf parents demonstrated better academic achievement and social functioning than Deaf Children of Hearing Parents. It is possible that the shared communication and identity between Deaf children of Deaf parents and their children allows the relationship to follow a similar pattern to that of hearing children and hearing parents. Polat (2003) postulated that psychosocial adjustment is also better for Deaf children whose hearing parents use a manual form of communication. In particular, Polat believed that hearing parents who use a manual form of communication are making an attempt to enhance and promote the most communication possible which, in turn, creates an environment of inclusion for the Deaf child within the family structure.

For the most part, it appears that the current literature findings continue to support older studies that show social and emotional differences between Deaf individuals (particularly those with hearing parents) and their hearing counterparts. For instance, older research using projective testing (i.e., Rorschach testing) has indicated that generally individuals who are Deaf tend to be less socially mature than their hearing counterparts (e.g., Levine, 1956; Neyhus, 1964). In particular, the authors of those studies suggested that individuals who are Deaf may have a restricted breadth of experience and that there might be a delay in social-emotional maturation. As a result, individuals who are Deaf will experience more difficulty integrating their social and emotional experiences and conducting thoughtful introspection (Meadow, 1968). Yet, when Deaf children are able to develop language fluency, attach themselves to a peer group, and develop a sense of self-identity, they are able to relate more closely to their hearing counterparts.

In contrast, Deaf children who are unable to develop any language fluency may suffer more significantly in social situations. Thus, Deaf children who also have an additional identification or diagnosis may be at greater risk for language delays and associated social skills deficits. Polat (2003) found that, when Deaf individuals had an additional diagnosis, whether it be physical or neurological, they tended to experience greater difficulty with social and emotional adjustment, which was previously found by Aplin, (1987), Chess and Fernandez (1980), Mertens (1993), and Sinkkonen (1994). Given that one of the core difficulties found amongst individuals with ASD is social interaction, it seems clear that individuals who are Deaf with ASD are at a particular disadvantage.

Communication and Social Skills Development of Individuals with ASD

With recent revisions to the DSM-5 (APA, 2013) ASD criteria, two core features make up the diagnostic criteria for Autistic Disorder: a) impairments in social communication and social interaction; and b) restricted, repetitive and stereotyped patterns of behaviour. These primary diagnostic criteria help to conceptualize the diagnostic features of ASD and focus on the impairments of verbal and non-verbal communication (APA, 2000). It is important to note, however, that the literature presented in this study is based on research using DSM-IV-TR criteria for diagnoses under the Pervasive Developmental Disorders umbrella. It is unclear how the recent changes to the ASD criteria will impact prevalence rates in the hearing population, much less the impact in the Deaf population.

Communication development and deficits. Research examining the development of hearing children with ASD indicates that increased communication abilities are generally related to better overall development (Garfin & Lord, 1986; McEachin, Smith, & Lovaas, 1993). Further, Lord and Paul (1997) found that, when children with ASD were able to develop functional communication (e.g., using sentences) before the age of 5, they were more likely to have better cognitive, language, adaptive and academic skills as teenagers. Yet, similar to the language development of children who are Deaf, the communication and language development and impairments of children with ASD vary greatly. For example, previous research using DSM-IV-TR criteria showed that up to half of the children diagnosed with Autistic Disorder failed to develop any verbal language (Klinger, Dawson, & Renner, 2003; Rutter, 1978). Further, many of these children struggled to learn a different modality of communication (e.g., gestures), thereby impacting their social communication and interactions (Wetherby, Prizant, & Schuler, 2001).

For those with ASD who are able to develop functional oral language (e.g., oral English), many often demonstrate deviant aspects to their communication that are characterized by immediate or delayed echolalia, abnormal prosody and pronoun reversal difficulties. As well, the enduring difficulties with the pragmatic or social aspects of language exacerbate these children's problems in communicating effectively with others (Tager-Flusberg, 1999, 2001; Klinger, Dawson & Renner, 2003). While individuals who were classified as having Asperger's Syndrome appear to have fewer difficulties with language development, they still experience social communication impairments (Tager-Flusberg, 1999, 2001).

Generally, children with ASD struggle to acquire the appropriate social communication skills to interact successfully with peers. Previous studies have shown that the social communication skills of elementary children with ASD are more restricted than their typically developing peers (Thiemann & Goldstein, 2001). In particular, children with ASD are less likely to request information from others, listen and respond to others, or engage in grouped social activities (VanMeter, Fein, Morris, Waterhouse, & Allen, 1997; Volkmar, Carter, Grossman, & Klin, 1997; Wetherby & Prutting, 1984). These difficulties can make the task of initiating or responding to and maintaining the social interactions with others more difficult.

Rapin and Dunn (1997) also found that children with ASD demonstrate significant difficulties responding to abstract questions (e.g., how and why) and may at times experience problems with concrete responses (e.g., who or what) when the question requires the child to infer the correct response. Such difficulties can impact the play of children with ASD because they may experience greater trouble extending abstract thinking into creative or imaginative play. Further, since the pragmatic or social aspects of language produce the most difficulty for children with ASD (Klinger, et al., 2003;

Lord & Paul, 1997; Tager-Flusberg, 1999, 2001; Wetherby, Schuler, & Prizant, 1997; Wetherby et al., 2001), it appears that this symptom of failing to use language for interpersonal communication might be one of the greater sources of stress for families (Bristol, 1984). Yet it may also be stressful for these children as it makes the process of initiating and maintaining friendships much more problematic.

Social Skills Development. As noted above, social skills deficits are also a central characteristic of ASD and these can include: difficulty imitating others both immediately or after a time delay, coordinating attention with others (joint attention; Klinger, Dawson & Renner, 2003), orienting to social stimuli, understanding other's emotions or facial expressions and participating in symbolic play (Dawson, Meltzoff, Osterling, & Rinaldi, 1998). Studies that involve neuro-typically developing children have shown that children between the ages of 9 and 14 months begin following the gaze of others and sharing in social engagement successfully (e.g., Butterworth & Jarrett 1991; Scaife & Bruner, 1975; Wellman, Phillips, Dunphy-Leli, & Lalond, 2004). Meanwhile, research conducted with children with ASD (e.g., Dawson et al., 2004; Sigman & Ruskin, 1999) indicates that the ability to orient towards social stimuli is impaired. Such impairments impact the later development of more complex communicative and social skills, such as joint attention (Dawson et al., 2004), and may be an identifying feature that separates children with ASD from other children who demonstrate pragmatic language and social competence difficulties.

Difficulties with more social aspects of language or communication are also demonstrated quite early in children with ASD. For example, these children demonstrate early impairments in social communication, such as taking into account another's intended meaning or perspective (e.g., Hale & Tager-Flusberg, 2005; Tager-Flusberg, 1996). As well, more non-verbal social communicative skills, such as affective sharing and joint attention (e.g., Dawson et al., 2004; Bernier, Webb, & Dawson, 2006) are significantly impacted.

Significant difficulties using mental states, such as emotions, desires, intentions, or beliefs (Gevers, Clifford, Mager, & Boer, 2006) to infer or attribute (Baron-Cohen, 1995) another person's communicative or social intents, have also been identified in children with ASD (Baron-Cohen, Leslie, & Frith, 1985). As a result, individuals with ASD can miss subtle cues within the social environment, misinterpret complex or abstract meaning in conversations, and lack problem solving skills in social situations because they find it difficult taking the perspective of another individual (Baron-Cohen, 1995).

For children with ASD, Fine (2006) argues that deficits in social interaction skills impact the child's ability to function in a social situation, but the addition of an impairment in communication "exacerbates the child's social processes and social development" impairments (p.154). Children with ASD are more likely to refrain from using verbal or non-verbal cues when communicating with others, which may further impact comprehension (e.g., sarcasm) or expression of their own thoughts. As a result, Fine (2006) asserts that, where impairments exist in one area (e.g., communication or social competence), there will be problems in another. Therefore, it would seem that for individuals who are Deaf and have ASD, they would be at a further disadvantage when attempting to develop language/communication and social skills, particularly when living primarily in a hearing environment. Yet, little is known about individuals who have a dual diagnosis of deafness and ASD.

Communication and Social Skills of Individuals Who Are Deaf with ASD

A literature search conducted through '*Psycinfo*' yielded a total of 14 articles ranging from 1975 to 2014 that examined individuals who were identified as Deaf and had a diagnosis of ASD. These studies tended to be case studies of one or two children or experimental designs with small sample sizes. Furthermore, these studies tended to include individuals from the United States or the United Kingdom, but there continues to be a dearth of information about the prevalence rates, services and family dynamics of Canadian individuals who are deaf with ASD. Additionally, little is known about the cognitive, social and communication development of these individuals, and how these abilities or difficulties are expressed.

Jure, Rapin, and Tuchman (1991), studied 46 children who were Deaf and also had ASD. The authors found that almost half of these children did not receive a second identification until approximately seven years after their first identification. For example, Roper, Arnold and Monteiro (2003) found that the age at which Deaf children in their study were given an ASD diagnosis was significantly later than the age of diagnosis for their hearing peers. To complicate matters, despite Early Hearing Detection and Intervention programs, not all children are first identified as Deaf at a young age, rather ASD is first diagnosed and with an auditory exam is the child identified as deaf. Such issues with identification and diagnosis can impact language development, communication and choice of modality should they be made later in development.

Hypotheses Examining Functioning of Deaf-ASD Individuals

As noted above, this study has two major goals, examining child information and examining parental information and each chapter will present the hypotheses that are associated with the goal of that chapter. Further, because there are multiple hypotheses within each chapter that examine a different aspect of functioning, the hypotheses are presented in connection to each of these areas of functioning. Taking into consideration the exploratory nature of this study and the previous findings of Jure and colleagues (1991), Roper and others (2003), as well as Myck-Wayne and colleagues (2011), the first objective of the current study is to examine the diagnostic process that individuals who are Deaf-ASD experience as well as the resources that are utilized by this population. This objective is examined in the following three sub-hypotheses:

1. Given previous Deaf-ASD diagnostic research, it was proposed that:
    - a) Because of infant hearing screening programs, the first identification made will be deafness and it will be made at a chronologically similar time to Deaf individuals without ASD.
    - b) Deaf-ASD individuals will receive their ASD diagnosis chronologically later than their hearing ASD counterparts.
    - c) Parents of Deaf-ASD individuals will report utilizing more resources within the Deaf community to assist their child's development. More specifically, they will report sending their child to a school for the Deaf.

In addition to the above information, this study sought to examine communication, social and behavioural characteristics amongst Deaf-ASD individuals. Roper, Arnold and Monteiro (2003) examined the cognitive and behavioural skills of 13 children who were Deaf and had ASD. They found that, amongst these children, phenotypic characteristics resembled those of hearing children with ASD. That is, deafness did not appear to add to the ‘autistic’ presentation.

More recently, Szymanski’s (Szymanski & Brice, 2008) pre-dissertation work focused on examining 19 Deaf and hearing parents' reports on their perception of the behaviour of their children, all of whom were Deaf with ASD. Overall, Szymanski and Brice (2008) found that children with a dual-diagnosis had significant difficulties with social interactions. However, it was also found that Deaf parents rated their child’s communication and behaviour skills as less problematic than the child’s ability to engage socially. In contrast, hearing parents of children with ASD reported that communication and social skill deficits were the most problematic with their children. Interestingly, Deaf and hearing parents of Deaf-ASD individuals did not indicate difficulties with their child’s communication skills to the same degree that parents of hearing children with autism reported. In particular, the authors found that Deaf children with ASD who possessed an expressive sign language vocabulary of at least 50 words, were reported by their parents as higher functioning in the areas of communication and social development. These children also demonstrated less repetitive or stereotypical behaviour, which their parents rated as less concerning compared to parent ratings of hearing children with ASD. As a result, the process of diagnosis may be more difficult for professionals when identifying ASD for a child who is Deaf, and similarly, providing appropriate resources and intervention may be delayed.

Guardino (2008) found that Deaf children who have an additional neurological disorder such as ASD, were more frequently placed in inappropriate educational settings that did not meet their needs from both an education and intervention perspective. Myck-Wayne and colleagues (2011) additionally found that interventions obtained and used for children who are Deaf with ASD were quite variable. For example, the authors reported that, despite all children having cochlear implantation, three of the four children in their study primarily used a visual mode of communication (e.g., Picture Exchange Communication System (PECS), or a form of sign language such as American Sign Language (ASL)). Further, three of the four families in their study chose to focus on the ASD related behaviours (e.g., establishing eye contact, identifying visual cues, and managing repetitive and stereotyped behaviours) by using Applied Behavioural Analysis interventions rather than using D/HH services once the ASD was identified.

The results from preliminary studies seem to indicate that individuals who are Deaf with ASD demonstrate the same phenotypic characteristics as hearing children with ASD, with the only difference being that they are Deaf. However, evidence from Szymanski's (Szymanski & Brice, 2008) study seems to suggest that this is not entirely true. In fact, they suggest from their study that parents of children who are Deaf-ASD do not rate the ASD symptoms as significantly concerning compared to parents of hearing children with ASD, particularly when these children have developed language. This evidence indicates that deafness may be a buffer for the presentation of more severe characteristics, particularly when language has been developed. Nevertheless, no research is available that has investigated the development of language in this population.

Given that Deaf children are already at a disadvantage for learning auditory or verbal forms of communication, understanding how children who are Deaf with ASD learn language becomes increasingly important. Such research is particularly imperative when language has been associated with greater gains in social and cognitive development in both the Deaf and ASD literatures (Andreassi, 2004; Berk, 2000; Lord & Paul, 1997).

The second goal within this chapter of the current study based on the previous research on this population, is to understand the pattern of communication and social skills that have developed in these three groups. As well, understanding the differences or similarities of individuals who are Deaf with ASD compared with individuals who are hearing with ASD or who are Deaf without ASD becomes important in order to address the needs of this unique population of individuals. Given these questions and the findings from previous research, a set of predictions that examine communication and social skills was made.

2. It was hypothesized that:
    a) Deaf-ASD individuals will be rated as having poorer communication skills compared with Deaf individuals, as rated by their parents on the Language Proficiency Profile (LPP, described in Measures section)
    b) Deaf-ASD individuals will demonstrate similar communication skill development compared with hearing ASD individuals as rated by their parents on the LPP
    c) Deaf- ASD individuals will demonstrate poorer social skills development compared to both hearing ASD and Deaf individuals as rated by their parents on the Social Integration Skills Questionnaire (SISQ, described in Measures section)

    d) Deaf- ASD individuals will demonstrate a greater number of ASD symptoms compared to Deaf individuals, as rated by their parents on the Childhood Autism Rating Scale-Parent (CARS-P, described in Measures section) symptom severity rating sub-scale
    e) Deaf-ASD individuals will demonstrate fewer or similar Autism Spectrum Disorder symptoms compared to hearing ASD individuals as rated by their parents on the CARS-P symptom severity rating sub-scale

Further, previous communication research conducted with both Deaf and hearing ASD populations has shown that, for children who are struggling to communicate, when a visual communication system has been introduced at an early age, communication can be better facilitated whether verbal language is attained or not (e.g., Bondy & Frost, 2001; Meier & Newport, 1990). Therefore, a third objective of this study was to examine the presence of and the impact of visual communication systems used in the home with individuals who are Deaf or hearing with ASD, and, particularly, on individuals who are Deaf-ASD.

3. It was hypothesized that:
    a) Individuals whose parents use some type of visual communication (e.g., ASL or PECS) in the home will demonstrate better communication skills as rated on the LPP than individuals whose parents do not use visual communication, regardless of the individual’s diagnosis or identification.
    b) Parents of Deaf-ASD individuals will be more likely to utilize visual communication with their child than parents of hearing ASD or Deaf individuals.

Chapter Two- Parental Stress, Coping and Empowerment

Familial Stress and Coping

In chapter one a more comprehensive understanding of the communication and social development of individuals who are Deaf with ASD was explored. Chapter two examines parent and caregiver functioning when they are caring for an individual who is Deaf with an ASD. In particular, this chapter examines the levels of stress, coping and empowerment that parents and caregivers may experience when caring for an individual who is Deaf or who has an ASD.

Pandit (2008) identified that for parents who are parenting a child with different needs their stressors and challenges tend to be ongoing and pervasive. Levels of stress can be impacted by parent involvement (Simmerman, Blacher & Baker, 2001), overall well-being, social support, and family-centred school services (Nachshen, Garcin & Minnes, 2005). Parents of children who demonstrate a greater number of behavioural, social and emotional difficulties also appear to experience higher stress levels and report a greater number of negative experiences (Nachshen et al., 2005).

Family Stress, Coping and Use of Resources

Previous research (e.g., Beckman, 1991; Innocenti, Huh, & Boyce, 1992; Kazak, 1987; Kazak & Marvin, 1984) has demonstrated that parents of children with special needs tend to report higher levels of stress related to their parenting skills than parents of children without special needs (Pipp-Siegel, Sedey, & Yoshinaga-Itano, 2002). Therefore, it is not enough to understand the individual who is developing with an identification, disability, or disorder as only an individual in isolation. Rather, research and professionals need to consider the individual within a social-cultural-familial context, which necessitates understanding the dynamics of the family as a whole. More specifically, it is important to consider how the disability or disorder adds to the stressors that are already present within the family setting.

Pipp-Siegel and colleagues (2002) identified stressors as: physiological, cognitive, or social-emotional entities. Previous research examining stress and coping of parents who have children with special needs indicates several variables that are important in understanding these families. In a meta-analysis, Yau and Li-Tsang (1999) found five main categories that appear to be correlated with familial adaptive functioning: (1) the marital relationship, (2) phenotypic characteristics of the child, (3) personal resources, (4) social resources, and (5) parental support groups. Additionally, from their meta-analysis Scorgie, Wilgosh, and McDonald (1998) indicated that there are four main categories of variables that can impact a family's coping ability. These are: (a) child variables, which can include type or degree of disability, age, gender, temperament or personality of child; (b) parent variables, that include maternal functioning, parent relationship, routine and flexibility; (c) family variables, such as family relationships, division of roles and responsibilities, problem-solving abilities, socio-economic status; and (d) other variables external to the family system such as working with professionals, social support, and societal views on disabilities.

The presence of stress can influence how individuals perceive their roles as parents and impact their coping or self-efficacy skills. Self-efficacy skills refer to how parents view their ability to parent; that is, how competent they feel as a parent (Kuhn & Carter, 2006). For example, Gelfand et al. (1992) found that, amongst hearing mothers of hearing children, there was a relationship between parental stress and depression. Therefore, when a family or a member of the family experiences stress, the ability to perform family roles, problem solve, and care for each other is greatly impacted (Feher-Prout, 1996), and the parent's own feelings of self-efficacy may be lowered. Furthermore, a stressor placed on a family can disrupt the pre-existing balance (McCubbin, Olson, & Larsen, 2001), which requires significant adjustment to cope or manage the new and already existing stressors within the family. Seligman and Darling (1997) proposed that, when there is a family member who has been diagnosed with a disorder or disability (e.g., Down Syndrome, developmental disabilities), the entire family system experiences a disruption, which in turn, further impacts that individual. Therefore, the development of coping and self-efficacy skills becomes increasingly important to protect the family unit, as well as the individuals within the family.

Several definitions of coping have emerged over time; however, they each refer to the management of stress. For example, Lazarus and Folkman (1984) viewed coping as a process by which the individual manages internal or external demands that are overwhelming or require more resources than the individual possesses. Smith et al. (2008) defined coping as the mechanism by which individuals respond to threats of stress. Further still, Eisenberg, Fabes, and Guthrie (1997) proposed that coping employs regulatory processes in several contexts where stress originates in individuals. Overall, coping appears to require many resources from individuals, and theorists seem to agree that there are two general types of coping mechanisms: 1) those that are problem-solving focused; and 2) those that are emotion-focused (Carver, Scheier, & Weintraub, 1989; Folkman & Lazarus, 1988). The goal of 'problem-focused coping' is to reduce or eliminate the stressor. As a result, individuals will engage in tasks that involve researching, problem-solving and goal-developing to tackle and solve the problem. In contrast, the goal of ‘emotion-focused’ coping is to change the emotional reaction that experienced in the presence of the stressor, rather than change the stressor itself (Folkman &n Lazarus, 1988).

Essex, Seltzer, and Krauss (1999) found that mothers of adults with severe intellectual disabilities who tended to engage in higher levels of problem-focused coping skills had lower levels of depression over time. In contrast, mothers who engaged in higher levels of emotion-focused coping reported increased feelings of burden and depression over time.

Conrad, Gross, Fogg, and Ruchala (1992) found that increased knowledge of their child’s behaviour or needs did not necessarily result in better mother-child interactions. Rather, when mothers gained knowledge and feelings of self-efficacy or confidence, their interactions with their children became significantly more effective. Therefore, it seems that parents who engage in more problem-focused coping are more likely to utilize resources which, in turn, can help to reduce the stressor itself and thereby maintain feelings of self-efficacy and even increase levels of empowerment.

Empowerment in the literature has been used to understand how communities, organizations and individuals can improve current experiences in that environment. The term empowerment can identify both a process and an outcome (Zimmerman, 1995) and for individuals, includes the ability to understand issues impacting their current situation, identify their beliefs about their own capacity to act on the issues, and their motivation to act (Shulz, Israel, Zimmerman, & Checkoway, 1995). For parents, it can appear as the ability to acknowledge and use support networks available to them by becoming knowledgeable of their child’s needs and active in their child’s care (Carpenter, 1997, Nachshen, 2005).

The sense of empowerment for parents of children with different developmental needs can be impacted by their ability to manage day-to-day situations and their ability to work with their service system (Shulz et. al., 1995). Spiker and colleagues (2002) also recognized that the child’s own social, emotional, and cognitive functioning can impact a parent’s ability to participate in setting and working towards intervention goals, which can in turn, influence their perceived competence and stress levels. Therefore, not only is it important to explore the stressors that affect families of Deaf-ASD individuals, but also to explore the coping, self-efficacy and resources used to manage these stressors.

Family Stress, Coping, Empowerment, and Resources when a Family Member is Deaf

Previous research (e.g., Hintermair, 2004; Mapp & Hudson, 1997; Meadow-Orlans et al., 2004; Morgan-Redshaw et al., 1990; Pipp-Siegel, Sedey, & Yoshinaga-Itano, 2002; Prendergast & McCollum, 1996) has examined the parent-child relationship when the child is Deaf. Associations between parent stress levels and variables such as communicative competence of the child, the evidence of additional disabilities or disorders, and parental hearing status have been established. In particular, the research indicated that parents who are Deaf experience relatively less stress than hearing parents of children who are Deaf. Studies have also shown that parents of children who are Deaf with additional disabilities or disorders or who demonstrate low communicative competence are significantly more stressed than hearing parents and Deaf parents of Deaf children (e.g., Hintermair, 2000a, 2006; Pipp-Siegel et al., 2002).

Greenberg and colleagues (1997) have asserted that the stressors experienced and the coping mechanisms used by families with individuals who are Deaf present a different set of challenges than those experienced by hearing families of hearing individuals with disorders or disabilities. More specifically, they argued that the medical terminology of 'deafness' is defined not only by degree of hearing loss, how much sound reception one has, or even by the educational or functional consequences. Yet, what also needs to be considered is the sociological and cultural identification of the Deaf child, and thereby their family. In particular, the introduction of a new language and culture has been reported to be a source of stress for many hearing parents of Deaf children (Calderon & Greenberg, 1993; Greenberg, Lengua, Calderon, 1997; Quittner, Blueckauf, & Jackson, 1990).

Given that approximately 90 percent of deaf children have hearing parents (Sarlin & Rainer, 1987), it is not surprising that many of these parents report significantly higher parenting stress, more limited social support networks, and higher emotional distress than hearing parents of hearing children (Quittner et al., 1990). Such challenges can be attributed to the ability to adjust to having a deaf child (Greenberg, 1983; Gregory, 1976; Schlesinger & Meadow, 1972), establishing an effective mode of communication that maintains their parenting role, implementing effective parenting strategies that are more visual in nature, and learning about Deaf culture and American Sign Language (ASL). Further, hearing parents of deaf children are faced with different educational, medical, and cultural demands to ensure their child receives the best available services (Greenberg, Lengua, Calderon, 1997).

Previous research (e.g., Lederberg & Mobley, 1990; MacTurk, Meadow-Orlans, Koester, & Spencer, 1993; Meadow-Orlans, 1994; Meadow-Orlans & Steinberg, 1993) indicates the importance of social support immediately following an identification. For example, Greenberg et al. (1997) found that higher levels of social support appeared to predict better parental adjustment to having a Deaf child. However, Quittner, Glueckauf, and Jackson (1990) argue that social support appears to be a buffer only in situations of acute stress, but when the stress is chronic (e.g., continued parenting a Deaf child), social support does not provide any significant emotional protection. Nonetheless, Morgan-Redshaw, Wilgosh, and Bibby (1990) found that hearing mothers of Deaf children often reported that access to social support in addition to developing proficient communication with their child was very important to their child-rearing experiences.

Similarly, it is also possible that degree of parenting stress may also be related to the time at which language intervention support is provided and how much is given. For example, Meadow-Orlans (1994) and Pipp-Siegel and colleagues (2001) reported that the majority of children in their studies were identified and enrolled in intervention programs prior to the child reaching the age of 2 and that parents of these children reported lower parenting stress than the Deaf children who had not received these services. Lederberg and Golbach (2002) found that, for families enrolled in early intervention programs, stress was only significantly higher in specific areas such as: worrying about their child's communication difficulties and future independent functioning, but not with their ability to parent their Deaf child.

Desjardin (2004; 2006) found that mothers who felt they were more knowledgeable and competent when developing their Deaf child's language skills were more likely to engage with them using a higher level of communication style. Other studies have also found that when hearing parents of Deaf children attempt to use visual modes of communication, there tends to be more meaningful communication exchanges (Calderon et al., 1998), which leads to greater language development amongst younger children (Moeller, 2000) and improved future educational development (Calderon, 2000; Calderon & Naidu, 2000; Yoshinaga-Itano, 2000).

Desjardin (2006) proposed that more positive self-efficacy skills, particularly in the area of language acquisition, can help mothers of Deaf children improve their own language skills, and support any additional programming and intervention for their children. Furthermore, Pipp-Siegel and others (2002) found that when hearing mothers of Deaf children were given the opportunity to access early intervention services, they did not exhibit more stress when compared with mothers of hearing children. In contrast, little research has focused on the impact of having a Deaf child on parents who are also Deaf. However, given that Deaf children of Deaf parents are more likely to share the same communication style from an early age, they are more likely also to share more positive experiences that promote a sense of Deaf identity through sign and interact with other Deaf individuals who support Deaf culture (Hindley, 2000). Such experiences are likely helpful in protecting the Deaf family from stressors that are related to the medical aspects of deafness and foster positive interactions between child and parent (Moores, 1987).

Hintermair (2006) found that, for parents of Deaf children, overall parent stress was highly correlated with greater child social-emotional difficulties, in particular behavioural problems as rated by the parents. However, Hintermair (2006) also indicated that support from friends, acquaintances, extended family, professionals, and other families with Deaf or HH children were associated with lower levels of stress. It also appears that the child's communicative competence, regardless of modality of language, is a protective or even a predictive factor of child development (Greenberg, Kusche, & Speltz, 1991; Hintermair, 2006; Knoors et al., 2003; Mitchell & Quittner, 1996; Vostanis et al., 1997). Moreover, when parents are also able to adapt their communication style to match their child's mode of communication there appears to be more positive child social and behavioural development reported by parents (Brubaker & Szakowski, 2000). Therefore, it seems that providing early intervention and services that offer communication tools and support to parents who attempt to implement these strategies in the home is important not only for the child's own development, but also for parents' well-being and positive and supportive family systems.

When it comes to utilizing resources to address language or educational goals for children who are Deaf, parents are faced with many options, most of which are associated with the mode of communication chosen (e.g., signed versus oral language). Additionally, these choices can vary significantly between parents who identify themselves as deaf or Deaf and those who are hearing (Feher-Prout, 1996). However, Hamner and Turner (1990) found that developing effective communication skills between parent and child plays a significant role in the social and cognitive development of the child. Therefore, for hearing parents, services that focus on communication and language development become very important.

Bernstein and Barta (1988) found that when hearing parents were asked about the available services for their Deaf child, many were satisfied with the educational programming their child was receiving, but felt uninformed about the specifics of this programming. Additionally, Meadow-Orlans and colleagues (1997) found that parents of Deaf children were quite positive about the support services they received. In particular, they felt supported by their child's teachers, their own spouses, therapists, other parents of Deaf children, and at times, by the Deaf community. Further, the authors found that hearing mothers rated these services and support people more positively than their Deaf or HH parent counterparts; as well, Caucasian mothers were also more positive than mothers of ethnic or visible minority identifications. Overall, Calderon and Greenberg (1999) found that when hearing mothers felt supported by the community, friends, intimate relationships, and extended family, they tended to cope better with life stressors and were better adjusted to life with a Deaf child. It appears then, that, by accessing services that promote communication between parent and child, participating in a positive educational environment, and participating in the Deaf community, hearing parents are better able to employ a competency-based model (Calderon & Greenberg, 1999) of coping. For Deaf and HH parents, who already share the same language as their Deaf child, the ability to communicate and interact with hearing professionals to obtain services for their child may be more of a concern and source of frustration (DiPietro, Knight and Sams, 1981).

It is important to note, however, that for Deaf children of hearing parents, hearing parents may choose to access similar services, but choose not to participate in the Deaf community. Instead, they may associate with other hearing parents of Deaf children or find support through the hearing community. Conversely, Deaf parents of Deaf children may be more likely to seek support within the Deaf community when trying to access new services. Such use of accessing services may also play a role in parent coping and empowerment. Hintermair (2006) argues that, when parents have access to personal and social resources, they are able to cope more effectively and therefore feel more empowered and competent to support their Deaf or HH child. In particular, he identified social resources as making use of people already associated with the family in addition to society networks (e.g., support groups, professionals, Deaf individuals in the community). Personal resources are more innate characteristics that an individual possesses such as their sense of self-esteem or efficacy, resiliency, optimism. Within the literature (e.g., Calderon & Greenberg, 1993; Pipp-Siegel et al., 2002; Quittner et al., 1990), it has been established that social and personal resources are effective in strengthening coping mechanisms and increasing empowerment for parents of Deaf and HH children.

Therefore, support that helps to increase feelings of coping and empowerment for parents of Deaf and HH children needs to be in the form of professional advice and support that is appropriate to their child (Luckner & Velaski, 2004; MeadowOrlans & Steinberg, 1993). In addition, support that enables parents to acquire confidence to effectively parent their child is necessary (Hintermair, 2006). For hearing parents of Deaf or HH children, this may mean finding a mutual and accessible form of communication in which both parent and child can use effectively with each other. It may also mean finding support with other parents and families who are having similar experiences.

Family Stress, Coping, Empowerment and Resources when a Family Member has ASD

In general, research (e.g., Abbeduto et al., 2004; Blacher & McIntyre, 2006; Eisenhower et al., 2005; Smith, Mailick Seltzer, Tager-Flusberg, Greenberg, & Carter, 2008) indicates that parents, particularly mothers, of children with ASD report experiencing significantly more stress and poorer well-being than parents of children with other special needs (e.g., Down syndrome, fragile X syndrome, developmental disabilities, or cerebral palsy). Furthermore, parents of children with ASD report experiencing greater stress on the family, and are more vulnerable to physical and psychological stressors (Allik et al., 2006; Bouma & Schweitzer, 1990; Fombonne et al., 2001; Lee, Harrington, Louie, & Newschaffer, 2008; Seltzer et al., 2004). For example, Hoppes and Harris (1990) found that mothers of children with ASD experienced less gratification (e.g., positive experiences or emotion, pleasure) with their child than mothers of children with Down syndrome.

Several factors have been associated with the increased levels of stress that these parents experience with their children with ASD. One factor is the child's communication skills. Ello and Donovan (2005) found that parent emotional distress was associated with their child's ability to communicate in a functional manner. That is, parents experienced more stress when they could not communicate and understand their child's needs and desires. A second factor that contributes to parental emotional distress is the level of challenging behaviour of the child (Allik et al., 2006; Baker et al., 2002; Bromley et al., 2004; Fombonne et al., 2001; Klassen et al., 2004; Lee et al., 2008).

Hastings and others (2005b) found that maternal stress was more highly associated with the behaviour problems of their preschool child rather than adaptive[‡] behaviour or severity of the ASD. Consistent with that view, Bebko and others (1987) reported that symptoms most commonly associated with ASD were those rated as the most severe and the most stressful by families. Similarly, Lecavalier et al. (2006) observed that stereotypical or ritualized behaviours were related to poorer parental outcomes, which suggests that the greater the severity of the core features of autism in a young child, the greater the caregiver stress.

For parents of older children with ASD, research has shown maternal well-being to improve over time (Lounds et al., 2007). In particular, Lounds and colleagues (2007) suggested that improvements in coping and well-being could be attributed to the development of more effective coping strategies over time. Yet, results from Bebko and colleagues' (1987) study found that parents tended to rate their older children’s symptoms as less severe. Townsend and others (1989) also reported that parents of older children with ASD tend to demonstrate higher levels of coping and well-being than parents of younger children with ASD, which suggests that they have adapted to their care giving role and their child’s symptomatology. Thus it seems that parents of younger and older children with ASD face different stressors and that these different stressors may be associated with different coping strategies, in addition to varying experiences with

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[‡] Adaptive functioning refers to the age-appropriate behaviours need to live independently and function appropriately and safely in daily life. In particular, these behaviours include the ability to communicate functionally, interact in socially appropriate ways, cope in and care for different environments (e.g., home, school, or work), and care for oneself (e.g., hygiene, dressing, knowledge of health and safety rules).

educational and social services. For example, Smith and colleagues (2008) found that, when mothers of toddlers engaged in problem-focused coping instead of emotion-focused coping, maternal well-being was improved. For mothers of adolescents, however, emotion-focused coping seemed to buffer maternal well-being, particularly when ASD symptoms were more severe. Yet, the authors found that, in general, for both groups higher levels of problem-focused coping and lower levels of emotion-focused coping were related to higher levels of maternal well-being for both groups of mothers at different stages of their child's development.

Weiss and colleagues (2012) found that, while problem-focused coping can be helpful, particularly when issues are manageable and there is support available, it may not be enough for parents of children who demonstrate more chronic behavioural issues or where there are multiple stressors. Thus, it may be more distressing for parents to try and change the situation when there are not enough resources to support them, resulting in lower sense of empowerment and higher levels of stress (Scheel & Rieckmann 1998). Wakimizu and others (2011) found that parents who experience lower levels of empowerment are less likely to be aware of services and make use of services available to them and may be less aware of social support. Additionally, these parents are more likely to make use of medication and visit the hospital with their child more frequently than parents who experience higher levels of empowerment.

Weiss, MacMullin, and Lunsky (2015) found that, for mothers of children with ASD, interventions that helped to promote empowerment contributed to positive outcomes. Thus, empowerment amongst mothers of children with ASD may help to alleviate immediate distress when in crisis or prevent any higher levels or stress to occur.

As noted above, Weiss and others (2012) argued that problem-solving coping may not necessarily account for parents' ability to cope, manage stress and feel empowered. Rather, psychological constructs such as psychological acceptance (refer to Weiss et al., 2012) may help with positive coping more in situations that cannot be changed or immediately settled. The literature on empowerment of parents of children with ASD indicates that higher levels of empowerment may help to lessen overall parental distress. Further, it seems that levels of empowerment are also moderated by the level of functioning of the child and accessibility to services. It seems that psychological acceptance of their child's functioning and behaviours may also play a role in parental functioning.

Research additionally indicates that there are differences between mothers and fathers of children with ASD. Hastings and others (2005a) found that mothers were more likely to be greatly impacted by their child's behavioural difficulties than fathers. Further, they found that maternal stress was influenced by any mood difficulties demonstrated by their partner. Conversely, paternal stress was influenced only by mood difficulties of their partner and not behavioural difficulties of their child. Several researchers (e.g., Konstantareas & Homatidis, 1992; Milgram & Atzil, 1988) proposed that these differences could be due to the increased involvement and care by mothers.

While the above research makes distinctions between mothers and fathers, Lee and others (2008) found that, in general, parents of children with ASD were more likely to report a lower quality of life and increased concerns for the welfare of their child than parents of children with other special needs. As well, parents of children with ASD were more likely to resign from their jobs to provide primary childcare, participate in fewer enjoyable activities (e.g., participate in book club, work out), become involved in fewer community services, and report a greater child caring burden than parents of children with Attention Deficit Hyperactivity Disorder (ADHD). Additionally, Higgins and colleagues (2005) found that caregivers of children with ASD tend to experience less marital satisfaction, and report greater problems creating family adaptability and cohesion than families with typically developing children. Thus, it is not surprising that caregivers of children with ASD are at greater risk for experiencing physical and psychological distress (e.g., Allik et al., 2006; Bouma & Schweitzer; Fombonne et al., 2001; Seltzer et al., 2004) and engaging in more passive coping behaviours (e.g., withdrawal) or emotion-focused coping behaviours (Twoy, Connolly, & Novak, 2007). Yet, there are also positive findings that suggest many caregivers of children with ASD who are more active in promoting their child's development are also more likely to report higher levels of self-efficacy (Kuhn & Carter, 2006) and less parenting stress than parents who do not engage in these activities.

With respect to services, Cassidy and colleagues (2008) found that families of younger children with ASD focused more often on accessing speech and language services and were less likely to seek out any specific therapeutic programs (e.g., Applied Behavioral Analysis, TEACCH, Hanen; Francis, 2005) without being prompted by professional recommendation. Further, of the sample of children four years or younger, Tomas and others (2007) found that, when families did seek out specific therapeutic programs, they accessed one or more major treatment approaches (e.g., TEACCH, ABA, Floor Time, Defeat Autism Now). Additionally, two-thirds of families of older children (i.e., school aged to adolescent) also used such services. The authors found that families with children between the ages of 5 and 8 years tend to use the widest range of services when compared with toddlers and older children (9-11 years). Additionally, families who faced higher levels of stress, but who also had higher levels of education, were more likely to access services for their child. Therefore, it is important for professionals to help provide recommendations for available services, education, and caregiver support at each stage of development. Kuhn and Carter (2006) indicated that when parents and caregivers have access to early intervention and additional services experience greater parental self-efficacy and overall well-being.

Family Stress, Coping and Resources When a Family Member is Deaf and has ASD

In general, studies have shown that caregivers of children with ASD and hearing caregivers of Deaf children experience higher levels of stress than caregivers of neuro-typically developing and hearing individuals respectively. Additionally, hearing parents of Deaf children appear to experience more stressors than Deaf parents of Deaf children. Therefore, it seems that in order to understand the family dynamics and experiences of parents of Deaf-ASD children, it becomes important to understand the experienced stressors, the coping mechanisms and the services accessed by these families. These variables are likely to differ not only between age groups, but also by parental hearing status (e.g., hearing, HH, Deaf) and identification and diagnostic experience.

Myck-Wayne, Robinson, and Henson (2011) found that all the parents of the four participating children in their study reported that once their child had been identified as deaf, they experienced difficulty and stress related to the ASD diagnostic process. The authors also found that parents were quite frustrated with the diagnostic experience not only because of the delay in identification, but also because there is a fragmentation of service. The four families in Myck-Wayne and colleagues' (2011) study reported feeling that they were "shuffled between" the D/HH and ASD service providers and that there was little collaboration to help meet the full needs of their child. As Jure and colleagues (1991) noted, these children often miss out on proper interventions that can be geared towards each individual diagnosis (e.g., amplification, Intensive Behavioral Intervention) for several years.

Jure and colleagues (1991) further concluded that the educational experiences for Deaf-ASD children tended to be "disastrous" and there was a significant lack of services for children who are Deaf with ASD. Similar difficulties were noted by Myck-Wayne et al. (2011) as three of the four participating children were placed in a special day class for hearing students with ASD whereas one child was placed in a D/HH classroom that did not necessarily specialize in ASD. These reports suggest that meeting the unique needs of these children may be a difficult task. Nonetheless, Jure and colleagues (1991) suggested that the most appropriate educational placement is within schools specifically geared towards educating Deaf children, where visual communication is predominant (e.g., ASL or Signed English).

Hypotheses Examining Experiences of Parents Who Have Deaf-ASD Children

Overall, previous research indicates that a single diagnosis such as deafness or ASD can have a significant impact on the family system. The fourth objective of this study was to understand the impact that an identification of deafness *and* a diagnosis of ASD can have on parental functioning. The resulting fourth set of hypotheses were:

4. Since ASD and deafness alone are associated with greater levels of parental stress, and also appear to impact levels of coping and empowerment in parents of children who are Deaf or who have ASD, it was hypothesized that:

a) parents of Deaf-ASD individuals will report greater levels of stress on the CARS-P stress rating sub-scale and on the QRS-F than parents of Deaf individuals or hearing ASD individuals

b) parents of Deaf-ASD individuals will report lower scores on coping and problem-solving attitudes on the F-COPES compared to parents of Deaf individuals and hearing ASD individuals

c) parents of Deaf-ASD individuals will report lower scores of feelings of empowerment on the three sub-scales (family, service system, community/political) of the FES compared with parents of Deaf individuals or hearing ASD individuals.

Method

Participants

Preliminary data from this study were obtained from parents participating in the Deaf Autreat in 2007 in South Dakota. The Deaf Autreat was a retreat-style conference in which approximately 15 to 20 families who have children who are Deaf and have ASD or other neurodevelopmental disorder participated in discussions and shared their personal experiences. For the purpose of this study, parents were invited to share information about their children and families by interview and questionnaires. Of the 20 parents attending, 11 provided information about their child's developmental history and their parenting experiences through interviews.

In addition to the interview data, eight parents of the 11 also completed questionnaires about their child. Two of those parents were the mother and father of one child. Therefore, while there were a total of eight parent participants who provided questionnaire information about themselves (see procedure section about questionnaire information), they provided information about seven individuals who were Deaf with ASD. At the time of data collection the ages of the seven children ranged between 2 years, 5 months and 13 years, 3 months (M = 7.45 years, SD = 4.40 years).

From the original questionnaire data provided by parents, all seven children were identified as Deaf. Further, four of the seven at the time of the Autreat had confirmation of one of the diagnoses under the DSM-IV-TR PDD disorders, now known as Autism Spectrum Disorder (ASD) under the DSM-5 criteria. The parents of the three remaining children reported that their child had a provisional diagnosis of an autism spectrum disorder. Given that all seven children had provisional or confirmed diagnoses, they formed the initial Deaf-ASD group, and were included in the Deaf-ASD group for the current study.

Given the initial data provided by the families from the Deaf Autreat, and the exploratory nature of this study, the sample size of the Deaf-ASD group was increased. In addition to the Deaf-ASD group, two comparison groups were established: hearing individuals with ASD and Deaf individuals without ASD, to identify any similarities and differences among these groups.

As a result, parents and caregivers of individuals of any age belonging to one of three groups were asked to participate in this study:

1) Individuals who are Deaf and also have an Autism Spectrum Disorder.
2) Individuals who are Deaf without a diagnosis of ASD. (Given the heterogeneity of the etiology of deafness and the clinical nature of the Deaf population, it was expected that individuals who comprise this group may in fact have additional medical or developmental diagnoses such as Language Delays, neurological impairments, or attentional deficits.)
3) Individuals with Autism Spectrum Disorders who are hearing regardless of their cognitive and developmental functioning.

For the purpose of this study, no age limit was defined because the target population (Deaf-ASD) is quite small and setting an age limit would have reduced the number of overall participants. Further, individuals who have cochlear implants were included in this study for both Deaf and Deaf-ASD groups. For clarity, since parents and caregivers were the ones to complete the questionnaire items, they will be referred to as the participants in this study.

Parent Participant Information. Overall, a total of *N*= 61 parents and caregivers participated by providing information about themselves and their child's communication skills on the LPP. However, five parents did not provide any more information about their child or their experiences, and therefore were only included in analyses examining hypotheses 1a and 1b as well as hypotheses 2a and 2b.

When all 61 participants were considered (i.e., analyses using LPP data), information about 54 children was obtained because seven children had both parents provide responses. Specifically, three fathers in the ASD group, one father in the Deaf group and three fathers in the Deaf-ASD group provided information in addition to the child's mother. When data were provided by one parent, those were the data used. For four of the children, the information provided about the child's communication, social skills, and behaviour was only from the fathers; for most others, it was the mothers. In cases where both parents provided data, the information from the mothers was used. This was to reduce variability and because there were not enough fathers who provided data to use as a standalone group for purposes of comparisons with mothers on these variables. To examine parent experiences on coping, empowerment and stress questionnaires, all parents who provided complete or nearly complete information were included. Specifically, when two parents provided information about their stress level, coping, and empowerment experiences in relationship to the same child, both parents' information was included. The purpose of including all those who provided information was to understand the perspective of each parent who participated in one of the three focus groups in this study. Given the small number of fathers who participated in this study, the data provided by both mothers and fathers were examined together as no comparisons between the parents could be made.

For analyses of parent participant information (i.e., parental stress, coping and empowerment), the total number of participants was *N* = 56. Of this sample, 45 reported being female caregivers (i.e., mothers or grandmothers) and 11 reported being male caregivers (i.e., fathers). Further, 53 reported that their auditory status is 'hearing' and eight reported that their hearing status is 'Deaf' (refer to Table 1 for participant information across child groups). Parent participants were also asked to provide information about the languages used in the home to communicate with their child. A total of 35 parents reported that they do not use ASL whereas 21 parents indicated that they use ASL as a language to communicate in their home (refer to Table 1 for participant information across child groups).

Table 1

Parent Characteristics Across Groups

	Child Group		
Parent Information	*ASD*	*Deaf*	*Deaf-ASD*
Parent participants	n = 20	n = 20	n = 21
Mother	17	19	15
Father	3	1	6
Hearing	17	19	17
Deaf	3	1	4
Hearing no ASL	14	15	8
Hearing ASL	3	4	9
Deaf ASL	3	1	4

Total parent participants N = 61

Child Participant Information. Overall, information about 37 males and 17 females was provided by the 61 parent participants (refer to Table 2 for child information across groups). When all three groups of children were considered, the youngest child included in this sample was 1 year, 10 months and the eldest was 24 years of age (*M* = 10.84, *SD* = 6.11). There were no between group differences for age; *F*(2, 48) = 1.17, *p* = .319.

Table 2

Child Characteristics Across Groups

	ASD		*Deaf*		*Deaf-ASD*	
Child Information	n = 17		n = 19		n = 18	
Male	14		8		15	
Female	3		11		3	
	ASD		*Deaf*		*Deaf-ASD*	
	M	*SD*	*M*	*SD*	*M*	*SD*
Age in years	9.77	6.08	9.97	6.13	12.23	5.88

Total number of children N = 54
Mean age between groups *n.s.*

Note: this sample includes the responses from parents who only completed the LPP, but excludes co-parenting father responses

Measures

Given the exploratory nature of this study, a range of measures was used to examine both parental and individual characteristics. All of the measures used in this study were questionnaires that do not have extensive normative data. However, the interest in this study was between-group comparisons; as a result, the differences in scores between each of these groups is more important than the comparison to typical norm referenced data. While normative data may be limited for some of these measures, the psychometrics of each are discussed below.

Measures administered to parents/caregivers were made available by two formats. In addition to the 11 paper copies completed in South Dakota, 12 paper copies were completed by parents and caregivers. In addition, to paper copy, 38 parents and caregivers completed the questionnaires by secure website. All participants provided their consent. Participants who completed the study online were also informed of the website's security. Following the completion of the study, information obtained from the website was downloaded to a secure computer and removed from the website to ensure confidentiality.

Parents and caregivers provided information about both their child's functioning and their own functioning. Measures that explored their child's functioning were the LPP-2, CARS-P Symptom Rating scale, and the SISQ, described below. These measures are presented first and measures that explored parent/ caregiver functioning are presented second. These measures are the CARS-P Stress Rating scale, FES, QRS-F (Factor 1), and F-COPES.

The Language Proficiency Profile-2. The LPP-2 (Bebko & McKinnon, 1993) is a questionnaire given to the person most familiar with the child's language in order to measure the development of overall language and communication skills, independent of any particular language or modality of expression. It is a multiple choice rating scale that assesses content, reference, use, cohesion, and form of language. These five sub-scales (i.e., content, reference, use, cohesion, and form) are rated on a scale of five options where options 'Past This Level' and 'Yes' receive scores of two; 'Emerging' receives a score of one; and 'Not Yet' and 'Unsure' receive scores of zero.

The LPP-2 is designed to assess children's language development and communication skills when children use a combination of languages (e.g., ASL, English, and other natural languages) and modalities of expression (e.g., verbal, manual signs, gestures). This assessment provides an initial understanding of the child's language as viewed by parents. The LPP-2 was found to have good concurrent validity (*r*=.79) with the 'Expressive Communication' subscale of the Vineland Adaptive Behavior Scale. Construct validity was determined by a panel of psycholinguistic/speech and language pathologists and by analyzing results obtained from a sample of hearing children, both of which confirmed a developmental trend (concordant developmental ratings by the panel of experts, and higher scores associated with increased communication skills and age among the hearing children). The LPP-2 and the LPP-NV (described in the next section) have been used in a number of studies with Deaf children (e.g., Bebko, Calderon & Treder, 2003) and they have been recently used with populations of children with ASD (Wells, 2011). This measure takes approximately 30 minutes to complete by a parent or guardian. Please refer to Appendix A for a copy of this measure.

Language Proficiency Profile – Non-Verbal (LPP-NV). The LPP-NV is a downward extension of the LPP-2, which is used to identify non-verbal communication skills when language skills are in question, or the child is pre-linguistic. In fact, this measure's primary focus is identifying the pre-lingual level of communicative development. Examining communication at this level is important, as children with ASD tend to demonstrate deficits at the pre-linguistic level of communication (e.g., absence of social gestures, lack of joint attention). The validity and reliability of this measure is currently being analyzed and initial findings indicate good strength as a screening tool. For the purpose of this study, the LPP-NV was completed only when the participant's strongest language skills were repetition of single words in imitation, purely echolalic language, or production of sounds, sign approximations, or less. The LPP-NV is comprised of the same sub-scales as the LPP-2 and is scored in the same manner. It takes approximately 10 minutes to complete by a parent or guardian. Please refer to Appendix B for a copy of this measure.

In this study, a total of four parents completed the LPP-NV for their child. In order to utilize their LPP-NV information in analyses incorporating the communication questionnaires (LPP-2 and LPP-NV) the two measures were combined and given the variable name LPP. That is, given that the LPP-NV is a downward extension and that those who are completing the LPP-2 will provide responses that are at the ceiling (i.e., will attain a maximum rating) on the LPP-NV, the maximum rating in each sub-section of the LPP-NV was added to each corresponding sub-domain of the LPP-2 for all participants for whom the LPP-2 was completed (Please refer to Table 3 for LPP-2 and LPP-NV sub-domain maximum scores and LPP sub-domain and total maximum scores when the LPP-2 and LPP-NV are combined). For those who only have LPP-NV scores, their LPP ratings continue to reflect the original information provided from the LPP-NV.

Table 3

LPP Maximum Total Scores

	Form	Content	Reference	Cohesion	Use	Total
LPP-NV	12	10	8	12	6	48
LPP-2	18	24	22	22	30	116
*LPP (inclusive)	30	34	30	34	36	164

*LPP inclusive scores used for analyses.

Note: The above indicates the separated LPP-NV and LPP-2 sub-domain maximum scores and LPP (inclusive) sub-domain and total rating scores when the LPP-NV and LPP-2 scores are collapsed into one measure.

To examine internal consistency for the Form, Content, Reference, Cohesion, and Use sub-scales, data from all three participant groups (i.e., ASD, Deaf, Deaf-ASD) were used. In the current study, when the two measures were collapsed into one overall measure, the measure demonstrated strong overall internal consistency, with a Cronbach alpha coefficient of .98. The Cronbach alpha coefficients were also strong for all sub-scales: Form (.92), Content (.95), Reference (.93), Cohesion (.85), and Use (.95).

***Social Integration Skills Questionnaire*.** The SISQ is a 25-item questionnaire that is adapted from the Autism Spectrum Quotient: Children’s Version (AQ-Child, Auyeung, Baron-Cohen, Wheelwright, & Allison, 2007) and the Peer Social Interactions Rating Scale (PSIRS; Soto, Robinson, & Hanson 2004). In particular, the SISQ questionnaire includes items from the AQ-Child factor labeled Social Skills, which produced a Cronbach's $\alpha = 0.94$. No information regarding the reliability or validity of the PSIRS is available. In the current study, the SISQ demonstrated strong internal consistency with a Cronbach alpha coefficient of .93. This questionnaire asks parents and caregivers to rate their child's behaviours or skills on a 4-item Likert scale that ranges from 0 (*Definitely Agree*) to 3 (*Definitely Disagree*). Lower scores on this measure indicate better ability to interact with others, whereas higher scores (e.g., 66 points or higher) indicate compromised ability to interact socially with others. Items 3, 6, 8, 9, 14, 16, 18, 20, and 21 are scored by reversing the scores (i.e., 0 = 3, 1 = 2, 2 = 1, and 3 = 0). This questionnaire takes approximately 10 minutes to complete (Please refer to Appendix C to review this measure).

Childhood Autism Rating Scale-Parent (CARS-P). The CARS-P is a 16-item questionnaire that examines the behaviours of children with autism, their severity, and their caregivers' feelings of stress that are associated with those behaviours. Bebko, Konstantareas and Springer (1987) adapted the Childhood Autism Rating Scale (CARS) developed by Schopler and colleagues (1980) to include parents' perceived stress that is associated with the behavioural symptoms that their child may demonstrate. Overall, this measure takes approximately 10 minutes to complete (Please refer to Appendix D for a copy of this measure). For the purpose of this study, the CARS-P sub-scales were separated. Specifically, the CARS-P symptom sub-scale was used in the analyses that examined child functioning. Subsequently, the CARS-P stress rating sub-scale was used to examine parent and caregiver functioning.

To rate their child's functioning, caregivers are asked to rate the individual's symptoms on a scale that ranges from 1 (*Normal for chronological age*) to 4 (*severely abnormal*). Scores greater than 30 are consistent with a diagnosis of Autism Spectrum Disorder, and scores ranging from 15 to 30 would be expected for neuro-typically developing children. This sub-scale was used with LPP and SISQ data to learn more about the child/individual functioning. Using data from this study, the symptom sub-scale of the CARS-P demonstrated strong internal consistency with a Cronbach alpha of .93.

In addition to the symptom sub-scale, parents are asked to describe how stressful each symptom is on a scale that ranges from 1 *(none at all*) to 4 (*extreme*). Higher scores indicated more stress that the parent experiences. This sub-scale was used with F-COPES, FES and QRS-F data to learn more about parent functioning. The authors of this measure reported satisfactory internal consistency with a coefficient alpha of .86 and split-half reliability of .85. In the Current study, internal consistency was measured with a Cronbach alpha coefficient of .91 and is considered strong.

A Short-Form of the Questionnaire on Resources and Stress (QRS-F). The QRS-F (Friedrich, Greenberg & Crnic, 1983) is a measure often used to study stress in families that include children with disabilities (Glidden & Floyd, 1997; Honey, Hastings, & McConachie, 2005). It explores caregivers' feelings about the child with a disability, how they deal with various stressors associated with their child, and how they make use of available resources. In particular, 52 questions comprise the measure and there are four factors: 1) parent and family problems; 2) parents' pessimism about their child's future;

3) child characteristics in relation to stressors on the parent; and 4) level of child's physical incapacity. Caregivers are asked to respond to items by indicating 'True' (score of one) or 'False (score of zero). This measure takes approximately 10 minutes to complete by a parent or caregiver. Please refer to Appendix E for a copy of this measure. For the purpose of this study, only Factor 1 (parent and family problems) was used as it has been identified as a good measure of stressful impact/ outcome (Jackson, 1996). In the current study, this sub-scale demonstrated strong internal consistency with a Cronbach alpha coefficient of .90.

Family Crisis Oriented Personal Evaluation Scales (F-COPES). The F-COPES (McCubbin, Olson, & Larsen, 1991) is designed to record effective problem-solving attitudes and behaviours that families develop to respond to problems or difficulties. This measure contains 30 items and has five sub-scales: 1) acquiring social support; 2) reframing; 3) seeking spiritual support; 4) mobilizing family to acquire and accept help; 5) and passive appraisal. The F-COPES asks caregivers to describe their experiences on a Likert scale that ranges from 1 (*strongly disagree*) to 5 (*strongly agree*). Higher scores within each sub-scale indicate more positive problem-solving attitudes, with the exception of passive appraisal in which items are reversed. Specifically, items 12, 17, 26, and 28 are reverse-scored. Subscale overall total scores are derived by summing all the item scores. The F-COPES is completed by a parent or caregiver and takes approximately 10 minutes to complete. Please refer to Appendix F for a copy of this measure. McCubbin et al., (1991) reported that the F-COPES has good internal consistency with a Cronbach alpha of .86 and strong factorial validity. In the current study the internal consistency for the F-COPES total was moderately good with a

Cronbach alpha coefficient of .73. Examining the internal consistency for each sub-scale, the Cronbach alpha was variable. In particular, it was good for acquiring social support (.75) and reframing (.75) sub-scales. It was also very strong for seeking spiritual support (.90). The Cronbach alpha was weaker for the mobilizing family (.63) and passive appraisal (.55) sub-scales.

Family Empowerment Scale (FES). The FES (Koren, DeChillo, & Friesen, 1992) is a questionnaire that explores how caregivers of a child with an emotional or developmental disorder feel about their own situation. Further, this measure examines what decisions caregivers feels empowered to make regarding their child. This is a 34-item questionnaire that looks at level of empowerment and expression of empowerment, and has three sub-scales: 1) family; 2) service system; 3) and community/ political. The FES asks caregivers to describe their situation on a Likert scale that ranges from 1 (*not true at all*) to 5 (*very true*). Higher scores within each subscale indicate a higher level of empowerment. The scores within the family and service system subscales range from 12 to 60 and scores on the community/political subscale range from 10 to 50. The authors of the measure reported that the FES has strong internal consistency, with Cronbach alphas of .88, .87 and .88 for the three sub-scales, and good validity. In the current study, the sub-scales demonstrated strong internal consistency. In particular, both the family and service system sub-scales had a Cronbach alpha of .80. The community/political sub-scale had a Cronbach alpha of .86. Parents and caregivers were asked to complete this questionnaire, which takes approximately 10 minutes to complete. Please refer to Appendix G for a copy of this measure.

Developmental history and services interview. When possible, parents and caregivers were asked to participate in an interview that explored their child's development. In particular, parents were asked about their child's communication and language development, the age at which Deafness and/or ASD was identified, their child's education, and the services that have been received or accessed (please refer to Appendix H). This interview was not mailed or placed on the website for parents to complete; rather was completed either in person or by phone. The purpose of the interview style was to understand and gain information about their child's developmental history. Given the nature of this data gathering style, however, only nine parents participated in this portion of the study. Therefore the results of this interview are qualitative in their presentation.

Procedure

In addition to Autreat families, parent/caregiver participants were recruited by solicitation through the official laboratory website of Dr. James Bebko (http://www.bebkolab.apps01.yorku.ca/), emails to professionals working with individuals in these populations, workshops, various outreach programs and through schools. As well, participants were recruited through website based forms of social media such as Facebook groups and on-line websites for which the York Research Ethics Board provided approval. Participants were offered a choice of completing the study either on-line or using paper copies.

Results

Results for Chapter One – Communication, Behaviour, and Social Skills

Hypothesis 1 results. Hypothesis 1a predicted that, amongst individuals in the Deaf-ASD group, the first identification made will be deafness or hearing loss, whereas the ASD will be identified second. Further, hypothesis 1b predicted that the ASD diagnosis will be identified chronologically later than it is in their hearing ASD counterparts. Due to lack of qualitative information from the majority of the current sample, information that was gained from the current sample was combined with qualitative information from the preliminary data. Using the qualitative data from 10 preliminary Autreat participants and one from the more recent sample, information from a total of 11 participants is reported. This information is based only on participants in the Deaf-ASD group and therefore, no direct comparison analyses with hearing individuals with ASD or Deaf individuals without ASD can be made for the purpose of this study.

According to the information provided on the 11 children, all were first identified as deaf and the diagnosis of ASD was second (see figure 1). While this is a small sample, it appears that the identification of deafness first and the diagnosis of ASD second is consistent with Jure, Rapin, and Tuchman’s (1991) findings. Specifically, following the identification of deafness, the ASD diagnosis tended to be made approximately two years later (*M* =2.35, *SD* =0.69, age range: 1-2.75 years) for the 11 individuals reported in this study. Further, all individuals were identified with a hearing loss or as deaf at birth or within the first two years (*M* = .41, *SD* = .63, age range: 0-1.67 years) and the secondary diagnosis of ASD was made within the first four years of age (*M* = 2.76, *SD* = 1.09, age range: 1-4 years). It is important to note, however, that these findings may not extend to the larger sample that is described in the remainder of this study.

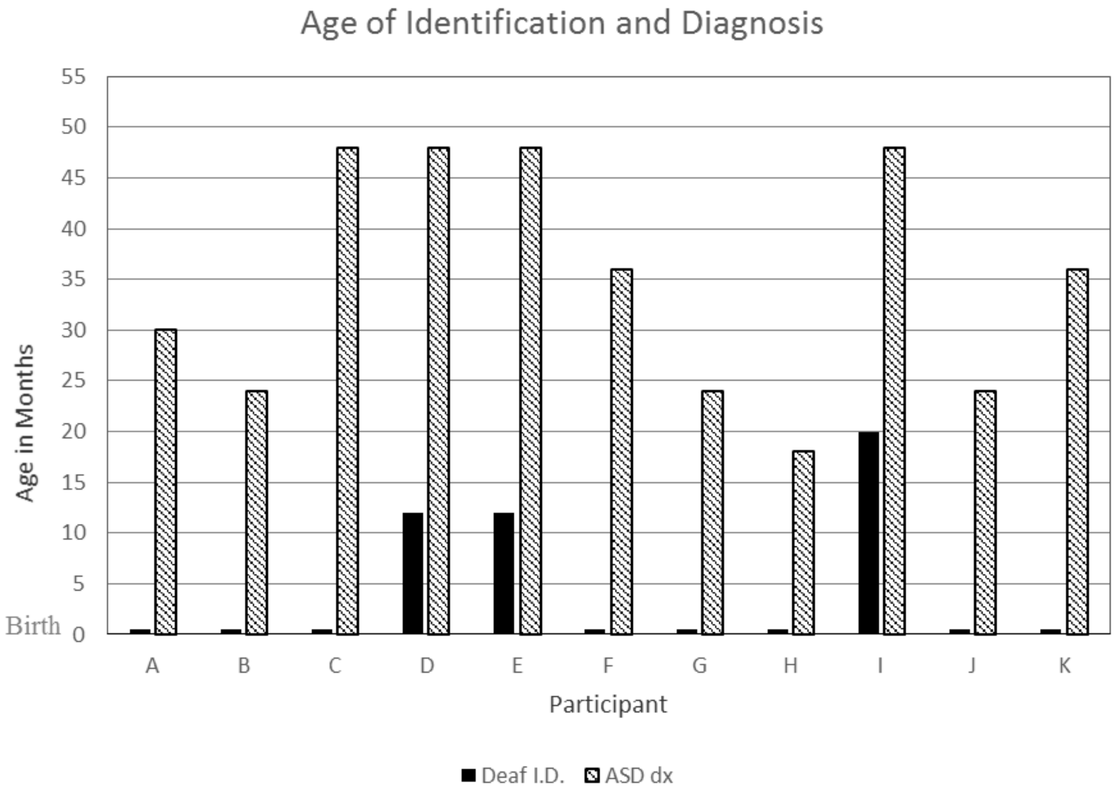

Figure 1. Age of Deaf Identification and ASD Diagnosis in Sub-Sample of Deaf-ASD Group (*n* = 12)

Hypothesis 1c postulated that parents of children who are Deaf - ASD will use more resources within the Deaf community. All parents within this sub-sample of 11 reported that their child was identified at birth or within the first two years as being deaf and that within this time period they provided their child with accessible forms of language or communication (e.g., ASL, PECS), either because they themselves use the same language (i.e., ASL) or because they accessed speech and language pathology services within the hearing community. Nonetheless, all of these parents reported identifying persisting communication and social difficulties that were over and above what might be expected of a Deaf child without ASD. These concerns prompted greater investigation into their child's development, which resulted in a diagnosis of ASD.

All parents of this sample of 11 reported that they and their child participated in different services such as physiotherapy, occupational therapy, speech and language therapy, and Applied Behavioural Analysis therapies, primarily within the hearing sector, in their hospitals. A total of 11 parents provided information about their child's service and academic setting experiences. Seven of these children attended schools for the Deaf and four attended schools in which they were integrated with hearing children.

Of the children attending schools for the Deaf, only two reported that their child was within an academic environment with other children who were also identified as Deaf with ASD and receiving programming specific to their developmental *and* communication needs. In contrast, parents of five of the children attending a school for the Deaf reported that their child's communication needs were met, but that understanding and accommodation for their developmental and learning needs were lacking. That is, parents reported that teaching staff within the school for the Deaf had little knowledge and training to work with children who have ASD.

Of the four children who attended an integrated hearing school, their parents reported that they were the only child within the school who was identified as Deaf. Thus, they noted that staff often had little knowledge of deafness and communication needs, and at times, little knowledge of providing support to individuals with ASD either. Overall, however, almost all of these parents reported that they have had to learn about services and intervention themselves in order to provide the best support for their child.

Hypothesis 2 results. Hypotheses 2a and 2b examined the communication skills as reported by parents on the LPP. In particular, it was hypothesized that individuals in the Deaf-ASD group would demonstrate poorer communication skills than individuals in the Deaf group, but similar communication skills to the individuals in the ASD group.

To compare the communication scores given by parents on the LPP amongst the three groups, a one-way ANOVA using GLM was conducted. The means and standard deviations are presented in Table 4. There was a significant difference of communication ability among the three groups $F(2, 46) = 15.26$, $p = <.001$.

Post-hoc tests using the Bonferroni correction revealed that individuals in the Deaf group were rated as having significantly better communication skills ($p = <.001$, $d = .46$) than individuals in the ASD group. Individuals in the Deaf group were also rated as having significantly better ($p = <.001$, $d = .57$) communication skills than individuals in the Deaf-ASD group. In contrast, there was no significant difference ($p = 1.000$) between the communication skills of individuals in the ASD and Deaf-ASD groups.

Table 4

Child Communication, Social and Symptom Functioning Across Groups

Measure	Group				Univariate Tests		
		n	*M*	*SD*	*df*	*F*	Sig. Partial Eta Squared
LPP Total Score	ASD	19	115.30	89.53	2	15.26	$p<.001$
	Deaf	15	153.70	77.30	46		η^2=.399
	Deaf-ASD	17	107.72	83.45			
CARS-P Symptom Rating Total Score	ASD	17	38.81	7.57	2	24.90	$p<.001$
	Deaf	17	20.31	5.42	42		η^2=.542
	Deaf-ASD	16	37.54	11.20			
SISQ Total Score	ASD	16	41.13	15.43	2	12.33	$p<.001$
	Deaf	16	22.31	11.84	37		η^2=.400
	Deaf-	10	48.33	14.44			

‘*n*’ based on parent participation for that measure

Hypotheses 2d and 2e compared the number of ASD related symptoms from the CARS-P as observed by parents in each of the three groups. Similar to the communication hypotheses, it was assumed that individuals in the Deaf-ASD group would demonstrate a similar number of ASD symptoms to those in the ASD group, but fewer symptoms than individuals in the Deaf group.

Examining parent responses about their child's ASD related symptoms amongst the three groups, a one-way ANOVA using GLM was conducted. The means and standard deviations are also presented in Table 4. There was a significant difference of ASD symptomatology among the three groups $F(2, 42) = 24.90$, p =< .001. Noting that scores of greater than 30 are consistent with ASD diagnosis, both ASD and Deaf-ASD group means fall within the ASD diagnostic range. In contrast, the group mean for the Deaf group is consistent with individuals whose scores on the CARS-P fall in the typical range (15-30).

Post-hoc tests using the Bonferroni correction revealed that individuals in the Deaf group were rated as having significantly fewer (p = <.001, $d = 2.81$) ASD related symptoms than individuals in the ASD group and Deaf-ASD group (p= <.001, $d = 1.96$). More specifically, individuals in the Deaf-ASD group demonstrated a greater number of ASD related symptoms compared to individuals in the Deaf group. When compared to individuals in the ASD group there was no significant difference ($p = 1.000$), indicating that individuals in these two groups demonstrated a similar number of ASD related symptoms. These results indicate support for the hypotheses that individuals in the Deaf-ASD group are less like their Deaf peers for ASD related symptoms and more like their hearing ASD peers.

Hypothesis 2c speculated that individuals in the Deaf-ASD group would demonstrate poorer social skills that individuals in both the Deaf and hearing ASD groups. An examination of the SISQ responses by parents using a one-way ANOVA using GLM indicated a significant difference among the three groups *F*(2, 37) = 12.33, *p* <.001.

Post-hoc tests using the Bonferroni correction revealed that individuals in the Deaf group in fact, demonstrated the fewest social difficulties compared with individuals in the ASD group (*p* = .002, *d* = 1.37) and individuals in the Deaf-ASD group (*p* = .001, *d* = 1.97). Therefore, this result indicates that individuals in the Deaf-ASD group do demonstrate poorer social skills than their peers in the Deaf group. However, Post-hoc tests also demonstrated that in fact, individuals in the Deaf-ASD group show similar social functioning as their peers in the hearing ASD group (*p* = .647) and not poorer functioning as was predicted in hypothesis 2c. These results indicate that individuals in the Deaf-ASD group are less like their Deaf peers in the area of social functioning and more like their hearing ASD peers.

Hypothesis 3 results. Hypothesis 3a and b postulated that, for any individual whose parents use ASL, their communication skills as rated on the LPP will be better than individuals who do not use ASL with their parents. Further, parents of individuals in the Deaf-ASD group would be more likely to use ASL with their child than parents in the Deaf or ASD groups.

A two-way ANOVA using GLM that incorporated both the child group and parent's use or non-use of ASL in the home was used. Overall, results demonstrated that there is no significant difference between parents who use ASL and parents who do not *F*(2, 51) = .217, *p* = .806. Further, the interaction between language use and group was not significant.

To further examine the difference between ASL use in the groups a Chi-square was used that included all 61 parent participants who provided information about their hearing status, language use, and their child's communication on the LPP. In particular, a Chi Square was conducted to explore the difference in the number of hearing or Deaf parents who use ASL in each child group. Since many of the cell frequencies are too small (i.e., they are five or less), the Chi Square could not be interpreted meaningfully.

Results for Chapter Two – Parental Stress, Coping and Empowerment

To examine all four hypotheses in the hypotheses 4 section, a one-way between-groups multivariate analysis of variance was performed to investigate the differences amongst the groups on levels of stress, empowerment, and coping. The choice to perform a MANOVA was two-fold: to lower the Type 1 error rate and to increase power given the small sub-sample sizes.

To conduct the MANOVA analysis examining parent ratings, the three child diagnosis categories were the independent variable and six parent rating dependent variables were: CARS-P stress rating, QRS-F factor 1 total, F-COPES (social support, reframing, spiritual support, mobilizing family, passive appraisal sub-scales), and FES (family, community/ political, and service sub-scales). Preliminary assumption testing was conducted to check for normality, linearity, univariate and multivariate outliers, homogeneity of variance-covariance matrices, and multicollinearity. Results of this testing indicated that the CARS-P stress total violates the assumption of equality of variances. Therefore, a more conservative alpha level (.01) was chosen. Box's test of Equality of Covariance showed a Box's M sig value of .004 indicating that assumption of homogeneity of variance-covariance has not been violated at the .001 level.

Hypothesis 4 results. Overall, there was a statistically significant difference among the three groups on the combined dependent variables: $F(20, 78) = 3.54$, $p < .001$, Wilks' Lambda = .275; partial eta squared = .476. When the results for the dependent variables were considered separately, all were considered to reach statistical significance $p < .001$. As a result, specific differences between the groups were examined. Please refer to Table 5 for univariate tests and group mean differences.

Post-hoc comparisons using the Bonferroni test were conducted for each measure. Post hoc comparisons for the CARS-P stress rating scale indicated that the mean stress rating score for the Deaf group was significantly different than the ASD group (p = <.001, d = 1.88) and Deaf-ASD group (p = <.001, d = 1.91). There was no significant difference between ratings of parents in the ASD and Deaf-ASD groups (p = 1.000). Post hoc comparisons for the QRS-F factor 1 total rating scale indicated that the mean stress rating score for the Deaf group was also significantly different than the ASD group (p = .037, d = 0.97) and Deaf-ASD group (p = <.001, d = 1.54). Again, no significant differences between parent ratings in the ASD and Deaf-ASD groups (p = .236) were identified. Taken together, these results consistently suggest that parents of Deaf individuals experience lower levels of stress than parents of individuals who have ASD or who are Deaf and have ASD. Further, these results indicate that parents in the ASD and the Deaf-ASD groups appear to experience similar levels of stress.

To examine the experiences of coping amongst parents in each of the three groups, post hoc comparisons for each of the F-COPES sub-scales were conducted. No significant differences between the groups were found on the reframing (p = .089), spiritual support (p = .181), and mobilizing family (p = .375) sub-scales. This indicates that parents in each of the three groups cope similarly when using reframing, spiritual support and family support. Significant differences between groups were, however, found on the sub-scale of social support. Specifically, parents in the Deaf group reported greater social support coping than did parents in the ASD group ($p = .003$, $d = 1.31$), whereas parents in the Deaf-ASD group did not vary in their social coping in comparison to parents in the Deaf ($p =.158$) and ASD ($p = .335$) groups. Findings on the passive appraisal sub-scale indicated no significant differences between parents in the ASD group and parents in the Deaf ($p = 1.000$) and Deaf-ASD ($p = .093$) groups. Significant findings were noted between parents in the Deaf group and parents in the Deaf-ASD group ($p = .034$, $d = 0.92$), indicating that parents in the Deaf group are better able to cope with their child's issues.

An examination of the FES sub-scale ratings between parents in each of the three groups was also conducted. Results from this study indicate that on the FES family sub-scale there is a significant difference between parents in the Deaf group and parents in the Deaf-ASD ($p = .032$, $d = 0.91$) group. Additionally, while not statistically significant, the difference between parents in the Deaf group and parents in the ASD group ($p = .068$) is marginal difference between these groups. These results indicate that parents in the Deaf group reported somewhat greater feelings of empowerment on the family sub-scale than parents in the Deaf-ASD group. No difference between parents in the Deaf-ASD and ASD groups was noted ($p = 1.000$).

Post hoc comparisons using the Bonferroni post-hoc comparisons on ratings of empowerment on the Community/ Political sub-scale of the FES revealed that the mean scores for parents in the ASD group were approaching significance between that of parents in the Deaf group (*p* = .058) and were significantly different from that of parents in the Deaf-ASD group (*p* = .004, *d*= 1.05). No significant rating differences were found between parents in the Deaf and Deaf-ASD groups (*p* = 1.000).

Similar findings were also found using the FES Service ratings. In particular, parents in the ASD group rated their experiences as significantly different from that of parents in the Deaf (*p* = .016, *d* = 0.96) and Deaf-ASD (*p* = .021, *d* = 0.96) groups. Again, no significant differences in ratings between parents in the Deaf and Deaf-ASD groups (*p* = 1.000) were indicated. Overall, post-hoc findings for the FES Service and Community/ Political sub-scales suggests that parents in the ASD group experience lower levels of empowerment than do parents of Deaf individuals or individuals who are Deaf with ASD. The results also indicate that parents in the Deaf and the Deaf-ASD groups appear to experience similar levels of empowerment and decision making ability outside of the parenting/family domain.

Table 5

MANOVA: Parent Perceived Stress, Coping and Empowerment across Diagnostic Groups

Measure	Group			Univariate Tests	
		M	*SD*	*F(2,48)*	Sig. Partial Eta Squared
CARS-P Stress Rating Scale Score	ASD	33.53	9.03	15.57	P<.001
	Deaf	20.56	3.67		$\eta^2=.393$
	Deaf-ASD	34.67	9.76		
QRS-F Factor 1 Total Score	ASD	7.65	4.89	9.76	P<.001
	Deaf	3.31	4.06		$\eta^2=.289$
	Deaf-ASD	10.56	5.26		
FES Family Sub-Scale Score	ASD	47.12	4.83	4.16	p=.022
	Deaf	51.19	4.40		$\eta^2=.148$
	Deaf-ASD	46.67	5.52		
FES Community/ Political Sub-Scale Score	ASD	27.39	8.99	6.08	p=.004
	Deaf	33.31	5.64		$\eta^2=.202$
	Deaf-ASD	35.44	6.08		
FES Service System Sub-Scale Score	ASD	47.47	5.43	5.51	p=.007
	Deaf	52.50	5.01		$\eta^2=.187$
	Deaf-ASD	52.17	4.32		
FCOPES Social Support Sub-Scale Score	ASD	22.59	4.81	6.26	p=.004
	Deaf	29.63	5.88		$\eta^2=.207$
	Deaf-ASD	25.72	6.33		
FCOPES Reframing Sub-Scale Score	ASD	30.41	5.47	2.54	p=.089
	Deaf	33.06	3.75		$\eta^2=.096$
	Deaf-ASD	29.56	4.62		
FCOPES Spiritual Support Sub-Scale Score	ASD	11.82	4.94	1.77	p=.181
	Deaf	9.38	4.47		$\eta^2=.069$
	Deaf-ASD	9.00	4.86		
FCOPES Mobilizing Family Sub-Scale Score	ASD	14.12	3.30	1.00	p=.375
	Deaf	15.31	2.47		$\eta^2=.040$
	Deaf-ASD	15.17	2.15		
FCOPES Passive Appraisal Sub-Scale Score	ASD	16.24	3.05	4.06	p=.016
	Deaf	16.69	2.77		$\eta^2=.158$
	Deaf-ASD	14.00	3.07		

Note: *n* = 17 for ASD group, *n* = 16 for Deaf group, *n* = 18 for Deaf-ASD group.

Discussion

Discussion of Chapter One Findings – Communication, Behaviour, and Social Skills

This study was broken into two chapters: a) child functioning and b) parent/ caregiver functioning. The first examined the characteristics of individuals who are Deaf and have ASD in comparison to individuals who are Deaf without ASD and to individuals who are hearing with ASD. Specifically, the first part of this study explored the age of identification and diagnosis, as well as the communication, ASD characteristics, and social functioning of these individuals. It was hypothesized that individuals in the Deaf-ASD group would resemble individuals in the ASD more similarly than individuals in the Deaf group on measures of communication, social skills and ASD related symptoms.

Results from the first group of hypotheses suggest that Early Hearing Detection and Intervention programs are being as, or more, effective in the identification of hearing loss and deafness at an early age than previous research has indicated. Further, it appears that in this study an earlier secondary diagnostic identification of ASD was associated with the earlier identification of deafness, which is earlier than reported by Jure et al. (1991). However, despite the finding that the diagnosis of ASD amongst Deaf children appears to be earlier within this group, it continues to be made at a later age than in their hearing counterparts. Specifically, individuals in the Deaf-ASD sample in this study were on average diagnosed with ASD at 33 months versus the previously documented 24 months in the hearing population as noted in the ASD literature (Baron-Cohen et al., 1992; Moore and Goodson, 2003).

It is possible that the earlier age of ASD diagnosis for this group was partly due to the early identification of deafness. That is, because individuals in this group were generally identified as deaf pre-lingually, the individuals in this sample may have been provided with accessible language at an earlier age, but continued to demonstrate significant language, communication and social deficits. Specifically, all parents reported persisting language and social concerns that impacted their child's development at a similar age to hearing children suspected of ASD. It is possible then, that the difficulty in identifying ASD in the Deaf population may be more the result of difficulties acquiring knowledge of both normative Deaf characteristics and typical ASD behaviours or symptoms within the general service provider sector. Professionals working with the ASD population may not often work with those in the Deaf population and vice versa. Therefore it is possible that good sensitivity and specificity, when using measures to identify ASD amongst individuals within the Deaf population, becomes much more difficult to attain.

Given the findings from this small sample size, it will be important for future research to use a larger sample in conjunction with a sample using information from participants who are hearing with ASD to make comparisons of diagnostic age. Specific questions that examine differences between the age of ASD diagnosis within hearing and Deaf populations and reasons for any age differences will be important. Further, if there does continue to be a significant difference between the diagnostic age of Deaf individuals and hearing individuals, future research should also explore the possible impact on language, cognition, adaptive functioning, and service access that discrepancies in diagnosis may have for the Deaf individual and their family.

While information gained in this study did not highlight services received, some information about academic access was gleaned from the current sample. Specifically, seven of the 11 children who were reported to attend school attended a school for the Deaf. However, parents continued to express concerns for their child's developmental and academic progress. Thus, while their child's visual communication needs are being met, educators within the Deaf community may not necessarily have the support and services they need in order to provide intervention and education that targets the needs of a Deaf student with ASD.

Conversely, for the students who attended a program within a hearing school, intervention and service targeting difficulties that are associated with ASD were better provided but significant gaps in communication and language input were reported, making it more difficult for the child to access some of the curriculum. Moreover, the two children attending a specialized classroom for children with ASD within a school for the Deaf were reported to be progressing well. While these results are based on a very small sample, they indicate the need for specialized programming that addresses both communication/language and ASD symptomatology.

Further, while results from this study indicate that individuals in the Deaf-ASD sample resemble their hearing ASD counterparts on communication, behaviour, and social skills, providing intervention that does not target all these domains may be a disservice to individuals in this population. Specifically, if they are only regarded as individuals who have ASD, then it may be possible that the necessity of considering mode of language may be ignored. Therefore, future research should explore impact of types of academic programs that individuals who are Deaf with ASD are accessing. As well research should identify which supports and interventions are being implemented in order to help professionals and educators apply them most effectively. Such research may also help to identify forms of intervention that are specialized to this population and focus on the unique challenges of communication and social skills development.

To explore impact of visual language on quality of communication, parents who participated in the Deaf Autreat and provided questionnaire data for this study, also provided qualitative information about their child's developmental and academic history. Two additional parents from this study also provided qualitative information, totaling 12 participants. All twelve parent participants who provided qualitative information indicated using visually accessible language (e.g., ASL, PECS) at home. In contrast, however, parents in both the Deaf and the Deaf-ASD groups of the larger sample generally indicated that a visual language was not accessible within the home. That is, most of the individuals included in the Deaf and Deaf-ASD groups did not have access to visual communication in the home and communication was primarily within an oral modality with their parents. Yet, individuals in the Deaf group were rated as having better communication skills than individuals in both ASD and Deaf-ASD groups, which suggests that any language delays within the Deaf group may have been minimal. Further, these results may suggest that for the Deaf group represented in this sample, type of language did not impact communication outcome. This was further explored with hypothesis 3 and use of ASL within the home.

The results of hypothesis 3a testing are interesting in that the communication skills of individuals as rated on the LPP by their parents did not vary significantly between parents who use ASL and those who do not use ASL. At face value, it appears that communication skills are then not necessarily reliant on the type of language modality (e.g., verbal versus visual) that parents use within the home, which may be contrary to the literature on language development of Deaf children. However, if type of language modality for each individual is examined, this lack of difference between the ASL and non-ASL users within each of the three groups in this study may be better accounted for by the language and communication interventions put in place in the home. That is, language and communication research conducted within the Deaf population indicates that when a language has been made accessible, language and communication development may not necessarily be severely negatively affected (Fitzpatrick, Crawford, Ni, & Durieux-Smith, 2011; Geers, Moog, Biedenstein, Brenner & Hayes, 2009; Hayes, Geers, Treiman & Moog, 2009; Lederberg, Schick & Spencer, 2012; Nittrouer, 2010).

It is possible that for many of the individuals included in this study, particularly in the Deaf group, they share the same language modality as their parents (e.g., oral English), and have developed communication proficiency as measured on the LPP because of the shared language. It is also important to note that the LPP results are complicated by the inclusion of hearing children with ASD, who are more likely to share the same language (e.g., oral English) as their parents.

Future research should therefore examine communication proficiency and language similarities within the Deaf-ASD group and between hearing and Deaf parents. Additionally, comparative research between Deaf-ASD and Deaf groups should include a larger more varied Deaf participant group that appears more representative of the general Deaf population with respect to language and communication proficiency. Such a comparison group may reveal less significant scores on the LPP. In particular, future studies should include Deaf individuals who were identified as Deaf post-lingual (after age 3) and/or who do not share any fluent language with their parents, and are more likely to have early childhood language deprivation and language delays. By including those individuals, the difference between the groups may be less identifiable and may continue to support the case that, to fully support the language development of Deaf individuals, the availability of a shared and accessible language, even for Deaf-ASD individuals is imperative.

As noted above, significant differences between the three groups were identified in the area of communication. Specifically, results from Hypothesis 2a and 2b support the hypothesis that Deaf-ASD individuals demonstrate poorer communication skills compared with Deaf individuals and similar communication skills to those in the hearing ASD group. Further, these results indicated that individuals in the Deaf group demonstrate the strongest communication skills amongst the three groups. Again, it is important to note that these results were reported even when ASL is not used in the home, indicating that, regardless of language, Deaf individuals may demonstrate better social communication skills than individuals who have ASD. Such an observation may be a critical distinction when examining the presence of ASD in the Deaf population, which would compromise those higher social communication skills.

Previous ASD and language research indicates that lack of joint attention and social engagement can significantly impact language development (e.g., Charman, 2003; Dawson et al., 2004; Toth, Munson, Meltzoff, & Dawson, 2006; Thurm, Lord, Lee, & Newschaffer, 2007). These results may further support the importance of joint attention and the development of language, which becomes crucial when the language is visual.

Deaf individuals (with or without ASD), who are not known to have difficulties in establishing joint attention and eye gaze, may be more likely to develop better language skills than those who struggle in this type of engagement. Individuals who are Deaf and have ASD, however, may be at a significant disadvantage for learning any type of visual communication (e.g., PECS, ASL, home signs).

As a result, it is important to recognize the impact that accessible language can have on the development of a child who is Deaf and has ASD. Given the number of parents who use ASL in each group, it was difficult to determine if there were any differences in communication skills within groups that could be associated with language use. Therefore, future research would need to include larger sample sizes within the groups to include an equal number of parents who use ASL and those who do not to compare any within-group differences.

The results from this study may also indicate that individuals in the hearing ASD and the Deaf-ASD groups may in fact struggle to develop language and communication skills because of other factors such as lack of joint-attention as well as potential cognitive and adaptive functioning delays. Therefore, these individuals may demonstrate poorer communication and language development regardless of the language being used in their environment. ASD and Deaf literatures have shown the correlation between poor language and adaptive functioning as well as cognitive ability. Therefore, future research should explore the relationship between cognitive and adaptive functioning with communication development, particularly for individuals who are Deaf with ASD. Similarly to hearing individuals with ASD or to Deaf individuals without ASD, it is suspected that those with better cognitive and adaptive capabilities will demonstrate better communication skills. Further, these individuals will also have access to a shared communication method with their parents. Thus, this research would need to have groups that are matched on cognitive and/or adaptive functioning and where there are similarly matched numbers of parents who use ASL and those who do not.

While Deaf-ASD individuals do demonstrate communication impairments similar to hearing individuals with ASD, it would seem that individuals who are Deaf with ASD are at a further disadvantage in comparison to Deaf individuals without ASD. Not only do individuals who are Deaf and have an ASD have difficulty accessing cues to help them attend to specific visual information, they are simply more likely to have difficulties attending to visual cues because of delays with joint attention and theory of mind. Therefore, Deaf-ASD individuals are unique because they require additional support in order to access visual communication. Moreover, if there are unique communication needs that identify differences in this group of individuals, then it may be possible that there are also specific social and behavioural indicators that have yet to be identified.

The data from this study indicate that individuals in the Deaf-ASD group appear dissimilar to their Deaf peers in the areas of social functioning and ASD related symptoms. Further, the data indicate that individuals in the Deaf-ASD group resemble those in the hearing ASD group. That is, individuals in the Deaf-ASD group demonstrated greater deficits in social functioning and an increased number of ASD symptoms compared to those in the Deaf group. Individuals in the Deaf-ASD group also demonstrated greater social skills deficits in comparison to individuals in the hearing ASD group. These results appear to be in contrast to the findings of Szymanski and Brice (2008) and suggest that future research is needed to explore this finding with a larger sample, whose communication and language skills are more varied. Given the current within-group sample sizes, this study did not examine the social skills and ASD characteristic differences with respect to communication proficiency differences. It is possible that communication differences within the Deaf-ASD group may reveal more information about ASD characteristics and social skills

These results reveal the importance of examining ASD-specific symptomatology when identifying the presence of ASD in Deaf individuals. It is particularly important to identify symptoms of ASD when examining communication and language development in the greater Deaf population. Amongst many Deaf individuals in the greater Deaf population, deficits or delays in language development place them at greater risk for social difficulties (Antia & Kreimeyer, 1998b; Meadow, 1968; Polat, 2003; Weisel, Most & Efron, 2005), but this does not necessarily mean that they have ASD. As noted above in the discussion of communication differences amongst the groups, it appears that it is not just communication that sets the groups apart. Rather, individuals in the Deaf-ASD group appear to resemble their hearing counterparts in the ASD population more similarly than individuals in the Deaf group who might experience communication deficits. This suggests that language difficulties over and above what might be expected from a child who is Deaf alone may signal a risk of ASD. Additional ASD-type characteristics, such as stereotypical behaviours and intense interests, would reinforce identification of that risk. It is possible that other differences not controlled for in this study such as cognitive and adaptive functioning may also alert professionals that a child is at risk of a potential ASD diagnosis. Such research may help professionals develop adaptations to ASD assessment tools and develop specific interventions that target the specific needs of this group.

During the time of the completion of this study there have been two significant changes in diagnostic methodology. First, the Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM-5; American Psychiatric Association, 2013) underwent its fifth revision, in which Autistic Disorder and Asperger's Disorder are now both classified under Autism Spectrum Disorder. As well there is a new addition of Social (Pragmatic) Communication Disorder that has been included. It will be important for future research to consider the impact of these new classifications on identification or non-identification of these disorders for individuals who are Deaf. The second change has been the improvement of genetic testing to identify gene mutations in individuals with ASD (e.g., Uddin et al., 2014). As more knowledge is gained about the possible markers for ASD, it is hoped that individuals who are also identified at an early age as Deaf may also experience earlier and more accurate identification and diagnosis in the future and that subtypes of genetic mutations that are related to the co-occurrence of ASD and deafness can be identified.

Discussion of Chapter Two Findings – Parental Stress, Coping and Empowerment

As noted above, this study examined the experiences of a child who is Deaf with an ASD and the experiences of their parents/caregivers. In particular, the second chapter examined differences between groups on levels of parental stress, coping, and empowerment. It was postulated that parents in the Deaf-ASD group would experience greater levels of stress and lower levels of coping and empowerment than parents in the Deaf and ASD groups. The original goal was to not only identify any differences in perceived experiences between parents in the Deaf, hearing ASD, and Deaf-ASD groups, but also between male (father) and female (mother) caregivers. Unfortunately, too few male caregivers participated in the study to make such comparisons.

The first hypothesis in this section examined the level of stress experienced by parents and caregivers who care for an individual who is Deaf with ASD. Specifically, it was postulated that parents of individuals in the Deaf-ASD group would report higher levels of stress than parents of individuals in the Deaf or ASD groups. What was found was that on the measures CARS-P stress rating and the QRS-F factor 1 scale, parents in the ASD and Deaf-ASD groups experienced significantly more stress than parents in the Deaf group. Further results from this study indicate that parents in the hearing ASD and Deaf-ASD groups are experiencing similar levels of stress.

An examination of parental coping was explored with the F-COPES sub-scales and it was hypothesized that parents of individuals in the Deaf-ASD group would report lower perceived ability to cope and problem solve than parents of individuals in the hearing ASD or Deaf groups. Interestingly enough, parents in the three groups did not vary in their use of reframing, spiritual support, and use of family to cope. Such results indicate that parents in each of these three groups make just as much use of or little use of these strategies to cope with parenting a child with different needs. It may not necessarily be the specific identification or diagnosis, but rather that there is one that impacts coping in these areas. Where differences were identified were on uses of social support and passive appraisal to cope. In particular, while there were no differences between parents in the Deaf-ASD group and parents in the Deaf and hearing ASD groups on the social support sub-scale, there were significant differences between parents in the Deaf and

ASD groups. Specifically, that parents in the Deaf group made much more use of social support than did parents in the hearing ASD group. It is unknown what kind of social support, for example support in the hearing community or Deaf community, which would be an important factor to consider when also examining empowerment and psychological acceptance of parents who have children that are Deaf or Deaf-ASD.

In addition to social coping, differences between groups on the passive appraisal sub-scale of the F-COPES were observed. No differences between parents in the ASD group and those in the Deaf and Deaf-ASD group were noted and seems consistent with the literature on stress and coping of children with special needs. In contrast, a significant difference between parents in the Deaf and Deaf-ASD groups was identified. Given that passive appraisal indicates the parent's ability to accept difficult issues, which minimizes their reactivity to their child, these results indicate that parents in the Deaf group may have developed higher levels of acceptance. As noted, there was no significant difference between parents in the Deaf and hearing ASD groups, and no difference between parents in the hearing and the Deaf ASD groups. It is possible that the similarity between parents in the hearing ASD and Deaf-ASD groups may be reflective of the phenomenon discussed in Weiss and colleagues' (2015) study of coping and acceptance of parents of children with ASD. That is, as a greater number of ASD symptoms or behavioural issues are observed from the child, the higher level of parental stress and lower level of acceptance of the current situation is also observed. For children who are also Deaf and have an ASD, parental coping may be further impacted as communication is also significantly hindered.

Previous literature examining functioning of parents of hearing individuals with ASD indicates greater perceived stress levels compared with parents of neuro-typical developing children (e.g., Abbeduto et al., 2004; Blacher & McIntyre, 2006; Eisenhower et al., 2005; Smith et al., 2008). The current results appear to parallel those studies, but in this case with parents of Deaf individuals with and without ASD. Thus, it is likely that the symptomatology, communication and social development issues associated with ASD diagnosis may have a direct influence on parental functioning regardless of whether the individual is hearing or Deaf. Support for parents may then need to have greater focus on managing ASD related behaviours and fostering communication skills with their child in order to create better feelings of coping and problem solving and thereby lower levels of stress. It is also possible that for parents of Deaf-ASD individuals, difficulties with diagnosis and accessing services may feed into levels of stress and lower levels of coping. Research into identifying and lessening the issues that professionals face when identifying Deaf-ASD individuals and their service needs may be helpful. Such research can help to identify the specific issues that make diagnosis and service provision difficult and help reduce any additional delays for these families.

In addition to stress and coping, parents and caregivers were asked about various types of empowerment to better understand their perceived experiences in three core areas of the FES (family, community/political, and service system). The FES specifically examined how caregivers in each group feel about their own situation, but also examined how empowered they feel in regards to the decisions they make for their child. It was hypothesized in this study that parents/caregivers of individuals who are Deaf with ASD would experience less empowerment and decision making power than parents of Deaf individuals or those who are hearing with ASD.

In these analyses, the trend that emerged for the service and community/political empowerment sub-scales was that parents in the ASD group experienced significantly lower levels of empowerment and decision making power than parents in the Deaf and Deaf-ASD groups. In contrast, parents in the Deaf and Deaf-ASD groups reported experiencing similar levels of service and community/political empowerment and decision making. These results are surprising given how little is known about individuals who are Deaf with ASD and how few services are available for these individuals. Because little is known about the social support and professional support that parents of individuals who are Deaf with ASD have, it will be important for future research to examine if support within the hearing community and/or Deaf community plays a role for parents in the Deaf-ASD group. Future research should also examine whether these differences are indeed significant with a larger sample and if ASD characteristics and social skills deficits play a role in the level of empowerment experienced by parents in these groups.

It may also be important to examine reasons why parents in the Deaf group report higher levels of empowerment. As noted earlier, the sample of Deaf individuals included in this study may in fact not be representative of the broader Deaf population. That is, if additional Deaf individuals who experienced early childhood language deprivation or late language acquisition were included, responses by their parents and caregivers may make the three groups more similar in experience.

Results of the FES family sub-scale, indicate that parents/ caregivers in the Deaf group reported significantly higher levels of empowerment and decision making power than parents in the hearing ASD and Deaf-ASD groups. There did not seem to be any differences in the levels of empowerment and decision making power in the family domain for parents in the hearing ASD and Deaf-ASD groups. These results suggest that parents in the Deaf group may experience more parenting self-efficacy with respect to their Deaf child, whereas parents with a child that has ASD may experience less parenting efficacy due to their child's ASD symptoms and behaviours. It is also possible that for parents of Deaf individuals, connections with services and community help to mediate feelings self-efficacy and empowerment.

For the service and community/political sub-scales, the results seem to suggest that for parents of Deaf-ASD individuals, it may not necessarily be the symptoms associated with ASD that impact their perceived feelings of empowerment, but possibly connections with services and community that they have established. More specifically, parents of Deaf-ASD individuals qualitatively reported associating more often within the Deaf community. Therefore, there may be something more protective and helpful about accommodating services to address ASD symptoms by finding support and services provided within the Deaf community than to accommodate services in the hearing sector to a child who is Deaf. If such a hypothesis is true, then a focus on increasing knowledge and support within the Deaf community may serve not only these families, but also professionals and service providers who work within the Deaf community. Future research, therefore, should focus on this interesting finding to determine what specifically does help to support families in feeling empowered in the community and with the services they receive. In addition, future research needs to examine the hypothesized connection between the ASD symptomatology of individuals in the Deaf-ASD group and the impact on parent stress, coping and empowerment.

Overall, this study highlights a number of findings about individuals who are Deaf with ASD and about their caregivers. With respect to diagnosis, it appears that the age at which Deaf individuals are being identified as deaf is earlier than previous identification research due to Early Hearing Detection and Intervention programs. Further, due to better diagnostic tools it appears that the age at which the diagnosis of ASD is made appears earlier than previously reported in the literature for individuals. For the Deaf-ASD group represented in this study, it appears that the deaf identification is consistently the first to be identified and that these individuals tend to appear more similar to hearing individuals with ASD in the areas of communication, social skills and behaviour than to Deaf individuals without ASD. For both hearing, and particularly for Deaf children with ASD, it is important to recognize the impact of not having access to meaningful language input, which can further disadvantage their developing language, communication, and social skills.

Taken together, individuals who are Deaf with ASD do demonstrate a number of similarities to their hearing counterparts with ASD and these characteristics can impact the experience of their caregivers. While these similarities suggest that individuals in the Deaf-ASD group resemble their hearing ASD counterparts, the present study results also suggest that Deafness plays a unique role in the presentation of the ASD features. This combined expression of features shapes the impact that Deaf-ASD characteristics have on caregivers, services, and diagnosis.

Limitations

Several limitations have been identified for this study. Little information about parental educational, socio-economic and cultural background (i.e., Deaf, hearing) was identified. Such information could help to understand more about parental coping and empowerment. Information about parents and caregivers may also provide more insight about the factors that impact the communication development of their child. The lack of cognitive and adaptive functioning data on the children is another significant limitation and the likelihood that the groups may differ on these important characteristics could be a confounding issue as these factors may mediate the communication, behavioural and ASD symptoms that are observed in these groups. As a result, it is difficult to attribute group differences conclusively to diagnostic status (Deaf, ASD, Deaf-ASD) versus these other more general characteristics, which may differ across groups. While it would be important for future studies to include standardized testing, obtaining such data can be difficult due to logistical reasons and the ability of other professionals to accurately assess children who are Deaf with ASD.

As noted above, this study appeared to have a more homogenous group of Deaf individuals, possibly positively skewing the child and parental functioning responses. Thus, the Deaf sample within this study may in fact be a limitation in itself as it may not be truly representative of the Deaf community. This supports the assertion that future research would benefit from matching individuals by cognitive and/or adaptive functioning to examine the similarities that Deaf-ASD children share with their hearing ASD and their Deaf counterparts.

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Appendix A

LANGUAGE PROFICIENCY PROFILE (LPP) – 2

(Adapted from Kendall School Materials)

J. Bebko and E. McKinnon, York University

(Updated, June, 2003)

NAME OF CHILD: ____
First Name Last Name

AGE OF CHILD: ________years ________months

GENDER OF CHILD: Male ____ Female ____

NAME OF PERSON COMPLETING FORM: ______________________________
First Name Last Name

RELATIONSHIP TO CHILD: ___________________________

FIRST LANGUAGE OF PERSON COMPLETING FORM: ___________________

DATE FORM COMPLETED: __________________________

The LPP is used to identify the developing language skills of children. Questions are presented in a sequence which reflects increasing language skills. The questionnaire was designed for use with children who may use a variety of means to communicate (e.g., hearing, deaf, language impaired children). Expressions like "saying/signing" or "words/signs" are used so that the questions can be used regardless of language used. NOTE: The LPP-NV should also be completed to identify non-verbal communication skills when those are in question, or if the child is primarily at the one- or two- word/sign level.

For each question, please mark the current abilities of your child.
The rating scale for each question includes 5 options.

Past This Level	-**Mark** this option if this item no longer applies to your child. (In several places you will see this column marked "n/a". This means that "Past This Level" is not applicable to this question.)
Yes	-**Mark** this option if your child currently has this skill.
Emerging	-**Mark** this option if your child is beginning to show this skill.
Not Yet	-**Mark** this option if your child does not yet show this skill.
Unsure	-**Mark** this option **ONLY** if you've had no opportunity to observe this in your child.

Appendix A

FORM

This section is concerned with the general form of the child's communication. In addition, we are here concerned with how easy it is to talk to the child, and how easily he/she communicates with others.

DOES THE CHILD...	Past this level	Yes	Emerging	Not Yet	Unsure
1. produce only single words/signs?					
2. usually report what is really <u>new</u> or <u>interesting</u> with this single word/sign? (Example: the child would say/ sign "Doggie" if a dog appears in the room)					
3. put two words/signs together? (Example: "Daddy book" or 'Book fall")					
4. get his/her message across, even though important parts of the message are left out? (Example: the verb may be left out, as in "You chair there" meaning "You [sit] in the chair over there")					
5. communicate messages that are complete in form; that is, none of the parts have been left out? (If the child leaves out mention of him/herself in the message, a "Yes" response may still be marked.)					
6. have little or no difficulty being understood by strangers who use the same language?					
7. tell brief stories or narratives? (These stories must be understood without questioning except for specific details.)					
8. sometimes use a roundabout way of referring to things or events? (Example: the "What-ya-ma-call-it" or the "Sitting thing" for chair)					
9. usually maintain a steady flow of conversation using accurate word-choices and common expressions?					
DID YOU HAVE DIFFICULTY WITH ANY OF THESE QUESTIONS? IF SO, WHICH QUESTIONS? PLEASE DESCRIBE THE DIFFICULTY.					

Appendix A

<u>CONTENT</u>

This area is concerned with what the child communicates about. That is, what kinds of objects, actions, and relationships are mentioned by the child?

DOES THE CHILD...	Past this level	Yes	Emerging	Not Yet	Unsure
1. discuss only things and actions which are visible in the immediate environment? The child is unable to discuss things that are absent.					
2. communicate about an object's disappearance or reappearance, but nothing more?					
3. comment on his/her own actions, or those actions which affect him/her directly?					
4. communicate about what other people are doing with objects? (Example: where an object is being moved to, or who has the object)					
5. comment on actions he/she wishes <u>others</u> to do, or to stop doing?					
6. combine several ideas into a single expression? (Example: "<u>Jeff needs</u> a <u>blue crayon</u>" expresses Jeff's need and some detail of what he needs.)					
7. express something he/she wants to do in the immediate future? (Example: "I want to go play with Sally")					
8. communicate about things or events that are linked in time or that are near one another? (Example: "<u>Go to the library</u> and get a <u>book</u> and come back" or "There's a dog and there's a horse")					
9. communicate about the cause and effect relation between two events? (Example: "He did it because he was angry" or "I can't go out until I finish my work")					
10. communicate about his/her own knowledge, beliefs, and uncertainties? (Example: "I don't know how long it takes to get there" or "I'm sure they're back now")					
11. communicate about a wide range of experiences and any ideas within his/her intellectual ability?					
12. describe <u>clearly</u> and <u>completely</u> the details of abstract systems, or things that have no concrete form? These <u>may</u> include the rules of complex games like chess, or the rules of multiplication or grammar.					
DID YOU HAVE DIFFICULTY WITH ANY OF THESE QUESTIONS? IF SO, WHICH QUESTIONS? PLEASE DESCRIBE THE DIFFICULTY.					

Appendix A

REFERENCE

This section is concerned with the child's ability to communicate about things which may or may not be present.

DOES THE CHILD...	Past this level	Yes	Emerging	Not Yet	Unsure
1. use only single words/signs? These are usually used to describe events or objects currently present.					
2. use physical or other nonverbal ways to give more information about a single word or sign? (Example: pointing at or holding a particular book while saying/signing "Book")					
3. communicate one part of the message using words or signs and a further part by using nonverbal means? (Example, saying /signing "Book", then sitting on your lap and opening the book for you to read to him/her)					
4. sometimes leave out the name of a certain object relevant, assuming the listener knows what has been left out? (Example: says/signs "Read", but does not mention "book")					
5. have the ability to express an entire message verbally or through sign language?					
6. try to refer to things that are not present at the time? (The child may have some difficulty doing this.)					
7. refer confidently to things in both the past and future?					
8. describe several related events in both the past and future? (Example: describe several things that happened in the morning, and things that will happen on the weekend)					
9. refer to imagined situations and their outcomes? (Example: "If I had a lot of money, I could... ")					
10. give enough background information to help any listener understand a message that has a lot of new information?					
11. describe clearly and completely the details of complex systems or things that are not present, to a person who doesn't know this information? This communication should be rich and clear enough to allow a person to understand. (Example: the operation of a 10-speed bike, or the rules of baseball)					
DID YOU HAVE DIFFICULTY WITH ANY OF THESE QUESTIONS? IF SO, WHICH QUESTIONS? PLEASE DESCRIBE THE DIFFICULTY.					

Appendix A

COHESION

This section is concerned with how the child maintains the flow of conversation. This includes the child's ability to take into account the perspective, knowledge and opinions of the other person.

DOES THE CHILD...	Past this level	Yes	Emerging	Not Yet	Unsure
1. primarily maintain the flow of conversation by repeating parts of what the other person has just expressed?(Example: If a parent comments "Look, there's a doggie! The child responds "Doggie!")					
2. participate in the conversation by paying attention to and referring to the same object as the listener?					
3. use parts of the questions asked by someone else to build his/her answer? (Example: to the question 'What colour is the ball?" the child will answer "The ball is blue.")					
4. keep others in a conversation by asking questions about objects or people even though he/she may know the answers?					
5. volunteer new information about a topic that others have introduced in a conversation?					
6. ask others for more information about topics being discussed?					
7. participate in and follow, without difficulty, a one-on-one conversation as it moves from topic to topic?					
8. have the ability to participate in and follow a conversation among many people, although he/she may not understand and/or remember specific details?					
9. converse, even with strangers, showing full understanding of the general meaning and details being discussed?					
10. fully understand even unfamiliar details on topics of interest after they have been discussed? (These details must be within his/her intellectual grasp.)					
11. use a number of methods to fix conversations if there is a misunderstanding? (Example. The child can reword or expand on a comment, or ask to have information made more clear.)					
DID YOU HAVE DIFFICULTY WITH ANY OF THESE QUESTIONS? IF SO, WHICH QUESTIONS? PLEASE DESCRIBE THE DIFFICULTY.					

Appendix A

USE

This section is concerned with what the child uses language for, or what functions the language serves for the child at this age.

DOES THE CHILD...	Past this level	Yes	Emerging	Not Yet	Unsure
1. use language as if communicating with him/herself or simply practising language and not expecting a response?					
2. do any of these	n/a	n/a	n/a	n/a	n/a
a) identify objects when asked?					
b) ask for objects and simple services?					
c) greet others?					
d) protest the actions of others?					
3. describe a broad range of his/her own actions on objects?					
4. identify objects and actions in pictures?					
5. describe people and objects in terms of <u>both</u> temporary (Example: emotional state) <u>and</u> permanent (Example: size or colour) characteristics?					
6. communicate about the actions and intentions of others?(Example: "He wants to go, too.")					
7. use language to create and maintain worlds of make-believe such as initiating play, assigning and regulating roles and acting out his/her part in this play?					
8. use language in active searches for information? (Example: "Tell me more" or "How does ... ? ")					
9. use language to report and question how one event contradicts another? (Example: "He cut his foot, but he didn't cry"					
10. use language as a tool for thinking? (Example: to work through math problems or daily concerns, such as planning what to say to someone)					
11. try to influence others primarily by expressing personal preferences? (Example: "Don't do that! I don't like it!")					
12. try to influence others by giving reasons which relate to more general principles? (Example: "Don't play that game! It's against the law.")					
use <u>accurately</u> any of the following verbs? (Please circle the ones used.) apologize get fired invite quit					
DID YOU HAVE DIFFICULTY WITH ANY OF THESE QUESTIONS? IF SO, WHICH QUESTIONS? PLEASE DESCRIBE THE DIFFICULTY.					

Appendix B

LPP-NV

EXTENSION OF THE LANGUAGE PROFICIENCY PROFILE-2 FOR NONVERBAL OR PREVERBAL COMMUNICATIVE BEHAVIORS

(Adapted in part from Kendall School Materials, Gallaudet University)

James M. Bebko, York University

(Updated June, 2003)

NAME OF CHILD: ____
First Name Last Name

AGE OF CHILD: ________years ________months

SEX OF CHILD: Male ____ Female ____

NAME OF PERSON COMPLETING FORM: ____________________________________
First Name Last Name

RELATIONSHIP TO CHILD: ___________________________

FIRST LANGUAGE OF PERSON COMPLETING FORM: ___________________

DATE FORM COMPLETED: ________________________

For each question, please mark the current abilities of the child.
The rating scale for each question includes 5 options:

Past This Level	-**Mark** this option if this item no longer applies to your child. (In several places you will see this column marked "n/a". This means that "Past This Level" is not applicable to this question.)
Yes	-**Mark** this option if your child currently has this skill.
Emerging	-**Mark** this option if your child is beginning to show this skill.
Not Yet	-**Mark** this option if your child does not yet show this skill.
Unsure	-**Mark** this option **ONLY** if you've had no opportunity to observe this in your child.

** NOTE: **Many children with single word/sign skills or much higher language will still show many of the skills listed on the LPP-NV. For example, an older child may quite appropriately "follow another person's line of looking to see what the person is looking at," or "participate in turn taking activities to continue interactions."** For these items, a "Yes" score should be given. If the child no longer uses this skill much, but used to, then "Past this Level" should be scored.

PLEASE DO NOT QUOTE WITHOUT PERMISSION

Appendix B

Form:

DOES THE CHILD:	Past This Level	Yes	Emerging	Not yet	Unsure
1. reach towards a desired object, opening and closing the fist while looking at it?					
2. reach towards the desired object, perhaps opening and closing the fist, while looking alternately between the object and a person who might help get the object?					
3. pull, tug or physically direct other people to move them or to get their help					
4. ask for help by giving the problem item (for example a jar with a closed lid) to someone for help?					
5. point to objects that may be out of reach?					
6. produce single word-like sounds or signs that are not real words or signs, but are attempts to communicate? The child may imitate, with some mistakes, a word or sign produced by someone else.					

Content:

DOES THE CHILD:	Past This Level	Yes	Emerging	Not yet	Unsure
1. anticipate interactions by smiling before an expected event (for example, a tickle) or by extending the arms when someone reaches to pick him or her up?					
2. communicate by pointing or reaching mostly for things that are his/hers (examples: clothing, bottle, or rattle)?					
3. communicate by pointing or reaching for things that are not clearly his/hers (examples: lights, toys, or foods)?					
4. gesture or use partial words to ask for things or actions by others?					
5. imitate an action in order to get someone to do it again?					

Appendix B

Reference:

DOES THE CHILD:	Past This Level	Yes	Emerging	Not yet	Unsure
1. follow another person's line of looking to see what the person is looking at?	n/a				
1. hold objects up for others to inspect?	n/a				
2. call attention to an object by touching or pointing to it?	n/a				
3. Use a particular sound, manual sign or gesture to refer consistently to the same thing?	n/a				

Cohesion:

DOES THE CHILD:	Past This Level	Yes	Emerging	Not yet	Unsure
1. show anticipation when a meal is being prepared or when an object is hidden during a peek-a-boo or other game?					
2. smile or wave or reach out to try to continue an interaction with someone (for example, to get the person to continue with a peek-a-boo game)?	n/a				
3. try to initiate a familiar game by handing something to another person, or perhaps by guiding their actions to start to play peek-a-boo?					
4. imitate actions of other people?					
5. start a familiar game or activity him or herself, such as by covering up an object, then suddenly removing it for a "There it is!" or peek-a-boo game?					
6. repeat words or signs, but not necessarily know their meaning?					

Use:

DOES THE CHILD:	Past This Level	Yes	Emerging	Not yet	Unsure
1. use verbal or nonverbal means to call attention to him or herself, besides crying or expressing discomfort?	n/a				
2. indicate recognition of familiar objects, and express surprise at things that are novel for him or her?	n/a				
3. participate in turn taking activities to continue interactions?	n/a				
4. use vocal or sign productions that sound or look like conversational language but have no real meaning?					

Appendix C

Social Integration Skills Questionnaire

Adapted from Auyeung, Baron-Cohen, Wheelwright, & Allison (2007) and Soto, Robinson, & Hanson (2004)

Please indicate which best describes your child's social interaction behaviours:

My Child:	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
1. Prefers to do things with others than on his/her own	0	1	2	3
2. Finds social situations easy	0	1	2	3
3. Would rather go to a library than a party	0	1	2	3 **
4. Finds him/herself drawn more strongly to people than to things	0	1	2	3
5. Enjoys social chit-chat	0	1	2	3
6. Finds it hard to make new friends	0	1	2	3**
7. Would rather go to the movies than a museum	0	1	2	3
8. Gets upset when daily routine is disturbed	0	1	2	3**
9. Does not know how to keep a conversation going	0	1	2	3**

10. Usually concentrates more on the whole picture, rather than the small details	0	1	2	3
11. Enjoys doing things spontaneously	0	1	2	3
12. Is good at social chit-chat	0	1	2	3
13. Enjoys social occasions	0	1	2	3
14. Finds new situations make him/her anxious	0	1	2	3**
15. Enjoys meeting new people	0	1	2	3
16. Does not engage in social interactions or play behaviours with peers	0	1	2	3**
17. Engages in positive interactions with peers such as interactive playing, conversing, or showing physical signs of affection	0	1	2	3
18. Engages in negative interactions with peers such as hitting, kicking, throwing objects, using negative language (e.g., “no, go away”) or displays negative inflection in gesture or voice	0	1	2	3**
19. Uses conventional means of communication for such as gestures, picture symbols, words, signs (does not include unintelligible vocalizations)	0	1	2	3

20. Tends to isolate him/herself during leisure time	0	1	2	3**
21. During leisure time will be near peers or engage in similar activities, but not interact with others;	0	1	2	3**
22. Plays or interacts with peers and communicates with them about the activity using conventional means of communication (e.g., gestures, signs, speech, or picture symbols)	0	1	2	3
23. Initiates interactions with peers to begin or join an on-going activity/game	0	1	2	3
24. When initiating interactions with peers, the peers respond positively (e.g., join in, answers)	0	1	2	3
25. Will respond positively or join an on-going activity when invited to interact by peers	0	1	2	3

Scoring: Higher scores indicate more difficulty interacting with others and lower scores indicate better interactions

*** indicate items to be reverse scored.

Appendix D

Childhood Autism Rating Scale – Parent (CARS-P)

Bebko, Konstantareas & Springer (1987) adapted from Schopler et al. (1980)

Symptoms	Symptom Rating 1 = Normal for Chronological Age 2 = Mildly Abnormal 3 = Moderately Abnormal 4 = Severely Abnormal	Stress Rating (How stressful is this for you) 1 = None at all 2 = A little bit 3 = Quite a bit 4 = Extreme
1. Ability to relate to people (i.e., does not return interest others show in him/her)		
2. Imitation (extent to which child imitates, verbal or motor)		
3. Appropriateness of emotions (e.g., giggling, crying, etc.)		
4. Unusual body movements and/or repetitive motions or routines		
5. Unusual ways of relating to objects (e.g., spinning cups)		
6. Difficulty with change in the environment (e.g., new living room furniture)		
7. Interest in visual information (e.g., staring at lights, avoiding eye contact)		
8. Response to sounds (i.e., over-reacts or under-reacts)		
9. Use of other senses (e.g., mouthing, licking, smelling, rubbing)		
10. Anxiety reaction (e.g., separation from parents, unusual fears)		
11. Verbal communication (e.g., mute, echoes, pronoun reversal, repetitive language)		
12. Nonverbal communication (e.g., use of or response to gestures)		
13. Extremes of activity level (i.e., high or low activity level)		
14. Intellectual abilities (e.g., rating '2' means even impairment in all intellectual areas; rating '4' means only some areas very impaired and others are normal)		
15. Self-injurious behaviour (e.g.,		

hitting self, head banging, teeth grinding or anything else that results in injury to self)		
16. Aggression to people or objects (e.g., hitting, biting, scratching, swearing)		

Appendix E

A SHORT-FORM OF THE QUESTIONNAIRE ON RESOURCES AND STRESS

(QRS-F; Friedrich, Greenberg and Crnic, 1983)

This questionnaire deals with your feelings about a child in your family. There are many blanks on the questionnaire. Imagine the child's name filled in on each blank. Give your honest feelings and opinions. Please answer all of the questions, even if they do not seem to apply. If it is difficult to decide True (T) or False (F), answer in terms of what you or your family feel or do *most* of the time. Sometimes the questions refer to problems your family does not have. Nevertheless, they can be answered True or False, even then.

1. ________ doesn't communicate with others of his/her age group. T F
2. Other members of the family have to do without things because of ____. T F
3. Our family agrees on important matters. T F
4. I worry about what will happen to _______ when I can no longer take care of him/her. T F
5. The constant demands for care for _______ limit growth and development of some-one else in our family. T F
6. _______ is limited in the kind of work he/she can do to make a living. T F
7. I have accepted the fact that _______ might have to live out his/her life in some special setting (e.g., institution or group home). T F
8. _______ can feed himself/herself. T F
9. I have given up things I have really wanted to do in order to care for ______. T F
10. ______ is able to fit into the family social group. T F
11. Sometimes I avoid taking ______ out in public. T F
12. In the future, our family's social life will suffer because of increased responsibilities and financial stress. T F
13. It bothers me that ______ will always be this way. T F
14. I feel tense whenever I take ______ out in public. T F
15. I can go visit with friends whenever I want. T F
16. Taking ______ on vacation spoils pleasure for the whole family. T F
17. ______ knows his/her own address. T F
18. The family does as many things together now as we ever did. T F
19. ______ is aware who he/she is. T F
20. I get upset with the way my life is going. T F
21. Sometimes I feel very embarrassed because of ______. T F
22. ______ doesn't do as much as he/she should be able to do. T F
23. It is difficult to communicate with ______ because he/she has difficulty understanding what is being said to him/her. T F
24. There are many places where we can enjoy ourselves as a family when _______ comes along. T F
25. _______ is over-protected. T F
26. _______ is able to take part in games or sports. T F
27. _______ has too much time on his/her hands. T F

28. I am disappointed that _______ does not lead a normal life. T F
29. Time drags for ________, especially free time. T F

30. _______ can't pay attention very long. T F
31. It is easy for me to relax. T F
32. I worry about what will be done with _______ when he/she gets older. T F
33. I get almost too tired to enjoy myself. T F
34. One of the things I appreciate about _______ is his/her confidence. T F
35. There is a lot of anger and resentment in our family. T F
36. _______ is able to go to the bathroom alone. T F
37. _______ cannot remember what he/she says from one moment to the next. T F
38. _______ can ride a bus. T F
39. It is easy to communicate with _______. T F
40. The constant demands to care for _______ limit my growth and development. T F
41. _______ accepts himself/herself as a person. T F
42. I feel sad when I think of _______. T F
43. I often worry about what will happen to _______ when I no longer can take care of him/her/ T F
44. People can't understand what _______ tries to say. T F
45. Caring for ______ puts a strain on me. T F
46. Members of our family get to do the same kinds of things other families do. T F
47. _______ will always be a problem to us. T F
48. _______ is able to express his/her feelings to others. T F
49. _______ has to use a bedpan or a diaper. T F
50. I rarely feel blue. T F
51. I am worried much of the time. T F
52. _______ can walk without help. T F

Family Information: (please indicate which is true for you)

I am ___________ 's MotherFather Step-mother Step-father

My child is _________ years old.

My child is in a: special classroom integrated classroom

Appendix F

Family Crisis Oriented Personal Evaluation Scales
(F-COPES; McCubbin, Olson & Larsen, 1991)

Purpose:

The Family Crisis Oriented personal Evaluation Scales (F-COPES) is designed to record effective problem-solving attitudes and behavior which families develop to respond to problems or difficulties.

Directions:

First, read the list of response choices one at a time.

Second, decide how well each statement describes your attitudes and behavior in response to problems or difficulties. If the statement describes your response *very well*, then circle the number 5 indicating that you STRONGLY AGREE; if the statement does not describe your response at all, then circle the number 1 indicating that you STRONGLY DISAGREE; if the statement describes your response to some degree, then select a number 2, 3, 4 or 5 to indicate how much you agree or disagree with the statement about your response.

WHEN WE FACE PROBLEMS OR DIFFICULTIES IN OUR FAMILY, WE RESPOND BY:	Strongly disagree	Moderately disagree	Neither agree nor disagree	Moderately agree	Strongly agree
1. Sharing our difficulties with relatives	1	2	3	4	5
2. Seeking encouragement and support from friends	1	2	3	4	5
3. Knowing we have the power to solve major problems	1	2	3	4	5
4. Seeking information and advice from persons in other families who have faced the same or similar problems	1	2	3	4	5
5. Seeking advice from relatives (grandparents etc.)	1	2	3	4	5
6. Seeking assistance from community agencies and programs designed to help families in our situation	1	2	3	4	5
7. Knowing that we have the strength within our own family to solve our problems	1	2	3	4	5
8. Receiving gifts and favors from neighbors (e.g., food, taking in mail, etc.)	1	2	3	4	5
9. Seeking information and advice from the family doctor	1	2	3	4	5

10. Asking neighbors for favors and assistance	1	2	3	4	5
WHEN WE FACE PROBLEMS OR DIFFICULTIES IN OUR FAMILY, WE RESPOND BY:	Strongly disagree	Moderately disagree	Neither agree nor disagree	Moderately agree	Strongly agree
11. Facing the problems “head-on” and trying to get solutions right away	1	2	3	4	5
12. Watching television	1	2	3	4	5
13. Showing that we are strong	1	2	3	4	5
14. Attending religious services (e.g, church)	1	2	3	4	5
15. Accepting stressful events as a fact of life	1	2	3	4	5
16. Sharing concerns with close friends	1	2	3	4	5
17. Knowing luck plays a big part in how well we are able to solve family problems	1	2	3	4	5
18. Exercising with friends to stays fit and reduce tension	1	2	3	4	5
19. Accepting that difficulties occur unexpectedly	1	2	3	4	5
20. Doing things with relatives (get-togethers, dinners etc.)	1	2	3	4	5
21. Seeking professional counseling and help for family difficulties	1	2	3	4	5
22. Believing we can handle our own problems	1	2	3	4	5
23. Participating in religious activities	1	2	3	4	5
24. Defining the family problem in a more positive way so that we do not become too discouraged	1	2	3	4	5
25. Asking relatives how they feel about problems we face	1	2	3	4	5
26. Feeling that no matter what we do to prepare, we will have difficulty handling problems	1	2	3	4	5
27. Seeking advice from a religious leader	1	2	3	4	5
28. Believing if we wait long enough, the problem will go away	1	2	3	4	5

29. Sharing problems with neighbors	1	2	3	4	5
30. Having faith in God	1	2	3	4	5

I am child’s (please circle): Mother Father Step-mother Step-father

Appendix G

FAMILY EMPOWERMENT SCALE
(FES; Koren, DeChillo & Friesen, 1992)

Below are a number of statements that describe how a parent or caregiver of a child with an emotional problem may feel about his or her situation. For each statement, please circle the response that best describes how the statement applies to you.

1 = Not true at all   2 = Mostly not true   3 = Somewhat true
4 = Mostly true   5 = Very true

1. I feel that I have a right to approve all services my child receives.	1	2	3	4	5
2. When problems arise with my child, I handle them pretty well.	1	2	3	4	5
3. I feel I can have a part in improving services for children in my community.	1	2	3	4	5
4. I feel confident in my ability to help my child grow and develop.	1	2	3	4	5
5. I know the steps to take when I am concerned my child is receiving poor services.	1	2	3	4	5
6. I make sure that professionals understand my opinions about what services my child nees.	1	2	3	4	5
7. I know what to do when problems arise with my child	1	2	3	4	5
8. I get in touch with my legislators when important bills or issues concerning children are pending.	1	2	3	4	5
9. I feel my family life is under control.	1	2	3	4	5
10. I understand how the service system for children is organized.	1	2	3	4	5
11. I am able to make good decisions about what services my child needs.	1	2	3	4	5
12. I am able to work with agencies and professionals to decide what services my child needs	1	2	3	4	5
13. I make sure I stay in regular contact with professionals who are providing services to my child	1	2	3	4	5
14. I have ideas about the ideal services system for children.	1	2	3	4	5
15. I help other families get the services they need.	1	2	3	4	5
16. I am able to get information to help me better	1	2	3	4	5

17. I believe that other parents and I can have an influence on services for children. 1 2 3 4 5

18. My opinion is just as important as professionals' opinions in deciding what services my child needs. 1 2 3 4 5

19. I tell professionals what I think about services being provided to my child. 1 2 3 4 5

20. I tell people in agencies and government how services for children can be improved. 1 2 3 4 5

21. I believe I can solve problems with my child when they happen. 1 2 3 4 5

22. I know how to get agency administrators or legislators to listen to me. 1 2 3 4 5

23. I know what services my child needs. 1 2 3 4 5

24. I know what the rights of parents and children are under the special education laws. 1 2 3 4 5

25. I feel that my knowledge and experience as a parent can be used to improve services for children and families. 1 2 3 4 5

26. When I need help with problems in my family, I am able to ask for help from others. 1 2 3 4 5

27. I make efforts to learn new ways to help my child grow and develop. 1 2 3 4 5

28. When necessary, I take the initiative in looking for services for my child and family. 1 2 3 4 5

29. When dealing with my child, I focus on the good things as well as the problems. 1 2 3 4 5

30. I have a good understanding of the service system that my child is involved in. 1 2 3 4 5

31. When faced with a problem involving my child, I decide what to do and then do it. 1 2 3 4 5

32. Professionals should ask me what services I want for my child. 1 2 3 4 5

33. I have a good understanding of my child's disorder. 1 2 3 4 5

34. I feel I am a good parent. 1 2 3 4 5

I am child's (please circle): Mother Father Step-Mother Step-father

Appendix H

DEVELOPMENTAL HISTORY & SERVICES INTERVIEW

Background Information:

1. Child’s name: ________________________________

2. Child’s gender: Male Female

3. Age: ______________ Grade:_______________

4. State/Province residing:______________________________

4. Birth order of the child: ___________________
   - any other children in the family?

   - any other siblings with a disorder or a health difficulty?

   - Either parent with a disorder or health difficulty?

5. Has an Autism Diagnostic Interview-Revised (ADI-R) been administered? If so, what were the results, would you be willing share a copy of the results?

Early Developmental History

1. Describe the pregnancy labor & birth of child.
   - were there any complications

2. Describe child’s first few weeks of life.
   - any significant health difficulties?
   - Anything atypical that was noticed by you or anyone else?

3. Describe the first year of life.
   - were developmental milestones on time, early, or late?

Identifying Problems in Development

1. When did you first notice that something was not quite right with child?
   - what was it that you noticed?

- How did you know it was atypical?

2. Who did you see? What did they do?

3. Were both difficulties identified at the same time?
   - if so how was this done?
   - If not how long was it until the second difficulty was identified
   - How did you know that there was a second difficulty?
   - How was the second difficulty identified?

4. To clarify: when did you first suspect deafness? And when did you first suspect a developmental disorder? What was done once both difficulties were identified?

<u>Nature of Disability/Disorder:</u>

1. What is the type of deafness? (e.g., congenital, due to illness etc.)

2. What is the degree of hearing loss?

3. What pervasive developmental disorder diagnosis does child have?

4. Are there any additional diagnoses that child has (e.g., ADHD, tourettes, etc.)?

<u>Communication</u>

1. Does your child use language to communicate?
   - if so which modality does your child use?
   - Is your child able to communicate using more than one modality? If so, how long has your child been able to communicate in each one?
   - How proficient is your child at communicating in each modality?
   - If not how do you communicate with your child?

2. At what age did your child begin to use language to communicate?

3. How well do you think your child understands you and that you understand your child?

4. Is your child able to express his/her thoughts on paper or on a word processor? At what age was he/she able to do so and how would you rate their written expression proficiency?

Social Interactions

1. Is your child aware of others and able to interact? Please describe your child's interactions with other people.
    - what are interactions like with adults
    - what are interactions like with children

Special Interests

1. Describe any special interests that your child may have.
    - if using language, how does your child let you know about his/her special interests?

Services

1. Are you aware of the resources available in your area of residence?
    - if so, please tell me about them
    - if not is this because there are none?

2. Have you used any of the resources available in your community?
    - if so, please tell me about them
    - what was helpful, unhelpful?
    - What were your responsibilities in obtaining, continuing these services?
    - Were you financially responsible for these services?
    - If financially responsible, were there any resources to help offset these costs?

3. When did you begin to use the services in your community?
    - how did you first access them?

Educational Resources

1. Describe the educational services that have been provided for your child.