Augmentative and Alternative Communication Use Among Developmental Disorders

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# Table of Contents

Table of Contents .................................................................................................................. 2

List of Tables .......................................................................................................................... 4

Abstract .................................................................................................................................. 5

Résumé ...................................................................................................................................... 6

Acknowledgments ................................................................................................................... 7

Introduction ............................................................................................................................. 8

Literature Review .................................................................................................................... 9

- Augmentative and Alternative Communication .................................................................... 9
- Autism Spectrum Disorders .................................................................................................. 13
- Down Syndrome .................................................................................................................. 18
- Cerebral Palsy ...................................................................................................................... 20

Current Study .......................................................................................................................... 23

Methods ................................................................................................................................... 23

- Participants ........................................................................................................................... 23
- Materials ............................................................................................................................... 24
- Procedure .............................................................................................................................. 24
- Data Analysis ......................................................................................................................... 25

Results .................................................................................................................................... 26

- AAC Prevalence Rates ......................................................................................................... 26
- Full Model .............................................................................................................................. 26
- All Diagnoses ......................................................................................................................... 29
- Autism Spectrum Disorders ................................................................................................. 31
List of Tables

Table 1: Descriptive Statistics .......................................................... 27
Table 2: Univariate Results of AAC Use and Diagnosis ...................... 28
Table 3: Univariate Results of AAC Use, regardless of Diagnosis .......... 29
Table 4: Univariate Results of Diagnosis, regardless of AAC Use .......... 30
Table 5: Univariate Results of AAC Use for Children with Autism Spectrum Disorder ...... 31
Table 6: Univariate Results of AAC Use for Children with Down Syndrome .................. 32
Table 7: Univariate Results of AAC Use for Children with Cerebral Palsy .................. 33
Abstract

Most studies in the field of augmentative and alternative communication (AAC) involve single-subject experiments or case studies. Little is known about actual prevalence rates of AAC use, or the characteristics of AAC users. For this study, parents of children with autism spectrum disorder (ASD), Down syndrome, and cerebral palsy (CP) completed an online survey to examine AAC use in each population. The communication, cognitive, and adaptive behaviour subtests of the Developmental Profile 3 were used. The difference in performance between AAC users and non-users was examined for children of each disorder. Results indicate a prevalence rate of AAC use of approximately 1 in 5 for each disorder and the combined sample. There were no significant differences found between AAC users and non-users diagnosed with ASD or CP, but AAC users with Down syndrome had lower scores than those who did not use AAC. Interpretations of the results and future directions were discussed.
Résumé

La plupart de la recherche dans le domaine de communication augmentative et alternative (CAA) comprenant des études de cas ou des études avec seulement un sujet. On sait peu des taux de prévalence réelle pour l’utilisation de CAA, ou les caractéristiques des utilisateurs de CAA. Pour cette étude, les parents des enfants atteints des troubles du spectre autistique (TSA), du syndrome de Down, et de la paralysie cérébrale (PC) ont complété une enquête en ligne afin d’examiner l’utilisation de CAA dans chaque population. Les sous-tests de communication, de cognition et de comportement adaptif du test anglais Developmental Profile 3 (Profile de développement 3) ont été utilisés. Les différences entre les enfants qui utilisent et qui n’utilisent pas les systèmes de CAA ont été examinées pour les enfants avec chaque trouble. Les résultats indiquent un taux de prévalence de l’usage de CAA d’environ 1 en 5, pour chaque trouble et pour l’échantillon combiné. Il n’y avait aucune différence significative entre les utilisateurs de CAA et les non-utilisateurs atteignent de TSA ou de PC, mais les utilisateurs de CAA avec le syndrome de Down avaient des scores plus faibles que ceux qui n’utilisaient pas le CAA. Les interprétations des résultats et les orientations futures sont discutées.
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Augmentative and Alternative Communication Use Among Different Developmental Disorders

Most people are aware of what it means to be able to communicate effectively; however, there exists a subset of the population who have communication problems that affect their ability to interact with others (Beukelman & Mirenda, 1998; Beukelman & Yorkston, 1989). Whether these impairments were acquired later on in life, or congenital, it is clear that these individuals could benefit from improving communication (Beukelman & Yorkston, 1989).

Augmentative and alternative communication (AAC) devices are used to either aid or replace common means of communication (Glennen, 1997a; Murray & Goldbart, 2009). They are generally used by individuals with communication difficulties, including those with developmental disorders (Wilkinson & Hennig, 2007). Some of the most common users of AAC devices are those with intellectual disabilities, autism spectrum disorder, and cerebral palsy (Sutherland, Gillon, & Yoder, 2005). In addition, children with Down syndrome also use AAC systems (Brady, 2008). Overall, there is a lot of variety among AAC users in terms sensory, perceptual, physical, language and cognitive skills (Higginbotham & Bedrosian, 1995).

AAC devices help children with developmental disabilities communicate their needs to others and increase speech production (Millar, Light, & Schlosser, 2006). However, the majority of studies in the field are single-subject designs (DeCoste, 1997; Millar et al., 2006). This means that little is known about the characteristics of AAC users, such as prevalence rates (Murray & Goldbart, 2009). There is also a lack of studies describing AAC users (Pennington, Marshall, & Goldbart, 2007). In order to supplement this gap in research, the current study aims to provide prevalence rates, to compare AAC users across different diagnoses, and to compare users to non-users. First, it is important to understand the nature of AAC, its effectiveness, and the diagnoses of those who use it.
Literature Review

Augmentative and Alternative Communication

**Description.** Augmentative and alternative communication systems either improve (augmentative) or replace (alternative) typical forms of speech/writing for individuals with impaired communication skills (Glennen, 1997a; Murray & Goldbart, 2009). Sign language could be included in this definition, but is typically considered its own field separate from AAC research (Murray & Goldbart, 2009). If an external device is used, then the AAC systems is aided; if no external devices are used, then the AAC system is unaided (Glennen, 1997a). An example of an unaided or no-tech system is gestures or manual signs. Aided systems can be low-tech, such as pictures or symbols; light-tech, such as simple computer devices; or high-tech, such as complex computerized voice output communication aids (VOCA; Murray & Goldbart, 2009; Wilkinson & Hennig, 2007). There is a wide variety of AAC systems offered (for a technical description of systems available, see Glennen, 1997b; for a comparison of systems, see Schlosser and Sigafoos, 2006). AAC systems can be used to supplement expressive language, receptive language, and social interactions (Murray & Goldbart, 2009).

Wilkinson and Hennig (2007) identified four roles of AAC: a) to enhance the expressive speech of individuals who can understand language to some extent, but have difficult producing it; b) to enable the expression of a variety of communication functions across different settings with different people; c) to reduce challenging behaviour such as aggression or unwanted social behaviours; and d) to function as a bridge to later linguistic development. Individuals who use AAC systems commonly do so for one or more of the above reasons.

AAC systems are typically implemented as early as possible, usually along with other behavioural interventions (Mirenda & Mathy-Laikko, 1989). Typically, children with
developmental disabilities will not rely on one type of AAC system; rather, a variety of AAC systems are used in different situations (Weitz, Dexter, & Morre, 1997). Some authors have attempted to determine prevalence data from their knowledge of speech disorder prevalence rates and access to services, but these data were arrived at through imprecise, non-experimental calculations, and do not examine particular participant factors such as diagnosis (Murray & Goldbart, 2009).

There are some issues with aided AAC systems. As some require external components, such as hand-held computer devices, portability needs to be considered (Wilkinson & Hennig, 2007). Individuals who use symbol systems to communicate are limited by the symbols and pictures provided to them (although this is less of an issue with electronic devices), and need to search for the correct symbol before using it (Wilkinson & Hennig, 2007). In order to use AAC devices, a person must first be able to either comprehend language or to comprehend the symbols used in their AAC devices (Romski & Sevcik, 1993). However, this restriction does not mean that individuals with cognitive deficits should be excluded from consideration for using AAC (Romski, 2005). Conversations with AAC users tend to be dominated by the conversation partner, who is more likely to initiate and may converse twice as often as the AAC user (Lund & Light, 2007). These conversations tend to take on a question and answer format, with AAC users asking questions infrequently and typically providing only confirmations or denials (Lund & Light, 2007). Most AAC users’ utterances contain only one word (Lund & Light, 2007).

Using AAC devices can require a life-long commitment, family and peer involvement, and up-to-date information about AAC (Mirenda & Mathy-Laikko, 1989). Due to the heterogeneity of AAC users (Pennington et al., 2007), and the likelihood of multiple deficits, it is important to use a multi-faceted approach to treatment that incorporates other therapies (Mirenda
& Mathy-Laikko, 1989). Parents are typically the people involved in selecting the AAC device, and generally find that there is a lack of access to AAC systems and knowledgeable educators (McNaughton et al., 2008). The decision of which AAC devices to use is difficult (Dowden, 1997) as many factors need to be considered, such as the AAC device interface, physical limitations, cognitive/linguistic factors, and social limitations (Higginbotham, Shane, Russell, & Caves, 2007). New technological advances have provided AAC users with a wider variety of options (Higginbotham et al., 2007; Wilkinson & Hennig, 2007; for a history of AAC use see Glennen, 1997a).

**Effectiveness.** Research into the effectiveness of AAC devices is difficult due to the heterogeneous nature of the group, in terms of both the users and the devices used (Higginbotham & Bedrosian, 1995; Pennington et al., 2007). Generally, studies supply suggestive, rather than conclusive evidence of efficacy (Millar et al., 2006; Schlosser & Sigafoos, 2006). However, there have been advances in research over previous years.

There has been concern that using AAC devices will cause children to become unmotivated to produce speech of their own accord (Romski, 2005; Weitz et al., 1997); however, the counterargument is that using AAC systems reduces pressure and allows the child to focus solely on communication rather than speech production (Millar et al., 2006). In a recent meta-analysis of the effects of AAC on natural language production by Millar, Light and Schlosser (2006), most studies showed a moderate gain in speech production for AAC users, with no studies showing a decrease in ability. Even though the gains were moderate, they should be considered in relation to the amount of words learned without AAC devices. In relative terms, AAC use is highly effective throughout the lifespan (Millar et al., 2006). Most of the studies reviewed were single subject experiments that only provided suggestive, rather than conclusive
evidence; still, the data suggest that AAC devices are effective at improving natural language (Millar et al., 2006; Schlosser, 2003). Schlosser and Sigafoos (2006) examined single-subject experimental studies and found only two studies met their stringent criteria for conclusive evidence, but still established that AAC systems are effective. Some studies have found that unaided systems are more effective than aided systems, but that there were no differences between the two in terms of maintenance and generalization (Schlosser & Lee, 2000). Among individuals with intellectual disabilities, some studies demonstrate an increase in language learning with aided AAC systems, but those involving individuals with severe disabilities tend to report no changes (Wilkinson & Hennig, 2007). There is evidence that, over time, AAC users will take less turns in a conversation but provide more complex contributions (Lund & Light, 2007). There is considerable linguistic growth across age groups for AAC users (Lund & Light, 2007).

There have been issues with the generalization of AAC use, with individuals sometimes unable to build upon what they have learned (e.g., request an object after learning labels) or use their AAC systems outside of the area of instruction (Calculator, 1988). AAC use is rarely spontaneous and typically requires prompting, especially with aided devices (Carter, 2003). The general solution to these issues is the “train and hope” technique (Schlosser & Lee, 2000). However, Schlosser and Lee (2000) performed a meta-analysis of effectiveness studies, and found that 87.5% of interventions were successful at yielding behaviour change, 84.6% were successful at generalization, and 46.4% were successful at maintenance. Therefore, it can be concluded that most AAC interventions generalize well, although they were less effective over time.
There are some issues with conversation partners of those using AAC devices. Partner involvement is especially important with low- and light-tech aided devices, which require some interpretation on the partner’s side (Wilkinson & Hennig, 2007). It is often necessary to train partners to how to use and understand the AAC system (Calculator, 1988; Wilkinson & Hennig, 2007). In a study examining the effectiveness of student requesting and rejecting, increased levels of spontaneity resulted in the students’ requests and rejections being less likely to be met (Carter, 2003). This was likely due to the unexpectedness of the communication efforts and the lack of training of the conversation partners. Individuals who use AAC tend to converse less with unfamiliar partners, but training conversation partners yields more complex interactions (Lund & Light, 2007). However, most interventions attempt to train AAC users and not their partners (Schlosser & Lee, 2000).

**Autism Spectrum Disorders**

**Description.** The term autism spectrum disorder (ASD) encompasses a range of Pervasive Developmental Disorders characterized by impairment in several areas: communication skills, reciprocal social interaction skills, and the presence of stereotyped behaviour, interests, and activities (American Psychiatric Association [*DSM-IV-TR*], 2000). A diagnosis of Autistic Disorder requires impairment in all three areas. A diagnosis of Asperger Disorder requires impairment in social interaction and the presence of stereotypy, but does not require any impairment in communication skills. A diagnosis of Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS, also called atypical autism) is used when a child is impaired in one or more of the areas mentioned above, but does not meet criteria for any other Pervasive Developmental Disorder, Schizophrenia, Schizotypal Personality Disorder, or Avoidant Personality Disorder (*DSM-IV-TR*, 2000). Most authors report that approximately 70 to
75% of children with ASD have below average intelligence (Beukelman & Mirenda, 1998; Fombonne, 2003a), but the source of these data are questionable due to the age of the original citations, the lack of empirical studies, and the use of language-based intelligence tests for individuals with a language deficit (Goldberg Edelson, 2006). Newer studies have reported prevalence rates of intellectual deficits closer to 50% (Goldberg Edelson, 2006). Autism was first described by Leo Kanner (1943), who presented 11 case studies of a disorder that was not previously classified. Asperger syndrome, often compared to high functioning autism, was first described by Hans Asperger (1991) in 1941. Current estimates place prevalence rates of ASD at 60 per 10,000 children (Fombonne, 2003b), and similar rates have been found in Canada (Fombonne, Zakarian, Bennett, Meng, & McLean-Heywood, 2006). There is no specific cause for ASD, but these disorders are highly heritable and generally believed to be a genetic disorder of brain development (Fombonne, 2003c).

**Communication Impairments.** One of the criteria for a diagnosis of autism is communication impairment, which can include a delay in or total lack of spoken language (with no compensatory modes of communication such as gesturing); an impairment in the ability to initiate or sustain a conversation with others; stereotyped or repetitive use of language or stereotypic language; and a lack of varied, spontaneous make-believe play or social imitative play (DSM-IV-TR, 2000). Children with autism typically have impaired or absent language, often in conjunction with a mental disability (Boucher, 2003), beginning with delayed or absent babbling as an infant (Landa, 2007). Approximately 50% of children with autism never develop sufficient speech to communicate (Beukelman & Mirenda, 1998). Individuals with Asperger syndrome do not typically suffer from language onset delays (Boucher, 2003). For children with autism who develop language, they will often experience impaired use of language, in that it is
typically employed for instrumental rather than social purposes (Boucher, 2003; Tager-Flusberg, 1996). For example, children with ASD will tend to use language to meet their needs, but not to express or share interest (Landa, 2007; Tager-Flusberg, 1996). This is both a language and a social deficit, which often tend to overlap (Landa, 2007). Joint attention, or the ability to shift attention between a conversation partner and the object being discussed, is also a core impairment of the disorder and hinders the learning of new words (Landa, 2007; Tager-Flusberg, 1996). Approximately 80% of children with autism can produce five or more words, with two-thirds of them having expressive or receptive language difficulties and the rest having pragmatic difficulties (Landa, 2007).

Children with autism also have impaired nonverbal communication skills, such as reading facial expressions, gesturing, and using vocal prosody (Boucher, 2003; Landa, 2007). However, children with ASD who have speech difficulties typically use nonverbal modes of communication, such as vocalizations, gestures, and touch, to convey their needs (Weitz et al., 1997). A common symptom among all children with ASD is better expressive than receptive language; however, the majority of their spoken language is formulaic and thus not truly generative expressive language (Boucher, 2003). Individuals with autism typically experience some difficulties with grammar, while this is less common for those with Asperger syndrome (Boucher, 2003). However, they usually have little to no impairment in deciphering phonemes, the sounds that make up words (Boucher, 2003; Landa, 2007). Children with ASD have some semantic impairments, ranging from mild for children with Asperger syndrome, to severe for lower functioning children with autism (Boucher, 2003; Landa, 2007). This means that they have difficulty with language comprehension, especially abstract or non-literal concepts such as metaphor and irony (Boucher, 2003). People with autism have a relative strength in visual-spatial
and visual-memory skills, and will sometimes use this strength to compensate for their communication deficits by attending strongly to the subtle cues that accompany speech (Beukelman & Mirenda, 1998).

The pragmatics of language are particularly difficult for children with ASD, with impairments ranging from moderate for children with Asperger syndrome, to severe for lower functioning children with autism (Boucher, 2003; Tager-Flusberg, 1996). Pragmatics refers to the conventions and rules of language use, including social knowledge (e.g. the proper way to address adults) and socio-cognitive understandings (e.g. taking another person’s knowledge into account) (Boucher, 2003). There is evidence that people with ASD lack a “theory of mind,” which means they have difficulty taking others’ perspectives into account (Tager-Flusberg, 1996); this accounts for several communication and social problems that ASD individuals face (Beukelman & Mirenda, 1998). The overall picture is that ASD involves communication impairment, rather than just language impairment (Fombonne, 2003c).

**AAC Use.** Children with autism are prime candidates for AAC use due to their communication difficulties (Mirenda, 2003; Schlosser & Wendt, 2008). Because of the uneven distribution of skills among children with autism, it is possible to gear AAC interventions to take advantage of strengths, such as visual-spatial skills, and target weaknesses, such as social interaction (Francis, 2005; Mirenda & Mathy-Laikko, 1989). AAC interventions with children with ASD should begin early, and be integrated with any other therapies (Beukelman & Mirenda, 1998).

There is evidence that AAC devices can assist both receptive and expressive language skills for children with ASD (Mirenda, 2001). In terms of functional communication, more research has been conducted with aided systems, which are easier to learn (Mirenda, 2003) but
demanding for individuals with fine motor difficulties (Mirenda, 2001). There is evidence that both unaided and aided systems, whether low- or high-tech, facilitate speech development and production in individuals with autism (Mirenda, 2003; Schlosser & Wendt, 2008). Much like studies examining the effectiveness of AAC for populations with developmental disabilities (Millar et al., 2006), most studies reveal a moderate gain in speech production in AAC users with ASD, with no studies detecting a decline (Schlosser & Wendt, 2008). AAC can be used in conjunction with a behavioural treatment (Francis, 2005), and has been shown to be successful when paired with reinforcements (Mirenda, 2003). However, there are some issues with generalization and spontaneity of use (Koegel, 2000). AAC interventions should be considered in a social context, and used within several settings to improve generalization (Beukelman & Mirenda, 1998). Naturalistic training (vs. stimulus-response training) is necessary to promote effective generalization of the skills learned (Weitz et al., 1997).

There are several types of AAC devices designed for use by children with autism. This large variety of AAC systems used is likely due to the range of impairments of children with ASD (Weitz et al., 1997). The Picture Exchange Communication System (PECS; Frost & Bondy, 2002) is a low-tech aided system with pictures designed for children with ASD. They can also benefit from high-tech computerized systems or VOCA, to capitalize on their visual learning styles, or simple orthographic communication systems, to capitalize on hyperlexic reading abilities often demonstrated by children with ASD (Weitz et al., 1997). Studies investigating the effectiveness of VOCAs in children with ASD have found conclusive evidence for improvement in requesting after interventions (van der Meer & Rispoli, 2010).
Down Syndrome

**Description.** Down syndrome is the most common chromosomal disorder in Canada, occurring approximately 1 in 800 live births worldwide, and approximately 14.4 in 10,000 total births in Canada (Health Canada, 2002). Down syndrome was first described by, and eventually named after, John Langdon Down (1866). The most common form of Down syndrome, otherwise known as Trisomy 21, is characterized by an error in cell division that results in an extra copy of chromosome 21 in the genetic code (3 copies instead of 2). More rarely, Down syndrome is also caused by unbalanced translocation, when part of chromosome 21 reattaches somewhere else, or somatic mosaicism, where only some cells have an extra chromosome 21 (Health Canada, 2002; Roberts, Price, & Malkin, 2007). The symptoms of Down syndrome vary from person to person, but children with Down syndrome are commonly developmentally delayed, have characteristic faces and are more likely to have certain health problems such as congenital heart defects (Health Canada, 2002).

**Communication Impairments.** There is a large variety of symptoms among children with Down syndrome; however, most children experience developmental delays and language deficits, particularly in language production, syntax, and intelligibility (Roberts et al., 2007). Hearing loss occurs in approximately two thirds of individuals with Down syndrome (Roizen, 2002), and many also experience structural problems of the mouth and tongue that affect speech production (Miller, Leddy, Miolo, & Sedey, 1995; Stoel-Gammon, 2001). This can lead to difficulties developing speech skills (Roberts et al., 2007). In terms of pre-linguistic skills, such as gestures, babbling and facial expressions, children with Down syndrome do not typically differ from other children (Roberts et al., 2007; Stoel-Gammon, 2001). However, they do have delays in phonological processing and life-long struggles with intelligibility (Stoel-Gammon,
Approximately 50% experience semantic issues, such as delays in receptive vocabulary and, to a greater degree, delays in expressive vocabulary (Miller et al., 1995); these delays tend to be on par with cognitive delays (Roberts et al., 2007). Syntax presents a larger problem for almost all individuals with Down syndrome (Miller et al., 1995), with issues such as shorter utterances and difficulty with verbs, although these skills continue to develop over time (Roberts et al., 2007). Language pragmatics, or the use of language in social situations, are a relative strength (Roberts et al., 2007). Individuals with Down syndrome continue to learn new language skills well into adolescence (Miller et al., 1995), and language skills tend to remain constant over time, although a large number of older individuals with Down syndrome develop symptoms of Alzheimer disease and its accompanying language decline (Roberts et al., 2007).

AAC Use. The delayed onset of speech and poor intelligibility of individuals with Down syndrome makes AAC systems a good fit (Brady, 2008). Approximately 75% of persons with Down syndrome have been exposed to manual signing throughout their lives, in order to improve initial communication when verbal attempts were unintelligible (Miller et al., 1995). The high prevalence of sign language could be due to the fact that this disorder is typically identified from birth and sign language is easy to use with very young children (Brady, 2008). Children with Down syndrome use both aided and unaided AAC systems, sometimes in combination, for both short periods of time and their whole lives (Brady, 2008). Without intervention, children with Down syndrome typically use gestures to communicate their needs (Brady, 2008; Roberts et al., 2007). Using multi-modal AAC devices (both aided and unaided) has been shown to increase speech production more than sign language alone (Foreman & Crews, 1998). Due to relative visual strengths (Foreman & Crews, 1998), aided AAC systems with visual aids tend to improve communication in children with Down syndrome (Brady, 2008). AAC systems have been shown
to increase speech productivity and expand total vocabularies for children with Down syndrome (Miller et al., 1995). AAC use typically diminishes over time, to be replaced by more conventional modes of communication (Brady, 2008; Miller et al., 1995).

**Cerebral Palsy**

*Description.* Cerebral Palsy (CP) is more of a description than a diagnosis, due the variety of pathologies and aetiologies (Badawi et al., 1998; Blair & Watson, 2006). There is no known cause for CP and multiple pathways to meet criteria, although there are several consistent risk factors such as low birth weight (Reddihough, 2011). Approximately 70-90% of cases are acquired before birth; another 6% are caused by birth complications, such as asphyxia (Krigger, 2006). About 24% of CP cases have no known cause (Beukelman & Mirenda, 1998). Genetic testing and new imagining techniques have allowed doctors to determine the cause for more and more children identified as having CP (Badawi et al., 1998). Brain lesions or maldevelopment, at varying times throughout development, can account for approximately 80% of cases of CP (Krägeloh-Mann & Cans, 2009). There is no known way to prevent the disorder (Blair & Watson, 2006). CP occurs in every 2-2.5 per 1000 live births (Odding, Roebroeck, & Stam, 2006), with a slightly higher prevalence rate of 2.57 per 1000 births in Canada (Robertson, Svenson, & Joffres, 1998; Smith, Kelly, Prkachin, & Voaklander, 2008). It is the most common cause of physical disability in childhood (Krägeloh-Mann & Cans, 2009).

CP was first described by William John Little (1861) as a life-long disorder. A typical definition of CP involves motor impairment (palsy) that has its origins in the brain (cerebral) and was acquired early in life (Blair & Watson, 2006; Rosenbaum et al., 2007). Individuals with CP also tend to have cognitive impairment and epilepsy (Blair & Watson, 2006; Odding et al., 2006). It is estimated that approximately 60-70% of individuals with CP suffer from intellectual
disabilities (Beukelman & Mirenda, 1998). With the goal of providing a universal description of CP, authors of a report supplied this definition:

Cerebral palsy (CP) describes a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour, by epilepsy, and by secondary musculoskeletal problems. (Rosenbaum et al., 2007, p. 9).

**Communication Impairments.** CP is characterized by motor and cognitive impairments that can have an effect on speech production (Krigger, 2006). Hearing problems and communication disorders are common (Reddihough, 2011). Up to 80% of individuals with CP have impairments in their speech (Odding et al., 2006). Approximately 20% have no speech at all, and 15% have indistinct speech (Andersen, Mjøen, & Vik, 2010). Many children with CP develop dysarthria (Mirenda & Mathy-Laikko, 1989), with estimates ranging from 21-88% (Beukelman & Mirenda, 1998). Speech problems are more common among individuals with CP who experience mixed muscle tone (Andersen et al., 2010).

When compared to typically developing children, those with CP are less likely to initiate conversations, take fewer turns in conversations, and do not ask as many questions (Pirila et al., 2007). They also have difficulties with gestures and facial expression, receptive and expressive language, and voice production (Pennington, Goldbart, & Marshall, 2004). Most children with CP who have cognitive impairments have both motor speech and verbal difficulties, whereas only approximately 50% of children with CP without cognitive impairments have communication difficulties, primarily in the motor speech domain only (Pirila et al., 2007).
**AAC Use.** Individuals with CP constitute the largest proportion of AAC users (Murphy, Marková, Moodie, Scott, & Boa, 1995). A demographic study in Norway found that 39% of individuals with CP, and 54% of those who experienced speech problems, used AAC systems (Andersen et al., 2010). AAC is typically used across settings, although it is sometimes used only in school/therapy settings (Murphy et al., 1995). Children whose language deficits are primarily in the motor domain are less likely to receive AAC interventions (Pirila et al., 2007). Any interventions typically occur early, as CP is often detected soon after birth (Mirenda & Mathy-Laikko, 1989). Due to the variety of motor and cognitive impairments associated with CP, an individually-targeted, team approach to AAC use is encouraged (Mirenda & Mathy-Laikko, 1989), with a variety of professionals (e.g., occupational and physical therapists, orthotics specialists) and a balance between their multiple therapies (e.g., motor development training, speech therapy, academic instructions) necessary (Beukelman & Mirenda, 1998). The number of people with CP using AAC is steadily growing with the increased access and technology of AAC systems (Murphy et al., 1995).

Typically, individuals with CP use aided AAC devices. These range from no-tech aided systems, such as pointing at or using eye gaze to direct attention to symbols; low-tech systems, such as eye gaze boards which register which symbol an individual is looking at or clock scanners, where an individual holds a button down until a dial points to the desired symbol; and high-tech systems, such as VOCA (DeCoste, 1997). These systems often require significant amounts of training for both the AAC user and the communication partner (DeCoste, 1997). Due to poor motor skills, many children with CP use high-tech AAC devices; however, using high-tech devices means a risk of equipment malfunctioning, as well as a high cost of replacement for systems that are less durable (DeCoste, 1997).
Current Study

The current study aims to examine the characteristics of AAC users who have ASD, Down syndrome, and CP. These participants were chosen because they are some of the most common diagnoses among AAC users and represent a variety of cases: a psychological disorder, a chromosomal disorder, and a brain disorder. Prevalence rates of AAC use will be determined, and differences between AAC users with each disorder will be compared. In addition, differences between users and non-users will be examined.

This study aims to provide information about the characteristics of AAC users. By examining their developmental differences, a general profile of the AAC user can be developed. Looking more specifically at each disorder allows the opportunity to see the differences among individuals who use AAC, and provides details about the AAC user.

Methods

Participants

Parents of children with developmental disabilities were recruited through online parent support websites in Canada (n = 110). Nineteen participants did not complete the Developmental Profile 3 portion of survey and were eliminated from the data pool, leaving 91 participants. Among these, 60.4% had children on the autism spectrum (including diagnoses of PDD-NOS, Asperger syndrome, and autism), 28.6% had children diagnosed with Down syndrome, 9.9% had children diagnosed with cerebral palsy, and 1.1% had children with a diagnosis in progress (see Table 1 for descriptive statistics). The mean age of the children was 8.78 years old (SD = 4.75, age range = 0.83 to 19.91 years old). The sample was 28.9% female (n = 19) and 79.1% male (n = 72). All participants agreed to participate through a mandatory initial consent question.
Materials

Participants completed a 20-minute, online survey (see Appendix A for complete survey) through the website SurveyMonkey (http://www.surveymonkey.com). The first section of the survey, completed by all participants, was written by the main experimenter and included questions about demographics and diagnoses. If the child used AAC devices, the participant was then directed to a section inquiring about the type of device(s) used, how often they was used, and whether the parents found it beneficial. This was accomplished by using the “skip logic” function in SurveyMonkey, which allows the researcher to direct participants to different areas of the survey based on their answers to a question.

All participants completed the final three sections, composed of the Adaptive Behaviour, Cognitive, and Communication subtests of the Developmental Profile 3 (DP-3; Alpern, 2007). The DP-3 is designed to assess developmental delays in children among five different areas: the three mentioned above, Physical Behaviour, and Social-Emotional. The DP-3 Adaptive Behaviour, Cognitive, and Communication subtests all have moderate test-retest reliability ($r = 0.82$, $r = 0.92$, $r = 0.82$, respectively), strong internal consistency reliability ($r = 0.91$, $r = 0.92$, $r = 0.93$, respectively), and good discriminant validity (i.e. there were significant differences when testing a clinical sample versus the mean, $p < 0.01$).

Procedure

Webmasters of websites for parents of children with autism, Down syndrome, and cerebral palsy were contacted (see Appendix B for website contact e-mail). They were informed about the study intentions, and asked to post a small description of the research, along with a link to the online survey, on their website or in their newsletter. The description of the research listed it as a study on communication abilities in children with autism, Down syndrome, and cerebral
palsy. The more specific goal of examining AAC use among these disorders was mentioned on the consent form, but not in the recruitment write-up. This was to avoid a selection bias of AAC users choosing to fill out the survey over non-users.

Participants were directed to our online survey link through these websites. All participants were required to answer the first question on the survey, asking for their consent to continue. Once the survey was complete, participants were asked if they wanted to receive their child’s specific results and/or the aggregated results of the study. If their answer was yes, then they were prompted to leave their e-mail address for further contact. No other reward was offered for completing the survey.

Aside from e-mail addresses, the survey was confidential and did not ask for any names. All data are stored online in the SurveyMonkey database. The database is accessible only with a log-in name and password. This ensures confidentiality of results.

**Data Analysis**

All data analysis was carried out using conducted using IBM’s Statistical Package for the Social Sciences. To analyze all results, a factorial multivariate analysis of variance (MANOVA) was conducted, with diagnosis and AAC use as the independent variables and responses on the three DP-3 subtests as the dependent variables. To analyze the effects of diagnosis, regardless of AAC use, a one-way MANOVA was conducted with Diagnosis as the independent variable and the three DP-3 subtest scores as the dependent variables. To analyze the effects of AAC, regardless of diagnosis, a one-way MANOVA was conducted, with AAC use as the independent variable and the three DP-3 subtest scores as the dependent variables. To analyze the effects of AAC use on each diagnosis, three one-way MANOVAs were conducted, using the diagnosis as the independent variable and the results on the three DP-3 subtests as the dependent variables.
Results

AAC Prevalence Rates

AAC prevalence was fairly consistent across diagnoses. Of all the participants with a diagnosis who answered the questions about AAC use, 22.2% \((n = 20)\) of individuals used AAC systems. There were 16.7% \((n = 15)\) of all respondents who used sign language only; for reasons mentioned earlier, sign language is not considered to part of AAC and therefore these children were not labelled as AAC users. Examining each diagnosis, 23.6% of children with ASD, 19.2% of children with Down syndrome, and 22.2% of children with CP used AAC devices (see Table 1). Among all AAC users, 75% \((n = 15)\) used some sort of picture system to aid communication, with PECS being the most common. Computerized, high-tech speech output systems were used by 60% \((n = 12)\) of AAC users. The most commonly used devices were Dynavox systems and iPod applications, such as Proloque2Go. Say It Sam was used for scheduling purposes. All participants but one reported that their children used their AAC devices multiple times per day.

Full Model

The results of the factorial MANOVA were not significant for AAC Use, \(F(3, 82) = 2.077, p = 0.110\), but significant for Diagnosis \(F(6, 164) = 0.776, p = 0.002\). Univariate analyses show no significant difference based on Diagnosis in the scores on the Cognitive subtest, \(F(2, 84) = 1.768, p = 0.174\), and the Communication subtest, \(F(2, 84) = 1.328, p = 0.271\), but trend towards significance on the Adaptive Behaviours subtest, \(F(2, 84) = 3.041, p = 0.053\) (see Table 2). This means that, while diagnosis had an effect when its relationship with AAC use was accounted for, individually there was no effect.
Table 1

*Descriptive Statistics*

<table>
<thead>
<tr>
<th>ACC Use</th>
<th>n</th>
<th>Developmental Profile 3 Subtest</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Adaptive Behaviour</td>
<td>Cognition</td>
<td>Communication</td>
<td></td>
</tr>
<tr>
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<td>Diagnosis</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Uses AAC</td>
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<td>50.00</td>
<td>0.000</td>
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<td>CP</td>
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<td>50.00</td>
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<td>61.43</td>
<td>30.237</td>
<td>61.43</td>
<td>30.237</td>
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<td>Total</td>
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<td>58.95</td>
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<td>62.67</td>
<td>27.641</td>
<td>58.89</td>
</tr>
<tr>
<td>T</td>
<td>90</td>
<td>67.16</td>
<td>28.961</td>
<td>66.90</td>
<td>29.302</td>
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</table>

*Note.* AAC = Augmentative and alternative communication; ASD = Autism spectrum disorder; DS = Down syndrome; CP = Cerebral palsy.
Table 2

Univariate Results of AAC Use and Diagnosis

<table>
<thead>
<tr>
<th>DP-3 Subtest</th>
<th>SS</th>
<th>df</th>
<th>MS</th>
<th>F</th>
<th>p</th>
</tr>
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<td>AAC Use</td>
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<td></td>
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<tr>
<td>Cognitive</td>
<td>3000.220</td>
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<td>.033</td>
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<td>Communication</td>
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<td>1953.333</td>
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<td>Diagnosis</td>
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<tr>
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<td>1708.431</td>
<td>3.041</td>
<td>.053+</td>
</tr>
<tr>
<td>Cognitive</td>
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<td>2</td>
<td>1145.622</td>
<td>1.786</td>
<td>.174</td>
</tr>
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<td>2</td>
<td>869.513</td>
<td>1.328</td>
<td>.271</td>
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<td>Adaptive Behaviour</td>
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<td>2</td>
<td>3448.891</td>
<td>6.140</td>
<td>.003**</td>
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<tr>
<td>Cognitive</td>
<td>6416.174</td>
<td>2</td>
<td>3208.087</td>
<td>5.002</td>
<td>.009**</td>
</tr>
<tr>
<td>Communication</td>
<td>6312.486</td>
<td>2</td>
<td>3156.243</td>
<td>4.819</td>
<td>.010*</td>
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<td>Error</td>
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<tr>
<td>Adaptive Behaviour</td>
<td>47183.665</td>
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<td>561.710</td>
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<tr>
<td>Cognitive</td>
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<td>84</td>
<td>641.364</td>
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<tr>
<td>Communication</td>
<td>55013.936</td>
<td>84</td>
<td>654.928</td>
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<td>Corrected Total</td>
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<tr>
<td>Adaptive Behaviour</td>
<td>74649.822</td>
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<tr>
<td>Cognitive</td>
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<tr>
<td>Communication</td>
<td>75276.322</td>
<td>89</td>
<td></td>
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</tr>
</tbody>
</table>

Note. AAC = Augmentative and alternative communication; DP-3 = Developmental Profile 3

* p < 0.05; ** p < 0.01; + trend towards significance

There was a significant interaction between AAC Use and Diagnosis $F(6, 164) = 4.191, p = 0.001$. It appears as though children with Down syndrome who do not use AAC devices have higher scores than those with ASD and CP, whereas those who use AAC devices demonstrate
more similar scores. This interaction was significant and participants showed similar profiles across the Adaptive Behaviours subtest, $F(2, 84) = 6.140, p = 0.003$, the Cognitive subtest, $F(2, 84) = 5.002, p = 0.009$, and the Communication subtest, $F(2, 84) = 4.819, p = 0.10$.

**All Diagnoses**

The results from the one-way MANOVA examining the differences based on AAC use, regardless of diagnosis, was not significant, $F(3, 87) = 1.932, p = 0.130$ (see Table 3). This means that, without considering their diagnosis, AAC users did not significantly differ from non-users in terms of communication skills, cognitive skills, and adaptive behaviours.

<table>
<thead>
<tr>
<th>DP-3 Subtest</th>
<th>SS</th>
<th>df</th>
<th>MS</th>
<th>$F$</th>
<th>$p$</th>
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<tbody>
<tr>
<td>AAC Use</td>
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<tr>
<td>Adaptive Behaviour</td>
<td>3750.660</td>
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<td>3750.660</td>
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<td>Cognitive</td>
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<td>2.397</td>
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<tr>
<td>Error</td>
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<td></td>
</tr>
<tr>
<td>Adaptive Behaviour</td>
<td>74805.187</td>
<td>89</td>
<td>840.508</td>
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<tr>
<td>Cognitive</td>
<td>74717.789</td>
<td>89</td>
<td>839.526</td>
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<tr>
<td>Communication</td>
<td>74653.377</td>
<td>89</td>
<td>838.802</td>
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<td>Corrected Total</td>
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<td></td>
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</tr>
<tr>
<td>Adaptive Behaviour</td>
<td>78555.846</td>
<td>90</td>
<td></td>
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<tr>
<td>Cognitive</td>
<td>77497.670</td>
<td>90</td>
<td></td>
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<tr>
<td>Communication</td>
<td>76663.824</td>
<td>90</td>
<td></td>
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<td></td>
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</tbody>
</table>

*Note. AAC = Augmentative and alternative communication; DP-3 = Developmental Profile 3*

* $p < 0.05$
There were significant differences in performance based on diagnosis, regardless of AAC use, $F(6, 170) = 0.698, p = 0.000$. This was true on the Adaptive Behaviour, $F(2, 87) = 13.721, p = 0.000$, Cognitive, $F(2, 87) = 9.797, p = 0.000$, and Communication, $F(2, 87) = 8.686, p = 0.000$, subtests (see Table 4). Looking at the mean scores, it appears as though children with Down syndrome are likely to perform highest, followed by children with CP and closely by children with ASD.

Table 4

Univariate Results of Diagnosis, regardless of AAC Use

<table>
<thead>
<tr>
<th>DP-3 Subtest</th>
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<th>df</th>
<th>MS</th>
<th>$F$</th>
<th>$p$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adaptive Behaviour</td>
<td>17900.692</td>
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<td>8950.346</td>
<td>13.721</td>
<td>.000***</td>
</tr>
<tr>
<td>Cognitive</td>
<td>14045.875</td>
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<td>7022.937</td>
<td>9.797</td>
<td>.000***</td>
</tr>
<tr>
<td>Communication</td>
<td>12529.757</td>
<td>2</td>
<td>6264.878</td>
<td>8.686</td>
<td>.000***</td>
</tr>
<tr>
<td>Error</td>
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<td></td>
</tr>
<tr>
<td>Adaptive Behaviour</td>
<td>56749.130</td>
<td>87</td>
<td>652.289</td>
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<tr>
<td>Cognitive</td>
<td>62368.225</td>
<td>87</td>
<td>716.876</td>
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<tr>
<td>Communication</td>
<td>62746.566</td>
<td>87</td>
<td>721.225</td>
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<tr>
<td>Corrected Total</td>
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</tr>
<tr>
<td>Adaptive Behaviour</td>
<td>74649.822</td>
<td>89</td>
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<tr>
<td>Cognitive</td>
<td>76414.100</td>
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<tr>
<td>Communication</td>
<td>75276.322</td>
<td>89</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Note. AAC = Augmentative and alternative communication; DP-3 = Developmental Profile 3

*** $p < 0.001$
Autism Spectrum Disorders

The results from the one-way MANOVA were insignificant, $F(3, 52) = 0.912, p = 0.184$. This means that there was no difference between AAC users and non-users on the DP-3 subtests used. The univariate analyses, examining the effects on each subtest individually, confirmed that there were no significant differences between users and non-users on the Adaptive Behaviour, $F(1, 54) = 0.231, p = 0.632$, Cognitive, $F(1, 54) = 0.024, p = 0.877$, or Communication $F(1, 54) = 0.102, p = 0.750$, subtests (see Table 5). Children with ASD who use AAC devices did not significantly differ from those who did not use AAC devices.

Table 5

<table>
<thead>
<tr>
<th>DP-3 Subtest</th>
<th>SS</th>
<th>df</th>
<th>MS</th>
<th>F</th>
<th>p</th>
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<tbody>
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<td>AAC Use</td>
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<td>Adaptive Behaviour</td>
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<td>Cognitive</td>
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<td>.024</td>
<td>.877</td>
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<td>.102</td>
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<tr>
<td>Error</td>
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</tr>
<tr>
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<tr>
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<td>26411.554</td>
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</tbody>
</table>

*Note. AAC = Augmentative and alternative communication; DP-3 = Developmental Profile 3*
**Down Syndrome**

The results from the one-way MANOVA were significant, \(F(3, 22) = 3.690, p = 0.027\). There was a difference between AAC user and non-users who have Down syndrome. Univariate tests revealed significant differences in the Adaptive Behaviour, \(F(1, 24) = 11.161, p = 0.003\), Cognitive, \(F(1, 24) = 8.886, p = 0.003\), and Communication, \(F(1, 24) = 7.261, p = 0.013\), subtests (see Table 6). Children who used AAC devices had lower levels of adaptive behaviour, cognitive and communication skills.

Table 6

*Univariate Results of AAC Use for Children with Down Syndrome*

<table>
<thead>
<tr>
<th>DP-3 Subtest</th>
<th>SS</th>
<th>df</th>
<th>MS</th>
<th>(F)</th>
<th>(p)</th>
</tr>
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<tbody>
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<td><strong>AAC Use</strong></td>
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<td>Adaptive Behaviour</td>
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<td>9490.147</td>
<td>11.161</td>
<td>.003**</td>
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<td>Cognitive</td>
<td>8247.262</td>
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<td>.006**</td>
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<td>7600.009</td>
<td>7.261</td>
<td>.013*</td>
</tr>
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</tr>
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<td>928.135</td>
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<td>Adaptive Behaviour</td>
<td>29897.385</td>
<td>25</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Cognitive</td>
<td>30522.500</td>
<td>25</td>
<td></td>
<td></td>
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<tr>
<td>Communication</td>
<td>32720.962</td>
<td>25</td>
<td></td>
<td></td>
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</tbody>
</table>

*Note. AAC = Augmentative and alternative communication; DP-3 = Developmental Profile 3*

* \(p < 0.05\); ** \(p < 0.01\)*
Cerebral Palsy

The results from the one-way MANOVA were not significant, $F(2, 6) = 2.444$, $p = 0.167$. Similar to the results found for children with ASD, AAC users and non-users with CP did not differ significantly on the Adaptive Behaviour, $F(1, 8) = 0.056$, $p = 0.820$, Cognitive, $F(1, 8) = 0.259$, $p = 0.626$, or Communication $F(1, 8) = 0.030$, $p = 0.867$, subtests (see Table 7). Children with cerebral palsy who use AAC devices did not significantly differ from those who do not use AAC devices.

Table 7

<table>
<thead>
<tr>
<th>DP-3 Subtest</th>
<th>SS</th>
<th>df</th>
<th>MS</th>
<th>$F$</th>
<th>$p$</th>
</tr>
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<tbody>
<tr>
<td><strong>AAC Use</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adaptive Behaviour</td>
<td>48.286</td>
<td>1</td>
<td>48.286</td>
<td>.056</td>
<td>.820</td>
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<tr>
<td>Cognitive</td>
<td>203.175</td>
<td>1</td>
<td>203.175</td>
<td>.259</td>
<td>.626</td>
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<tr>
<td>Communication</td>
<td>24.008</td>
<td>1</td>
<td>24.008</td>
<td>.030</td>
<td>.867</td>
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<tr>
<td><strong>Error</strong></td>
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<tr>
<td>Adaptive Behaviour</td>
<td>6063.714</td>
<td>7</td>
<td>866.245</td>
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<tr>
<td>Cognitive</td>
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<td>7</td>
<td>799.745</td>
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<td><strong>Corrected Total</strong></td>
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<td></td>
<td></td>
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<tr>
<td>Adaptive Behaviour</td>
<td>6112.000</td>
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<tr>
<td>Cognitive</td>
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<td>8</td>
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<tr>
<td>Communication</td>
<td>5622.222</td>
<td>8</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

*Note. AAC = Augmentative and alternative communication; DP-3 = Developmental Profile 3*
Discussion

The prevalence rate of AAC users remained fairly consistent across disorders, ranging from 19.2 to 23.6%. This stability of AAC use was interesting, in that it was lower than previous estimates of 39% (Andersen et al., 2010). However, those estimates were for cerebral palsy only, which was the smallest sample size among the diagnoses analyzed in this study. Although small sample sizes makes generalization from our sample size problematic, the stability of the prevalence of AAC use supports the rate of approximately 1 in 5 children with developmental disorders.

The reason for the consistency of AAC use could be that there is similar access to services for all children with developmental disorders. It is unlikely that the same proportion of children among all disorders need communication aid, and the data on communication issues within each disorder support that. However, it seems to be true that a similar proportion of children with each disorder have access to AAC devices. This difference could be due to limited resources, whether through the government or schools.

When examining the differences between AAC users and non-users, the majority of significant findings were for individuals with Down syndrome, where children who did not use AAC tended to show higher levels of cognitive skills, communication skills and adaptability. Indeed, children with Down syndrome who did not use AAC performed in the average range for all subtests, while every single child with Down syndrome who used AAC performed in the lowest possible range, significantly below average. In contrast, all children with ASD and CP performed in the significantly below average range. This means that our sample of ACC non-users with Down syndrome is of considerably more average intellectual ability than every other
group. This accounts for our significant results in that area. Any difference found between AAC users and non-users is likely an artifact of this discrepancy.

There is also the issue of ceiling and floor effects. The measurement used, the DP-3, has a maximum score of 130 and a minimum score of 50. Of all participants, 63.7% scored the lowest possible scores on all the subtests, which consisted of 76% of children with ASD, 77.8% of those with CP, but only 27.2% of those with Down syndrome. This led to lower sensitivity, especially among children with ASD and CP, the two groups that did not demonstrate any significant differences based on AAC use. It is possible that using a test designed to assess performance of lower functioning individuals would be better suited to the task of finding differences between children with developmental disorders.

The consistency of the prevalence rate of AAC use, combined with the lack of significant difference among AAC users, whether combined or separated based on diagnosis (except Down syndrome), could mean AAC users and non-users simply share similar characteristics. AAC users can include individuals who range on their cognitive skills, communication skills, and adaptability. The same is true of non-users. This speaks to the heterogeneous nature of each group.

Another explanation could be that AAC users score closer to average, while non-users have a higher dispersion. For example, one could make the argument that AAC users must be low on communication skills, because they need to augment or replace their current communication modes; however, they cannot be too low because there is some degree of skill required to properly use an AAC device. Thus, AAC users represent the middle ground of skill level. The standard deviations for the AAC users were smaller than those of non-users, which indicates that the scores of AAC users are closer to the mean than non-users.
Some limitations in our current sample include the small and unbalanced sample size. Parents of individuals with ASD were the highest responders, followed by parents of children with Down syndrome, and finally by a small number of parents of children with CP. In subject recruitment, there were more national and regional websites for parents of children with autism than with Down syndrome, and many fewer websites for parents of children with CP. This meant the subject pool for CP was much lower, and likely affected the rate of response. Participants in the study filled out the survey online, which means that these individuals were internet-users who frequent parent support websites. This selection bias means that children whose parents are less technologically advanced or who do not seek out support from other parents online were less likely to respond. These individuals are probably less likely to seek out AAC systems for their child, especially high-tech systems, which may lead to an over-estimate of prevalence rates of AAC use. As well as a possible sampling issue, this could also affect equitable access to resources, as parents who do not use the internet or these support sites may be less aware of the services offered. However, in light of the fact that our estimate of AAC use among cerebral palsy was lower than previous results, it seems unlikely that this selection bias has inflated our prevalence rate.

**Future Research and Implications**

The current study aimed to fill a gap left by research in describing how AAC users differ from non-users. While the results comparing users to non-users were inconclusive, some interesting interpretations arose. There needs to be further examination of the range of scores AAC users achieve, to determine if they are a less dispersed than scores of non-AAC users. The researchers should be certain to employ tests that have sensitivity for detecting differences in the lower functioning range. By understanding the profile of AAC users, especially based on
different disorders, more educated recommendations can be made as to the type of AAC system that would benefit them the most.

The prevalence rates of AAC use were consistent at approximately 1 in 5 in for each diagnosis and for the combined sample. This leads to interesting questions about how many parents whose children need access to AAC systems, but run into difficulty in obtaining these systems. Questions arise about how many parents of children feel their child needs an AAC device and how many would like access to but are unable to receive an AAC system. Additionally, it is also important to examine awareness of services offered (or lack thereof), to determine if this is a factor in AAC usage. These data could help inform the healthcare system and individuals who work with children with developmental disabilities.
References


Appendix A

AAC Survey

AAC Use and Different Developmental Issues

Research Consent Form

McGill

AAC use among children with autism, cerebral palsy and Down syndrome

Researcher: Jessica Ganten, M.A. Candidate, School/Applied Child Psychology
Supervisor: Dr. Steven Shaw, PhD
Contact information: connectionslab.educ@mcmill.ca

Welcome to our study!

The Connections Lab at McGill University is investigating the differences in communication abilities of children with autism, Down syndrome, and cerebral palsy. More specifically, we are looking at similarities and differences in children who use and who don’t use augmentative or alternative communication (AAC) devices. We want to see if children with similar communication difficulties but with different developmental issues display different characteristics. In addition, we are looking for prevalence rates of AAC use in these populations. This study is being performed as part of the completion of a Master’s program at McGill University.

Your participation in the study involves completing a short, twenty minute, online survey. The survey will ask about your child’s communication skills, cognitive abilities, and adaptive behaviour. Your participation is voluntary and you may choose not to participate or to withdraw at any time by clicking the “exit survey” link on the top of the webpage or closing your browser. Your name will not be stored with your information, and neither your name nor your information will ever be revealed to those outside of the study.

You may choose to receive an e-mail with the results of the study once data has been collected. This information includes both the study results and the results for your child’s developmental profile on the communication skills, cognitive abilities, and adaptive behaviour sub-tests.

This is useful for understanding your child’s strengths and weaknesses and for developing specific interventions. This is optional and your e-mail address will never be resold or used again once the study is complete.

If you have any questions or concerns regarding your rights or welfare as a participant in this research study please contact the McGill Research Ethics Officer at 514.398.6891 or lynda.mcmill@mcmill.ca. The research ethics board number is 263-1210.

We look forward to having you participate!

* I have read the above and agree to participate in this study.

☐ Yes, I would like to participate in this study.
☐ No, I decline to participate in this study

Demographics

How old is your child?
Year: 
Month: 

When was your child born?
Date: DD MM YYYY

[Input fields for date]
### AAC Use and Different Developmental Issues

**Is your child male or female?**
- Female
- Male

**What is your relationship to your child?**

**What province/territory does your child live in?**
- Alberta
- British Columbia
- Manitoba
- New Brunswick
- Newfoundland and Labrador
- Northwest Territories
- Nova Scotia
- Nunavut
- Ontario
- Prince Edward Island
- Quebec
- Saskatchewan
- Yukon

**How would you refer to the area in which you live?**
- Urban
- Suburban
- Rural
- Other (please specify)
AAC Use and Different Developmental Issues

Does your child use augmentative or alternative communication (AAC) devices? These are any tools used to either aid or replace communication. For example, a text-to-voice computer or Picture Exchange System Communication System (PECS).

- [ ] Yes
- [ ] Yes, but only sign language
- [ ] No

AAC Use Questions

What sort of augmentative or alternative communication (AAC) devices does your child use? Please provide as much detail as possible about all communication aids used.

[ ]

At what age did your child first start using AAC devices?

[ ]

How often does your child use AAC devices now? Please specify frequency (per day, per week, etc.).

[ ]

How has your child's AAC use changed with time? Please provide as much information as possible.

[ ]

Do you feel as though your child has benefited from AAC use? Please elaborate.

[ ]

Developmental Profile

Instructions

Where to start

Read and answer of the questions on the following pages by selecting Yes or No.

Some of the questions refer to boys and some refer to girls. Please answer all of the questions regardless of whether your child is a boy or a girl.

When to stop

Please answer every item on each scale, even if it asks about skills or behaviours typical of a child much older or
# AAC Use and Different Developmental Issues

**Scoring Tips**

Most of the questions ask whether your child does perform a task. To score a Yes, your child must not only be able to perform the task, he or she must actually perform it some of the time. However, a few of the questions ask whether your child can perform a task. For these questions, a Yes means that your child has shown at least once that he or she is able to perform the task.

Some questions ask about skills or behaviours that your child mastered long ago and does not use any more, for example, "Does your child babble or use other sounds that seem to be attempts to talk?" Your child may have babbled for a while but then moved on to other forms of speech. You would answer Yes to this question because babbling is a behaviour that your child performed successfully in the past.

If you are not sure whether to answer Yes or No to a question, please make your best guess.

## Communication Scale - Page 1/2

1. Does your child usually look toward the source of a sound when it starts, such as a person beginning to talk?
   - Yes
   - No

2. Does your child babble to imitate words or speech, like he is pretending to talk?
   - Yes
   - No

3. Does your child raise her arms (or make a similar gesture) when she is about to be picked up?
   - Yes
   - No

4. Does your child sometimes imitate spoken "words" such as da-da or ma-ma?
   - Yes
   - No

5. Does your child answer an adult's words by using gestures, such as waving "bye-bye" when an adult says good-bye, or shaking the head up and down for "yes" or side to side for "no" when an adult asks something?
   - Yes
   - No
### AAC Use and Different Developmental Issues

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>6. Does your child clearly understand what you mean when you say &quot;no&quot;?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>7. Does your child tell that she wants &quot;more&quot; or &quot;another&quot; by using words or gestures?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>8. Does your child use sounds (real words or word-like sounds) to tell what he wants? An example is saying &quot;wa-wa&quot; for water.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>9. Does your child usually follow instructions of three or more words? Examples are &quot;Find your shoe,&quot; &quot;Bring the bottle,&quot; or &quot;Put the book on the table.&quot;</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>10. Does your child use a sentence of at least two words? Examples are &quot;Daddy goes,&quot; or &quot;Doggie drinks,&quot; or &quot;Baby walks.&quot;</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>11. Does your child correctly follow two-step instructions? Examples are &quot;Take off your clothes and get into the tub&quot; or &quot;Pick up the washcloth and wash your face.&quot;</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>12. Does your child put two or more words together to make sentences? Examples are &quot;Me go,&quot; &quot;You give,&quot; &quot;Tom want.&quot;</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Yes</td>
</tr>
</tbody>
</table>
### AAC Use and Different Developmental Issues

13. Does your child say the names of people whom she does not see every week (such as grandparents)?
   - Yes
   - No

14. Does your child name (not just repeat) at least 20 things that she sees in pictures?
   - Yes
   - No

15. Does your child either repeat parts of nursery rhymes or join in when others say them?
   - Yes
   - No

16. Does your child use at least 50 words when speaking?
   - Yes
   - No

17. Can your child say or sing at least two nursery rhymes, or sing two songs or commercials? Examples are "Happy Birthday" and "Jingle Bells." Your child must sing at least one verse from each song.
   - Yes
   - No

---

### Communication Scale - Page 2/2

18. Does your child understand at least three of the following four nonverbal gestures: (1) shoulder shrug, meaning "I don't know" or "I'm not sure"; (2) touching index finger to lips, meaning "be quiet"; (3) thumbs up, meaning "okay"; (4) a wink, either as a friendly greeting or to mean "I'm just kidding"?
   - Yes
   - No
<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>19. Can your child tell a story by looking at the pictures in a book?</td>
<td>Yes, No</td>
</tr>
<tr>
<td>It's okay if she leaves out parts of the story not shown by the pictures.</td>
<td></td>
</tr>
<tr>
<td>20. When asked, does your child sometimes give his first name and last</td>
<td>Yes, No</td>
</tr>
<tr>
<td>name?</td>
<td></td>
</tr>
<tr>
<td>21. Has your child sung a song of at least 30 words by himself?</td>
<td>Yes, No</td>
</tr>
<tr>
<td>22. Can your child tell people (by speaking or holding up fingers) how</td>
<td>Yes, No</td>
</tr>
<tr>
<td>old she is now, how old she was last year and how old she will be next</td>
<td></td>
</tr>
<tr>
<td>year?</td>
<td></td>
</tr>
<tr>
<td>23. Does your child recognize a printing of her first and last names?</td>
<td>Yes, No</td>
</tr>
<tr>
<td>24. Does your child show understanding of cause and effect by using</td>
<td>Yes, No</td>
</tr>
<tr>
<td>words such as because or since? An example is &quot;I should be able to</td>
<td></td>
</tr>
<tr>
<td>watch TV later tonight because there is no school tomorrow.&quot;</td>
<td></td>
</tr>
<tr>
<td>25. Can your child say at least two words that rhyme with each of the</td>
<td>Yes, No</td>
</tr>
<tr>
<td>following: head, tree, and nose?</td>
<td></td>
</tr>
</tbody>
</table>
AAC Use and Different Developmental Issues

26. Can your child read at least five written words and somehow show understanding of what they mean?
   - Yes
   - No

27. Can your child retell (in about 5 minutes) the plot of a story, play, or TV show? Your child must be able to tell the whole story (not just the exciting parts).
   - Yes
   - No

28. Does your child read a simple story aloud so that someone who is only listening can follow the story?
   - Yes
   - No

29. Does your child write or print from memory at least 20 words with correct spellings?
   - Yes
   - No

30. When your child wants to get in touch with someone, can he dial a phone number, call information for an unknown number, or look up an e-mail address on a computer?
   - Yes
   - No

31. Does your child talk to friends for at least an hour, most days? The conversation can be on the phone or during non-school "hang-out" time.
   - Yes
   - No

32. Has your child written and mailed a letter, without adult help except for spelling and the address?
   - Yes
   - No
### AAC Use and Different Developmental Issues

33. Does your child use a computer word processing program to complete written assignments for school?
   - Yes
   - No

34. Does your child, without help, write an e-mail or instant message that is at least five sentences long?
   - Yes
   - No

### Cognitive Scale - Page 1/2

1. Does your child laugh and show joy?
   - Yes
   - No

2. When you put a toy in your child’s hands, does she seem clearly aware of the toy for at least 5 seconds?
   - Yes
   - No

3. Does your child show likes or dislikes for some people, places, or things (other than food)?
   - Yes
   - No

4. Does your child hold things in both hands and bang them together?
   - Yes
   - No

5. Does your child imitate something an adult does, such as pointing?
   - Yes
   - No
## AAC Use and Different Developmental Issues

6. When you ask your child where someone is, does he usually look toward the person?
   - [ ] Yes
   - [ ] No

7. When you move a toy out of sight, does your child look for it in the right place?
   - [ ] Yes
   - [ ] No

8. When an adult points to something, does your child usually look where the pointed?
   - [ ] Yes
   - [ ] No

9. When asked, does your child point to at least one body part, either on herself or on a doll?
   - [ ] Yes
   - [ ] No

10. Does your child use pencils or crayons to make marks on any surface?
    - [ ] Yes
    - [ ] No

11. When asked, does your child point to something pictured in a book or magazine?
    Examples are "Show me the cow" or "Where is the truck?"
    - [ ] Yes
    - [ ] No

12. When asked, does your child ever give "one more" of something or take "one more" spoonful of food?
    - [ ] Yes
    - [ ] No
## AAC Use and Different Developmental Issues

13. When playing with a doll or stuffed animal, does your child show understanding that it represents a living thing? This would include trying to feed, dress, or put to sleep the doll or stuffed animal.
   - Yes
   - No

14. Does your child point to at least 20 things or pictures when they are named?
   - Yes
   - No

15. When asked, does your child point correctly to at least 2 colours?
   - Yes
   - No

16. Does your child say size words (*large* or *big*, and *little* or *small*) correctly?
   - Yes
   - No

17. Does your child try to copy a circle with a pencil or crayon?
   - Yes
   - No

18. Does your child understand what *three* means? For example, when asked, your child hands you three pieces from a bowl of candy.
   - Yes
   - No

19. Does your child ever sort things by color or shape or size?
   - Yes
   - No

20. When asked, does your child correctly place something *between*, *under*, or *over* something else? Your child must do all three placements.
   - Yes
   - No
## AAC Use and Different Developmental Issues

21. Does your child draw a cross or plus sign (+) after an adult makes one?
   - Yes
   - No

### Cognitive Scale - Page 2/2

22. Does your child know the difference between living and nonliving things? For example, does your child correctly name things that are alive (such as dogs, bugs, horses) and things that are not alive (such as chairs, blankets, toys)?
   - Yes
   - No

23. When you place six things in front of your child, can she count them correctly?
   - Yes
   - No

24. If your child listened to a short story of about 10 sentences, could he answer simple questions about the main facts of the story? Examples are the names of the main characters and the order of events in the story.
   - Yes
   - No

25. Can your child count up to 15?
   - Yes
   - No

26. Does your child draw or copy a square? The square must have right angle corners and all four sides should be about the same size.
   - Yes
   - No

27. When asked, can your child take out 13 objects from a group of 20 objects?
   - Yes
   - No
### AAC Use and Different Developmental Issues

28. Can your child tell a penny from a nickel and a dime by naming or pointing to the penny?
   - [ ] Yes
   - [ ] No

29. Can your child name the seven days of the week and answer which day comes before and after any given day? For example, your child must be able to tell you what day comes before and after Thursday.
   - [ ] Yes
   - [ ] No

30. Does your child print or write words using both capital and small letters correctly?
   - [ ] Yes
   - [ ] No

31. Does your child answer correctly when asked to subtract one single digit number from another? For example, "What is 9 minus 4?"
   - [ ] Yes
   - [ ] No

32. Does your child spell out loud common five-letter words that are not names? Examples include *water*, *chair*, *light*, and *mouse*.
   - [ ] Yes
   - [ ] No

33. Does your child answer correctly when asked for today's date, day, month and year? All four must be correct.
   - [ ] Yes
   - [ ] No

34. Does your child know and use at least three telephone numbers, mailing addresses, or e-mail addresses?
   - [ ] Yes
   - [ ] No
AAC Use and Different Developmental Issues

35. Does your child answer correctly when asked to multiply single-digit number by 2 (such as 8 times 2)?
   - Yes
   - No

36. Can your child tell the correct time to within 1 minute, using a regular dial clock with a big hand and a little hand?
   - Yes
   - No

37. Can your child do multiplication problems through the sixth table with only a few errors? For example, your child knows the answers to 6 times 9, 5 times 8, 4 times 3, and so on.
   - Yes
   - No

38. Does your child usually write script style, rather than printing letters?
   - Yes
   - No

Adaptive Behavior Scale - Page 1/2

1. When your child is hungry or thirsty and sees a bottle or bared breast, does he move toward it?
   - Yes
   - No

2. Does your child hold a bottle with his hands or feet while drinking from it? (This includes holding the breast while breast-feeding.)
   - Yes
   - No

3. Does your child try to get things that are just out of reach?
   - Yes
   - No
AAC Use and Different Developmental Issues

4. Does your child reach out and grab something that he could not reach from his original position?
   - Yes
   - No

5. Does your child pick up a toy that she has dropped on the floor?
   - Yes
   - No

6. Does your child drink from a cup or sippy cup while she is being held by someone else?
   - Yes
   - No

7. Does your child look for and find a toy that is covered or hidden and is at least 2 feet away?
   - Yes
   - No

8. Does your child help with dressing by holding out arms for the sleeves or feet for the shoes?
   - Yes
   - No

9. Does your child take off shoes or socks without help?
   - Yes
   - No

10. Does your child drink from a child-sized cup or glass without help? (A little spilling is okay.)
    - Yes
    - No
<table>
<thead>
<tr>
<th>Question</th>
<th>Option 1</th>
<th>Option 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>11. Does your child use a spoon without help? (A little spilling is okay.)</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>12. Does your child use a fork for eating solid foods?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>13. Does your child undo at least two of these fasteners: large buttons, snaps, shoelaces, zippers, Velcro?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>14. Does your child put things away in at least three different places? Examples are cereal box in pantry, toys in toy basket, pillow on bed, dirty clothes in hamper.</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>15. Does your child take off a pullover or T-shirt without help?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>16. Does your child put on his shoes? (It is okay if he does not tie his shoes or if he puts them on the wrong feet.)</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>17. Does your child urinate in the toilet without help? This includes taking down and pulling up clothing, and flushing the toilet.</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>18. Does your child usually wash his face and hands and dry them without help?</td>
<td>Yes</td>
<td>No</td>
</tr>
</tbody>
</table>
19. **Does your child select and play a video recording (DVD, videotape)?** This means being able to turn on the TV, insert the recording, and work the controls without help.
   - [ ] Yes
   - [ ] No

20. **Does your child dress completely except for shoelace tying?** Your child must manage regular shirt or blouse buttons and zippers.
   - [ ] Yes
   - [ ] No

21. **Does your child use a mouse, touchpad, or other computer pointing device to point and click on things on a computer screen?**
   - [ ] Yes
   - [ ] No

22. **Does your child care for his own bowel movements without help?** This means undressing, wiping, and dressing.
   - [ ] Yes
   - [ ] No

23. **Does your child operate a computer to play a simple computer game or use basic educational software?**
   - [ ] Yes
   - [ ] No

24. **Does your child usually use a table knife for spreading butter or jam on bread or crackers?**
   - [ ] Yes
   - [ ] No
<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>25. When asked, does your child state all of these items: first name, last name, sex, age, home city or province/territory?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>26. Can your child fix a bowl of cereal? This includes getting the bowl, cereal, and milk, and pouring both cereal and milk into the bowl.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>27. Is your child able to fix a sandwich? This includes getting the right foods from the kitchen and putting them together in a sandwich.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>28. Does your child dial a telephone call? Your child must enter at least seven numbers on the keypad to dial the call.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>29. Does your child wash herself without help? This means getting the bath or shower ready and washing and drying completely.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>30. Does your child use a knife correctly for cutting ground meat, toast, or other similar foods? He may still need help with unground meats (such as steak).</td>
<td></td>
<td></td>
</tr>
<tr>
<td>31. At a restaurant, does your child order from a menu without help?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### AAC Use and Different Developmental Issues

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>Does your child take care of a minor cut or scrape without help?</td>
<td>Yes, No</td>
</tr>
<tr>
<td>This means washing the injury and using antibiotic ointment and/or bandages.</td>
<td></td>
</tr>
<tr>
<td>Has your child prepared at least two of the following foods without help: eggs (any style), popcorn, canned or packaged soup, cake, hot cereal, pudding or Jell-O?</td>
<td>Yes, No</td>
</tr>
<tr>
<td>Does your child communicate with a friend using a telephone, computer, or cell phone, without adult help? The communication must last at least 30 minutes and happen at least twice per week.</td>
<td>Yes, No</td>
</tr>
<tr>
<td>Does your child use the Internet to find and play video games?</td>
<td>Yes, No</td>
</tr>
<tr>
<td>Does your child take care of money well enough that she is allowed to buy some things without asking or telling adults?</td>
<td>Yes, No</td>
</tr>
<tr>
<td>Can your child make a video recording of a TV program (using a digital video recorder, DVD recorder, or videotape recorder) without adult help?</td>
<td>Yes, No</td>
</tr>
</tbody>
</table>

### Survey Results

Do you wish to receive individual results of this study?

- Yes
- No
AAC Use and Different Developmental Issues

Do you wish to receive the aggregated results of this study?

☐ Yes
☐ No

Survey Results

Please enter your e-mail address below to receive individual or aggregated results for this study.

End of Survey

Thank you for participating in our survey!

If you have any questions or comments, please e-mail the experimenter:

Jessica Ganten
M.A. Candidate
School/Applied Child Psychology
McGill University
cosnctionslab.educ@mcgill.ca
Appendix B

Recruitment E-mail

Hello,

We are currently conducting a study at the Connections Lab at McGill University to examine the communication differences among Canadian children with autism, cerebral palsy and Down syndrome. More specifically, we are looking at differences among children who use and who don't use augmentative and alternative communication systems. We would appreciate it if you could post a link to our anonymous, twenty-minute, online survey on your [message boards/forums/website/newsletter – as applicable]. Here is what we would like to include:

Dr. Steven Shaw’s Connections Lab at McGill University is conducting a study that examines communication differences among Canadian children diagnosed with autism, cerebral palsy, and Down syndrome. Our anonymous, online survey takes less than 20 minutes to complete. Once complete, you have the option of receiving not only the results of the study, but also your child's individual results on the Developmental Profile 3 sub-tests completed. This is useful for understanding your child's strengths and weaknesses in their communication and cognitive abilities as well as their adaptive skills. For more information and to begin the survey, please click here: https://www.surveymonkey.com/s/NDXG89S

Or e-mail the investigator, Jessica Ganten, for additional information at connectionslab.educ@mcgill.ca.

Thank you very much for helping us with this study.

Jessica Ganten
M.A. Candidate
School/Applied Child Psychology
McGill University

Dr. Steven Shaw
Supervisor
Department of Educational Psychology
McGill University