# AUGMENTATIVE AND ALTERNATIVE COMMUNICATION IN CANADIAN CHILDREN WITH DEVELOPMENTAL DISABILITIES

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# Abstract

This thesis presents a two-part investigation of AAC use within a sample of children who have Developmental Disabilities (DD) with or without autism. Study 1 was derived from an online survey of 148 parents of children with DD. Within this sample, the types of AAC systems most commonly used and the levels of communication achieved are described. These variables were compared in children with autism to children with DD only. Factors affecting AAC use were examined (i.e., age, adaptive skills, and maladaptive behaviour). Study 2 involves an in-depth telephone interview with 12 parents of children who use an AAC system. Interview questions focused on four main areas; AAC use in general (e.g., communication level, functional use, participation), AAC service use/barriers (e.g., initial training, follow-up support, wait-lists, eligibility, parent satisfaction), experience across time (e.g., transitions, maintenance), and considerations of AAC use specific to children with autism (e.g., generalization, self-stimulatory use).

## Dedication

This thesis is dedicated to my parents and my husband. To my mother who always answered my tough questions and who spent many a long night going over and above working on elaborate projects with me. To my father who always encouraged me to be the best at what I do, and who has always been unwavering in his support. To my husband, who provided me with the stability and love I needed to keep working towards my goals, and for not being frustrated when I needed to do school work for hours on end.

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# Introduction

## Augmentative and Alternative Communication (AAC)

Communication is an integral and essential component of a person's daily life. It provides a way by which an individual can convey his/her needs and wants, and it facilitates participation in social relationships and activities (e.g., school, employment, family, and community). The current study focuses on children who have significant developmental disabilities (DD), defined here as having an Intellectual Disability (or mental retardation) in the Moderate, Severe, or Profound range. They may also be diagnosed with a variety of other disorders such as: genetic syndromes, physical disabilities, Autism Spectrum Disorder (ASD), and may have problem behaviour or mental health difficulties such as aggression, self-injury, and anxiety. Children with DD often fail to develop speech or develop only limited/non-functional speech, limiting their ability to communicate with others (National Research Council, 2001). Since many individuals with DD cannot rely on natural speech to meet their communication needs, they are often candidates for Augmentative and Alternative Communication (AAC; Beukelman & Mirenda, 2005).

AAC refers to various methods or technology used to supplement or facilitate spoken communication for individuals who require assistance for speaking and/or writing, and whose gestural, written, and/or spoken language is not adequate to meet their communication needs. AAC works to reduce the pressure of speech production, and allows individuals to bypass some of the motor and cognitive demands of speech production, by using a system with four primary components; symbols, aids, strategies, and techniques (ASHA, 2004). Symbols can be graphic, auditory, gestural, and textured or tactile.

## Types of AAC Systems

Traditionally, there are two types of AAC systems, 'unaided' and 'aided'. Unaided systems do not require the use of an external device. These include systems like sign languages or gestural cueing systems. Aided systems involve an external aid or device that stores or displays symbols. AAC systems can be categorized according to the level of technology involved. There are Basic systems (e.g., yes/no switches, alphabet boards, symbol-based topic boards, communication books, written labels), Low/mid-tech systems with more structured AAC interventions (i.e., Picture Exchange Communication System [PECS]), and High-tech systems termed Voice Output Communication Aids (VOCAs) or Speech Generating Devices (e.g., Dynavox, Springboard, and iPADs with communication applications or "apps"). These systems have digital or synthesized speech and features such as text-to-speech capabilities.

**Sign language.** Sign language was the first approach used as a form of AAC for individuals with DD. Sign language training involves teaching children with DD to make requests for preferred items or activities by manually producing the sign that corresponds to the preferred item or activity (Tincani, 2004). For individuals who have problems with articulation and speech intelligibility or speech production, gestural imitation is often an easier alternative. Associations between a sign and its representation may allow a child with DD to acquire language faster since it is easier to visualize and remember (e.g., the sign for "drink" mimics the action of bringing a glass to your mouth and drinking).

However, not all signs are iconic. Some may be abstract in nature and these signs may be more difficult for a child with DD to learn. In addition, Sign language is not visually constant. Once a sign is made it does not remain for the child to reference at a later time. In order to use Sign language properly a child needs the cognitive and memory skills required to remember a sequence of signs, understand their meaning, and then generate signs to respond with. This may not be possible for some children with DD and often such children use only a few individual signs or sign approximations (modified signs) to express basic needs and wants (e.g., more, finished), rather than an actual Sign *language* such as American Sign Language. However, "higher functioning" children may be able to benefit from the complexity of actual Sign language which provides the opportunity to use a variety of unique signs that facilitate complex communication at a conversational pace (like speech-based languages). It is also an inexpensive option in that it does not require any expensive equipment. This eliminates the difficulties involved in maintaining and updating an aided AAC system (e.g., laminating pictures in a PECS system, fixing glitches in a VOCA system). As well, because there is not a physical device, it can be easily used in a variety of environments where other systems such as PECS and VOCAs may not be as practical (e.g., around water, at a sporting event, or at recess). Despite these benefits, a critical disadvantage of Sign language is that every person in a child's environment must be able to understand and use Sign language for that child to communicate and participate fully (Mirenda & Erikson, 2000). A child using Sign language would still be unable to communicate with strangers and members of the larger community (e.g., ordering food at McDonalds). For children who are unable to communicate using Sign language due to the high cognitive demand or whose environments do not support the use of Sign language, other aided AAC systems may be more useful.

**Picture Exchange Communication System (PECS).** One of the most commonly used aided AAC systems is PECS (Bondy & Frost, 1994). In PECS, small laminated pictures (or symbols or other visual materials like candy wrappers) are used to represent objects, verbs, people, places, and activities. Typically, pictures relevant to the child are printed on laminated cards along with a written label (e.g., a picture of a cookie and the label "cookie"). These pictures are then fastened with Velcro® in an individualized communication binder. A child must scan the page for the correct symbol, select the symbol by removing it from the binder, engage the person with whom he or she wishes to communicate, and "exchange" the picture for an object, activity, or social interaction. PECS is a communication system based on the principles of Applied Behaviour Analysis (ABA). Specific ABA techniques of prompting, error correction, chaining, shaping, and reinforcement are used to teach children to use PECS. Training prompts are gradually faded until a child can exchange pictures with a communicative partner independently. This is done through six phases (Frost & Bondy, 2002). PECS users need not have any particular prerequisite skills such as those that are needed to become efficient at other AAC systems (e.g., eye contact, matching, picture discrimination, and imitation) as the program teaches these critical skills while the individual develops functional communication skills. PECS is particularly useful for children who have DD or autism because it not only provides children with a communication system, but it also addresses the motivational issues and social challenges common in children with DD and/or autism.

During the system's development, Bondy and Frost followed 85 children, taught to use PECS, for 5 years. They found that 59% acquired speech independently of visual supports, while 30% spoke while using PECS (Frost & Bondy, 2002). There is evidence that PECS use can be generalized across people (Tincani, Crozier, & Alazetta, 2006), stimuli (Marckel, Neef, & Ferreri, 2006), and activities (Schwartz, Garfinkle, & Bauer, 1998). Hoffman, Horton, Bondy, and Frost (2009) meta-analyzed 34 peer-reviewed published reports on PECS and showed that PECS was associated with improvement in communication in most cases. When they compared PECS to other AAC systems (e.g., VOCAs, Sign language), they found that individuals who used PECS performed similarly or better. The children using PECS were communicating with their parents, teachers, and members of the community. Most children learned to request, some learned to describe, and a small number used their pictures to improvise (i.e., generate novel utterances by using the pictures in new/abstract ways). PECS use was also associated with increases in speech production, social approach, and communicative repertoires (e.g., using text instead of pictures). In addition, PECS use was found to decrease negative problem behaviours.

Unfortunately, as Howlin, Gordon, Pasco, Wade, and Charman (2007) point out, few schools receive on-site expert training in how to implement PECS properly, and fewer still receive ongoing consultation and monitoring. As a result, many children are exposed to incomplete or incorrect versions of PECS, limiting their ability to use the system properly. Howlin et al. (2007) assessed the effectiveness of PECS when teachers were provided with expert training and consultation in the use of PECS with children who have autism. Using a randomized controlled trial, they found that, immediately following treatment, rates of initiation and PECS usage increased significantly. However, there were no increases in frequency of speech, improvements on autism diagnostic measures, or language test scores. Most notably, treatment effects were not maintained once active intervention ceased. This highlights the variable results seen in real-life settings where optimal treatment/training programs are not always available.

**Voice-Output Communication Aids (VOCAs).** Due to their desire to have the newest therapies and technologies available for their child, parents often request or obtain High-tech AAC systems involving electronic voice output. Similar to PECS, VOCA systems use pictures/symbols presented on a screen. Unlike PECS, however, a child must have certain prerequisite skills (e.g., picture discrimination and fine motor skills) to use his/her device functionally. The child must scan the display and choose the desired symbol by pressing it. Once a symbol is pressed, a verbal output results, e.g., "I want, cookie". Certain VOCA systems can be programmed to contain several levels of communication displays, beginning with general categories (e.g., food, clothing) and progressing to specific items (e.g., specific types of desired snacks, or types of clothing) to promote more complex communication. This type of system can also be programmed to contain entire phrases or sentences linked to a specific button (e.g., Mummy, I want a chocolate chip cookie, please). In this way, a child may appear to reach a more complex level of communication than he/she would using PECS. Each VOCA can be programmed to the specific communication needs and capabilities of the individual child taking into consideration his/her preferences and usual environments. Tablets such as Apple iPADs are an example of a new and less expensive VOCA system. They can be programmed in a similar way to traditional VOCAs, although there is a paucity of research investigating and comparing the wide variety of different software programs (i.e., apps) available.

There are several limitations to the functional use of VOCAs in populations of children with DD. First, traditional VOCA systems (e.g., Dynavox, Springboard, etc.) are expensive, heavy, and cumbersome. It can be especially difficult to incorporate them into the child's natural environments. Conversely, iPADs and other tablet devices are less expensive, easily accessible, lighter, and less stigmatizing, although it still may not be possible to use them in all environments a child may encounter (e.g., during a sporting activity). Second, although the intention of VOCA systems is for the user to communicate with others, a child using a VOCA system can bypass several important steps necessary for bidirectional communication. For example, a child does not need to engage the attention of the communicative partner, initiate eye contact, nor monitor whether his/her partner listened to the request, he/she need only push a button. Without engaging a partner, this is not considered communication. As well, since many common toys mimic this type of voice output many children may not recognize the device as a communication tool, especially if no communication training has occurred. Unfortunately, a comprehensive training and implementation program for VOCAs, like the one created for PECS, has not yet been established. This creates a very difficult problem for professionals recommending these devices. Given the huge variety of software programs and devices available, there is currently no way to evaluate the quantity or quality of training given to parents and children, nor the appropriateness of the software.

The current project includes a description of which AAC systems, such as PECS, VOCAs and tablets, are currently used by Canadian children with DD as well as how well these systems are being used (i.e., where, with whom, and for what communicative functions).

## Assessment and Barriers to AAC Access

Given the variety of disorders that lead to speech problems, it is not surprising that there are many AAC systems and devices to choose from. These devices are designed to meet a variety of needs. For example, an individual with Cerebral Palsy may require a device that bypasses the motor demands of speech and communication, while an individual with severe DD may require a device that bypasses some of the cognitive demands of speech and communication. It is important that a thorough assessment is conducted to determine the appropriate AAC system for each individual child. According to best practice, a multidisciplinary team should determine how efficiently the child is currently communicating, his/her current and future communication needs, the AAC system most appropriate for the child, the appropriate training necessary for the child to learn to use the system properly, and a method to evaluate the outcomes (Beukelman & Mirenda, 2005). The child's environment and the people in it should also be taken into account during the assessment process. The current study examined these two latter points and included parent report about the assessment process, including types of professionals involved, how well parents feel their child's AAC system suits his or her needs, satisfaction with the assessment process, and whether follow-up was conducted.

Despite best practice recommendations, the children who use an AAC system and their parents face many barriers. Government funding is a commonly discussed barrier to service receipt. This may involve the initial cost of the equipment but also the costs involved with providing adequate training and support to parents, teachers/staff, and children. This lack of funding often limits services received (e.g., quantity and quality of services), and prevents proper follow-up (i.e., maintenance and generalization). In addition, there are many other barriers to successful AAC system use. For example, a child may be unable to use his/her AAC system properly because people in his/her environment may lack training, the AAC system itself may have limitations, and/or there may be cognitive and/or physical limitations of the child which impact on his or her ability to benefit from the AAC system (Beukelman & Mirenda, 1988). Identifying and addressing these barriers is key to enhancing the likelihood that an AAC system is used successfully.

In addition, eligibility for AAC services in various jurisdictions has been a controversial topic in AAC research (Ogletree & Pierce, 2010). Individuals with DD may be deemed ineligible for an AAC system for several reasons. The National Joint Committee for the Communicative Needs of Persons with Severe Disabilities (NJC; 2003) is an interdisciplinary group dedicated to improving communication-related policies and practices. They have identified eight *a priori* criteria that have been used to exclude people from AAC services: 1) lack of a discrepancy between an individual's cognitive and communicative functioning, 2) age (i.e., too young or too old), 3) diagnostic labels that imply "low functioning", 4) lack of prerequisite language skills, 5) previous treatment failure, 6) restrictive interpretations of educational, vocational, and/or medical necessity (e.g., when a medical need is addressed, but a communication need is not, in the same child, due to a lack of funding), 7) lack of trained professionals, and 8) lack of funding/financial resources. The current project explored barriers to effective AAC use and eligibility as reported by Canadian parents of children with DD. The study included questions specific to service receipt including: quality of services, length of services, whether appropriate training was provided for parents and children, and whether follow-up services were provided (i.e., was the AAC system monitored and adapted as the child aged and his/her communication needs changed?).

### Factors Related to Successful AAC Use

Individuals with different disabilities have different needs in terms of their communication. They vary in their ability to communicate successfully using their device or system and in the level of language complexity they can achieve using their AAC method. There is much debate concerning the communication goal(s) for individuals who use AAC systems. According to Light (1989), in order to use AAC successfully, users should be able to request, protest, answer questions, ask questions, express emotions, and build relationships. Light, Beukelman, and Reichle (2003) identified four main functions communication should accomplish: 1) communicate needs/wants, 2) provide information transfer, 3) allow for social closeness, and 4) allow for social etiquette. Added to that list by Beukelman and Mirenda (2005) is the importance of establishing an internal dialogue (within one's own mind), which would be difficult to evaluate except by self-report. Also important, the individual should be able to generalize these communication skills to natural contexts (e.g., at home, in the community) and different people (e.g., parents, teachers, grandparents) as well as maintain these skills over time.

In populations of children with DD (versus children who are deaf or have only motor limitations), this level of communication complexity may not always be possible because of the existing cognitive skills of the child. Parents and clinicians often highlight the difficulty of generalizing the use of the device to different settings. For example, a child may use his/her device proficiently in a supported school setting but not at home. Schlosser and Lee (2000) analyzed 50 single-subject experimental studies in order to investigate the effectiveness, generalization, and maintenance of AAC use. They found that interventions were effective in terms of behaviour change but they could not report on generalization and maintenance due to the tendency for researchers to "train and hope" the results would generalize and be maintained (Stokes & Baer, 1977). Sigafoos et al. (2004) investigated a single case whereby generalization of AAC was successfully demonstrated in the home. Researchers trained parents initially and provided follow-up support to maintain progress. Thus, it appears that successful communication, maintenance and generalization to other settings is possible but much more research needs to be conducted on this topic (Schlosser & Lee, 2000).

Ogletree and Pierce (2010), in a review paper, disagree with the notion that there must be a goal of "successful communication". Instead, they emphasize that each individual with speech needs should be given appropriate intervention to maximize the communication of which he/she is capable. These authors indicate that services need to target the individual with an AAC system, his/her family, others around him/her, and take into consideration the individual's environment. Ogletree and Pierce emphasize a multidisciplinary team approach and the importance of follow-up to maintain up-to-date treatment. Rowland et al. (2012) argue for a structured process (ideally conducted by a multidisciplinary team) to provide accommodation for the child in school settings, and to develop suitable intervention goals for AAC users. The team should take into account language, cognitive, social/behavioural, and motor issues (Beukelman & Mirenda, 2005). Although these papers have provided thought provoking arguments important for the field of AAC system use, they provide only recommendations which will need to be empirically studied and verified. To date, empirical studies with large sample sizes, investigating the types of AAC systems being used in DD populations and how effectively they are being used are sorely lacking in the literature.

In addition to the particular system and service-related factors, characteristics of the child may also affect the success of AAC use. Although there is discussion of the importance of tailoring AAC systems to the individual needs of the child based on his/her abilities, surprisingly few studies have addressed what child factors are associated with AAC use and its effectiveness. Currently, research is limited to studies with small participant samples or qualitative studies which do not allow an analysis of these factors. In a qualitative study of seven children with DD, McNaughton et al. (2008) found that operational competence (e.g., upkeep and programming), linguistic competence (e.g., vocabulary, sentence building skills), social competence (e.g., gaining attention, asking questions), and strategic competence (e.g., introducing system to others, using multiple strategies) were needed to use AAC, as reported from a parent perspective. The authors were unable to comment on overall group trends affecting AAC use, such as whether older children use AAC systems more efficiently than younger children. Group based research is particularly challenging in the DD population because of the low incidence of disabilities and large variability among individuals (Ganz et al., 2011). As a result, even quantitative studies are often single-case design studies with one to five participants.

Ganz et al. (2011) conducted a meta-analysis of 24 such single-case design studies (with a total *n* of 58) on the use of aided AAC systems in individuals with ASD. The researchers used an effect size measure to investigate (a) the impact of AAC interventions on individuals diagnosed with different subcategories of ASD, as well as additional diagnoses, and (b) the effects of AAC interventions on individuals in different age groups. There are some limitations to this study, although it provides an important direction for future research. One limitation, common in single-case design studies is that data reported for each individual are based on different outcome measures. Although that may be beneficial clinically, the use of a group design to compare children with ASD to those with DD in the present study allows for more detailed examination of specific variables related to AAC use, measured in a consistent manner. Ganz and colleagues (2011) found that children who were diagnosed with ASD (only) had better treatment outcomes than children who had multiple diagnoses (ASD + DD), and that children with multiple diagnoses had better treatment outcomes than children with multiple diagnoses as well as a sensory impairment (e.g., vision or hearing impairment). Effect sizes were moderate to large for these differences. Based on these results, it appears that children who are more impaired or affected by more disabilities are less likely to use AAC effectively, suggesting that other individual factors such as, cognitive ability and adaptive skill level may be important factors impacting how children use AAC systems. In the current study some of these child factors are included using a larger sample than most other studies in the literature.

Results of the meta-analysis suggested that children of preschool age (<5 years of age) showed better outcomes than children whose treatment was implemented at older ages, i.e., elementary (age 6-10 years) or secondary (age 11 years and older). Effect sizes were moderate to large for these results (Ganz et al., 2011). The effect size for elementary and secondary age groups did not differ, suggesting that age at time of treatment has implications for how well children learn to use AAC systems. It is discouraging that children often wait to begin AAC use, resorting to it as a last option when all other attempts to teach a child to speak are exhausted. Age was considered as a factor in the current study, within a sample with a wide age range.

One study by Harding et al. (2011) investigated how an AAC intervention could be implemented effectively with two children with profound and multiple disabilities. They found that AAC did enhance several aspects of the children's communication and hypothesized that the intervention was successful because the researchers were careful to choose AAC strategies based on the children's receptive language, communication ability, and cognitive ability. The researchers identify that studies should be done in this area to determine what factors are important to ensure successful AAC use. Adaptive behaviour is highly correlated with communication and cognitive abilities and, therefore, it is predicted that adaptive skill level may be related to AAC use, e.g., to the type of AAC system used, or how well children communicate using their AAC system.

There are several studies investigating maladaptive behaviour and AAC use. These studies do not investigate maladaptive behaviour as a factor affecting AAC use, but rather as an outcome variable indicating successful AAC use. Since it is often the case that maladaptive behaviour results when an individual is unable to communicate effectively, successful intervention with AAC can result in a reduction of maladaptive behaviour. For example, a study by Robinson and Owens (1995) found that a 27-year-old woman showed a reduction in maladaptive behaviour when pictures were introduced as a communication system. To date, however, the degree to which maladaptive behaviour affects AAC use (the reverse relationship) has not been investigated. In the current study, children's level of maladaptive behaviour was examined in relation to variables representing AAC system use.

## AAC and Autism

The current study will also address how children with ASD use AAC and the challenges and considerations that may be unique to children with ASD. ASD is a neurodevelopmental disorder characterized by deficits in social-communication together with restricted, repetitive, and stereotypic patterns of behaviour, interests, and activities (American Psychiatric Association [APA], 2013). Children with ASD exhibit considerable variability in the presentation of symptoms and the severity of their disorder. There is no one constellation of impairments that is identifiable in every child.

According to the most recent study by the Centers for Disease Control and Prevention (CDC, 2012) 1 in 88 (more than 1%) children are diagnosed with ASD. Children with ASD often have varying degrees of co-morbid intellectual disabilities and it is estimated that 70-75% of individuals with Autistic Disorder (autism) also have DD (Perry et al., 2011). The severity level of DD varies from mild to profound. Similarly, children with autism also show varying degrees of language abilities (APA, 2013). Approximately one-third to one-half of children with autism fail to develop functional speech and are identified as non-verbal (Perry et al., 2011). Although children with autism who have some functional speech may benefit from an AAC system, it is typically non-verbal children who are AAC users. Several AAC interventions have been used with individuals with autism and are documented in the literature.

Studies investigating the use of Sign language in individuals with autism show mixed results but suggest that, even after extensive training, learned signs may not be used functionally or spontaneously, and may not be maintained or generalized to other settings (Mirenda, 2003; Sundberg & Partington, 1998; Watson, Layton, Pierce, & Abraham, 1994). As a result, Sign language is not a commonly used AAC system for children with autism in Canada, although many children may use a few signs or approximations functionally (e.g., more, finished).

PECS (Bondy & Frost, 1994), discussed earlier, is the most commonly used AAC system for children who have ASD. Since the original study (Bondy & Frost, 2001, Bondy, Tincani, & Frost, 2004), many empirical studies have demonstrated the effectiveness of PECS as an AAC intervention for individuals with autism. Sulzer-

Azaroff, Hoffman, Horton, Bondy, and Frost (2009), in a meta-analysis of 34 articles, found that PECS was a successful AAC intervention equal to, or superior to, other AAC systems. They also found improved communication in the majority of children with autism. In support of these findings, a recent Canadian study (Koudys, 2011; McFee, 2011) showed that PECS could be successfully implemented in a community sample of 22 low functioning children with autism. Although children with relatively higher cognitive and adaptive skills within the sample were more likely to master the higher phases of PECS, children with significant impairments in cognitive functioning and adaptive skills were still able to learn to use PECS effectively, at least at a basic level. These gains were associated with improved social communicative behaviour and reductions in problem behaviours (Koudys, 2011). The current study will also investigate what factors are important for successful AAC use in a variety of systems, as defined by the types of communication skills children can accomplish with AAC.

VOCAs are becoming a popular AAC system among children with autism (Mirenda, 2001). Lancioni and colleagues (2007) reviewed 16 studies in which VOCAs were used with children with autism and DD and found that, of the 39 individuals studied, all but three showed some success with their VOCA. This success ranged from learning a single message for a single item, to a variety of items to request a range of stimuli (e.g., Schepis, Reid, Behrman, & Sutton, 1998). However, from these results, we cannot conclude that a different AAC system could provide similar or better outcomes.

Tincani (2004) compared the effects of PECS and Sign language training on the acquisition of requesting skills (requesting a preferred object) in two children with autism. For one child, Sign language training resulted in increased requesting, while PECS training offered the same result for the other child. The author suggests that the appropriate selection and successful use of an AAC system depends on the individual child characteristics or prerequisite skills before training (e.g., imitation and motor skills). It appears that the selection of an AAC system is very specific to the needs of the individual child.

## The Current Study

Across the field of AAC research, in populations of children with DD and ASD, there is a need for empirically validated research with better methodology, larger sample sizes, and replications of current findings. This is particularly true in the area of DD research, where much of the empirical evidence is in the beginning stages, or is extrapolated from other populations (e.g., non-disabled children, or children with ASD or other disabilities; Wilkinson & Hennig, 2007). There are several topics that require further investigation, including three that were the focus of the present study: understanding AAC use in Canadian children with DD and ASD, individual child factors affecting AAC use, and understanding parent experiences of AAC services.

In order to address these topics, the current thesis was designed to provide valuable information about the parental experience of AAC system use in a current sample of Canadian children with DD, from two separate studies. Study 1 involves examining AAC system use in a large, Canada-wide sample of children with various types of DD (including ASD). Within the overall sample, children with who use AAC systems were compared to those who do not use AAC systems, in terms of different child factors (communication level with speech, age, adaptive skills, maladaptive behaviour, and diagnosis). Then, several questions specific to AAC users were examined further. Specifically, I examined the types of AAC systems most commonly used, whether a single system or multiple systems were used, the level of communication attained with the help of AAC, as well as a comparison between children's expressive communication level with speech and their expressive communication level using their AAC system (to see whether AAC results in a better level of communication). These AAC outcome variables were then investigated in relation to four child factors [diagnosis (i.e., ASD or DD), age, adaptive behaviour, and maladaptive behaviour].

In order to supplement the quantitative but limited nature of the data in Study 1, Study 2 involved an in-depth qualitative interview with a small sample of parents whose children use an AAC system. Study 2 explored four areas; AAC use in general (e.g., communication levels, functional use, participation), AAC service use/barriers (e.g., initial training, follow-up support, reluctance to use the device in certain situations, etc.), experience across time (e.g., transitions between devices, maintenance), and considerations of AAC use specific to children with autism (e.g., generalization, problem behaviour due to the device, e.g., repetitive use of the device). Analysis and interpretation of the data collected in these two studies will have important implications informing decisions regarding eligibility, system choice, training, implementation, use, and follow-up. Results will also inform parents, service providers, health care practitioners, and policy makers.

# Study 1

## Methods

### Data Collection

Data for Study 1 were collected through GO4KIDDS, Great Outcomes for Kids Impacted by Severe Developmental Disabilities, which is a CIHR Emerging Team research program of studies that aim to provide a better understanding about the health, well-being, and social inclusion of school-aged children with severe developmental disabilities and the experiences of their families. Severe DD was used to describe children with an Intellectual Disability and IQs in the Moderate, Severe, or Profound range. In addition, many of the children also have genetic or other syndromes (e.g., Down syndrome, Rett syndrome), physical disabilities and disorders (e.g., cerebral palsy, seizures), sensory system limitations (e.g., deafness, vision impairments), autism, problem behaviour (e.g., aggression, self-injury), and/or mental health difficulties (e.g., anxiety, depression). There are four projects within the GO4KIDDS initiative: a "Report Card" Survey, consisting of a Basic and Extended Survey; a Family Quality of Life Study; a Social Inclusion Study; and a Health Care and Service Utilization Survey.

The GO4KIDDS project received ethical approval from York University's Human Participants Review Committee and multiple other organizations and this specific M.A. study received ethics clearance from York University as well. Permission was obtained from the GOKIDDS Executive to use data on relevant questions from the GO4KIDDS online survey for the secondary analyses included in this thesis. Participants for the GO4KIDDS studies were recruited over a period of several years through parent organizations and service agencies. Parents gave consent to participate in the study and were offered $50 as an honorarium for their time.

### Participants

The participants were148 parents of boys and girls with severe DD from across Canada. Parents who had completed both the Basic and Extended GO4KIDDS survey were included.

**Parent/Respondent Characteristics.** The sample was composed of 92% biological parents, 95% of whom were female, and 77% of whom were married. The average age of the respondents was 42 years (range from 28 to 58 years; see Table 1). The average Socioeconomic Status score on the Barratt was 40 (see Table 1 and the Measures section for more information; Barratt, 2006). The range of scores varied through the full possible range from 9 to 66, i.e., the sample was very heterogeneous. A majority of the sample participants (66%) reside in Ontario, while the rest were distributed across six provinces and one territory (see Table 1). Twenty-three percent of parents report a country of birth other than Canada and 16% of parents reported a first language other than English. This is not surprising given Canada's multicultural population. These demographic results may or may not be representative of all parents of children with DD but it is clear that the sample is quite heterogeneous and inclusive.

**Child Characteristics.** The children in the current sample were 70% male and between the ages of 3 and 19 years old, with a mean age of 11 years (see Table 2). A large proportion of the sample had parent-reported physical difficulties that could have an impact on how the child communicates using an AAC system. Specifically, between 55%

and 79% of the sample had problems using their hands, or other motor difficulties, as well as difficulties feeding or eating. A smaller, but still substantial proportion of the sample, reported major vision and/or hearing impairments (approximately 10% for each category; see Table 2). The sample showed varied levels of expressive communication with speech with more children showing lower levels of expressive communication with speech and very few children able to communicate about a wide range of topics in a meaningful way (22%) (See Table 2). These sample characteristics are in keeping with the selection criteria for the GO4KIDDS Survey research.

In order to investigate diagnosis as a factor of AAC system use the children were divided into two groups: an ASD group consisting of individuals with ASD (plus DD) and a DD only group consisting of individuals with DD who do not have ASD. These diagnoses were based on parent report only; no diagnostic measures were available to confirm the diagnoses. The ASD group consisted of 55% of the sample (*n*=82) and included 71 boys and 10 girls. The DD group consisted of 45% of the sample (*n*=66), and included 33 boys and 33 girls.

## Measures

Data for Study 1 consisted of a subset of questions from the GO4KIDDS Survey, related to the child's communication (the dependent variables), as well as demographics, and the adaptive and maladaptive scores from the SIB-R (described below).

### Communication Variables

The specific questions of interest related to communication and AAC use from the GO4KIDDS Survey (the dependent variables) were: level of spoken language (5-point ordinal scale), use of AAC (yes/no), which type(s) of AAC, and how well the child communicates with the AAC system (5-point ordinal scale; see Appendix C, page 118). The 5-point ordinal scale for communication level (same scale for communication with speech and for communication with AAC) was subsequently reduced to a 4-point scale by combining the two highest levels of communication (which were rarely or never selected in this sample). The resulting levels of communication were: 1. able to use very little meaningful communication, 2. able to communicate basic needs and wants, 3. able to communicate needs, wants, and some ideas, 4. able to communicate about topics in a meaningful way. These scores were compared for speech versus AAC to get a crude estimate of whether communication level was "improved" or was rated by parents as falling in a higher category with AAC.

### Demographics

Demographic variables describing both the respondent (the parent) and the child were taken from the GO4KIDDS Survey and reported to describe the current sample (See Appendix D). Parent variables included: the respondent's relationship to the child, marital status, gender, age, province, country of birth, and first language. In addition, highest level of education and current occupation were combined using the Barratt Simplified Measure of Social Status (Barratt, 2012), and an overall Barratt score was reported in order to provide an estimate of each participant's Socio-economic Status (SES). The Barratt measure is based on the Hollingshead scale (1975) but has been updated in two ways: the list of occupations and their ratings have been updated, and a generational shift in social status over time has been accounted for. The measure, originally intended for

University students, has been adapted for use in research with families of children with disabilities, with permission of the author. The education level and occupation of each parent are coded, and the mean of the two parents used (or only one if a single parent), resulting in a score which can range from 8 to 66, with higher scores indicating higher SES.

### Child Variables

The following variables from the GO4KIDDS Survey were used to describe the child with DD: gender, age, diagnosis of DD and/or ASD (by parent report), and the proportion of the sample with physical difficulties that could have an impact on communication (i.e., major hearing impairment, major vision impairment, problems using hands, other motor problems, and feeding or eating difficulties).

**The Scales of Independent Behavior – Revised (SIB-R; Bruininks, Woodcock, Weatherman, & Hill, 1996).** The SIB-R is a comprehensive, norm-referenced, standardized assessment measure designed to assess skills from infancy to adulthood (80+) that are needed to function independently, in home, social, school, work, and community settings. There are long and short versions of the SIB-R. In the GO4KIDDS Survey, the first 35 items of the Short Form were used with permission of the publishers. The Full Scale SIB-R consists of 14 adaptive behavior clusters (gross motor, fine motor, social interaction, language, comprehension, language expression, eating & meal preparation, toileting, dressings, personal self-care, domestic skills, time and punctuality, money and value, home/community, and orientation). The short form samples questions from each of these behaviour clusters. The Short Form is meant to be used as a screening/evaluation tool for individuals of any age and takes approximately 15 to 20 minutes to complete. The Problem Behavior Scale includes eight areas of maladaptive behaviour (e.g., hurtful to self, socially offensive behaviour, etc.) and includes ratings of both frequency and severity.

The SIB-R was standardized on a sample of 2,182 individuals aged from 3 months to 90 years. The SIB-R manual (Bruininks et al., 1996) reports psychometric properties for samples with and without intellectual disabilities. Reliabilities for both samples range from .80 to .90. Test–retest reliabilities (4 weeks apart) for children aged 6 to 13 (*n* = 31) were in the .90s. Inter-rater reliabilities between mothers and fathers of typically developing children (*n* = 26) were in the .80s and .90s, and between teachers of children with an intellectual disability (*n* = 30) were in the .70s to .90s. A variety of derived scores are available from the SIB-R. The two specific scores reported for Study 1 are Adaptive Age (age equivalents, in months) and the Maladaptive Behavior Index.

## Results and Discussion (Study 1)

### Comparing Users to Non-Users in the Overall Sample

Within the overall sample, 63 of the 148 parents (42%) reported that their child used an AAC system. In order to investigate differences between children who use AAC and those who do not, AAC users and non-users were compared in terms of their expressive communication, diagnosis, age, adaptive age, and maladaptive behaviour. Not surprisingly, there was a significant difference in the spoken communication levels (on the 4-point scale) of children who use AAC systems and those who do not, such that children who use AAC are more likely to have lower levels of spoken communication ($\chi^2$=20.62, *p*<.001; see Table 3 and Figure 1). We would expect that children who use an AAC system would be more likely to be non-verbal and/or have less expressive language than children who do not use AAC.

In the sample, children who used AAC did not differ in age from children who did not (*t*=1.31, *p*=.20; see Table 3). They did, however, differ in terms of their adaptive skill level. Using the SIB-R adaptive age equivalent scores, children who used an AAC system had significantly but not greatly lower adaptive ages (mean of 33 months) than children who did not use AAC (mean of 43 months) (*t*=2.04, *p*=.04; see Table 3). AAC users did not differ significantly from non-users in terms of SIB-R Maladaptive Behavior scores (*t*=.01, *p*=.99; see Table 3).This is an interesting result since it is typically believed that children with lower levels of communication have higher levels of maladaptive behaviour. This may possibly be an indication that AAC systems are providing an effective way for children to communicate and subsequently reducing maladaptive behaviour. Overall, these results indicate that children who use AAC systems have lower levels of expressive communication and are functioning at a lower level in terms of their adaptive skills, although they do not have higher levels of maladaptive behaviour and there are no differences in age from nonusers of AAC within the GO4KIDDS sample. Subsequent sections of the results will focus on these 63 children who use AAC systems, in more detail.

## Describing the characteristics of Canadian children who use AAC systems

**Type of AAC system.** Parents reported that their children used a variety of different types of AAC systems. In the survey parents were asked to identify or provide a description of the type of AAC used. As a result of the unstructured nature of the question, the detail provided by parents varied (e.g., some parents reported specific software systems, while others reported the type of system only). For this reason, AAC systems could not be organized into the categories traditionally seen in AAC research (i.e., Low-tech, Mid-tech, High-tech). Instead, AAC systems were classified into four categories based on the type or estimated complexity of the system: Basic, PECS, VOCAs, and Sign Language. When multiple AAC systems were reported by parents, AAC systems were categorized based on the most sophisticated AAC system reported, since the primary AAC system could not be determined/identified from the survey data in most cases.

The category ***Basic*** systems included the following AAC systems; simple yes/no switches, pointing to pictures to request, modified or basic use of signs, and use of gestures. Fourteen children or 24% of the sample used Basic AAC systems to communicate (see Table 4).

Participants were included in the ***PECS*** category if they specifically indicated that their child used PECS rather than just noting the use of pictures. Due to the nature of the question (online survey), we were unable to determine whether children, or their communicative partners were really using the PECS system (i.e., implemented following the treatment manual), were properly trained in PECS, or what level of PECS children had achieved. Nineteen children or 32% of our sample were reported to be using PECS (see Table 4).

The third category included Voice Output Communication Aids (VOCAs). Again, due to the nature of the question in the survey, it was difficult to determine the complexity of the system software, so any device with a voice output function was categorized in the ***VOCA*** category (including iPADs). Eighteen children or 31% of our sample used VOCAs to enhance their communication (see Table 4). Within this category, iPADs represent a new option that is gaining popularity as an AAC system for reasons discussed earlier. Five of 18, or 26%, of the participants who reported using a VOCA specifically reported using an iPAD with a specialized app for communication. This represents 8% of the total sample of AAC users.

Sign language represented the final category of AAC system type. Children whose parents reported using Sign language specifically were placed into the ***Sign*** category, which included children who used sophisticated Sign language, rather than a few signs or sign approximations. Due to the nature of the question it is possible that some children were categorized here who actually use signs only as a basic gestural AAC system rather than a more sophisticated signed language. Eight children, that is, about 14% of the sample were reported to be using Sign language (see Table 4).

Overall, 56% of AAC users used a Low-tech AAC system or PECS to communicate (see Table 4). This is not entirely surprising given that basic low-tech systems and PECS are easier to access, use, and maintain. They are less expensive, and more readily available to parents, therapists, and teachers. A further investigation of challenges faced by parents and their children who use AAC related to choice of system will be highlighted in Study 2.

**Number of AAC systems used.** Within our sample, many children who use more complex systems also rely on lower tech systems to communicate. That is, 29% were reported to use multiple systems or strategies. Parents reported various combinations of PECS, speech, sign, gestures, and VOCAs. Parental report of the number of systems used ranged from one AAC system to a combination of four different systems. This trend towards reporting multiple systems was more prevalent in parents of children using VOCAs. Within this category 56% of parents reported multiple communication systems (see Figure 2). In fact there was a difference between the types of AAC systems used and whether or not children reported using single or multiple systems. Children who used Basic AAC, PECS, or Sign language versus VOCAs were more likely to use a single system ($\chi^2=10.44, p=.015$; see Figure 2). There may be several reasons for this trend. First, it may be possible that a child has not fully transitioned to his/her new system and must temporarily rely on previous methods of communication. This can help children to gain confidence in a new system while still having a familiar communication system to rely on. It is also possible that a child is not using his/her more sophisticated system efficiently and therefore relies on other communication strategies as well. Perhaps the system is not well matched to the child's communication abilities and needs. This discrepancy may be due to the characteristics and cognitive potential of the child (e.g., prerequisite skills necessary for use), and/or it may be due to a lack of support and training in the child's communication partners. For example, a child transitioning from

PECS to a VOCA may have difficulty navigating from one category of pictures to another (e.g., choosing *food* from one array, then choosing *dessert*, then choosing *cookie*, when for PECS he/she only needs to choose one picture for *cookie*). The child may be unable to complete this task due to his/her cognitive or attentional limitations, or because he/she was not explicitly taught by a qualified or knowledgeable instructor.

**Level of communication achieved with AAC.** The proportion of children achieving each of the four levels of communication with their AAC system is shown in Table 4. Unfortunately, even with their AAC system, 54% of AAC users are reported to use very little meaningful communication or to communicate only basic needs and wants with their device or system. About one-quarter of AAC users were able to communicate needs, wants and some ideas with the aid of their device. The remaining 20% were able to communicate about topics in a meaningful way. In order to investigate this finding further, children's expressive communication level using speech was compared to their expressive communication level with the help of their AAC systems. Children were categorized into two groups based on whether their communication improved or did not improve (based on these simple categories) with the help of their AAC system. Overall, about half of AAC users improved with the use of their AAC system, while half did not (see Table 4). This finding supports the idea that AAC systems enhance the communication abilities over speech of some children with DD, as intended, which is encouraging. On the other hand, 50% of the sample seems not to be showing benefit from the use of AAC and remains at the same level of communication with or without their system. This is a somewhat disheartening result, and leads to the obvious question, why are 50% of children not benefitting from the use of AAC? Does the fault lie within the service system? Are children not receiving enough support to make a real difference? Perhaps the child's limitations may also contribute to his/her capacity to benefit from his/her system (e.g., cognitive limitations, slow learning style). Does the child's environment and the people within it support him/her in using AAC? Due to the limitations of the current study measures and the way in which the data were collected, these questions cannot be answered in Study 1. However, these queries did provide the rationale for Study 2 and will be addressed there.

### Investigating AAC Use by Diagnosis

In order to investigate the effect of diagnosis on AAC use, children were compared based on whether they had ASD and DD or DD only. The two diagnostic sub-groups were first compared for differences in descriptive variables (i.e., age, adaptive age, and maladaptive index score) as shown in Table 5. The two groups did not significantly differ in age ($F$=.01, $p$=.937), or adaptive age ($F$=.08, $p$=.783). However, they did differ significantly on the maladaptive index score ($F$=7.86, $p$=.007) with children in the ASD group showing significantly higher levels of maladaptive behaviour than children with DD. Increased levels of maladaptive behaviour may affect how children with ASD use their AAC systems, and it may impact the types of systems available to them. For example, it is possible that parents may be less likely to invest in an expensive or fragile system if it is likely to be thrown or dropped.

The two diagnostic groups were then compared in terms of how they use AAC systems, type of AAC system, multiple system use, level of expressive communication with speech and AAC, and whether or not they show improvement with AAC, as shown in Table 5. The results suggest that children with DD use different types of AAC systems compared to children with ASD. There was a significant difference in the proportion of the two groups using the different types of AAC systems ($\chi^2$=8.43, *p*=.038; see Table 5). Post-hoc tests indicated that children in the DD group were more likely to be using Sign language ($X^2$=4.98, *p*=.026), while children in the ASD group were more likely to be using PECS ($X^2$=4.16, *p*=.038; see Figure 3). Interestingly, the likelihood of using only one AAC system compared to multiple systems, did not differ by diagnosis ($\chi^2$=.90, *p*=.344; see Table 5).

When investigating how the two groups of children communicate using speech, there was no difference in the levels of communication achieved in children with ASD compared to children with DD ($\chi^2$=5.19, *p*=.159; see Table 5 and Figure 4). Likewise, there was no significant difference between children with ASD or DD in communication level using their AAC system ($X^2$=2.02, *p*=.733; see Table 5 and Figure 5).

Next the level of expressive communication with speech was compared to that with AAC to determine whether or not there was an improvement. Approximately, 60% of children with ASD improved with the use of their AAC system, while only about 40% of children with DD improved with the use of their AAC system but this difference was not significant ($\chi^2$=2.05, *p*=.153; see Table 5).

Since there were no differences between the ASD and DD groups in age or adaptive skill level, the levels of communication using speech, or with their AAC system, and no differences in improvement with the use of their AAC system, the finding that children with ASD use different types of systems than children with DD cannot be explained by the variables discussed here. Maladaptive behaviour level was the only significant difference found between the groups. If anything, that difference might be expected to be associated with children with ASD using more basic, low-tech, or inexpensive systems, but this was not consistent with the result found here that children with ASD were more likely to use PECS systems, and children with DD were more likely to use Sign language. This difference in choice of systems may be due to differences in symptom profiles not measured here, or it may be a reflection of the types of programs and access to professionals commonly available to children with ASD, allowing them and their families more access to specific types of AAC systems (i.e., PECS). PECS systems may be more available to children with ASD because they are often incorporated into ASD-specific treatment programs. It is also possible that increased rates of maladaptive behaviour may lead to increased services/treatment in order to reduce the behaviour, leading to recommendations for communication systems. As well, children with ASD were somewhat more likely to improve their communication with the use of their system (i.e., 60% compared to 40%); it is possible that children with more funding and supportive services may be more likely to improve their communication. This result will be further explored in Study 2.

### Investigating AAC Use by Age

As mentioned previously, it was hypothesized that age may play a role in AAC system use. As children mature and their communication abilities develop they may progress to different types of AAC systems, they may be more likely to be using more than one type of AAC system, they may have higher levels of communication, and be more likely to have improved their communication skills from speech while using their AAC system. Contrary to expectation, age did not prove to be a significant factor in the variables investigated in relation to AAC use within this survey. The age of AAC users did not differ depending on the type of AAC system used ($F$=.15, $p$=.932; see Table 6). Additionally, age was not related to whether children used one AAC system or multiple AAC systems ($t$=.13, $p$=.898; see Table 6). In fact, age did not have a significant effect on how well children communicated with the use of their AAC system, and it did not have an effect on whether or not they improved their communication with AAC ($F$=.80, $p$=.500; $t$=-.49, $p$=.628; see Table 6).

Although these results seem surprising, it is important to acknowledge that the variables and questions asked may not have been sensitive enough to measure the effect of age. As well, the design of the survey is cross-sectional and does not allow before and after comparisons. The improved/non-improved variable measures communication with speech and the communication with AAC both at the time of survey completion. It is possible that age may have an effect on communication if the parents had been asked about how their child's communication has progressed over time. On the other hand, there may be other factors that play a larger role than age in how children with DD use AAC. A further discussion of Adaptive Age and Maladaptive Behaviour, discussed next, provide additional information.

## Investigating AAC Use by Adaptive Skill Level

Adaptive skill level was another factor investigated to determine whether it had an effect on AAC use within the current sample. The adaptive age equivalent from the SIB-R was found to be a significant factor affecting some variables related to AAC use, but not others. The adaptive age of AAC users did not differ depending on the type of AAC system used ($F$=2.02, $p$=.122; see Table 7). This was a surprising finding given that it was hypothesized that children with a higher adaptive skill levels would be more likely to use more sophisticated or complex AAC systems, such as Sign language or VOCAs. Although adaptive age was not related to the type of AAC system, it did have an effect on whether children were using a single AAC system, or several systems ($t$=3.37, $p$=.001; see Table 7). This supports the original hypothesis that children who use multiple systems would have lower adaptive skills (20 months on average versus 35 months). Children with a lower adaptive age may use their AAC system less efficiently requiring them to rely on multiple methods of communication. They may be unable to transition to a more sophisticated system successfully and, as a result, continue to rely on older more Basic AAC systems. Supporting this finding, children with a lower adaptive age also showed lower levels of communication using their AAC device ($F$=5.99, $p$=.001; see Table 7). Children who communicated at lower levels (level 1 or 2) had lower adaptive age scores (18 and 24 months) than children who were capable of more meaningful communication (level 3 or 4) whose mean adaptive ages were 42 and 55 months, a substantial difference. This is an important confirmatory result since adaptive age does in part measure communication ability and thus the two should be related. Surprisingly, adaptive age was not related to whether children's expressive communication level with AAC improved from their communication level with speech when using their AAC system (*t*=-.88, *p*=.382; see Table 7). Again, this comparison is a crude representation of 'improvement' and does not reflect improvement over time, only level of communication with speech compared to level of communication with AAC at the time of survey completion. It is likely that adaptive behaviour skill level may play a role in how children progress in their communication, and learn to use their AAC system efficiently over time, although this was not measured here.

Overall, results suggest that adaptive age level is related in important ways to how children communicate using AAC systems and, thus it is surprising that it is not related to the type of AAC system chosen. In order for children to use AAC systems accurately and efficiently, the type of system and complexity of that system should be well matched to the child's abilities. This does not seem to be the case within the current sample. Other factors may have an effect on why or how AAC systems are chosen for children and the maladaptive index score, discussed in the next section, may provide further insight.

### Investigating AAC Use by Maladaptive Behaviour

The SIB-R Maladaptive Behaviour Index was another factor investigated in relation to AAC use within the current sample. As previously noted, the Maladaptive Index score did have a significant effect on the type of AAC system used (*F*=3.11, *p*=.034; see Table 8). Specifically, children who used PECS and Low-tech AAC systems showed more extreme negative scores, indicating higher levels of maladaptive behaviour. Children who used VOCAs showed and Sign language showed lower levels of maladaptive behaviour. Post-hoc tests (based on the Least Significant Difference method) indicate a significant difference between children who use PECS and those who use VOCAs or Sign language (*p*=.010; *p*=.022; see Table 8), such that children who use PECS have significantly higher levels of maladaptive behaviour than children who use VOCAs and Sign language. Maladaptive behaviour may play an important role in choosing an AAC system. For practical reasons children with higher levels of maladaptive behaviour may use lower-tech systems or PECS because parents and service providers do not want more expensive systems broken or damaged. Despite higher levels of adaptive behaviour and/or a higher ability to communicate effectively with AAC, they may be using lower-tech systems for funding or practical reasons. However, an alternative explanation may be related to diagnostic differences. Sign language and VOCA use were related to the lowest level of maladaptive behaviour, while PECS users showed the highest levels of maladaptive behaviour. This is not surprising given the proportion of children with ASD in the groups. The PECS category contains 13 children with ASD and 6 children with DD, the sign category is primarily composed of children with DD instead of ASD (7 children with DD and 1 with ASD), while the VOCA category is composed of a relatively equal number of children with ASD and DD (10 children with ASD and 8 with DD). Maladaptive behaviour can be a key component of the ASD diagnosis, and not surprisingly the ASD group did show significantly higher levels of maladaptive behaviour (as discussed previously). As a result, this effect of diagnosis may help to explain why children who use PECS show higher maladaptive behaviour than children using AAC in the low-tech category.

Maladaptive behaviour did not have an effect on the other AAC variables investigated. Specifically, it did not have an effect on whether children were using a single AAC system, or several systems ($t$=.49, $p$=.623; see Table 8). In addition, communication level with AAC was not related to the maladaptive behaviour index score ($F$=.53, $p$=.663; see Table 8). Not surprisingly, whether or not a child improved with the use of his/her AAC system from speech was also not related to maladaptive behaviour ($t$=.42, $p$=.674; see Table 8). Based on these results, it is clear that maladaptive behaviour has an important interaction with AAC system use, specifically on the type of system chosen for a child. Still, there are other factors, such as diagnosis, that complicate this relationship. In reality, many different factors affect how and which type of AAC system is chosen for a particular child, and maladaptive behaviour is just one of these factors. A more detailed and in-depth look into how maladaptive behaviour affects AAC use was investigated in Study 2.

# Study 2

## Methods

### Data Collection

Parents of children with DD who are also AAC users were recruited for Study 2 over a one year period using several different techniques. The first technique involved providing appropriate families a package containing an information letter and an informative flyer (see Appendix A). These families were invited to participate by a member of the thesis committee through her private practice (though another staff member contacted them to avoid undue influence). They were mailed a package with the necessary information to contact the researchers. The second technique involved parents contacting researchers after reading advertisements on the following websites: www.go4kidds.ca, www.caslpa.ca, and www.osla.on.ca. The third technique involved contacting eligible participants from previous GO4KIDDS studies who had agreed to be contacted for future research projects. A fourth and final technique involved contacting parents through the administrative staff of a special disability school. An informative flyer was printed in the weekly newsletter and sent home to the parents of children attending the school. Once parents made contact with the researchers, the informed consent process was completed over the phone (see Appendix B). The telephone interview completed by parents was used to investigate AAC system use and barriers faced by children with DD who use an AAC system in a more in-depth qualitative manner.

The overall GO4KIDDS project received ethical approval from York University's Human Participants Review Committee and multiple other organizations. In addition, this specific MA study including telephone interviews with parents received ethics clearance from York University. Parents were offered $50 as an honorarium for their time.

## Participants

Parents were eligible to participate in Study 2 if their child had a DD, including ASD, and currently used an AAC system as his/her primary method of communication. All participants except for one child had used AAC for longer than 6 months. This child had used PECS for 2 to 3 months and was not fully trained to use the system. A portion of the interview was completed with this parent (a large proportion was not applicable, e.g., questions asking about transitions, and communication skills with AAC were not possible because the child used only one system, and was on Phase 1 of PECS. Relevant questions regarding selection criteria, and eligibility, etc., were asked.

**Parent/Respondent Characteristics.** The sample was composed of 12 parents, all of whom were biological parents, 10 (83.3%) of whom were female, and nine of whom (75%) were married. The average age of the respondents was 42 years (see Table 9), and ranged from 30 to 53 years of age. The average Socioeconomic Status score on the Barratt was 19 (see Table 9 and the Measures section for more information; Barratt, 2006). This score had a low mean and a limited range, indicating that the sample was not very heterogeneous and may not be representative of all parents of children with DD in Canada. Similarly to Study 1, 33% of parents report a country of birth other than Canada, and 25% of parents reported a first language other than English, but all spoke English well enough to participate in the interview.

**Child Characteristics.** The children in the current sample were between the ages of 4 and 17 years, with a mean age of about 11 years (see Table 10), a similar age range to Study 1. Within the sample, seven children were male (58%), while five children were female (42%). Similarly to Study 1, a large proportion of the sample reported physical difficulties that may potentially be related to how a child communicates using an AAC system. Specifically, five out of 12 children (42%) had problems using their hands, six children (50%) had problems with motor coordination, while one (8%) child had other motor difficulties. Also relevant, a smaller proportion of the sample reported major vision and hearing impairments (approximately 17% and 8% respectively; see Table 10). In terms of the 5-point scale communication level (later reduced to 4 points as in Study 1), the majority of the sample showed low levels of expressive communication with speech. Only one child (8%) was able to communicate basic wants and needs with speech, while 11 children (92%) were only able to use very little meaningful speech (see Table 10). In order to describe the level of adaptive functioning of the sample, the Full Scale SIB-R was used to measure adaptive and maladaptive functioning (see Table 10 and the Measures section for more information). The children in Study 2 had, on average, an age equivalent of approximately 38 months (*SD*=16.02), and a maladaptive index score of -23.5 (*SD*=19.17). These were similar to the values found in Study 1. As in Study 1 children were categorized based on diagnosis (i.e., ASD and DD or DD only). Within the Study 2 sample, nine children (75%) were in the ASD group, while three were in the DD group (25%). Due to the inequality of the diagnostic groups and the small sample size, I was unable to investigate group-based differences quantitatively. However I was able to comment qualitatively on the unique aspects of parent experiences of AAC use in children in the two groups.

## Measures

The following parent-report measures were used to answer the research questions below:

**Go4KIDDS Extended Survey.** A subset of questions were used from the GO4KIDDS questionnaire related to Preliminary/Background Information, demographics, and communication (see Appendix D).

**The SIB-R** was also used to describe the adaptive and maladaptive functioning of the sample. The SIB-R is a comprehensive, norm-referenced, standardized assessment measure designed to assess skills from infancy to adulthood (80+) that are needed to function independently, in home, social, school, work, and community settings. Given that Study 2 involved a telephone interview, the Full Scale SIB-R was used for the Study 2 sample (while Study 1 used only the first 35 items of the Short Form). The Full Scale SIB-R is meant to measure adaptive behaviour for individuals of any age and takes approximately 45 minutes to complete. It consists of 14 adaptive behavior clusters (gross motor, fine motor, social interaction, language, comprehension, language expression, eating & meal preparation, toileting, dressings, personal self-care, domestic skills, time and punctuality, money and value, home/community, and orientation). An Age Equivalent score can be reported for each of the 14 adaptive behavior clusters. A total score was derived by taking the median of the 14 age equivalent scores. The Problem Behavior Scale (on both short form and full scale) includes eight areas of problem behaviour (e.g., hurtful to self, socially offensive behaviour) in three behavioral clusters (internalized, asocial, and externalized), resulting in the Maladaptive Behaviour Index, with a more negative score indicating more severe maladaptive behaviour.

**Parent Interview.** An in-depth telephone interview that took approximately 1.5 to 2 hours was conducted with parents. The interview focused on AAC system use in children with DD and included a subset of questions adapted from the dissertation/study by Koudys (2012). Other questions were constructed for purposes of the present study based on the literature and clinical experience of the student and supervisory committee. The questions and results are separated into four sections: General AAC use; transitions and AAC use over time; AAC services, barriers and eligibility; and special considerations for children with ASD who use AAC (see Appendix C). Each section further divides into subtopics described below.

***General AAC Use.*** Parents were asked about factors that were important when selecting an AAC system for their child (Selection Factors). They were asked to come up with examples independently and speak qualitatively about their experience. Once parents finished, the interviewer provided further examples and asked if the examples provided were also relevant. Parent responses were then placed into one or more of the following categories: portability of the system, ease of use, cost of system, availability of training in how to use the system, recommendation of an expert, prescription by an AAC clinic, research evidence to support use of the system, belief that their child would be able to learn and use the system, and their child's skill repertoire. Categories were chosen based on a review of selection factors reported in the literature. As in Study 1, questions related to communication and AAC use from the GO4KIDDS Survey are reported. They are: level of spoken language (5-point ordinal scale), use of AAC (yes/no), which type(s) of AAC, and how well the child communicates with the AAC system (5-point ordinal scale; see Appendix C and Measures section: Study 1 for more information). Unlike Study 1, parents were asked whether their child could perform specific communication skills with the help of his/her AAC system. This allowed for a more thorough and in-depth look at how children with DD communicate using AAC. Parents were asked whether their child could complete a particular skill with AAC. They were then asked to describe an example of their child performing that skill, how well their child could perform the skill (on a 5-point Likert scale), and whether that skill was performed similarly or differently in different environments and with different people. Parents were asked about the following communication skills: requesting, choosing, protesting, accepting, getting and directing the attention of others, asking for help, labelling objects, labelling emotions, asking questions, answering questions, beginning, maintaining, ending an interaction, describing objects, and describing stories or events. Some of the skills chosen were adapted from a dissertation by Koudys (2012), and the rest were added based on a literature review.

Parents were also asked about participation with AAC, that is, in which environments and with whom are children using their AAC systems. The environments included: school, home, family gatherings, community, recreational activities, clinical settings, and other. The people included: teachers, educational assistants, classmates, parents/guardians, siblings, grandparents, other relatives, strangers, non-school peers, therapists, and other. A question asking how well the child was using his/her AAC system in each environment and with whom was also asked. Responses were rated on a 6-point Likert scale: Doesn't use system, very poorly, poorly, alright/ok, well, very well.

***Transitions and use over time.*** Parents were asked how many systems their child was currently using, as well as the number of systems used over time. They were asked why they transitioned from each system they had tried to the subsequent system until they reached their current system. This was designed to describe the transition process for children who use AAC. Parents were also asked to comment on the overall transition process for themselves and their child. Once finished discussing the transition process they were asked to categorize their experience on a 4-point Likert scale as: easy, alright/ok, difficult, or very difficult.

***AAC Services.*** Parents were asked a series of questions regarding AAC services they had accessed, including whether their child had ever received a formal AAC assessment, the kind of support they were given when they received an AAC system (i.e., none, single sessions, group sessions), how many sessions they received, the length of each session, if they ever received follow-up support, if they were happy with the system chosen for their child (yes/no; i.e., not satisfied, somewhat satisfied, satisfied, very satisfied), if they felt the services were useful to them and their child (yes/no; i.e., not useful, somewhat useful, useful, very useful), if they felt their child's system maximized his/her communication abilities (yes/no; i.e., not at all, somewhat, yes, definitely), if they felt confident helping their child with his/her device (yes/no; i.e., not at all, somewhat, yes, definitely), and if AAC services adequately maintained their system over time (yes/no; i.e., not at all, somewhat, yes, definitely). Parents were asked to identify a yes or no for each question, they were then asked to classify their response based on the scales specified above, and asked to comment qualitatively on the aforementioned questions. Parents were also asked about barriers or challenges they had faced. Parents were first asked to comment independently, and were then asked whether specific examples (identified as important in the AAC literature) applied to them. Parent responses were classified into the following categories: lack of funding, waitlist for services, lack of professionals available, lack of parent training, lack of teacher training, inadequate services, problems with the system itself, child characteristics, lack of follow-up support, ineligibility for services, lack of AAC clinic, and other barriers. Parents were asked if the challenges they mentioned were resolved (if possible) by service providers, and if yes, how well those challenges were resolved (i.e., not at all, somewhat, yes, definitely). Parents were then asked to comment in general about their experience of the AAC service system and whether there were any issues they had not mentioned and would like to.

***Special considerations for children with ASD who use AAC.*** The final section of the parent interview was designed to ask about specific considerations or additional difficulties faced by children who have ASD and DD and who use AAC systems. Parents were asked if they believed their child faced additional difficulties when using his/her AAC system because of his/her diagnosis of ASD, they were then asked to describe those difficulties and how they appeared to affect the child's ability to use his/her AAC system (i.e., not at all, somewhat, yes, definitely). Based on the literature and experiences of the researcher's questions, specific questions believed to be relevant for children with ASD were asked. Parents were asked about repetitive and self-stimulatory behaviours, that is, if their child engages in these behaviours, whether they affect system use, etc. Parents were also asked if service providers suggested any techniques to manage problems or if a system was switched because of these difficulties. Parents were also asked about their child's motor control and whether it affected AAC use (i.e., not at all, somewhat, yes, definitely), as well as their child's ability to connect socially with others. Parents were asked if AAC has helped their child to improve their social connectedness (i.e., not at all, somewhat, yes, definitely), and they were also asked if social difficulties still persist with their AAC system (i.e., not at all, somewhat, yes, definitely). Finally, parents were asked in general how AAC systems have enhanced their child's life.

## Results and Discussion (Study 2)

### General AAC Use

Parents provided a rich amount of qualitative data that allowed a more in-depth understanding of the answers to the questions detailed above. Comments will be summarized in the following sections regarding selection factors that were important, pros and cons of different types of systems, the quality of the child's communication, and the child's social participation.

**Selection Factors.** Parents were asked what factors were important when selecting an AAC system for their child. Figure 6 shows how often parents chose to endorse each category (see Method section). The most commonly endorsed selection factors were: belief that your child will be able to learn and use his/her AAC system, ease of use, portability, and child skills. Ten out of 12 (83.3%) parents reported that it was important that their child would be able to learn and use the AAC system selected. Nine parents (75%) believed it important that the AAC system selected be easy to use. Eight parents (66.7%) also believed it was important that the system chosen be portable. This was especially relevant for younger children who had difficulty carrying large or heavy systems. Portability was an important factor overall because parents wanted the child to be able to carry the AAC system with him/her in different environments (e.g., at school). For this reason parents reported purchasing cases and protective equipment for electronic AAC devices (e.g., the iPAD). Interestingly, only seven parents (58.3%) reported that their child's skill repertoire was important when selecting an AAC system. According to the literature, an important part of the selection process of an AAC system involves the proper assessment of a child's communication skills and matching those skills to an appropriate device. It is, therefore, surprising that more parents did not find this factor important while selecting an AAC system for their child. In addition, six parents (50%) reported that the recommendation of an expert was important when selecting an AAC system for their child. When asked whether a recommendation from an AAC clinic was important for their decision, only two parents (16.7%) reported that it was an important factor in their decision. These findings are rather surprising since, recommendations from experts and assessments by AAC clinics are considered best practice. It is also surprising that 50% of parents reported selecting an AAC system for their child with no professional recommendations at all. Of these six parents, five (41.7% of the overall sample) also reported that cost was an important factor when selecting an AAC system for their child. These parents reported that waiting lists, funding difficulties, inadequate services, and difficulty accessing proper services, led them to select their child's AAC system on their own. Although 50% of parents are selecting their child's AAC system independent of professional guidance, only one parent reported that she consulted relevant research evidence when selecting an AAC system for her child, and only three parents reported that availability of training in how to use the system was important in informing their decision. These results seem to indicate that many parents are selecting AAC systems on their own, based on insufficient information, and are not being adequately supported by AAC services when selecting an AAC system for their child. A further discussion of barriers faced by parents can be found in the AAC Services section below.

**Types of AAC systems used.** In Study 1 participants reported AAC system types that fell into one of four categories (i.e., Basic/Low-tech, PECS, VOCAs, and Sign). Participants in the current study fell into only two of those categories, that is, 25% of the sample reported using PECS as their primary AAC system, while 75% of the sample reported using VOCAs as their primary AAC system (see Table 11). This difference is likely due to the inclusion criteria used in Study 2 as well as the proportion of ASD diagnoses. Study 2 required that participants use AAC as their primary method of communication, while Study 1 did not ask if AAC was the child's primary method of communication. As a result, it is likely that children who do not use AAC as their primary method of communication but who use AAC to supplement their communication are included in Study 1 but not in Study 2. Another important difference between the samples in Study 1 and 2 is the proportion of children with ASD compared to those with DD only. Participants in Study 1 are approximately equally divided into children with DD and ASD, while 75% of the participants in Study 2 have a diagnosis of ASD. According the results of Study 1, children with ASD are more likely to use PECS. This may help to explain the different types of AAC systems used by the two samples.

Although only PECS and VOCAs were reportedly used as primary AAC systems, the majority of the sample was exposed to other AAC systems and strategies. As a result parents did comment qualitatively on the pros and cons of AAC systems falling into all four categories, as discussed in Study 1. Throughout the course of the interview parents made many qualitative comments regarding the positive and negative aspects of different AAC systems they had tried. A summary of those comments is discussed below.

***Basic/Low Tech AAC.*** Parents reported that Basic AAC systems such as yes/no switches, using pictures to request, and using basic signs, are useful in several ways. They reported that these methods are easy for their child to use and access and require less effort for the child to figure out. As well, they are often a faster option when the child's primary system is not easily accessible, e.g., “His pictures have magnets and are stuck on the fridge, so whenever he needs something at home it's easier for him to just go get one and bring it to me.” Parents also reported that Basic AAC systems are much cheaper and do not require expensive and sophisticated equipment. “Last year he threw his iPAD in the pool so since then I'm afraid to let him use it in certain situations, so when we go out he uses signs or pictures and we leave the iPAD at home.” Conversely, parents expressed many negative aspects of Basic AAC systems, that is, Basic systems do not allow for more complex communication, they can be limiting and, in the case of basic signs, are not universally understood. Parents expressed that their children quickly outgrew Basic AAC systems and needed something more complex and more motivating to allow for communication growth and development. "He wasn't motivated to use his system because it wasn't capable of communicating what he wanted, so he would get frustrated, then he would lash out or avoid social situations altogether."

***Sign language.*** Although Sign language is a very successful and commonly used AAC system among children and people with DD, within the current sample of children with severe DD it was not a successful communication intervention. Parents reported that they tried Sign language because, if used properly, it can be a sophisticated language allowing for complex communication that approximates the flow and flexibility of speech. It was often recommended by professionals as a good option to try as a first AAC strategy since "it doesn't need any equipment", and can be used in most environments. Despite the positive aspects of Sign language mentioned here, it was not a successful communication intervention for children with severe DD in the current sample for many reasons. First of all, parents identified that it is not universally known, so children who attend public schools often cannot communicate with their peers and teachers. As well, it limits communication within the family itself: "It was a lot of work to teach myself Sign, and then he could only communicate with me, not with his brother, or his grandparents. So we had to find him something else so he could communicate with everyone." Another problem outlined by parents was the difficulty children have learning complex Sign language. Since signs are mostly not iconic they can be difficult to recall, organize into a thought or sentence, and require memory to remember what someone said or what a child intends on saying. Due to this cognitive demand, many children with DD cannot master complete Sign language. Many are only capable of learning a small number of signs and quickly outgrow the communication strategy, e.g., "Signs were useful at first, because her imitation was good, but it was too complicated for her, and she used too many sign approximations, so other people couldn't understand her. She was unable to learn complex Sign language, so we needed to find something else for her." For this reason, many parents of children with DD choose AAC systems that involve symbols that are iconic in nature (physical representations of objects that remain observable for reference) and easily understood by others. These types of systems (i.e., PECS & VOCAs) provide an easier way for children with severe DD to communicate and will now be discussed.

***PECS.*** Parents reported both positive and negative aspects of PECS. First, parents identified that PECS was a well-organized system that allowed their children to communicate better. One parent commented, "I appreciate that he has something to work towards, and I know what to do so he can reach specific goals. Also he can work on it during therapy and his therapists know how to teach him which is good." Another spoke about what her child accomplished when using PECS, "It's like he now has a voice, he's less frustrated, and he can tell me what he wants, it's really changed his life and allowed us to experience his personality". PECS has also allowed some children to communicate in more complicated and creative ways, "She can use different pictures to represent different things when she doesn't have the exact picture in her book, the other day she brought me a picture of a square to represent a different object she had seen, I couldn't believe she would be that creative. Sometimes she even jokes around with us, showing us funny pictures and laughing." According to parent report, PECS functions as a successful AAC intervention for many children with DD. Although it works for some, there are still negatives to its use. Parents report that children can outgrow the PECS system as they age, "My child's vocabulary is too large, there weren't enough pictures to represent everything he needed to communicate, his binder had too many pages and was completely full. We needed to find something more practical to allow him to grow." Parents also reflected that it was time consuming to find, print, laminate, and Velcro a picture each time their child learned a new word, "It's hard to keep up, he always loses pictures and sometimes I'm too busy to bother replacing them right away." Another parent reported that his child's PECS system was stigmatizing in certain situations, "He stands out from the other kids and he looks so obvious when he wears his PECS binder around his neck on a strap." A different parent also highlighted that it was more stigmatizing and less developmentally appropriate as children age, "When a 7-year-old hands you a strip saying "*I want cookie*" it's not as strange looking as when a 16-year-old does. As my child got older he was no longer motivated to use his system, he didn't like it anymore and would rip his pictures." Although parents did have concerns about the PECS system, there was an overall consensus that, at the time their child was using the system, it was a very worthwhile approach that promoted language learning and helped their child to establish an important communication base.

***VOCAs.*** As a majority of parents reported that their child was using VOCAs as his/her primary communication system, parents had quite a few positive and negative comments about VOCAs. Parents felt that VOCAs were easier to use, both for the child and parent. They highlight that, "Now all I need to do is take a picture of something in his environment and put it into his device.", "I find that my son is much more motivated to use his iPAD, he enjoys navigating through the displays, and likes bringing it places with him. We had a hard time getting him to bring his PECS binder."; "We don't have to worry about losing pictures anymore." Parents feel that VOCAs allow their children to communicate with those around them, and even simple communication can be important to a family's functioning and quality of life, for example: "He can tell me that he wants a drink now, so I don't have to constantly worry if he's thirsty."; "It's easier to determine what is bothering him, our house is much more peaceful now." Parents of older or higher functioning children report that VOCA systems allow their children to communicate in a more sophisticated way, for example, one parent shared: "My son can send me a string of pictures outlining what he wants to do, for example, a picture of grandma, a house, and cookies, meaning that he wants to go to grandma's house to eat some cookies.". It was also important to parents that iPADs were universally understood, e.g., "He can go to McDonalds, ask for a hamburger, and people understand him." Not only can the iPAD be used for communication but parents appreciate that it can be used to accomplish other things, for example: "I can program what she did on the weekend into her device, and she can share it with her schoolmates for show-and-tell", "He can work on spelling, and math at school.", and "We can use his iPAD to prepare him for different social situations using a specific app, that way we can try to avoid behavior problems when we go to new places.". Specific to iPAD use, parents reported that they appreciated the relative low cost of the device and the software. They also were pleased with the responsiveness of the software developers of the most commonly used software (i.e., Proloquo2go). Other benefits to the iPAD included less stigma than other devices. Parents reported that their children looked less out of place when using the iPAD because many other children also have iPADs. Most importantly, parents believed that VOCA systems gave their children a unique voice, for example, "It's fun to see him express himself like a teenage boy, he finds ways to joke around with me and be goofy, and he enjoys communicating."

Despite the numerous positives, parents reported difficulties specific to VOCA systems. Parents report that traditional VOCA systems (e.g., Dynavox) are large, bulky, heavy, and difficult for children to carry around. Parents are also concerned with the cost associated with VOCA systems, "I'm afraid to let him bring it around with him because he may drop it or throw it. I'm not willing to pay and wait for it to get replaced again." Parents report that waiting lists for formal AAC assessments are long, so many are not willing to wait for a more expensive VOCA system; instead many parents purchase an iPAD out of pocket (see AAC Services section for more information). For this reason parents often have difficulty allowing their children to bring the iPAD to school "The school wanted me to sign a waiver saying they were not responsible if it was lost, stolen, or broken. I don't want to take that risk." Some parents also had difficulty with training/helping their child to use VOCA systems, "I don't know what to do with my child next. We're stuck at requesting and I have no idea how to get him to do other things. There is very little support for iPADs, at least with PECS I knew what to work on next." Overall, it appears that VOCAs provide a successful communication intervention for children with DD. It is apparent that iPADs show a lot of promise, and can be a valuable intervention tool. However, it is important to find a way to provide more support for parents who choose VOCA and iPAD systems for their children with little to no professional guidance.

**Communication with AAC.** Children in the current sample used their AAC systems to accomplish a variety of communication goals. The majority of the sample were capable of very little meaningful communication with speech (91%); however there was greater variability in their level of communication with the help of their AAC system. Using the same broad question used in Study 1, an overall picture of communication emerges. Only one child (8%) remains capable of very little meaningful communication with AAC (see Table 11). This particular case resulted because the child had not yet mastered PECS and was still in training. This child represents the one child who did not improve with the help of AAC. According to parent report, five children (41.7%) were able to communicate basic needs and wants with the help of their AAC system, three (25%) children were able to communicate needs, wants and some ideas, while another three (25%) were capable of communicating about a limited number of topics in a meaningful way. Consequently, 11 children showed improvement when their level of communication with speech was compared to their level of communication with AAC. These results suggest that within the current sample, AAC effectively improves how children with DD communicate.

Since these questions were broad in nature, a more in-depth look at the specific functional skills children were able to use with AAC was conducted. Children with DD were capable of a variety of communication skills with the help of their AAC systems. The most common involved requesting (n=10, 91%; see Figure 7), and making a choice (n=9, 82%). In terms of frequency, parents indicated that 9 of the 10 children requested most of the time or always when appropriate. One child performed the task rarely. Unlike requesting, parents reported that five children rarely used their AAC system to choose, while five used it sometimes, or most of the time to choose. As seen in Figure 7, three children (27%) were able to answer a question, label objects or emotions, and describe a story or event, with the help of their AAC system. When investigating the frequency of labelling behaviours, two children performed the skill rarely, while one performed it most of the time. All three children who reportedly described stories or events did so rarely. One child who was capable of answering questions did so sometimes, while two children did so most of the time. Less frequent communicative functions such as describing an object, protesting, accepting, getting/directing attention, asking for help, and beginning, maintaining, and ending an interaction were used by only two or one child (18%, 9%; see Figure 7). Parent report indicated that children performed these behaviours rarely using their AAC system. Although at initial inspection it appears that children are using their AAC systems for a variety of communication functions, they are predominately using their system to request objects, and make choices. They are less likely to engage in more sophisticated types of communication with the help of their AAC systems. Parents also reported that these more sophisticated communication behaviours were often accomplished through a great deal of guidance and support by parents (i.e., not fully independently). Overall, these results confirm that the majority of children with DD are capable of communicating their basic needs and wants with AAC. These results provide supplementary evidence that the majority of children improve in communicative skill with AAC, relative to speech, but that their communication remains limited.

**Participation with AAC.** Parents were asked to report in what environments and with whom their children used their AAC systems and how well they use their AAC system in each environment and with each person. Figure 8 shows a graphical representation of the number of children using their AAC systems in different environments and with different people commonly encountered in their daily lives. Related environments and people are clustered together in order to better understand the results.

***School.*** The majority of children (i.e., n=9) used their AAC systems at school and with their teachers and educational assistants. According to their parents, three children used their AAC system poorly at school, five used their system ok or well, and three used their AAC system very well at school. This was the same for children's interactions with their teachers. Not surprisingly, parents did not report the same levels of AAC use with their children's classmates. Only five children used their AAC systems with their classmates, three of those children used their systems very poorly, one alright/ok, and one very well. Anecdotally, the child who used his system very well with classmates did so in an integrated school setting where his peers were charged with helping him to complete his homework. Several children who did not use their systems with their classmates or who used them poorly are in special education classrooms or schools, where the other children also have communication difficulties. For these children, communication with adults was more likely in the classroom.

***Home.*** Not surprisingly the majority of children use their AAC systems at home (n=9, 92%), most commonly with their parents (n=12, 100%), but sometimes with other family members as well. How well children used their AAC system at home with their parents varied; one child used his system poorly, four children used their system ok, two used their system well, and five used their system very well. Most children also used their AAC system with their siblings, that is, 75% (n=9). Of these, four used their systems very poorly or poorly, two used their systems ok, and three used their systems very well. Anecdotally, some parents reported that the child's siblings did not understand how to use the AAC system properly. Some parents reported that the child's sibling also has a DD and, as a result, the two are less likely to communicate with each other. Conversely, three parents reported a strong bond between siblings, one parent reported that her child's older sibling was primarily responsible for teaching the child how to use the device. We also asked parents about how their child used his/her system at family gatherings, with grandparents and with other relatives. Four children used their system at family gatherings, one used their system very poorly, two ok, and one used their system well. Reasons why children did not use their systems often or well included that family gatherings were busy, loud, and difficult for children with DD. Many parents indicated that they often avoided these situations. Overall, children did not use their systems often or well with family members outside of their immediate family. Of the four children

(33%) who used their systems with grandparents, three used their system ok, while only one used their system very well. Three children used their systems with other relatives (e.g., aunts, uncles, cousins), two used their system very poorly, while one used their system ok. Parents reported that grandparents and other relatives did not understand the purpose of the child's AAC system. As well, children were less familiar with other relatives, showing less motivation to communicate, and preferring to communicate with their parents.

***Community.*** Unfortunately, only three children (25%) used their AAC system in the community (n=3, 25%). Parents reported that community activities such as going to the store were often difficult for children with DD, "I would rather just go through the drive thru at Wendy's and eat at home, than have an embarrassing outburst in the restaurant." . Parents also highlighted that when such community communications did occur, they were very guided (e.g., a button is programmed in the device to ask for a child's specific order, the sentence is constructed for the child). Two of the children who were reported to be using AAC in the community used it very poorly, while one used it ok. Sadly, even fewer children used some form of AAC while participating in recreational activities (n=2, 17%). Many parents indicated that their child could not use their AAC device during a recreational activity (e.g., a pool). First, parents identified that activities involving physical exercise make it difficult to use an AAC system like PECS or VOCAs (e.g., it is hard to run and throw a basketball while holding a binder or device). Second, parents fear that their child's device may break or be ruined. One parent highlighted a different issue, "It is impossible for my son to use his device outside in the bright sun because the screen becomes very difficult to see, because of this he cannot participate very well in recess and often stays inside." The parents of the two children who did use AAC in these types of community situations indicated that, while their child engaged in a recreational activity, they reverted to Basic/Low Tech systems, (e.g., a couple of laminated pictures, or basic signs). These children used their systems poorly, and ok while participating in recreational activities. Children with DD have similar problems when communicating with strangers and non-school peers. Two children (17%) reported using their AAC system to communicate with strangers and non-school peers. Some parents reflected that their children didn't have any non-school peers and were not encouraged to talk to strangers. Both children who used their system with strangers did so very poorly, while the children who used their system with non-school peers did so ok and well. Overall, children with DD did not participate well in community activities and with people with whom they were less familiar.

***Clinical Settings.*** When parents were asked if their child used AAC in clinical settings, there were varied levels of use reported. This may be due to the range of ages and the variety of therapies received by the children sampled. Older children and children with DD only were less likely to be actively participating in therapies. This explains why three children (25%) do not use their AAC system in clinical settings. Nine children (75%) do use their AAC system in clinical settings. Of the children who use AAC in clinical settings, two used their systems very poorly and poorly, three used their systems ok, two used their systems well, and two used their systems very well. These results were consistent with AAC use with therapists in general and they suggest that children with

DD who use AAC use their devices differently with different therapists and with different kinds of therapists. One parent reflected that, “She uses her system with her ABA therapist, but not with her SLP who is trying to teach her speech goals.”

**Transition Process and Experience Over Time**

Six children, that is, 50% of the sample are currently using more than one AAC system, ranging from one to four systems at present. Not surprisingly, children try multiple systems over time, and transitioning from one system to another is experienced by most parents and children. Understanding this transition process is important to properly grasp parents' experience. Parents reported that children used one to five AAC systems over time with an average of three systems tried (SD=1.2; see Table 12 for exact values and category frequency). Parents were asked in general to reflect upon the transition process and to indicate whether their own and their child’s experience of transition was: easy, good, somewhat difficult, or difficult. Fifty percent of parents (n=6) reported an easy or good transition, while 50% of parents (n=6) reported a somewhat difficult or difficult transition. Reasons for transitioning included: wanted something faster/more efficient, easier to use, more portable, less stigmatizing, more universal, developmentally appropriate, matched to communication abilities, and more motivating. Most importantly, parents wanted their child to achieve new communication goals, and reach his/her potential. Parents wanted their child to express himself/herself, establish his/her unique personality, and be able to take value from interacting with others. The majority of parents reported advocating for their child, trying to convince professionals to transition their child to more complex devices. This often caused difficulty and will be discussed further within the context of eligibility (see AAC Services section). Conversely, some parents reported that they had no input when selecting a new device for their child, and that the decision was made solely as a result of a school or professional recommendation. In order to reflect upon whether children were successfully transitioned to the appropriate device, parents were asked if their child's current communication system was well matched to his/her abilities. Ten parents reported that their child's system was well matched, while two parents reported that their child's system was not well matched to his/her abilities. Those parents indicated that they were currently in the process of transitioning from the child's current device to a new one. Overall, parents expressed that the transition process was difficult, and that more supportive services were needed during that time.

## AAC Services and Barriers

**AAC Services.** The majority of the sample has not received the level of service recommended as 'best practice' by the literature (see Introduction). Only 33% (n=4) of children received a formal AAC assessment (see Table 13). The remainder (n=8) received their AAC systems informally through different kinds of therapy programs (e.g., IBI or ABA), or bought the AAC systems out of pocket (i.e., the iPAD). When asked about the kind of support received, two parents reported that they had received no support of any kind, while 10 reported that they had received support in the form of individual sessions. Parents reported an average of three sessions (SD=2.3), with a broad range of zero to 30 sessions. Each session was an average of 1.18 hours in length (SD=0.6) and duration ranged from 30 minutes to 2 hours. Only one child received formal follow-up support from AAC services, while 50% (n=6) received follow-up services of some kind. These services included informal support through other therapy programs (e.g., ABA services), or EA support in school (see Table 13).

Parents were then asked about the usefulness of the services they received. Nine parents reported that AAC services received were useful, while two reported that they were not. When asked how useful they perceived the services to be, four parents indicated that services were not useful or were somewhat useful, while seven parents indicated that services were useful or very useful (see Table 14). When parents were asked about how satisfied they were with AAC services, 59% (n=7) of parents reported being satisfied with services. When parents were asked how satisfied they were, six were not satisfied or somewhat satisfied, while six were satisfied or very satisfied. When asked qualitatively, many parents who said they were satisfied still reported problems and challenges associated with the services they received.

In order to investigate the quality of the services provided, parents were asked if they were satisfied with the system eventually chosen for their child. Interestingly, all parents indicated that they were satisfied with the system chosen. When asked to rate their satisfaction, only two parents were somewhat satisfied, the rest (n=10) were satisfied or very satisfied. Given that parents had input in the selection process and that some even chose a system independently or with little guidance from professional services, this result may be less reflective of AAC services themselves. Seven parents also indicated that the system chosen maximizes their child's communication abilities, and 10 felt confident helping their child use his/her device. A majority of parents also believed that the services they received adequately maintained their child's system over time (see Table 15 for scaled results). Based on these results, it appears that parents and children access AAC services through a variety of different services and programs. It appears that a minority of parents access formal AAC services while the majority find help through different sources. Parents also appear to be satisfied with some aspects of the services they receive but not with others. Qualitatively, parents report a variety of experiences that range from positive to negative.

**Barriers and Challenges.** Parents reported a number of challenges that involved barriers within the service system, as well as barriers within the individual child. Figure 9 shows the types of challenges reported and the frequencies of those challenges within the sample. The barriers reported were: lack of funding (n=8, 67%), waitlists for services (n=7, 58%), lack of parent and teacher training (n=7, 58%), inadequate services in general (n=6, 50%), problems with the device itself (n=6, 50%), characteristics within the child that inhibit AAC use (n=6, 50%), lack of follow-up support (n=5, 41.7%), lack of awareness of an AAC clinic in the area (n=5, 41.7%), and a child being deemed ineligible for AAC services (n=5, 41.7%). Parents were also asked whether any of the challenges they have faced were resolved by service providers. Only four parents reported that their challenges were resolved, five parents reported that they were not at all resolved, two reported that they were somewhat resolved, two reported that yes they were resolved, while another two reported that they were definitely resolved (see Table 15).

Parents had many qualitative comments in support of these results. Funding issues and long waiting lists were very relevant to parents, "The waitlist was over a year. I just couldn't wait for him to miss a chance to learn something. I couldn't do that to my child so I went out the bought the iPAD myself." Parents reflected that AAC Services are fractured, disorganized, and difficult to access. They also reported that professional knowledge of AAC services varies, "What kind of system you use depends on the person you get." They highlight that professionals are often not aware of, or trained in how to give AAC services, "I had to go into my son's school to teach his teachers how to use his system with him. They expect him to use it really well in order to become eligible for funding, but they have no idea how to teach him how to use it properly. It seems a bit unfair to me." As reflected in the previous quote, children are often required to undergo a trial phase where the child must prove that he/she can benefit from using the AAC system in question. Until this can be proven, funding and support is not given. Parents also reported a disconnect (not enough communication) between AAC services in the school system and private/public AAC services, "My child has two devices with different software, and is often learning different things at home and at school. It only confuses him.". In addition, parents report difficulty accessing services and are sometimes not aware of the AAC services available to them e.g., "What are AAC clinics?" Overall, parents report that some service providers seem to have a lack of creativity, effort and persistence with children who take longer to learn, "We need to come up with new and exciting ways to get kids to learn instead of working on the same things in the same ways, repeating something that's not working, over and over."

Children in the current sample experienced a variety of educational placements. Some were integrated into the public school system, while others were placed in segregated classrooms and schools. Overall, there was a difference in access to services in regular classrooms when compared to specialized disability schools. It appeared that children in integrated or mainstreamed classes were more likely to have informal supports not specific to AAC, while children in segregated disability schools were more likely to have formal AAC assessments and follow-up support.

Overall, parents reported that, although some aspects of AAC services need to be improved, there are substantial benefits as well. "I don't know where my child would be without his device, it has really changed his life. I am thankful for all the help we have received throughout the years. Some professionals have been ok, but some have been really amazing." Parents also reported that although they had difficulty accessing formal AAC services, they were really pleased with the informal supports they received, for example, through ABA services.

### Special considerations for children with ASD who use AAC

Parents were asked several questions related to specific symptoms of ASD that could impact how a child communicates with AAC. When asked whether their child had any additional difficulties communicating with AAC because of a diagnosis of ASD, seven parents (78%) acknowledged that their children did have additional difficulties (see Table 16). Parents reported a lack of social skills and motivation as being the biggest additional difficulty. Parents were then asked specifically about repetitive use, motor difficulties, and social difficulties. Seven parents (78%) reported that their children used their AAC system in a repetitive manner; responses were distributed across the levels of the question. Although many children with ASD exhibited these behaviours, their behaviour varied in the level of impact it had on their communication with AAC. Parents were then asked if their child had any motor difficulties that could affect his/her communication with AAC. Four parents (44%) reported motor difficulty but, of those four, only one parent reported that it impeded the use of AAC. Parents were then asked if service providers had given them any techniques to manage these difficulties, and if those problems were resolved. Only two parents reported that they were given techniques by service providers, and only one reported that the problem was resolved. Finally parents were asked if the AAC system was changed based on these difficulties and all seven parents said it was not changed. To investigate how AAC systems impact social skills, parents were asked if AAC helped to enhance their child's ability to connect socially with others. Eighty-nine percent of parents (n=8) reported that AAC did enhance their child's ability to connect socially. Parents were also asked if social difficulties remain despite the improvement and the majority (n=8; 89%) said that yes their child's social difficulties persist. These results indicate that ASD symptoms, specifically repetitiveness, motor difficulties, and social skill difficulties, have an effect on how children use AAC. It is important to keep these difficulties in mind while selecting an AAC system and training a child to use it.

## General Discussion

The purpose of this study was to investigate AAC use in a sample of Canadian children. Study 1 investigated group based differences in AAC use in a large Canada-wide sample, while Study 2 investigated AAC use in a more in-depth manner by exploring the qualitative experiences of 12 parents of Canadian children with DD. The following discussion will compare complementary findings from the results of Study 1 and 2 and discuss the implications of the findings for children with DD and their parents, as well as the implications for future research.

There are some differences between the samples in Studies 1 and 2 that are important to keep in mind when interpreting the results. Study 1 had a much larger sample and investigates group differences in AAC use (e.g., Users vs. Non-users, ASD vs. DD), and factors affecting AAC use (e.g., age, adaptive behaviour). On the other hand, Study 2 had a smaller sample and investigates more in-depth qualitative questions. Study 1 had an approximately equal proportion of children with ASD and DD allowing for comparisons between the two groups, while Study 2 had a higher proportion of children with ASD (75%). Study 1 included children who use AAC as a secondary communication strategy to supplement or augment their communication; while it was required that a child uses AAC as his/her primary method of communication in order to be included in Study 2. Study 1 had a more varied sample in terms of socio-economic status and is likely to be more representative of the Canadian population of children with DD, while Study 2 had a more homogenous sample and a high proportion of stay-at-home mothers. Considering the results from Studies 1 and 2 together provides a more complete understanding of the experiences of children with DD and their parents.

### General AAC Use

Results from Study 1 showed that Canadian children with DD use a variety of methods to supplement and augment their communication. Children who use AAC are more likely to have lower levels of expressive communication than non-users of AAC, although they still may use some speech. They are also likely to have lower levels of adaptive skills when compared to children with DD who do not use AAC. Children who use AAC and who also have ASD are more likely to use PECS systems. It also appears that children who use AAC as their primary method of communication are more likely to use PECS or VOCAs and are less likely to use Basic systems or Sign language. These findings suggest that diagnosis is related to the type of AAC used in both samples.

It appears that, within both samples, children are likely to be using multiple AAC systems or communication strategies concurrently. This was more common in Study 2 participants (i.e., 29% of children in Study 1, 50% of children with Study 2), although this was not explored thoroughly in Study 1. This implies that children and their parents may not be able to find one AAC system that meets all of their needs. In both samples, children varied in their level of communication with the help of AAC, which is consistent with the literature. Although they did vary somewhat, the majority of children still displayed low levels of communication with the aid of their AAC system. There is much debate in the literature concerning a description of worthwhile and successful communication with AAC use.

In order to explore how children are benefiting from AAC, Study 1 provided a preliminary investigation of communication level with speech compared to communication level with AAC. Approximately 50% of children in Study 1 showed improvement from speech, that is, the level of communication endorsed by parents when children communicated using speech, compared to the level endorsed when communicating using AAC. This was a surprising result leading to the conclusion that 50% of the sample is not benefitting significantly from using an AAC system. In order to investigate this result more thoroughly, we asked the same question in Study 2, and also designed a series of questions to determine whether children were capable of engaging specific communication skills with AAC. This allowed us to estimate more reliably what children were capable of accomplishing with AAC. When parents were asked the same question, 11 of 12 (92%) parents in Study 2 indicated that their child's communication abilities with AAC improved from what he or she was capable of using speech.

This result may be explained by the differences in the samples of Study 1 and 2. The children in Study 2 used AAC as their primary method of communication, used different types of systems (i.e., PECS and VOCAs), and were more likely to have ASD than the children in Study 1. One, all, or a combination of these differences may be responsible for the increased success of the children in Study 2. Relating this result back to the literature, it appears that the majority of children with DD are capable of requesting and choosing with their AAC system. According to the way the current study defines communication levels, this equates to communicating basic wants and needs.

When asked about how AAC affects social skills, parents reflected that AAC improves social closeness but that some difficulties remain. According to Light (1989), to be successful AAC users, children should be able to: request, protest, ask questions, answer questions, express emotions, and build relationships. According to Light, et al. (2003), they should also be able to communicate wants and needs, transfer information, and allow for social closeness and etiquette. Children should also be capable of generalizing these communication skills to different environments and people, allowing them to better participate in their lives. Results from Study 2 indicate that children with DD do attempt to use AAC in a variety of environments and with a variety of people. However, most efficient use is limited to home and school, and with parents and teachers. Children do not participate in, or participate very poorly in, other environments and with other people (e.g., in the community, or with other relatives) indicating that they have difficulty generalizing AAC skills learned at home and at school. Other studies have also highlighted this difficulty, and suggested that more research needs to be done in this area (e.g., Schlosser & Lee, 2000). According to parents, more effort needs to be made to help children with DD participate more fully.

The results of the current study suggest that children with DD may not be able to accomplish all of these communication goals with AAC. This does not necessarily mean that they cannot successfully communicate with AAC. Consistent with the opinions of Ogletree and Pierce (2010), parent comments help to clarify that children with DD are using AAC successfully. Parents reflect that even 'small' communication accomplishments can make a significant impact on the way in which a child with DD can interact with and experience the world. Accordingly, Ogletree and Pierce emphasize that children do not need to accomplish 'successful communication', as defined by Light and colleagues, to benefit from AAC use.

In order to investigate General AAC use further, a future study should divide children who use AAC into groups based on whether they use AAC as a primary or secondary method of communication. Future studies should also investigate the use of AAC as a treatment intervention within populations of children with severe DD, measuring communication levels using standardized measures pre- and post-treatment. This type of empirical design would allow for a more in-depth investigation of different factors affecting AAC use (e.g., diagnosis, IQ, adaptive skills, age, etc.). It would also help to provide a concrete and objective way to measure communication levels through direct observation. It may also be useful to directly measure AAC use across different settings and with different people in the child's environment. A prospective or longitudinal design would also allow a better understanding of how age and progression over time affect AAC use in children with DD.

### AAC Services and Barriers

Study 1 provided a first look into how specific factors predict AAC use (e.g., diagnosis, IQ, adaptive skills, maladaptive behaviour). Understanding how these factors affect or are associated with AAC use, is crucial for selecting an appropriate AAC system for an individual child, and for developing and delivering efficient and useful training programs. Qualitatively, parents in Study 2 confirmed that these factors are important. Not surprisingly, parents in Study 2 highlight an overwhelming need for more support and guidance in terms of AAC use. Current research highlights the importance of proper assessment, taking into account the individual with AAC, his/her family, other people around him/her, and his/her environment (Ogletree & Pierce, 2010). Ogletree and Pierce (2010) also highlight that a multidisciplinary team should be involved in the assessment/selection process, and that maintenance and follow-up services should be provided. Results from Study 2 describe how parents of children with DD experience AAC services. Overall, it appears that the availability and quality of Canadian AAC services are variable, at best. Parents report varying degrees of access and satisfaction during the selection process, initial training, system maintenance, follow-up, and when transitioning from one system to another. Some parents report difficulty receiving funding and becoming eligible to receive AAC services and systems. Consistent with the literature, parents reported a variety of barriers that included: barriers within the service system, barriers in the environment, and barriers within the child. Ogletree and Pierce (2010) discuss eligibility as a controversial topic in AAC research. Within the Study 2 sample of AAC users, parents reported difficulties with their child becoming eligible for AAC systems. Parents reported having to wait to see if their child was capable of using his/her AAC system during a trial period before they were prescribed the system. Future studies should look into eligibility issues within a sample of AAC users, non-users, and potential users to better understand how eligibility affects children who do not receive funding compared to those who do. The current study was unable to fully explore this issue since all of the children in Study 2 did become eligible for AAC and were current users.

Based on the results of Study 2, it does not appear that Canadian children are receiving services that meet best practice guidelines. Moving forward, parents highlight the need for more structured training programs specifically designed to help children use more sophisticated AAC systems. Service providers should understand that parents may be accessing services from several different sources or none at all, and may be purchasing AAC systems on their own with little to no professional support or guidance. Given that they are inexpensive and easy to purchase, iPADs are becoming commonly used as an AAC system. Unfortunately, little research has been done on how they are used by children with DD, and no formal training program is available for parents and children (as there is for PECS). Establishing a standardized (but individualized) program will be important to support parents and children in the future, especially given the advantages and potential of iPADs outlined by parents.

Overall, parents in Study 2 reported drastically different experiences depending on where and from whom they accessed services. As well, they reported varying degrees of understanding about the types of services available to them. It appeared that children in our sample who were recruited from a special school for children with disabilities, seemed to have better access to services and tended to receive better quality care (best practice), while parents of children who were integrated into the mainstream school system seemed to express more frustration with services, less satisfaction, were more likely to purchase an AAC system out of pocket, and take on the responsibility of training their child how to use AAC on their own. In the future, it will be important to ensure that all Canadian children with DD have equal access to quality AAC services.

## Special Considerations for children with ASD

The current study suggests that symptoms of ASD may interfere with how children with DD use AAC. Tendencies to push buttons repetitively, difficulties with motor control, social difficulties, and increased levels of maladaptive behaviour should be taken into consideration when selecting an appropriate system for a child with ASD, and care should be taken to address these difficulties in AAC interventions and training programs.

## Limitations

The current study had several limitations. As mentioned previously, Study 1 was part of a larger online survey and was not originally designed to investigate factors important for AAC use. As a result, many of the questions used to perform the analyses were rather crude in nature. For example, questions about communication level were based on a simple question on a 5-point scale, not on an objective measurement of communication. As well, "improvement" was measured by comparing parent responses to two separate questions, one about speech and one about AAC, answered at one point in time, and were not a measure of improvement over time (e.g., pre/post). Due to the design of the questions in Study 1, additional details needed to clarify some results were not available to the researchers (e.g., the software used for some VOCA systems, whether children were using actual Sign language or just a few basic signs, if AAC was a child's primary method of communication). As well, questions were not in-depth and provided only more general group-based information. However, Study 1 allowed us to compare users vs. non-users of AAC, factors affecting AAC use, and had a large, nation-wide sample. Study 2 was based on a much smaller study and the sample may not be fully representative of all Canadian children with DD and their parents. Study 2 was designed to provide more in-depth qualitative information, and due to its small sample size group-based differences could not be investigated.

Results from both studies are based on parent report. Although parent report is a reliable and useful way to collect information, it is not necessarily unbiased, and reflects one perspective. It is important to keep in mind that every parent's perspective is unique; and parents may interpret questions differently and place value on different things. In Study 2, the researchers attempted to provide parents with structured and standardized ways to quantify their responses, however it seems likely that parent responses were not always consistent.

Another limitation associated with parent report is reflected in the time parents spend with their child. That is, parents may not be fully aware of how their child acts in all environments. Since, in most cases, parents do not attend school with their children, they may not be fully aware of how their child uses AAC at school. Because the interview asked questions specific to participation at school, it is possible that those questions do not fully represent AAC participation at school. A future study could attempt to involve service providers and school personnel in the interview process in order to collect more complete information from different sources.

Despite these possible limitations, the parents interviewed for the current study seemed well informed and knowledgeable about their children's use of AAC systems. They provided detailed and important information about their experiences. Overall, they conveyed feelings of love, passion, hope, determination, and persistence when talking about their children and their children's care. Most importantly, they emphasized the importance of communication in their children's lives. Based on the results of this study, we can say that AAC does help children to communicate with others and participate more fully in their lives, allowing them to have a voice. The results also suggest that service providers, schools, and health care professionals need to work together to provide Canadian children with DD and their families the more effective and consistent services and supports they deserve.

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Table 1
*Study 1 Parent Descriptives*

| | | *n* (%) or *M* (SD) | Range |
|---|---|---|---|
| Relationship to Child (N=147) | | | |
| | Biological parent | 135 (91.8) | |
| | Adoptive parent, step parent, other | 12 (8.2) | |
| Marital Status (N=147) | | | |
| | Married or common-law | 113 (76.9) | |
| | Separated, divorced, single, widowed, other | 34 (23.1) | |
| Gender (N=146) | | | |
| | Male | 8 (5.4) | |
| | Female | 138 (94.5) | |
| Age (N = 148) | | 42.33 (7.05) | 28.04 – 57.91 |
| Barratt Score (N = 141) | | 40.41 (12.96) | 9.00 – 66.00 |
| Distribution Across Canadian Provinces (N=148) | | | |
| | Ontario | 98 (66.0) | |
| | British Columbia | 22 (15.0) | |
| | Alberta | 16 (10.8) | |
| | Manitoba | 5 (3.4) | |
| | Newfoundland | 2 (1.4) | |
| | Nova Scotia | 2 (1.4) | |
| | Prince Edward Island | 2 (1.4) | |
| | NorthWest Territories | 1 (0.7) | |
| Parent Country of Birth (N=145) | | | |
| | Canada | 111 (76.6) | |
| | Other Country | 34 (23.0) | |
| Parent First Language (N=145) | | | |
| | English | 122 (84.1) | |
| | Other Language | 23 (15.9) | |

Table 2

*Study 1 Child Descriptives*

| | | *n* (%) or *M* (SD) | Range |
|---|---|---|---|
| Gender (N=147) | | | |
| | Male | 104 (70.7) | |
| | Female | 43 (29.3) | |
| Age (years; N = 148) | | 10.91 (3.56) | 3.15 – 19.43 |
| SIB-R Adaptive Age (months; N=148) | | 38.95 (28.47) | 3.00 – 161.00 |
| SIB-R Maladaptive Index (N=147) | | -15.90 (13.20) | -56.00 – 4.00 |
| Physical difficulties | | | |
| Major Hearing Impairment | | 15 (10.1) | |
| Major Vision Impairment | | 15 (10.1) | |
| Problems Using Hands | | 59 (39.9) | |
| Other Motor Problems | | 79 (53.4) | |
| Feeding or Eating Difficulties | | 55 (37.2) | |
| Communication Level with Speech (N=143) | | | |
| | 1 | 51 (35.7) | |
| | 2 | 24 (16.8) | |
| | 3 | 37 (25.9) | |
| | 4 | 31 (21.7) | |
| AAC Use (N=148) | | | |
| | Users | 63 (42.6) | |
| | Non-Users | 85 (57.4) | |
| Diagnosis (N=148) | | | |
| | ASD | 82 (55.4) | |
| | DD | 66 (44.6) | |

*Note.* 1 = Able to use very little meaningful communication, 2 = Able to communicate basic needs and wants, 3 = Able to communicate needs, wants, and some ideas, 4 = Able to communicate about topics in a meaningful way.

Table 3

*Characteristics of Users (n=63) compared to Non-Users (n=85) in the Overall Sample*

| Variable | Value | Users<br>*n*(%) | Non-users<br>*n*(%) | $\chi^2$ | *p* |
|---|---|---|---|---|---|
| Communication Level with Speech (N=143) | | | | | |
| | 1 | 32 (52.5) | 19 (23.2) | 19.44 | <.001 |
| | 2 | 12 (19.7) | 12 (14.6) | | |
| | 3 | 12 (19.7) | 25 (30.5) | | |
| | 4 | 5 (8.2) | 26 (31.7) | | |
| Diagnosis (N=148) | | | | | |
| | ASD | 33 (40.2) | 49 (59.8) | | |
| | DD | 30 (45.5) | 36 (54.5) | .62 | .32 |
| | | *M* (SD) | *M* (SD) | *t* | *p* |
| Age (years) (N=148) | | | | | |
| | | 10.47 (3.35) | 11.25 (3.35) | 1.31 | .20 |
| SIB-R Adaptive Age (months) (N=148) | | | | | |
| | | 33.46 (27.82) | 43.01 (28.43) | 2.04 | .04 |
| SIB-R Maladaptive Index (N=147) | | | | | |
| | | -15.89 (13.76) | -15.91 (12.85) | .01 | .99 |

*Note.* 1 = Able to use very little meaningful communication, 2 = Able to communicate basic needs and wants, 3 = Able to communicate needs, wants, and some ideas, 4 = Able to communicate about topics in a meaningful way.

Table 4

*Study 1 Outcomes of Children Who Use AAC Systems (n=63)*

| Variable | Value | *n* (%) |
|---|---|---|
| Primary Type AAC (*n*=59) | | |
| | Low-Tech | 14 (23.7) |
| | PECS | 19 (32.2) |
| | VOCAs | 18 (30.5) |
| | Sign | 8 (13.6) |
| Systems Used (*n*=59) | | |
| | Single | 42 (71.2) |
| | Multiple | 17 (28.8) |
| Communication Level with AAC (*n*=61) | | |
| | 1 | 11 (18.0) |
| | 2 | 22 (36.1) |
| | 3 | 16 (26.2) |
| | 4 | 12 (19.7) |
| Communication with AAC Compared to Speech (*n*=59) | | |
| | Improved | 30 (50.8) |
| | Not improved | 29 (49.2) |

*Note.* 1 = Able to use very little meaningful communication, 2 = Able to communicate basic needs and wants, 3 = Able to communicate needs, wants, and some ideas, 4 = Able to communicate about topics in a meaningful way.

Table 5

*AAC Use in Relation to Children's Diagnosis*

| Variable | Value | ASD (*n*=33)<br>*M* (SD) | DD (*n*=30)<br>*M* (SD) | *F* | *p* |
|---|---|---|---|---|---|
| Age (*n*=63) | | 10.43 (3.72) | 10.51 (3.96) | .01 | .937 |
| Adaptive Age (*n*=63) | | 34.39 (29.16) | 32.43 (26.74) | .08 | .783 |
| Maladaptive Index (*n*=62) | | -20.24 (14.00) | -10.93 (11.87) | 7.86 | .007 |
| | | ASD<br>*n* (%) | DD<br>*n* (%) | $X^2$ | *p* |
| Primary Type AAC (*n*=59) | | | | | |
| | Low-Tech | 5 (17.2) | 9 (30.0) | 8.43 | .038* |
| | PECS | 13 (44.8) | 6 (20.0) | | |
| | VOCAs | 10 (34.5) | 8 (26.7) | | |
| | Sign | 1 (3.4) | 7 (23.3) | | |
| Systems Used (*n*=59) | | | | | |
| | Single | 19 (65.5) | 23 (76.7) | .89 | .344 |
| | Multiple | 10 (34.5) | 7 (23.3) | | |
| Communication Level with Speech (*n*=61) | | | | | |
| | 1 | 20 (64.5) | 12 (40.0) | 5.19 | .159 |
| | 2 | 3 (9.7) | 9 (30.0) | | |
| | 3 | 6 (19.4) | 6 (20.0) | | |
| | 4 | 2 (6.5) | 3 (10.0) | | |
| Communication Level with AAC (*n*=61) | | | | | |
| | 1 | 7 (21.9) | 4 (13.8) | 2.02 | .733 |
| | 2 | 11 (34.4) | 11 (37.9) | | |
| | 3 | 9 (28.1) | 7 (24.1) | | |
| | 4 | 5 (15.6) | 7 (24.1) | | |
| Communication with AAC Compared to Speech (*n*=59) | | | | | |
| | Improved | 18 (60.0) | 12 (41.4) | 2.05 | .153 |
| | Not | 12 (40.0) | 17 (58.6) | | |

*Note.* 1 = Able to use very little meaningful communication, 2 = Able to communicate basic needs and wants, 3 = Able to communicate needs, wants, and some ideas, 4 = Able to communicate about topics in a meaningful way.

*Note.* Post-hoc tests involved comparing each category against the remaining three categories in 4, 2 by 2 Chi-Square tests. The results indicate that there is a significant difference in the PECS category, such that children with ASD are more likely to use PECS than children with DD ($X^2$=4.16, $p$=.038). Post-hoc tests also indicate that there is a significant difference in the Sign category, such that children with DD are more likely to use Sign language than children with ASD ($X^2$=4.98, $p$=.026).

Table 6

*AAC Use in Relation to Children's Age*

| Variable | Value | *M* (SD) | F or *t* | *p* |
|---|---|---|---|---|
| Primary Type AAC (*n*=59) | | | | |
| | Low-Tech | 10.42 (4.26) | .15 | .932 |
| | PECS | 10.30 (3.90) | | |
| | VOCAs | 10.99 (3.19) | | |
| | Sign | 11.03 (3.87) | | |
| Systems used (*n*=59) | | | | |
| | Single | 10.68 (3.75) | .13 | .898 |
| | Multiple | 10.54 (3.68) | | |
| Communication Level with AAC (*n*=61) | | | | |
| | 1 | 9.89 (4.08) | .80 | .500 |
| | 2 | 10.39 (4.07) | | |
| | 3 | 9.73 (3.62) | | |
| | 4 | 11.86 (3.60) | | |
| Communication with AAC Compared to Speech (*n*=59) | | | | |
| | Improved | 10.13 (3.55) | -.49 | .628 |
| | Not improved | 10.63 (4.29) | | |

*Note.* 1 = Able to use very little meaningful communication, 2 = Able to communicate basic needs and wants, 3 = Able to communicate needs, wants, and some ideas, 4 = Able to communicate about topics in a meaningful way.

Table 7

*AAC Use in Relation to Children's Adaptive Age (months)*

| Variable | Value | *M* (SD) | F or *t* | *p* |
|---|---|---|---|---|
| Primary Type AAC (*n*=59) | | | | |
| | Low-Tech | 24.77 (22.90) | 2.02 | .122 |
| | PECS | 35.12 (21.58) | | |
| | VOCAs | 25.67 (19.71) | | |
| | Sign | 38.00 (31.16) | | |
| Systems used (*n*=59) | | | | |
| | Single | 34.76 (25.66) | 3.37 | .001 |
| | Multiple | 19.94 (7.87) | | |
| Communication Level with AAC (*n*=61) | | | | |
| | 1 | 18.27 (19.13) | 5.99 | .001 |
| | 2 | 24.27 (13.81) | | |
| | 3 | 42.00 (23.65) | | |
| | 4 | 55.42 (42.45) | | |
| Communication with AAC Compared to Speech (*n*=59) | | | | |
| | Improved | 31.47 (29.37) | -.88 | .382 |
| | Not improved | 37.97 (27.16) | | |

*Note.* 1 = Able to use very little meaningful communication, 2 = Able to communicate basic needs and wants, 3 = Able to communicate needs, wants, and some ideas, 4 = Able to communicate about topics in a meaningful way.

Table 8

*AAC Use in Relation to Children's Maladaptive Index Score*

| Variable | Value | *M* (SD) | F or *t* | *p* |
|---|---|---|---|---|
| Primary Type AAC (*n*=58) | | | | |
| | Low-Tech | -17.00 (16.58) | 3.11 | .034 |
| | PECS | -23.00 (11.78) | | |
| | VOCAs | -11.41 (11.49) | | |
| | Sign | -10.13 (11.33) | | |
| Systems used (*n*=58) | | | | |
| | Single | -15.81 (13.78) | .49 | .623 |
| | Multiple | -17.77 (13.72) | | |
| Communication Level with AAC (*n*=60) | | | | |
| | 1 | -14.82 (16.79) | .53 | .663 |
| | 2 | -17.86 (13.61) | | |
| | 3 | -13.00 (12.23) | | |
| | 4 | -13.00 (10.83) | | |
| Communication with AAC Compared to Speech (*n*=58) | | | | |
| | Improved | -14.45 (12.72) | .42 | .674 |
| | Not improved | -15.93 (2.59) | | |

*Note.* 1 = Able to use very little meaningful communication, 2 = Able to communicate basic needs and wants, 3 = Able to communicate needs, wants, and some ideas, 4 = Able to communicate about topics in a meaningful way.

*Note.* When comparing Maladaptive Index Score based on Primary Type of AAC post-hoc tests based on the Least Significant Difference (LSD) method indicated a significant difference between PECS and VOCAs (*p*=.010), and a significant difference between PECS and Sign (*p*=.022), such that children who use PECS have significantly higher levels (more negative scores) of maladaptive behavior than children who use VOCAs or Sign language.

Table 9

*Study 2 Parent Descriptives (N=12)*

| | | *n* (%) or *M* (SD) | Range |
|---|---|---|---|
| Relationship to Child | | | |
| | Biological parent | 12 (100.0) | |
| | Adoptive parent, step parent, other | 0 (0.0) | |
| Marital Status | | | |
| | Married or common-law | 9 (75.0) | |
| | Separated, divorced, single, widowed, other | 3 (25.0) | |
| Gender | | | |
| | Male | 2 (16.7) | |
| | Female | 10 (83.3) | |
| Age | | 41.73 (6.05) | 30.0 – 53.0 |
| Barratt Score | | 18.82 (8.49) | 7.5 – 35.0 |
| Parent Country of Birth | | | |
| | Canada | 8 (66.7) | |
| | Other Country | 4 (33.3) | |
| Parent First Language | | | |
| | English | 9 (75.0) | |
| | Other Language | 3 (25.0) | |

Table 10

*Study 2 Child Descriptives (N=12)*

| | | *n* (%) or *M* (SD) | Range |
|---|---|---|---|
| Gender | | | |
| | Male | 7 (58.3) | |
| | Female | 5 (41.7) | |
| Age (years) | | 11.56 (3.34) | 3.89 – 17.81 |
| SIB-R Adaptive Age (months) | | 38.23 (16.01) | 20.50 – 74.00 |
| SIB-R Maladaptive Index | | -23.50 (19.17) | -52.00 – 3.00 |
| Physical difficulties | | | |
| Major Hearing Impairment | | 1 (8.3) | |
| Major Vision Impairment | | 2 (16.7) | |
| Problems Using Hands | | 5 (41.7) | |
| Problems With Motor Coordination | | 6 (50.0) | |
| Other Motor Problems | | 4 (33.3) | |
| Communication Level with Speech | | | |
| | 1 | 11 (91.4) | |
| | 2 | 1 (8.3) | |
| | 3 | 0 (0.0) | |
| | 4 | 0 (0.0) | |
| Diagnosis | | | |
| | ASD | 9 (75.0) | |
| | DD | 3 (25.0) | |

*Note.* 1 = Able to use very little meaningful communication, 2 = Able to communicate basic needs and wants, 3 = Able to communicate needs, wants, and some ideas, 4 = Able to communicate about topics in a meaningful way.

Table 11

*General Outcomes of Study 2 Children (N=12)*

| Variable | Value | *n* (%) |
|---|---|---|
| Primary Type AAC | | |
| | PECS | 3 (25.0) |
| | VOCAs | 9 (75.0) |
| Systems Used | | |
| | Single | 6 (50.0) |
| | Multiple | 6 (50.0) |
| Number of Systems Used Currently | | |
| | One | 6 (50.0) |
| | Two | 4 (33.3) |
| | Three | 1 (8.3) |
| | Four | 1 (8.3) |
| Communication Level with AAC | | |
| | 1 | 1 (8.3) |
| | 2 | 5 (41.7) |
| | 3 | 3 (25.0) |
| | 4 | 3 (25.0) |
| Communication with AAC Compared to Speech | | |
| | Improved | 11 (91.7) |
| | Not improved | 1 (8.3) |

*Note.* 1 = Able to use very little meaningful communication, 2 = Able to communicate basic needs and wants, 3 = Able to communicate needs, wants, and some ideas, 4 = Able to communicate about topics in a meaningful way.

Table 12

*Transitioning and Experience Over Time (N=12)*

| Variable | *M* (SD) | Min – Max |
|---|---|---|
| Number of Systems Used Over Time (N=12) | 3 (1.2) | 0 – 5 |
|  | Value | *n* (%) |
| Number of Systems Used Over Time (categories; N=12) |  |  |
|  | One | 1 (8.3) |
|  | Two | 5 (41.7) |
|  | Three | 2 (16.7) |
|  | Four | 3 (25.0) |
|  | Five | 1 (8.3) |
| Experience of Transition (N=10) |  |  |
|  | Easy | 2 (16.7) |
|  | Good | 3 (25.0) |
|  | Somewhat Difficult | 4 (33.3) |
|  | Difficult | 1 (8.3) |
| Is Current System Matched to Communication Abilities? (N=12) |  |  |
|  | Yes | 10 (83.3) |
|  | No | 2 (16.7) |

Table 13

*Parent Experience of AAC Services*

| Variable | Value | *n* (%) |
|---|---|---|
| Formal AAC Assessment? (N=12) | | |
| | Yes | 4 (33.3) |
| | No | 8 (66.7) |
| Number of Professionals Involved in Selection of AAC System (N=12) | | |
| | None | 3 (25.0) |
| | One or Two | 5 (41.7) |
| | Three or More | 4 (33.3) |
| Kind of Support (N=12) | | |
| | None | 2 (16.7) |
| | Single Sessions | 10 (83.3) |
| | Group Sessions | 0 (0.0) |
| Follow-up Support (N=10) | | |
| | Formal Follow-up Support from AAC Clinic | 1 (8.3) |
| | Ongoing Support Through School or Therapy | 5 (50.0) |
| Number of Sessions (N=12) | | |
| | None | 2 (16.7) |
| | 1 – 3 | 7 (58.3) |
| | 4 – 10 | 1 (8.3) |
| | 10 or More | 2 (16.7) |
| Length of Sessions (N=10) | | |
| | 30 minutes | 1 (10.0) |
| | 1 hour | 7 (70.0) |
| | 2 hours | 2 (20.0) |
| | *M* (SD) | Min – Max |
| Number of Sessions (N=12) | | |
| | 3 (2.3) | 0 – 30 |
| Length of Sessions (hours; N=10) | | |
| | 1.18 (0.6) | .50 – 2 |

Table 14

*Parent Experience of AAC Services (cont'd.)*

| Variable | Value | *n* (%) |
|---|---|---|
| Usefulness (N=11) | | |
| | Yes | 9 (81.8) |
| | No | 2 (18.2) |
| Usefulness Scale (N=11) | | |
| | Not Useful | 1 (9.1) |
| | Somewhat Useful | 3 (27.3) |
| | Useful | 1 (9.1) |
| | Very Useful | 6 (54.5) |
| Satisfaction with Support (N=12) | | |
| | Yes | 7 (58.3) |
| | No | 5 (41.7) |
| Satisfaction with Support Scale (N=12) | | |
| | Not Satisfied | 3 (25.0) |
| | Somewhat Satisfied | 3 (25.0) |
| | Satisfied | 2 (16.7) |
| | Very Satisfied | 4 (33.3) |
| Satisfied with System Chosen (N=12) | | |
| | Yes | 12 (100.0) |
| Satisfied with System Chosen Scale (N=12) | | |
| | Not Satisfied | 0 (0.0) |
| | Somewhat Satisfied | 2 (16.7) |
| | Satisfied | 3 (25.0) |
| | Very Satisfied | 7 (58.3) |
| Maximizes Communication Abilities? (N=11) | | |
| | Yes | 7 (63.6) |
| | No | 4 (36.4) |
| Maximizes Communication Abilities Scale (N=11) | | |
| | Somewhat | 5 (45.5) |
| | Yes | 3 (27.3) |
| | Definitely | 3 (27.3) |

Table 15
*Parent Experience of AAC Services (cont.)*

| Variable | Value | *n* (%) |
|---|---|---|
| Confident Helping (N=12) | | |
| | Yes | 10 (83.3) |
| | No | 2 (16.7) |
| Confident Helping Scale (N=12) | | |
| | Not at all | 0 (0.0) |
| | Somewhat | 3 (25.0) |
| | Yes | 4 (33.3) |
| | Definitely | 5 (41.7) |
| System Maintenance (N=11) | | |
| | Yes | 8 (72.7) |
| | No | 3 (27.3) |
| System Maintenance Scale (N=11) | | |
| | Not at all | 3 (27.3) |
| | Somewhat | 1 (9.1) |
| | Yes | 4 (36.4) |
| | Definitely | 3 (27.3) |
| Modified System Over Time (N=11) | | |
| | Yes | 6 (54.5) |
| | No | 5 (45.5) |
| Modified System Over Time Scale (N=12) | | |
| | Not at all | 4 (36.4) |
| | Somewhat | 2 (18.2) |
| | Yes | 3 (27.3) |
| | Definitely | 2 (18.2) |
| Challenges Resolved? (N=11) | | |
| | Yes | 4 (36.4) |
| | No | 7 (63.6) |
| Challenges Resolved Scale (N=12) | | |
| | Not at all | 5 (45.5) |
| | Somewhat | 2 (18.2) |
| | Yes | 2 (18.2) |
| | Definitely | 2 (18.2) |

Table 16
*ASD Specific Results*

| Variable | Value | *n* (%) |
|---|---|---|
| Additional Difficulty (N=9) | | |
| | Yes | 7 (77.8) |
| | No | 2 (22.2) |
| Repetitive Use (N=9) | | |
| | Yes | 7 (77.8) |
| | No | 2 (22.2) |
| Impede Use (N=7) | | |
| | Not at all | 3 (42.8) |
| | Somewhat | 2 (28.6) |
| | Yes | 1 (14.3) |
| | Definitely | 1 (14.3) |
| Motor Difficulty? (N=9) | | |
| | Yes | 4 (44.4) |
| | No | 5 (55.5) |
| Impeded Use? (N=4) | | |
| | Yes | 1 (25.0) |
| | No | 3 (75.0) |
| Techniques From Service Providers? (N=7) | | |
| | Yes | 2 (28.6) |
| | No | 5 (71.4) |
| Problem Resolved? (N=7) | | |
| | Yes | 1 (14.3) |
| | No | 6 (85.7) |
| System Change? (N=7) | | |
| | Yes | 0 (0.0) |
| | No | 7 (100.0) |
| Connects Socially?(N=9) | | |
| | Yes | 8 (88.9) |
| | No | 1 (11.1) |
| Social Difficulties Remain? (N=9) | | |
| | Yes | 8 (88.9) |
| | No | 1 (11.1) |

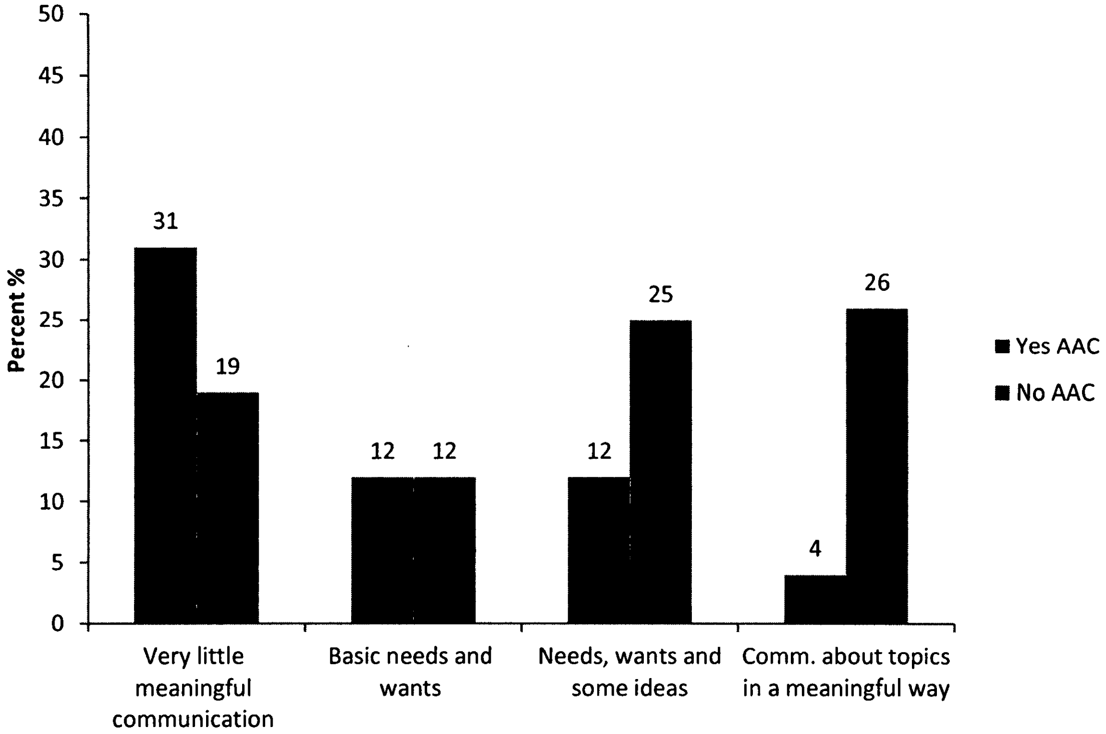


*Figure 1.*Expressive Communication Levels of AAC Users Compared to Non-AAC Users in the Overall Sample

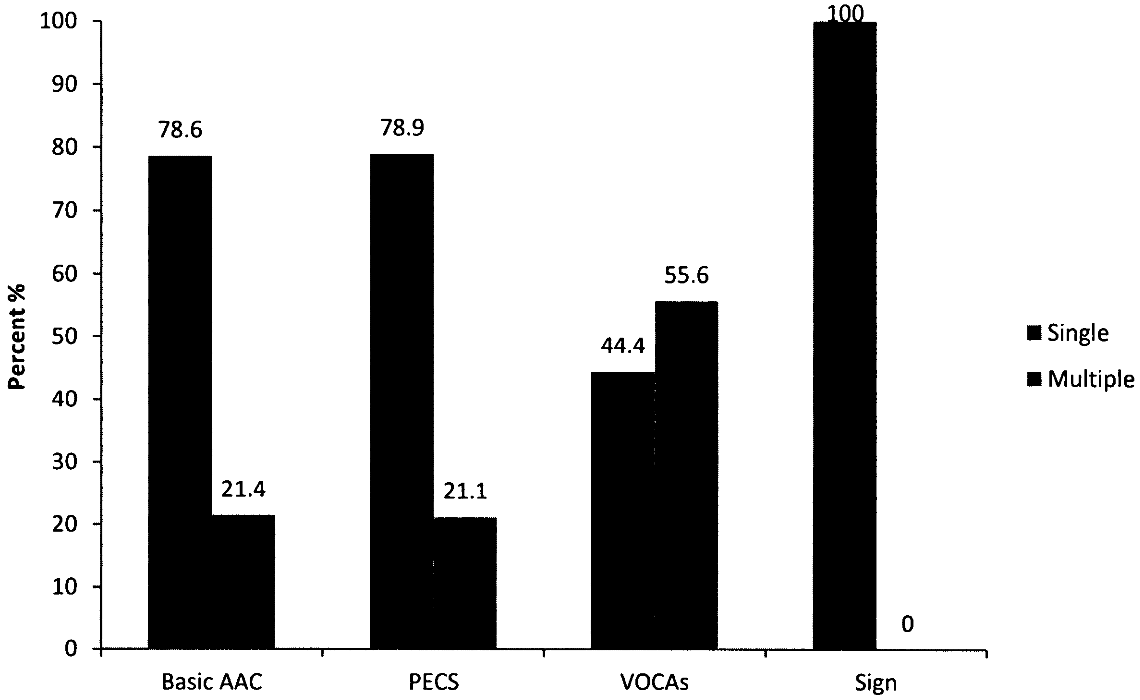


*Figure 2.*Percentage of Mixed or Multiple Systems Depending on the Type of AAC System Used

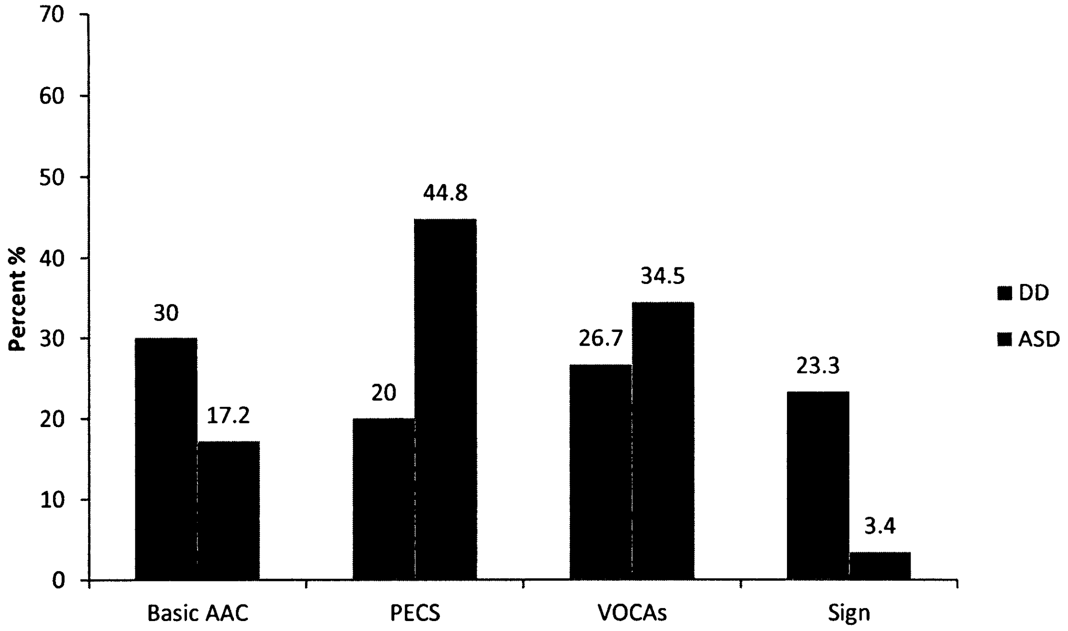


*Figure 3.* Type of AAC System by Diagnosis

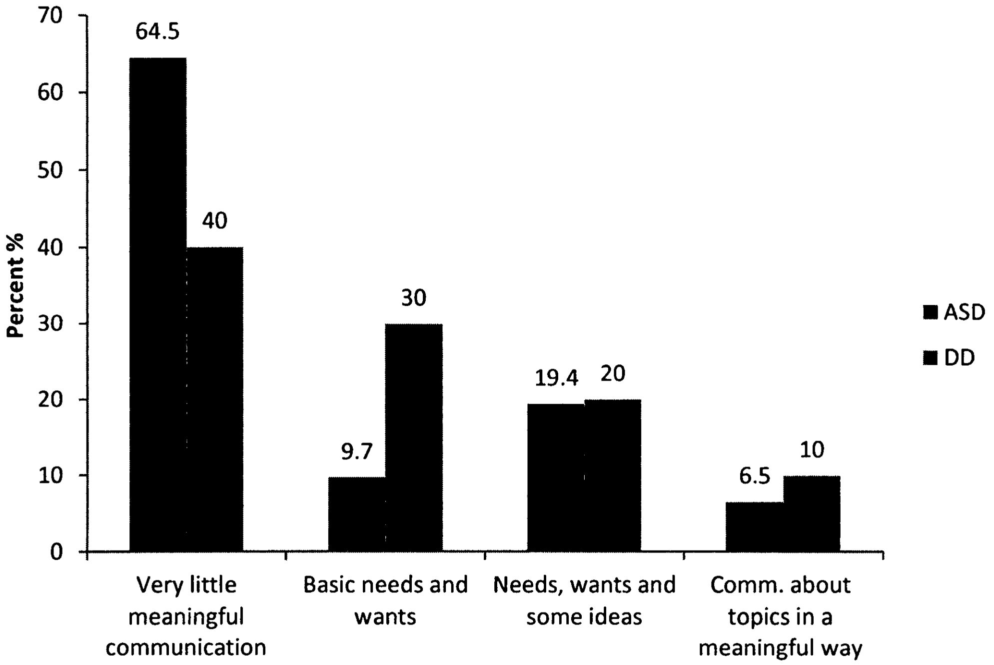


*Figure 4.* Expressive Communication Levels with Speech by Diagnosis in Children Who Use AAC

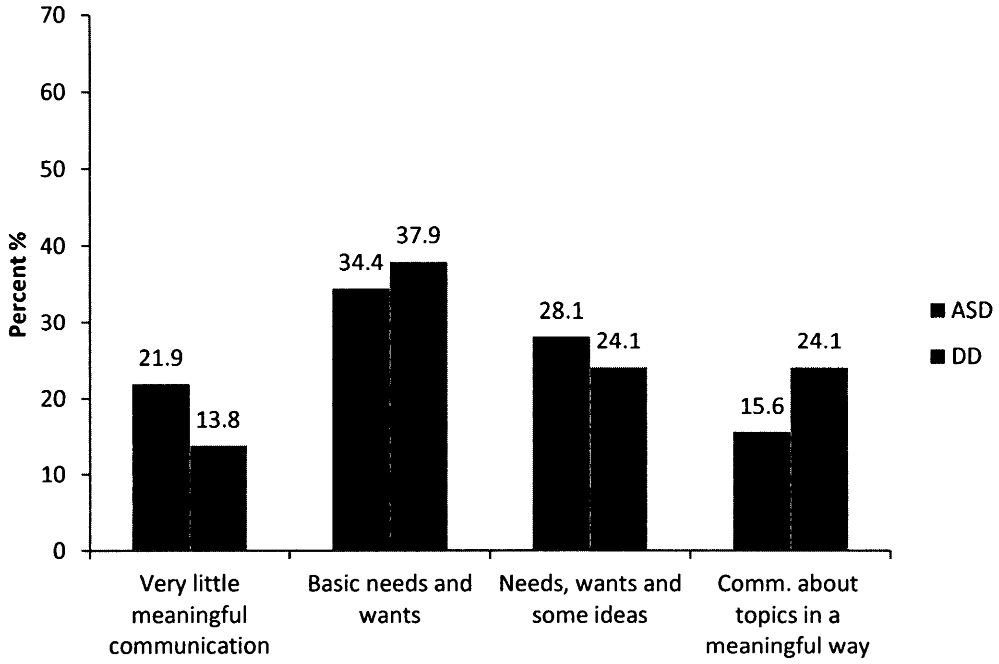


*Figure 5.* Expressive Communication Levels with AAC by Diagnosis

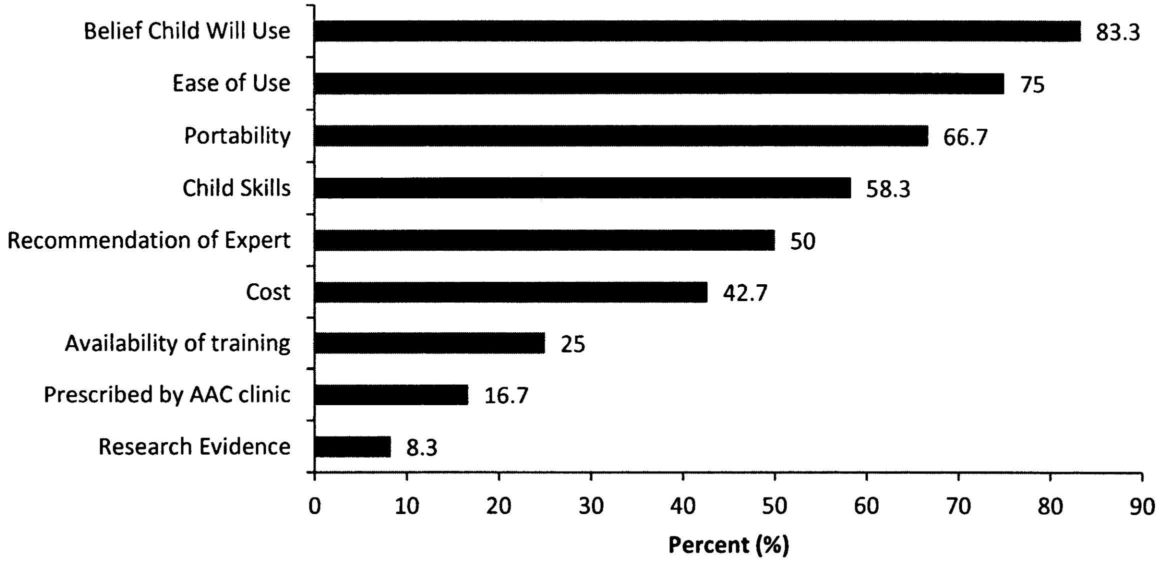


*Figure 6.* Factors Identified as Important When Selecting an AAC System by Parents.

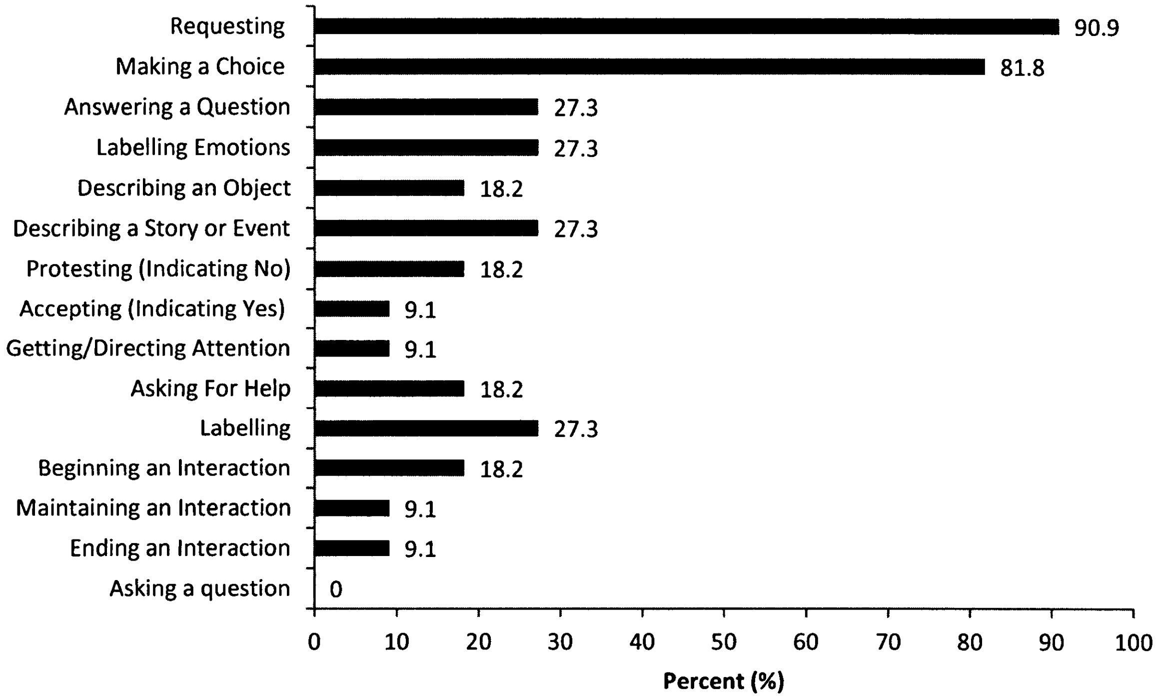


*Figure 7.* Frequency of Children Who Use Different Communication Skills with the Help of Their AAC System.

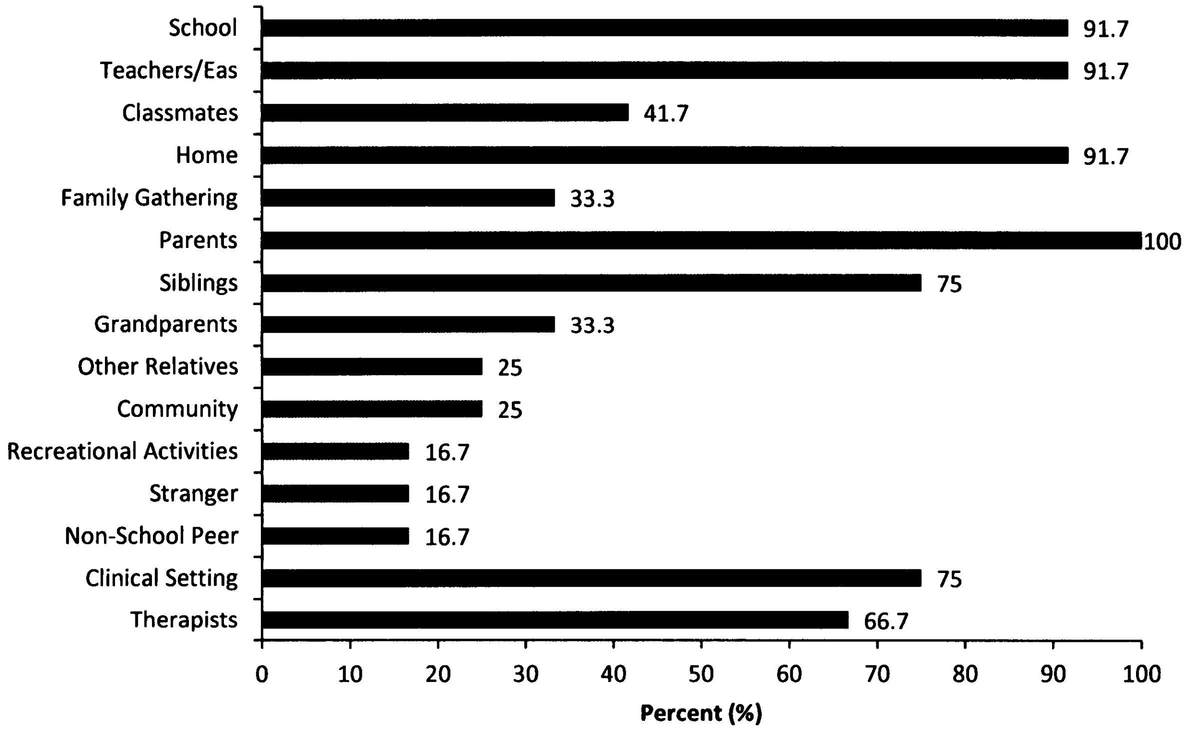


*Figure 8.* Participation.Frequency of Children Who Use Their AAC System in Different Environments and with Different People. Colours Group Together Related Environments and People.

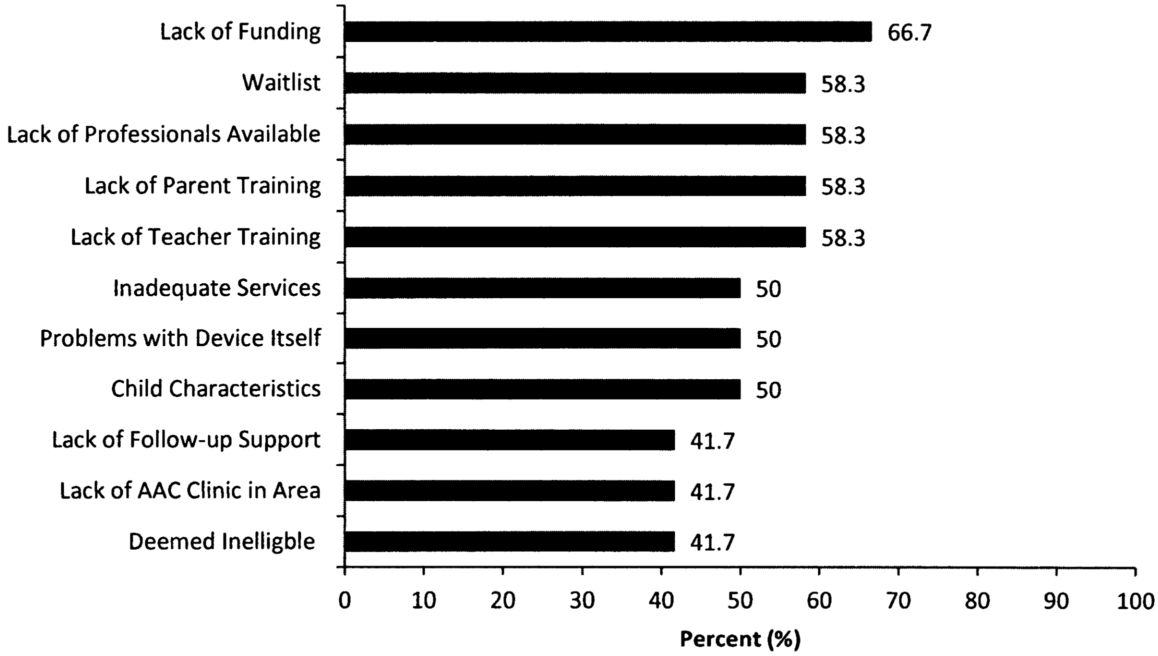


*Figure 9.* Types of Barriers and Challenges

## Appendix A

## Letter of Information

Sept 2012

**Dear Parents,**

We are writing to request your participation in a study about how children with disabilities communicate using different methods, sometimes called Augmentative and Alternative Communication systems (AAC). If your child uses one of these systems (such as a voice output device or a picture communication system) we would like to talk to you about your experience. The study will identify how AAC systems help children with developmental disabilities to communicate and interact with others. We would also like to identify challenges that prevent parents and children from properly using AAC systems. We hope that our study will have important implications informing parents, parent organizations, service providers, managers of health and social services, health care practitioners and policy makers throughout Canada. This may lead to improved services for children with communication difficulties.

This study has been approved by the Human Participants Review Subcommittee of York University, Toronto, ON, Canada. Any concerns can be addressed to the Secretary, HPRC, Office of Research Ethics, 309 York Lanes, (416) 736-2100 ext. 55201. Melissa Rourke, who will be conducting telephone interviews with parents, is a master's candidate in the clinical developmental psychology program at York University, Toronto, Ontario, Canada. The Graduate Program may be contacted at: Behavioural Sciences Building, ext. 55290. This research is being supervised by two professors of child psychology at York University, Dr. Adrienne Perry, and Dr. James Bebko, as well as a speech-language pathologist, Tracie Lindblad.

### What would be involved?

You will be asked to complete a telephone interview of approximately one and a half hours in length. You will be asked general background information about yourself and your child, as well as detailed information concerning your child's communication and AAC system use. We will ask you about your child's communication abilities, the services you have received for your child's AAC system, your satisfaction with those services, as well as challenges you have faced.

### What are the risks and benefits?

There are no appreciable risks to you or your child from participating in this study. Your child is not directly involved. There are no direct benefits to you or your child, however, information collected through this study will contribute to help improve AAC services and awareness.

**Will your privacy be protected?**

Yes, all information will be kept confidential, within the limits of the law (the only exception being if a child is in danger). Once collected, information will be stored securely in a locked filing cabinet at York University. Electronic files will not contain any identifying information and will be password protected. The only people who will have access to the information will be the research team. We will not share any information with other service providers unless you sign a consent form requesting us to do so. No individual will be identified by name or in any way.

Thank you for reading this letter and considering our request. If you are interested in participating or if you have any questions, please feel free to contact us by phone or email (see below). As well, if you decide to participate in the study an informed consent form is enclosed in this mailing along with a self-addressed envelope. Please read the form thoroughly, sign and put in the mail. Thank-you for your consideration.

Sincerely,

Melissa Rourke, B.Sc., Master's Candidate
(416) 736-2100 ext.40266
perrylab@yorku.ca

Adrienne Perry, Ph.D., C. Psych., BCBA
(416) 736-5115 x 33765
perry@yorku.ca

York University, Department of Psychology
Behavioural Sciences Building
4700 Keele Street
Toronto, ON, Canada, M3J 1P3

## Informative Flyer

# AAC System Use Study

- **Melissa Rourke, a master's candidate in the clinical developmental psychology program at York University, is seeking parents of 4- to 18-year old children with moderate to severe Developmental Disabilities for her thesis research.**
- **This study has been approved by York Universities Research Ethics Board.**

**Participants:**

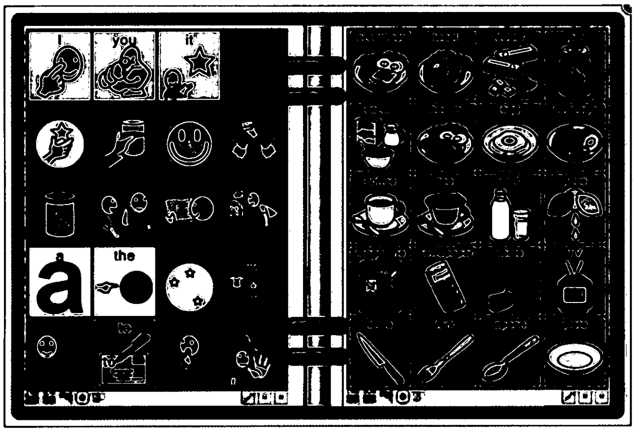
- We are looking for parents who have a child with a developmental disability. For example; children with autism **OR** children with other developmental disabilities.
- Children must be currently using an **Augmentative or Alternative Communication (AAC)** device to participate. For example; Picture Exchange Communication System (PECS) or a speech generating system.

**Goal:** To gain important information about AAC use in Canadian children through interviews with parents, including common challenges faced by parents and children.

YORK UNIVERSITÉ UNIVERSITY
redefine THE POSSIBLE.

**perrylab@yorku.ca**

**(416) 736-2100**
**ext. 40266**
**Or 1-877-233-4337**
**Ask for Teresa Lee or**
**Melissa Rourke**



The interview will take approximately **1.5 hours** over the phone.

Families will be offered a **$50** honorarium for their time.

go4kidds
Great Outcomes for Kids Impacted by Severe Developmental Disabilities

## Appendix B

## Informed Consent

Phone Script

**Date**:

Parent report of AAC system use in a current sample of Canadian children with developmental disabilities

**Purpose of the research:** As explained in our letter (Did you receive and read the letter? ☐ yes, ☐ no). The current research project will investigate the experiences of parents and their children with developmental disabilities who use Augmentative and Alternative Communication systems (AAC). The study will identify how AAC systems help children with developmental disabilities to communicate and interact with others. We would also like to identify challenges that prevent parents and children from properly using AAC systems. We hope that our study may inform people who deliver AAC services, leading to improved services for children with communication difficulties. Does your child use some sort of AAC system currently? ☐ yes, ☐ no

**What you will be asked to do in the research**: You will be asked to complete a telephone interview of approximately one and a half hours in length. You will be asked general background information about yourself and your child, as well as detailed information concerning your child's AAC system use. We will ask you about your child's communication abilities, the services you have received for your child's AAC system, your satisfaction with those services, and challenges you have faced.

**Risks and discomforts**: We do not foresee any risks or discomfort from your participation in the research.

**Benefits of the research and benefits to you**: Parents who participate (and complete all components of the study), will receive $50 to compensate them for their time. Otherwise, there are no direct benefits to you for participating in this research; however we hope to use the results to inform others and contribute to current research involving children with developmental disabilities.

**Withdrawal from the study**: The current study is entirely voluntary and you can stop participating in the study at any time, for any reason, if you so decide. Your decision to stop participating, or to refuse to answer particular questions, will have no impact whatsoever on your child or family receiving service from any organization in the future. In the event you withdraw from the study, all associated data collected will be immediately destroyed wherever possible.

**Confidentiality**: All information you supply during the research will be held in confidence and, your name will not appear in any report or publication of the research. Your data will be safely stored in a locked filing cabinet or password protected computer file, and only research staff will have access to this information. Your data will be stored for 10 years following completion of the study, and will be destroyed at this time. Confidentiality will be provided to the fullest extent possible by law.

**Questions about the research?** If you have questions about the research in general or about your role in the study, please feel free to contact Dr. Adrienne Perry either by telephone at (416) 736-5115, extension 33765, or by e-mail (perry@yorku.ca). This research has been reviewed and approved by the Human Participants Review Sub-Committee, York University's Ethics Review Board and conforms to the standards of the Canadian Tri-Council Research Ethics guidelines. If you have any questions about this process, or about your rights as a participant in the study, please contact the Sr. Manager & Policy Advisor for the Office of Research Ethics, 5th Floor, York Research Tower, York University (telephone 416-736-5914 or e-mail ore@yorku.ca).

**Researchers:**

| | |
|---|---|
| Melissa Rourke, B.Sc., Master's Candidate | Adrienne Perry, Ph.D., C. Psych., BCBA |
| (416) | (416) 736-5115 x 33765 |
| rourke22@yorku.ca | perry@yorku.ca |

**Legal Rights and Signatures:**

I Melissa Rourke have explained the current study to ____________________ and answered any questions he/she had. I believe he/she understands the nature of the study and voluntarily consenting to participate.

________________________ **Date** ________________________
Participant

**Signature** ________________________ **Date** ________________________
Principal Investigator

York University, Department of Psychology
Behavioural Sciences Building
4700 Keele Street
Toronto, ON, Canada, M3J 1P3

# Appendix C

| | |
|---|---|
| Today's Date: | Click here to enter text. |
| Birthdate: | Click here to enter text. |
| Age: | Click here to enter text. |

**AAC System Use** – Parent Interview

Child Code: Click here to enter text. Child's name: Click here to enter text.

Gender: ☐ male ☐ female

Person Completing Questionnaire: Click here to enter text.

Parent/Guardian name: Click here to enter text.

## Background Information

***"I would like to begin by asking you some background information about [xxxxx]."***

1. ***"What is [xxxxx]'s diagnosis?"*** Click here to enter text.

   ☐ Developmental Disability, Intellectual Disability, Global Developmental Delay, or Mental Retardation

   ☐ Autism, Pervasive Developmental Disorder (PDD) or Autism Spectrum Disorder (ASD)

   ☐ Other syndrome or diagnosis (please specify): Click here to enter text.

   E.g., Down syndrome, Prader-Willi syndrome, Fragile X syndrome, Rett syndrome, PKU (Phenylketonuria), Cerebral Palsy, Fetal Alcohol Syndrome (FAS) or Fetal Alcohol Spectrum Disorder (FASD), Dual diagnosis (intellectual disability and psychiatric disorder)

2. ***"Has [xxxxx] been given an intellectual assessment by a psychologist?"***

   ☐ yes ☐ no, If yes, ***"Did the report you received indicate a level of functioning? Or, Which level of functioning best describes your child's level of ability?"***

   ☐ Mild or borderline developmental/intellectual disability

   ☐ Moderate developmental/intellectual disability

   ☐ Severe developmental/intellectual disability

   ☐ Profound developmental disability

   ☐ Unspecified or unknown: Click here to enter text.

3. ***"Does [xxxxx] have any other medical problems?"***
   ☐Problems using his/her hands (e.g., picking things up, holding a pencil)
   ☐ Other problems with motor control/coordination (e.g., very clumsy)
   ☐ Major Vision Impairment
   ☐ Major hearing impairment
   ☐ Other (please specify): Click here to enter text.

4. ***"What level of help or support does [xxxxx] need (e.g., toileting, dressing, eating)?"***
   ☐ Requires support for almost all aspects of life
   ☐ Requires support for most, but not all aspects of life
   ☐ Requires support for some aspects of life
   ☐ Requires support for only a few aspects of life
   ☐ Does not require support

5. ***"How much does [xxxxx] understand spoken language?"***
   ☐ Able to understand very little spoken language
   ☐ Able to understand some basic language and simple instructions in familiar contexts (e.g. sit down)
   ☐ Able to understand most basic instructions and questions
   ☐ Able to understand most routine everyday language
   ☐ Able to understand complex language about a wide range of topics

6. ***"How much does [xxxxx] use spoken language to communicate?"***
   ☐ Able to use very little meaningful speech
   ☐ Able to communicate basic needs and wants
   ☐ Able to communicate needs, wants, and some ideas
   ☐ Able to communicate within a limited range of topics in a meaningful way
   ☐ Able to communicate about a wide variety of topics in a meaningful way

AAC Use (General and Experience Across Time)

7. ***"Now I'm going to ask you some questions specific to [xxxxx]'s AAC use."***
   ☐ No, does not use any alternative systems (If no, do not proceed with interview)
   ☐ Yes, uses AAC

Current Communication System:

***"Can you tell me which communication system(s) [xxxxx] currently uses?*** *If he/she uses a combination of AAC systems, describe how he/she uses each one, and indicate which system is the dominant or most commonly used system."*

☐ Speech: Click here to enter text.

☐ Sign: Click here to enter text.

☐ PECS: Click here to enter text.

☐ Other picture systems (e.g., picture point, picture boards): Click here to enter text.

☐ Voice output communication aids (VOCAs): Click here to enter text.

☐ iPAD: Click here to enter text.

☐ Other (e.g. a combination of more than one system): Click here to enter text.

**Picture Exchange Communication System (PECS)** – Supplemental Questions

1. How does your child communicate with PECS/pictures? Click here to enter text.
2. Did you or [____] participate in any formal PECS training workshops or programs? ☐ yes ☐ no
   If yes, please describe the training received: Click here to enter text.
   Which professionals were involved? Click here to enter text.
   How long did it last and how intensive was it? Click here to enter text.
3. Which level or phase of PECS did [____] achieve? Click here to enter text.
4. Based on the above answers how would you qualify parent report of PECS
   ☐ Bidirectional comm using PECS – manualized approach
   ☐ Using pictures to comm – without formal PECS training
   ☐ Using pictures to request – adapted picture selection system
   ☐ Picture Schedules
   ☐ Other: ____________________________________

**Voice Output Communication Systems (VOCAs)** – Supplemental Questions

1. What is the name of the device?
   ☐ PUT MULTIPLE CHOICE OPTIONS HERE
   ☐
2. What is the name of the software/app?
   ☐PUT MULTIPLE CHOICE OPTIONS HERE
   ☐
3. Did you or [____] participate in any formal training workshops or programs? ☐ yes ☐ no
   If yes, please describe the training received:
   Click here to enter text.
   Which professionals were involved?
   Click here to enter text.
   How long did it last and how intensive was it?
   Click here to enter text.

**iPADs/App-based Electronic Devices** – Supplemental Questions

1. What type of electronic device is [____] using for communication?
   Click here to enter text.
2. What is the name of the software/app?
   Click here to enter text.
3. Can you describe the software program (i.e. complexity)?
   Click here to enter text.
4. Did you or [____] participate in any formal training workshops or programs? ☐ yes ☐ no
   If yes, please describe the training received:
   Click here to enter text.
   Which professionals were involved?
   Click here to enter text.
   How long did it last and how intensive was it?
   Click here to enter text.

8. ***"Can you indicate generally how well [xxxxxx] communicates using his/her system?"***
   ☐ Able to use very little meaningful communication
   ☐ Able to communicate basic needs and wants
   ☐ Able to communicate needs, wants, and some needs
   ☐ Able to communicate within a limited range of topics in a meaningful way
   ☐ Able to communicate about a wide variety of topics in a meaningful way

***"What factors were important in selecting a communication system for [xxxxxx]?"***

☐ Portability of the system
☐ Ease of use (how easily it would be to use)
☐ Cost of the system
☐ Availability of training in how to use this system
☐ Recommendation of expert
☐ Prescribed by an Augmentative Clinic
☐ Research evidence to support use of system
☐ Belief that your child would be able to learn this system and would use it
☐ Your child's skill repertoire (e.g., ability to imitate, presence or absence of speech, interest or understanding of pictures)
☐ Other: Click here to enter text.

9. Communication History:
   ***"Can you tell me all of the AAC systems/approaches [xxxxxx] has been exposed to IN THE PAST in order from [xxxxxx]'s earliest system to his/her most recent?"*** For each system as the parent to provide a brief description of the system, his/her age when it was tried, and how long it was used. ******ASK Supplementary Questions with specific questions for PECS, VOCAs, and iPADs if the parent indicates that the child uses or has tried one of these systems. Ask questions 17 through 21 if more than one system indicated here.*
   ☐ Choose an item. Speech: Click here to enter text.
   ☐ Choose an item. Sign: Click here to enter text.
   ☐ Choose an item. PECS: Click here to enter text.
   ☐ Choose an item. Other picture systems (e.g., picture point, picture boards): Click here to enter text.

☐ Choose an item. **Voice output communication aids (VOCAs, ipads):** Click here to enter text.

☐ Choose an item. **Other:** Click here to enter text.

**Picture Exchange Communication System (PECS)** – Supplemental Questions

5. How does your child communicate with PECS/pictures? Click here to enter text.
6. Did you or [____] participate in any formal PECS training workshops or programs? ☐ yes ☐ no
   If yes, please describe the training received: Click here to enter text.
   Which professionals were involved? Click here to enter text.
   How long did it last and how intensive was it? Click here to enter text.
7. Which level or phase of PECS did [____] achieve? Click here to enter text.
8. Based on the above answers how would you qualify parent report of PECS
   ☐ Bidirectional comm using PECS – manualized approach
   ☐ Using pictures to comm – without formal PECS training
   ☐ Using pictures to request – adapted picture selection system
   ☐ Picture Schedules
   ☐ Other: ________________________________

**Voice Output Communication Systems (VOCAs)** – Supplemental Questions

4. What is the name of the device?
   ☐ PUT MULTIPLE CHOICE OPTIONS HERE
   ☐
5. What is the name of the software/app?
   ☐PUT MULTIPLE CHOICE OPTIONS HERE
   ☐
6. Did you or [____] participate in any formal training workshops or programs? ☐ yes ☐ no
   If yes, please describe the training received:
   Click here to enter text.
   Which professionals were involved?
   Click here to enter text.
   How long did it last and how intensive was it?
   Click here to enter text.

**iPADs/App-based Electronic Devices** – Supplemental Questions

5. What type of electronic device is [____] using for communication?
   Click here to enter text.
6. What is the name of the software/app?
   Click here to enter text.
7. Can you describe the software program (i.e. complexity)?
   Click here to enter text.
8. Did you or [____] participate in any formal training workshops or programs? ☐ yes ☐ no
   If yes, please describe the training received:
   Click here to enter text.
   Which professionals were involved?
   Click here to enter text.
   How long did it last and how intensive was it?
   Click here to enter text.

10. ***"Can you tell me why [xxxxxx] switched from his/her first AAC system to a new one, until his/her current AAC system is reached? Can you also tell me why each system did not work for him/her?"***
    ☐ 1 → 2: Click here to enter text.
    ☐ 2 → 3: Click here to enter text.
    ☐ 3 → 4: Click here to enter text.
    ☐ 4 → 5: Click here to enter text.

11. ***"How would you describe the transition process from one AAC system to another (do you think the transition followed a logical progression, mirroring the child's dev)?"*** Click here to enter text.

12. ***"Which AAC system was easiest to use and why (for you? For your child?)?"*** Click here to enter text.

13. ***"Which AAC system do you feel was the best for [xxxxx] and why?"*** Click here to enter text.

14. ***"Do you feel like [xxxxxx]'s current device best serves his/her communication needs and is well matched to his/her communication abilities?"*** ☐ yes ☐ no
    **[Choose an item.]**: Click here to enter text.

15. ***"Do you think [xxxxxx] uses his/her current device properly?"*** ☐ yes ☐ no
    If not;
    - ☐ ***"How is it improperly used?"*** Click here to enter text.
    - ☐ ***"Why do you feel it is improperly used?"*** Click here to enter text.

16. ***"Now I'm going to ask you about how [xxxxxx] uses his/her system in different environments and with different people. Can you tell me which system he/she uses in each environment and how well he/she uses that system on a scale from 1 to 5?"*** *Ask parent to indicate why the child doesn't use his/her system in certain environments, or with certain people.
    - ☐ School: ☐ yes ☐ no **[Choose an item.]**: Click here to enter text.
        - Teachers/Educational Assistants: ☐ yes ☐ no **[Choose an item.]**: Click here to enter text.
        - Classmates: ☐ yes ☐ no **[Choose an item.]**: Click here to enter text.

- ☐ Home: ☐ yes ☐ no [**Choose an item.**]: Click here to enter text.
- ☐ Family Gatherings: ☐ yes ☐ no [**Choose an item.**]: Click here to enter text.
    - Parents/Guardians: ☐ yes ☐ no [**Choose an item.**]: Click here to enter text.
    - Siblings: ☐ yes ☐ no [**Choose an item.**]: Click here to enter text.
    - Grandparents: ☐ yes ☐ no [**Choose an item.**]: Click here to enter text.
    - Other relatives (e.g., cousins, aunts, uncles): ☐ yes ☐ no [**Choose an item.**]: Click here to enter text.

- ☐ Community (e.g., McDonald's, park): ☐ yes ☐ no [**Choose an item.**]: Click here to enter text.
- ☐ Recreational Activities (e.g., sport): ☐ yes ☐ no [**Choose an item.**]: Click here to enter text.
    - Strangers: ☐ yes ☐ no [**Choose an item.**]: Click here to enter text.
    - Non-school peers: ☐ yes ☐ no [**Choose an item.**]: Click here to enter text.

- ☐ Clinical Settings (Speech, OT/PT, IBI/ABA): ☐ yes ☐ no [**Choose an item.**]: Click here to enter text.
    - Therapists/other health professionals (if more than one, indicate overall & for each):

  Overall: ☐ yes ☐ no [**Choose an item.**]: Click here to enter text.

    1) [**Choose an item.**]: Click here to enter text.
    2) [**Choose an item.**]: Click here to enter text.
    3) [**Choose an item.**]: Click here to enter text.
- ☐ Other: ☐ yes ☐ no [**Choose an item.**]: Click here to enter text.

***"The following set of questions will address your child's communication skills using his/her <u>current</u> AAC system. Keep in mind that for each scenario I will ask you if [xxxxx] ever performs the skill, how he/she child performs the skill, how often he/she performs the skill, in which environments and with which people he/she performs the skill. Remember I would like to know about [____]s current ways of communicating, not how he/she has communicated in the past."***

17. ***"Can you describe how [xxxxxx] <u>requests/asks for things</u> he/she wants or needs, for example a favorite food/drink, toy, activity, or place?"*** (e.g., takes you to items, asks with words/pictures/signs, cries, gets things on own, behaviour/tantrums): Click here to enter text.
    - Which AAC system(s)/method of communication does he/she use to do this (e.g., speech, sign, PECS, VOCA, iPAD, negative behaviour, other)? Click here to enter text.
    - How often does he/she do this in general? Choose an item.

| Where? | Frequency | Quality? (what does beh look like) | With Whom? | Frequency | Quality? (what does beh look like) |
|---|---|---|---|---|---|
| **School** | Choose an item. | Click here to enter text. | **Parents/Guardians** | Choose an item. | Click here to enter text. |
| **Home** | Choose an item. | Click here to enter text. | **Grandparents** | Choose an item. | Click here to enter text. |
| **Family Gatherings** | Choose an item. | Click here to enter text. | **Other Relatives (e.g., cousins, aunts, uncles)** | Choose an item. | Click here to enter text. |
| **Community (e.g., McDonald's, park)** | Choose an item. | Click here to enter text. | **Teachers** | Choose an item. | Click here to enter text. |
| **Recreational Activities (e.g. sport)** | Choose an item. | Click here to enter text. | **Classmates** | Choose an item. | Click here to enter text. |
| **Clinical Setting (e.g., speech,** | Choose an item. | Click here to enter text. | **Therapists/Other Health Professionals** | Choose an item. | Click here to enter text. |

| | | | | | |
|---|---|---|---|---|---|
| **OT/PT, IBI/ABA)** | | | | | |
| **Other: Click here to enter text.** | Choose an item. | Click here to enter text. | **Strangers** | Choose an item. | Click here to enter text. |

18. ***"Can you describe how [xxxxxx] chooses between two things and indicates preference?"*** (e.g., a cookie versus a goldfish)
    - Which AAC system(s)/method of communication? Click here to enter text.
    - How often does he/she do this in general? Choose an item.

| Where? | Frequency | Quality? (what does beh look like) | With Whom? | Frequency | Quality? (what does beh look like) |
|---|---|---|---|---|---|
| **School** | Choose an item. | Click here to enter text. | **Parents/Guardians** | Choose an item. | Click here to enter text. |
| **Home** | Choose an item. | Click here to enter text. | **Grandparents** | Choose an item. | Click here to enter text. |
| **Family Gatherings** | Choose an item. | Click here to enter text. | **Other Relatives** | Choose an item. | Click here to enter text. |
| **Community** | Choose an item. | Click here to enter text. | **Teachers** | Choose an item. | Click here to enter text. |
| **Recreational Activities** | Choose an item. | Click here to enter text. | **Classmates** | Choose an item. | Click here to enter text. |
| **Clinical Setting** | Choose an item. | Click here to enter text. | **Therapists/Other Health Professionals** | Choose an item. | Click here to enter text. |
| **Other: Click here to enter text.** | Choose an item. | Click here to enter text. | **Strangers** | Choose an item. | Click here to enter text. |

19. ***"Can you describe how [xxxxxx] <u>protests</u> when he/she doesn't want to do something or indicates no?"*** (e.g., runs away, turns or shakes head, hits, pushes item away, cries, uses words/pictures signs)
    - Which AAC system(s)/method of communication? Click here to enter text.
    - How often does he/she do this in general? Choose an item.

| Where? | Frequency | Quality? (what does beh look like) | With Whom? | Frequency | Quality? (what does beh look like) |
|---|---|---|---|---|---|
| **School** | Choose an item. | Click here to enter text. | **Parents/Guardians** | Choose an item. | Click here to enter text. |
| **Home** | Choose an item. | Click here to enter text. | **Grandparents** | Choose an item. | Click here to enter text. |
| **Family Gatherings** | Choose an item. | Click here to enter text. | **Other Relatives** | Choose an item. | Click here to enter text. |
| **Community** | Choose an item. | Click here to enter text. | **Teachers** | Choose an item. | Click here to enter text. |
| **Recreational Activities** | Choose an item. | Click here to enter text. | **Classmates** | Choose an item. | Click here to enter text. |
| **Clinical Setting** | Choose an item. | Click here to enter text. | **Therapists/Other Health Professionals** | Choose an item. | Click here to enter text. |
| **Other: Click here to enter text.** | Choose an item. | Click here to enter text. | **Strangers** | Choose an item. | Click here to enter text. |

20. ***"Can you describe how [xxxxxx] accepts something or indicates yes?"*** (e.g., reaches, takes item, nods head, smiles, vocalizes/says "yes")
    - Which AAC system(s)/method of communication? Click here to enter text.
    - How often does he/she do this in general? Choose an item.

| Where? | Frequency | Quality? (what does beh look like) | With Whom? | Frequency | Quality? (what does beh look like) |
|---|---|---|---|---|---|

| | | | | | |
|---|---|---|---|---|---|
| **School** | Choose an item. | Click here to enter text. | **Parents/Guardians** | Choose an item. | Click here to enter text. |
| **Home** | Choose an item. | Click here to enter text. | **Grandparents** | Choose an item. | Click here to enter text. |
| **Family Gatherings** | Choose an item. | Click here to enter text. | **Other Relatives** | Choose an item. | Click here to enter text. |
| **Community** | Choose an item. | Click here to enter text. | **Teachers** | Choose an item. | Click here to enter text. |
| **Recreational Activities** | Choose an item. | Click here to enter text. | **Classmates** | Choose an item. | Click here to enter text. |
| **Clinical Setting** | Choose an item. | Click here to enter text. | **Therapists/Other Health Professionals** | Choose an item. | Click here to enter text. |
| **Other: Click here to enter text.** | Choose an item. | Click here to enter text. | **Strangers** | Choose an item. | Click here to enter text. |

21. ***"Can you describe [xxxxxx] child gets the attention of those around him/her or directs them to things?"*** (e.g., calls by name, screams, approaches, tugs at clothing, pulls hand, points)
    - Which AAC system(s)/method of communication? Click here to enter text.
    - How often does he/she do this in general? Choose an item.

| Where? | Frequency | Quality? (what does beh look like) | With Whom? | Frequency | Quality? (what does beh look like) |
|---|---|---|---|---|---|
| **School** | Choose an item. | Click here to enter text. | **Parents/Guardians** | Choose an item. | Click here to enter text. |
| **Home** | Choose an item. | Click here to enter text. | **Grandparents** | Choose an item. | Click here to enter text. |
| **Family Gatherings** | Choose an item. | Click here to enter text. | **Other Relatives** | Choose an item. | Click here to enter text. |
| **Community** | Choose an item. | Click here to enter | **Teachers** | Choose an item. | Click here to enter text. |

| | | | | | |
|---|---|---|---|---|---|
| | | text. | | | |
| **Recreational Activities** | Choose an item. | Click here to enter text. | **Classmates** | Choose an item. | Click here to enter text. |
| **Clinical Setting** | Choose an item. | Click here to enter text. | **Therapists/Other Health Professionals** | Choose an item. | Click here to enter text. |
| **Other: Click here to enter text.** | Choose an item. | Click here to enter text. | **Strangers** | Choose an item. | Click here to enter text. |

22. ***"Can you describe how [xxxxxx] indicates that he needs help?"***
    - Which AAC system(s)/method of communication? Click here to enter text.
    - How often does he/she do this in general? Choose an item.

| Where? | Frequency | Quality? (what does beh look like) | With Whom? | Frequency | Quality? (what does beh look like) |
|---|---|---|---|---|---|
| **School** | Choose an item. | Click here to enter text. | **Parents/Guardians** | Choose an item. | Click here to enter text. |
| **Home** | Choose an item. | Click here to enter text. | **Grandparents** | Choose an item. | Click here to enter text. |
| **Family Gatherings** | Choose an item. | Click here to enter text. | **Other Relatives** | Choose an item. | Click here to enter text. |
| **Community** | Choose an item. | Click here to enter text. | **Teachers** | Choose an item. | Click here to enter text. |
| **Recreational Activities** | Choose an item. | Click here to enter text. | **Classmates** | Choose an item. | Click here to enter text. |
| **Clinical Setting** | Choose an item. | Click here to enter text. | **Therapists/Other Health Professionals** | Choose an item. | Click here to enter text. |
| **Other: Click here to enter text.** | Choose an item. | Click here to enter text. | **Strangers** | Choose an item. | Click here to enter text. |

23. ***"Can you describe how [xxxxxx] labels or names things he/she sees?"*** (e.g., uses pictures, signs, words):
    - Which AAC system(s)/method of communication? Click here to enter text.
    - How often does he/she do this in general? Choose an item.

| Where? | Frequency | Quality? (what does beh look like) | With Whom? | Frequency | Quality? (what does beh look like) |
|---|---|---|---|---|---|
| **School** | Choose an item. | Click here to enter text. | **Parents/Guardians** | Choose an item. | Click here to enter text. |
| **Home** | Choose an item. | Click here to enter text. | **Grandparents** | Choose an item. | Click here to enter text. |
| **Family Gatherings** | Choose an item. | Click here to enter text. | **Other Relatives** | Choose an item. | Click here to enter text. |
| **Community** | Choose an item. | Click here to enter text. | **Teachers** | Choose an item. | Click here to enter text. |
| **Recreational Activities** | Choose an item. | Click here to enter text. | **Classmates** | Choose an item. | Click here to enter text. |
| **Clinical Setting** | Choose an item. | Click here to enter text. | **Therapists/Other Health Professionals** | Choose an item. | Click here to enter text. |
| **Other: Click here to enter text.** | Choose an item. | Click here to enter text. | **Strangers** | Choose an item. | Click here to enter text. |

24. ***"Can you describe how [xxxxxx] begins to interact with someone?"*** (e.g., calls by name, approaches, tugs at clothing, pulls hand)
    - Which AAC system(s)/method of communication? Click here to enter text.
    - How often does he/she do this in general? Choose an item.

| Where? | Frequency | Quality? (what does beh look like) | With Whom? | Frequency | Quality? (what does beh look like) |
|---|---|---|---|---|---|

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|---|---|---|---|---|---|
| **School** | Choose an item. | Click here to enter text. | **Parents/Guardians** | Choose an item. | Click here to enter text. |
| **Home** | Choose an item. | Click here to enter text. | **Grandparents** | Choose an item. | Click here to enter text. |
| **Family Gatherings** | Choose an item. | Click here to enter text. | **Other Relatives** | Choose an item. | Click here to enter text. |
| **Community** | Choose an item. | Click here to enter text. | **Teachers** | Choose an item. | Click here to enter text. |
| **Recreational Activities** | Choose an item. | Click here to enter text. | **Classmates** | Choose an item. | Click here to enter text. |
| **Clinical Setting** | Choose an item. | Click here to enter text. | **Therapists/Other Health Professionals** | Choose an item. | Click here to enter text. |
| **Other: Click here to enter text.** | Choose an item. | Click here to enter text. | **Strangers** | Choose an item. | Click here to enter text. |

25. ***"Can you describe how [xxxxxx] maintains an interaction with someone?"*** (e.g., maintains eye contact, smiles, uses PECS bi-directionally)
    - Which AAC system(s)/method of communication? Click here to enter text.
    - How often does he/she do this in general? Choose an item.

| Where? | Frequency | Quality? (what does beh look like) | With Whom? | Frequency | Quality? (what does beh look like) |
|---|---|---|---|---|---|
| **School** | Choose an item. | Click here to enter text. | **Parents/Guardians** | Choose an item. | Click here to enter text. |
| **Home** | Choose an item. | Click here to enter text. | **Grandparents** | Choose an item. | Click here to enter text. |
| **Family Gatherings** | Choose an item. | Click here to enter text. | **Other Relatives** | Choose an item. | Click here to enter text. |
| **Community** | Choose an item. | Click here to enter text. | **Teachers** | Choose an item. | Click here to enter text. |

| | | | | | |
|---|---|---|---|---|---|
| **Recreational Activities** | Choose an item. | Click here to enter text. | **Classmates** | Choose an item. | Click here to enter text. |
| **Clinical Setting** | Choose an item. | Click here to enter text. | **Therapists/Other Health Professionals** | Choose an item. | Click here to enter text. |
| **Other: Click here to enter text.** | Choose an item. | Click here to enter text. | **Strangers** | Choose an item. | Click here to enter text. |

26. ***"Can you describe how [xxxxxx] ends an interaction with someone***?"
    - Which AAC system(s)/method of communication? Click here to enter text.
    - How often does he/she do this in general? Choose an item.

| Where? | Frequency | Quality? (what does beh look like) | With Whom? | Frequency | Quality? (what does beh look like) |
|---|---|---|---|---|---|
| **School** | Choose an item. | Click here to enter text. | **Parents/Guardians** | Choose an item. | Click here to enter text. |
| **Home** | Choose an item. | Click here to enter text. | **Grandparents** | Choose an item. | Click here to enter text. |
| **Family Gatherings** | Choose an item. | Click here to enter text. | **Other Relatives** | Choose an item. | Click here to enter text. |
| **Community** | Choose an item. | Click here to enter text. | **Teachers** | Choose an item. | Click here to enter text. |
| **Recreational Activities** | Choose an item. | Click here to enter text. | **Classmates** | Choose an item. | Click here to enter text. |
| **Clinical Setting** | Choose an item. | Click here to enter text. | **Therapists/Other Health Professionals** | Choose an item. | Click here to enter text. |
| **Other: Click here to enter text.** | Choose an item. | Click here to enter text. | **Strangers** | Choose an item. | Click here to enter text. |

27. ***"Can you describe how [xxxxxx] asks a question?"*** (who, what, where, when, how, why?)
    - Which AAC system(s)/method of communication? Click here to enter text.
    - How often does he/she do this in general? Choose an item.

| Where? | Frequency | Quality? (what does beh look like) | With Whom? | Frequency | Quality? (what does beh look like) |
|---|---|---|---|---|---|
| **School** | Choose an item. | Click here to enter text. | **Parents/Guardians** | Choose an item. | Click here to enter text. |
| **Home** | Choose an item. | Click here to enter text. | **Grandparents** | Choose an item. | Click here to enter text. |
| **Family Gatherings** | Choose an item. | Click here to enter text. | **Other Relatives** | Choose an item. | Click here to enter text. |
| **Community** | Choose an item. | Click here to enter text. | **Teachers** | Choose an item. | Click here to enter text. |
| **Recreational Activities** | Choose an item. | Click here to enter text. | **Classmates** | Choose an item. | Click here to enter text. |
| **Clinical Setting** | Choose an item. | Click here to enter text. | **Therapists/Other Health Professionals** | Choose an item. | Click here to enter text. |
| **Other: Click here to enter text.** | Choose an item. | Click here to enter text. | **Strangers** | Choose an item. | Click here to enter text. |

28. ***"Can you describe how [xxxxxx] answers a question?"*** (who, what, where, when, how, why?)
    - Which AAC system(s)/method of communication? Click here to enter text.
    - How often does he/she do this in general? Choose an item.

| Where? | Frequency | Quality? (what does beh look like) | With Whom? | Frequency | Quality? (what does beh look like) |
|---|---|---|---|---|---|
| **School** | Choose an item. | Click here to enter text. | **Parents/Guardians** | Choose an item. | Click here to enter text. |

| | | | | | |
|---|---|---|---|---|---|
| **Home** | Choose an item. | Click here to enter text. | **Grandparents** | Choose an item. | Click here to enter text. |
| **Family Gatherings** | Choose an item. | Click here to enter text. | **Other Relatives** | Choose an item. | Click here to enter text. |
| **Community** | Choose an item. | Click here to enter text. | **Teachers** | Choose an item. | Click here to enter text. |
| **Recreational Activities** | Choose an item. | Click here to enter text. | **Classmates** | Choose an item. | Click here to enter text. |
| **Clinical Setting** | Choose an item. | Click here to enter text. | **Therapists/Other Health Professionals** | Choose an item. | Click here to enter text. |
| **Other: Click here to enter text.** | Choose an item. | Click here to enter text. | **Strangers** | Choose an item. | Click here to enter text. |

29. ***"Can you describe how [xxxxxx] shows emotion? Does [xxxxxx] label his/her emotions?"*** (e.g., happiness, excitement, anger, upset):
    - Which AAC system(s)/method of communication? Click here to enter text.
    - How often does he/she do this in general? Choose an item.

| Where? | Frequency | Quality? (what does beh look like) | With Whom? | Frequency | Quality? (what does beh look like) |
|---|---|---|---|---|---|
| **School** | Choose an item. | Click here to enter text. | **Parents/Guardians** | Choose an item. | Click here to enter text. |
| **Home** | Choose an item. | Click here to enter text. | **Grandparents** | Choose an item. | Click here to enter text. |
| **Family Gatherings** | Choose an item. | Click here to enter text. | **Other Relatives** | Choose an item. | Click here to enter text. |
| **Community** | Choose an item. | Click here to enter text. | **Teachers** | Choose an item. | Click here to enter text. |
| **Recreational Activities** | Choose an item. | Click here to enter text. | **Classmates** | Choose an item. | Click here to enter text. |

| | | | | | |
|---|---|---|---|---|---|
| **Clinical Setting** | Choose an item. | Click here to enter text. | **Therapists/Other Health Professionals** | Choose an item. | Click here to enter text. |
| **Other: Click here to enter text.** | Choose an item. | Click here to enter text. | **Strangers** | Choose an item. | Click here to enter text. |

30. ***"Can you tell me how [xxxxxx] describes things?"*** (e.g., a blue shirt, shoes too big):
    - Which AAC system(s)/method of communication? Click here to enter text.
    - How often does he/she do this in general? Choose an item.

| Where? | Frequency | Quality? (what does beh look like) | With Whom? | Frequency | Quality? (what does beh look like) |
|---|---|---|---|---|---|
| **School** | Choose an item. | Click here to enter text. | **Parents/Guardians** | Choose an item. | Click here to enter text. |
| **Home** | Choose an item. | Click here to enter text. | **Grandparents** | Choose an item. | Click here to enter text. |
| **Family Gatherings** | Choose an item. | Click here to enter text. | **Other Relatives** | Choose an item. | Click here to enter text. |
| **Community** | Choose an item. | Click here to enter text. | **Teachers** | Choose an item. | Click here to enter text. |
| **Recreational Activities** | Choose an item. | Click here to enter text. | **Classmates** | Choose an item. | Click here to enter text. |
| **Clinical Setting** | Choose an item. | Click here to enter text. | **Therapists/Other Health Professionals** | Choose an item. | Click here to enter text. |
| **Other: Click here to enter text.** | Choose an item. | Click here to enter text. | **Strangers** | Choose an item. | Click here to enter text. |

31. ***"Can you describe how [xxxxxx] tells stories or describes events?"*** (e.g. special outing, what he/she did at school that day)
    - Which AAC system(s)/method of communication? Click here to enter text.
    - How often does he/she do this in general? Choose an item.

| Where? | Frequency | Quality? (what does beh look like) | With Whom? | Frequency | Quality? (what does beh look like) |
|---|---|---|---|---|---|
| **School** | Choose an item. | Click here to enter text. | **Parents/Guardians** | Choose an item. | Click here to enter text. |
| **Home** | Choose an item. | Click here to enter text. | **Grandparents** | Choose an item. | Click here to enter text. |
| **Family Gatherings** | Choose an item. | Click here to enter text. | **Other Relatives** | Choose an item. | Click here to enter text. |
| **Community** | Choose an item. | Click here to enter text. | **Teachers** | Choose an item. | Click here to enter text. |
| **Recreational Activities** | Choose an item. | Click here to enter text. | **Classmates** | Choose an item. | Click here to enter text. |
| **Clinical Setting** | Choose an item. | Click here to enter text. | **Therapists/Other Health Professionals** | Choose an item. | Click here to enter text. |
| **Other: Click here to enter text.** | Choose an item. | Click here to enter text. | **Strangers** | Choose an item. | Click here to enter text. |

AAC Service Use/Barriers

***"So now I'm going to ask you some questions about AAC services you have received for [xxxxxx] and some questions about challenges you may have faced."***

Educational/Treatment History:

32. ***"Which educational placements or therapies has [xxxxxx] received?"***
    - ☐ Integrated Preschool/School Attendance (ask for description): Click here to enter text.
    - ☐ Specialized camp/Recreational Program (ask for description): Click here to enter text.
    - ☐ In home support/programming (ask for description): Click here to enter text.
    - ☐ Speech Language Therapy: Click here to enter text.
    - ☐ Occupational Therapy: Click here to enter text.
    - ☐ Physiotherapy: Click here to enter text.
    - ☐ Intensive Behavioural Intervention (IBI) >20 hours per week: Click here to enter text.
    - ☐ Applied Behaviour Analysis services (ABA) <20 hours per week: Click here to enter text.
    - ☐ Other (ask for description): Click here to enter text.

Assessment Process:

33. ***"Which professionals were involved in [xxxxxx]'s AAC assessment process? Which one was the primary or lead professional?"***
    - ☐ Speech-Language Pathologist
    - ☐ Occupational Therapist
    - ☐ Physiotherapist
    - ☐ Behavioural Therapist
    - ☐ IBI Instructor Therapist or Senior Therapist
    - ☐ Psychologist
    - ☐ Multidisciplinary Team
    - ☐ Other: Click here to enter text.

34. ***"How many professionals were involved in the AAC system assessment process for [xxxxxx]?"*** Click here to enter text.

35. ***"Can you describe the support you were given when the AAC device was prescribed for [xxxxxx]?"***

| | How Many? | How Long? | Quality? Useful/Informative? | What did they provide? (e.g., follow-up services: maintenance/generalization) | Enough/Satisfied? | Other Comments |
|---|---|---|---|---|---|---|
| ☐None | Click here to enter text. | Click here to enter text. | ☐yes ☐no<br>**Choose an item.**<br>Click here to enter text. | Click here to enter text. | ☐yes ☐no<br>**Choose an item.**<br>Click here to enter text. | Click here to enter text. |
| ☐Single Sessions | Click here to enter text. | Click here to enter text. | ☐yes ☐no<br>**Choose an item.**<br>Click here to enter text. | Click here to enter text. | ☐yes ☐no<br>**Choose an item.**<br>Click here to enter text. | Click here to enter text. |
| ☐Group Sessions | Click here to enter text. | Click here to enter text. | ☐yes ☐no<br>**Choose an item.**<br>Click here to enter text. | Click here to enter text. | ☐yes ☐no<br>**Choose an item.**<br>Click here to enter text. | Click here to enter text. |
| ☐Follow-up Sessions | Click here to enter text. | Click here to enter text. | ☐yes ☐no<br>**Choose an item.**<br>Click here to enter text. | Click here to enter text. | ☐yes ☐no<br>**Choose an item.**<br>Click here to enter text. | Click here to enter text. |

36. ***"Are you happy/satisfied with the AAC system chosen for [xxxxxx]?"*** ☐yes ☐no [**Choose an item.**]: Click here to enter text.

37. ***"Do you think the device chosen maximizes [xxxxxx]'s ability to communicate?"*** ☐yes ☐no [**Choose an item.**]: Click here to enter text.

38. ***"Do you feel confident helping [xxxxxx] use his/her AAC system?"*** ☐yes ☐no [**Choose an item.**]: Click here to enter text.

39. ***"Do you think AAC services have adequately supported [xxxxxx] in maintaining his/her AAC system?"*** ☐yes ☐no **[Choose an item.]**: Click here to enter text.

40. ***"Do you think AAC services have adequately modified [xxxxxx]'s AAC system as he/she ages and/or progress in his/her communication abilities?"*** ☐yes ☐no **[Choose an item.]**: Click here to enter text.

41. ***"Overall, what kinds of challenges have you encountered regarding [xxxxxx]'s use of his/her AAC system?"*** (provide examples if necessary – the major bullet points. If the parent indicates that their child was deemed ineligible, ask the parent why) Click here to enter text.

    ☐ Lack of funding/financial resources Click here to enter text.
    ☐ Put on waitlist Click here to enter text.
    ☐ Denial of services or deemed ineligible due to: Click here to enter text.
        ☐ Too low functioning (lack of a discrepancy between an individual's cognitive and communicative functioning)
        ☐ Diagnostic label that implies low functioning
        ☐ Too high functioning (e.g. some speech)
        ☐ Echolalia mistaken for speech
        ☐ Too young
        ☐ Too old
        ☐ A lack of necessary prerequisite language skills
        ☐ Poor performance with a device during a trial period
        ☐ Previous treatment failure
    ☐ Being told to wait for AAC services (e.g., to see if speech develops), if yes why? Click here to enter text.
    ☐ Lack of trained professionals: Click here to enter text.
    ☐ Lack of a regional AAC clinic/program within my immediate area: Click here to enter text.
    ☐ Lack of training available or accessible for parents: Click here to enter text.
    ☐ Lack of training available or accessible for teachers/EAs, therapists, etc.
    ☐ Lack of follow-up support: Click here to enter text.
    ☐ Inadequate services (e.g., did not meet your child's needs adequately): Click here to enter text.

☐ Problems with the device itself (e.g., maintenance, repairs needed, not updated, etc.): Click here to enter text.
☐ Characteristics/tendencies of your child that prevent him/her from properly using his/her AAC system: Click here to enter text.
☐ Other: Click here to enter text.

42. ***"Have the challenges we discussed earlier been adequately addressed by service providers? Were they were resolved?"*** (indicate yes/no and describe how they were resolved):
    - Challenge: Click here to enter text. ☐yes ☐no [**Choose an item.**]: Click here to enter text.
    - Challenge: Click here to enter text. ☐yes ☐no [**Choose an item.**]: Click here to enter text.
    - Challenge: Click here to enter text. ☐yes ☐no [**Choose an item.**]: Click here to enter text.
    - Challenge: Click here to enter text. ☐yes ☐no [**Choose an item.**]: Click here to enter text.

43. ***"Do you have any other comments or questions regarding AAC services?"*** Click here to enter text.

AAC Use and ASD (Complete questions 43 and 44 if child has a diagnosis of ASD, questions 45 onwards are asked for all participants)

44. ***"Do you think [xxxxxx] has additional difficulties using his/her AAC system because of his/her autism***?" ☐yes ☐no

45. ***"Can you describe what things specific to [xxxxxx]'s autism have affected the proper use of his/her AAC system***?" Click here to enter text.

46. ***"Has [xxxxxx] ever used an AAC system in a repetitive or self-stimulatory manner?"*** (if needed specify that this can apply to any AAC system they have had over time) ☐yes ☐no
    If yes,
    ☐ ***"What kind of behaviours did/does [xxxxxx] engage in?"*** Click here to enter text.

- ☐ ***"What kind of AAC system(s) did/does [xxxxxx]use repetitively?"*** Click here to enter text.
- ☐ ***"Have you switched from one system to another because of these behaviours?"*** Click here to enter text.
- ☐ ***"How much does this repetitiveness impede [xxxxxx]'s ability to use his/her AAC system properly?"*** **[Choose an item.]**: Click here to enter text.
- ☐ ***"Have service providers implemented or shown you any techniques to manage these tendencies/behaviours?"*** ☐yes ☐no
- ☐ ***"Please Describe":*** Click here to enter text.
- ☐ ***"Was it useful in resolving the problem?"*** ☐yes ☐no **[Choose an item.]**
- ☐ ***"Was the device changed?"*** ☐yes ☐no

47. ***"Has [xxxxxx] had difficulties with motor control?"*** (e.g., coordination, planning etc.) ☐yes ☐no, If yes,
    - ☐ ***"What are these difficulties?"*** Click here to enter text.
    - ☐ ***"Have they impeded [xxxxxx]'s ability to use his/her AAC system?"*** ☐ yes ☐ no **[Choose an item.]**

48. ***"Do you think [xxxxxx]'s AAC device has enhanced his/her ability to connect socially with others?"*** ☐ yes ☐ no **[Choose an item.]**

49. ***"Does [xxxxxx] still have social difficulties when using his/her AAC system?"*** ☐ yes ☐ no **[Choose an item.]** Please describe: Click here to enter text.

50. ***"How do you feel your child's AAC system enhances or has enhanced his/her life?"*** Click here to enter text.

51. ***"Can you tell me three things you love about your child or that he/she is good at?"*** Click here to enter text.

***"Thank-you so much for your time, I am very appreciative of your participation in our study."***

## Appendix D

**Demographics** – Taken from GO4KIDDS Basic and Extended Survey

**Preliminary/Background Information.**

52. *"What is your birthday?"* (DD/MM)? ____/____/____

G2. What is your ethnic background?

_______________________________________

A1. What is your postal code? ______________

G3. What is the best way to describe the size of your community:

1. Remote area of Canada
2. Rural area of Canada
3. Suburban area of Canada
4. Urban area of Canada

| | |
|---|---|
| G9. Please answer these questions about yourself, the person completing the interview: | G10. Please answer these questions about partner or other caregiver: |
| What gender are you? | What gender is he/she you? |
| 1. Male | 1. Male |
| 2. Female | 2. Female |
| What is your relationship to the child? | What is his/her relationship to the child? |
| 1. Biological parent | 1. Biological parent |
| 2. Adoptive parent | 2. Adoptive parent |
| 3. Step parent | 3. Step parent |
| 4. Grandparent | 4. Grandparent |
| 5. Other (please specify): ______________ | 5. Other (please specify): ______________ |
| What is your marital status? | What is your marital status? |
| ☐ Married | ☐ Married |
| ☐ Single | ☐ Single |
| ☐ Common-Law | ☐ Common-Law |
| ☐ Divorced | ☐ Divorced |
| ☐ Separated | ☐ Separated |
| ☐ Widowed | ☐ Widowed |

| | |
|---|---|
| Country of birth:<br>____________________________ | Country of birth:<br>____________________________ |
| If born outside of Canada, how many years have you lived in Canada? _______ | If born outside of Canada, how many years have you lived in Canada? _______ |
| What is your first language?<br>____________________________ | What is your first language?<br>____________________________ |
| What is the highest level of education completed?<br>1. Less than 7th grade<br>2. Junior high/Middle school (9th grade)<br>3. Partial high school (10th or 11th grade)<br>4. High school graduate<br>5. Partial College (at least one year)<br>6. College/University graduate<br>7. Graduate degree | What is the highest level of education completed?<br>1. Less than 7th grade<br>2. Junior high/Middle school (9th grade)<br>3. Partial high school (10th or 11th grade)<br>4. High school graduate<br>5. Partial College (at least one year)<br>6. College/University graduate<br>7. Graduate degree |
| What is your occupation? Please be specific (e.g., legal secretary, bank executive, truck driver):<br>______________________________________ | What is your occupation? Please be specific (e.g., legal secretary, bank executive, truck driver):<br>______________________________________ |
| Do you currently work outside the home?<br>1. Not currently<br>2. Part-time<br>3. Full-time | Do you currently work outside the home?<br>1. Not currently<br>2. Part-time<br>3. Full-time |