Adaptive Functioning in Children with Developmental Delays Receiving Early Intervention:
Patterns and Profiles
Ashleigh E. Yule
McGill University, Montreal
August 2008

A thesis submitted to McGill University in partial fulfillment of the requirements for the degree of Master of Arts in Educational Psychology specializing in School/Applied Child Psychology

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Abstract

The present study was undertaken to investigate patterns of adaptive functioning in children with developmental delays in an early intervention (EI) context. The primary caregivers of 60 children with development delays receiving multidisciplinary EI services completed a standardized assessment of children’s adaptive behaviour and a demographic questionnaire. Adaptive variables were analysed across six diagnostic categories to determine if and how children with different developmental delays exhibited unique adaptive profiles within EI contexts. Distinctive patterns of adaptive behaviour emerged for children in each diagnostic grouping, suggesting that EI programming can be planned according to the diagnosis. Findings also provide a foundation for subsequent analyses of change over time in the adaptive functioning of children with developmental delays in EI contexts.
Résumé

Cette étude a été entrepris pour examiner le fonctionnement adaptif chez les enfants ayant des délais développementaux dans un contexte d’une intervention précoce. Les gardiens de 60 enfants ayant des délais développementaux qui reçoivent des interventions précoces multidisciplinaires ont complété une évaluation standardisée du comportement adaptif de leurs enfants ainsi qu’un questionnaire démographique. Les variables adaptives ont été analysées parmi 6 catégories diagnostiques pour déterminer si et comment les enfants ayant des délais développementaux ont montré des profils adaptifs uniques parmi des contextes d’intervention précoce. Des profils distinctifs du comportement adaptif ont été dévoilés chez les enfants dans chaque groupe diagnostic. Ceci suggère qu’une programmation d’intervention précoce peut être planifiée selon le diagnostic. De plus, les résultats ici fournissent une base pour des analyses subséquents du changement temporel dans le fonctionnement adaptif des enfants ayant des délais développementals dans une contexte d’une intervention précoce.
Acknowledgements

I would like to acknowledge my supervisor, Professor Ingrid E. Sladeczek, for her guidance, encouragement, and invaluable support throughout the planning and preparation of this thesis. I have been inspired by her balanced approach and expertise in the field, and I appreciate her attentive and enthusiastic supervision.

I would also like to thank my colleagues from the Canadian Early Intervention Research Team, Anastasia Karagiannakis, Nancy Miodrag, Jennifer Saracino, Heidi Oppen, as well as the countless research volunteers who provided me with valuable assistance and input for this project. The shared research planning, coordination, data collection, and scoring in our research laboratory were an immense help to me as I completed the data analyses and writing of this thesis.

Finally, I would like to express deep gratitude to my husband, parents, sister, extended family members, and friends for their support, attention, and patience during my educational pursuits, most especially this thesis. And to baby Noah, who joined me early in the course of this thesis, I was honoured to write this thesis with you in my life. I love you and I am so happy you are here.
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Introduction

Adaptive behaviour is generally defined as an individual’s ability to engage in daily activities to meet the personal and social demands of the environment (Heber, 1961; Nihira, Leland, & Lambert, 1993; Sparrow, Cicchetti, & Balla, 2005). It is considered an essential component of everyday functioning, and is generally conceptualized as a multidimensional construct that includes such skills as functional communication, social competence, self-help, and locomotion (Doll, 1935, 1965; Sparrow et al., 2005). Current models of adaptive functioning hold that the adequacy of an individual’s functioning in these areas is determined by the expectations and standards within that individual’s environment, and as such, that an individual’s adaptive functioning may change based on environmental factors, including changes in setting, interventions, or trauma (e.g., natural disasters, abuse) (McGovern & Sigman, 2005; Sparrow et al., 2005). Along these lines, adaptive behaviour relies not on an individual’s true ability to engage in daily activities, but rather on an individual’s typical performance of those daily activities. If an individual is capable of completing a particular task, but rarely does so when required, the individual’s adaptive functioning is considered to be lacking in that area (Lee & Park, 2007; Sparrow et al., 2005). The general conceptualization of adaptive functioning implies that it is developmental, becoming more complex as the individual grows older and the demands of that individual’s environment increase (Dykens, Hodapp, Ort, & Leckman, 1993; Sparrow et al., 2005).

Rationale

Adaptive behaviour represents a significant area of difficulty for children with developmental delays (American Association on Mental Retardation, 2002; de Bildt et al., 2005; Fidler, Hepburn, & Rogers, 2006; Loveland & Kelley, 1991; Volkmar et al., 1987). Children with developmental delays may have a specific congenital or acquired condition that leads to
delays in particular areas of functioning, including self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, or economic self-sufficiency), or be at risk for meeting these criteria later in life (Developmental Disability Assistance and Bill of Rights Act, 2000). Early intervention is crucial for children who have or are at risk for developmental delays as the early years of life provide the foundation for subsequent learning and development (Blackman, 2002; McCain, Mustard, & Shanker, 2007). Indeed, most early intervention (EI) programmes for children with developmental delays address adaptive skills such as functional communication, socialization, life skills, and leisure activities within their curricula because these skills play an essential role in supporting daily functioning (see Guralnick, 2003; Leaf & McEachin, 1999; Lovaas, 2003; Maurice, Green, & Luce, 1996; McCollum, 2002).

Although the provision of EI services is varied and depends upon the context within which services are delivered (e.g., medical, educational), the general consensus in the field is that EI includes systematically planned methods of intervention that are administered during the pivotal years of a child’s life and are geared at enhancing child development and sustaining and supporting the family (Bailey, Aytch, Odom, Symons, & Wolery, 1999; Blackman, 2002; Carpenter, 2005; Guralnick, 1997; Oser & Ayankoya, 2000). Nonetheless, diversity in EI programming makes its overall effectiveness difficult to assess at a global level (McCollum, 2002). Therefore, a narrower, more specialized approach that addresses the impact of EI on specific areas of development within specific populations is needed to establish what works best for whom (McCollum, 2002).

Given that many children with developmental delays receive EI services, and that one of the central goals of most EI programmes is to improve daily functioning (Blackman, 2002), assessing the impact of EI on adaptive functioning is a crucial element in evaluating the overall
effectiveness of EI for these children. Unfortunately, limited information is available about factors that might predict improvements in adaptive behaviour for children with developmental delays, even within EI contexts (Bryson, Rogers, & Fombonne, 2003; Fidler et al., 2006; McGovern & Sigman, 2005). Therefore, examining the impact of EI on the adaptive behaviour of children with developmental delays is an important step in ascertaining the overall impact of EI for these children and their families.

Before the effect of EI on the adaptive behaviour of children with developmental delays can be fully explored, it is necessary to develop a thorough understanding of the adaptive patterns and profiles of children with developmental delays who are receiving EI services. Although adaptive functioning profiles in children with certain types of developmental delays have previously been documented in normative and clinical samples (Carter et al., 1998; Dykens et al., 1993; Fidler et al., 2006; Sparrow et al., 2005), less information is available about such patterns within a wider range of specific diagnostic categories amongst children with developmental delays who are receiving EI services (Hauser-Cram, Warfield, Upshur, & Weisner, 2000; McCollum, 2002). For this reason, and as a first step in the process of examining change over time in the adaptive functioning of children with developmental delays in EI contexts, the present study consists of an analysis of these patterns and profiles within several diagnostic categories in an EI context.

Purpose

The purpose of the present study was to investigate patterns of adaptive functioning in children with developmental delays who are receiving EI services. The goal of the study was to determine if and how children with different developmental delays exhibit unique adaptive profiles within EI contexts. Adaptive variables that were analysed across diagnostic categories were functional communication, daily living skills, socialization, and motor skills, as well as overall adaptive
behaviour. These comparisons were evaluated in light of previously documented normative and clinical profiles of adaptive functioning in children with certain diagnoses (when available), to ascertain whether these established profiles are maintained in children who are receiving EI services. When previously documented profiles were not available for particular diagnoses (e.g., Global Developmental Disorder), emergent patterns of adaptive functioning in children with these diagnoses were analysed and described. Ultimately, the purpose of these analyses was to facilitate the eventual development of a broader picture of what works best for whom by assessing the impact of EI on adaptive functioning in children with developmental delays.
Literature Review

A review of the relevant literature is presented herein to develop a thorough understanding of the adaptive patterns and profiles of children with developmental delays. Working definitions of key constructs, namely adaptive functioning and developmental delay, are presented first, followed by a discussion of what is known about adaptive profiles in children with specific diagnoses, including Pervasive Developmental Disorder, Cerebral Palsy, Down syndrome, Fragile X syndrome, Global Developmental Delay, and Williams syndrome. Subsequently, early intervention (EI) theory and practice are reviewed in the context of children with developmental delays. Finally, the research questions addressed within the present study are presented in light of current conceptualizations of the impact of EI on the adaptive functioning of children with developmental delays.

Adaptive Functioning

Adaptive behaviour is generally defined as an individual’s ability to engage in daily activities to meet the personal and social demands of the environment (Nihira et al., 1993; Sparrow et al., 2005). Such daily activities include functional communication, appropriate social relations, play and leisure skills, locomotion, self-care, community skills, and personal safety (Doll, 1935, 1965; Sparrow et al.). Adaptive behaviour refers to the activities individuals actually do in day-to-day situations and is considered an essential component of everyday functioning (Dykens, 1995; Eaves & Ho, 2004).

Current models of adaptive functioning hold that the adequacy of an individual’s functioning in daily tasks is determined by the expectations and standards within that individual’s environment, and as such, that an individual’s adaptive functioning may change based on environmental factors, such as setting, interventions, or trauma (e.g., natural disasters, abuse; Eaves & Ho, 2004; McGovern & Sigman, 2005; Sparrow et al. 2005). Adaptive behaviour
relies not on an individual’s true ability to engage in daily activities, but rather on that individual’s typical performance of those daily activities. In this way, if an individual is capable of completing a particular task, but rarely does so when required, the individual’s adaptive functioning is considered to be lacking in that area (Lee & Park, 2007; Sparrow et al.). The general conceptualization of adaptive functioning implies that it is developmental, in that it typically becomes more complex as the individual grows older and the demands of that individual’s environment increase (Dykens et al., 1993; Sparrow et al., 2005). Because adaptive behaviour plays such a central role in determining an individual’s success in daily life, it is a fundamental consideration for populations with conditions that affect daily functioning.

Individuals with developmental delays are one such population.

*Developmental Delays*

Definitions of developmental delays vary as a function of the region or setting in which they are addressed (Saracino, 2007). As such, research addressing developmental delays must delineate a clear operational definition of the term developmental delay. For the purpose of this study, the selection of a definition that was inclusive, functional, and reflective of the individuals who commonly access EI services was paramount. To this end, in the context of the present study, the term developmental delay is used to refer to a specific congenital or acquired condition or delay that affects individuals’ self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, or economic self-sufficiency (Developmental Disability Assistance and Bill of Rights Act, 2000). This includes individuals who are diagnosed with or who are considered to be at risk for such delays. In accordance with this definition, and because the focus of the present study is to examine adaptive functioning of children with developmental delays in the context of EI, we are looking specifically at children from birth to nine years of age who meet, or who are at risk of meeting, the aforementioned criteria.
Adaptive Functioning in Children with Developmental Delays

Adaptive behaviour represents a significant area of difficulty for children with various developmental delays. In general, and by definition, developmental disabilities are associated with significant delays in psychosocial development and considerable difficulties in adaptive functioning. Thus, children with developmental delays typically struggle in more than one adaptive domain (Sigafoos, Roberts-Pennell, & Graves, 1999, Voelker, Johnston, Agar, Gragg, & Menna, 2007; Weiss, Diamond, Denmark, & Loveland, 2003). These challenges can have grave impact on eventual self-maintenance, independence, and overall adjustment in children with developmental disabilities as they become adolescents and adults (Fisch, Simensen, & Schroer, 2002). As such, developing an understanding of adaptive functioning in children with developmental delays is critical to effectively supporting these children.

With this in mind, exploring adaptive behaviour in the context of specific syndromes allows researchers to discern the way particular conditions affect adaptive behaviours in children affected by these syndromes (Dykens & Hodapp, 2001; Wishart, 2007). Researchers have examined adaptive behaviour deficits in individuals with several conditions that encompass developmental delays, including Pervasive Developmental Disorders (e.g., de Bildt et al., 2005; Fisch et al., 2002; Freeman, Del’Homme, Guthrie, & Zhang, 1999; Lee & Park, 2007; Loveland & Kelley, 1991; Volkmar et al., 1987), Cerebral Palsy (e.g., Berrin et al., 2007; Diamond & Kontos, 2004; Sayer, Pianta, Marvin, & Saft, 2001; Varni et al., 2005), Down Syndrome (e.g., Fidler et al., 2006; Wishart, 2007), Fragile X Syndrome (e.g., Fisch et al., 2002; Dykens et al., 1993; Roberts, Boccia, Baily, Hatton, & Skinner, 2001; Roberts, Hatton, & Bailey, 2001), and Williams Syndrome (Brock, Jarrold, Farran, Laws, & Riby, 2007; Mervis & Klein-Tasman, 2000; Mervis, Robinson, Rowe, Becerra, & Klein-Tasman, 2003). A review of this literature is presented to guide the current discussion of adaptive behaviour in children with developmental
delays, as adaptive profiles for each condition were explored in the present study. The literature is also reviewed to expose gaps in our understanding of the adaptive patterns and profiles of these groups in the context of EI programming.

*Children with pervasive developmental disorders.* As outlined in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR, American Psychiatric Association, APA, 2000), the Pervasive Developmental Disorder (PDD) diagnostic category comprises five persistent developmental disorders of infancy, childhood, or adolescence including Autistic Disorder, Rett’s Disorder, Childhood Disintegrative Disorder, Asperger’s Disorder, and Pervasive Developmental Disorder- Not Otherwise Specified (PDD-NOS). Broadly speaking, PDDs are characterized by difficulties with verbal and non-verbal communication, social reciprocity, and restricted patterns of behaviour (APA, 2000). In addition to the core features of PDD, many individuals with PDDs also demonstrate cognitive functioning significantly below normal levels (Altevogt, Hanson, & Leshner, 2008; Fombonne, 1999; Frith, 1996; Hill & Frith, 2003). Despite these commonalities, manifestations of symptoms in individuals with PDD vary widely to create a spectrum of impairment that can range from mild to severe (Hill & Frith, 2003). Overall, the cluster of common symptoms relates to impaired adaptive functioning in individuals with PDD (Fisch et al., 2002).

A number of researchers have examined adaptive behaviour in individuals with PDDs. This research has tended to focus on children with a subset of PDDs that include Autistic Disorder, Asperger’s Disorder, and PDD-NOS, as these are the most common PDDs and are commonly referred to as Autistic Spectrum Disorders (ASDs; Fombonne, 2003; Miodrag, 2007). It has been documented that lower overall levels of adaptive functioning are present in the ASD population (e.g., Bibby, Eikeseth, Martin, Mudford, & Reeves, 2002; Carter et al., 1998; Eaves...
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& Ho, 2004; Gillham, Carter, Volkmar, & Sparrow, 2000; Lee & Park, 2007; McGovern & Sigman, 2005). For example, several research groups, including Loveland and Kelley (1991), Carter and colleagues (1998) and Gillham and colleagues (2000) have provided evidence for unique adaptive profiles in individuals with ASD, in that individuals with ASD tend to exhibit significant deficits in socialization, relative strengths in daily living skills, and intermediate communication skills. This unique profile of adaptive behaviour has been substantiated in normative and clinical samples of individuals with ASD, but its presence in ASD groups who have received or who are receiving EI services is less clear (Eaves & Ho, 2004).

Because adaptive behaviour is modifiable (Sparrow et al., 2005), researchers have also examined developmental change in the adaptive behaviour of individuals with ASD. For example, McGovern and Sigman (2005) assessed continuity and change in a variety of characteristics essential to the adjustment of individuals with ASD over the life span. Noting a lack of available information about developmental change in the adaptive behaviour of individuals with ASD, the researchers set out to test the hypotheses that (a) children with ASD would demonstrate improvements in adaptive functioning from middle childhood to adolescence and young adulthood with rates of improvement positively associated with intelligence, and (b) children with ASD who were more involved with their peers in the middle childhood period would make larger gains in adaptive behaviour than children who were less socially engaged. By assessing diagnosis, adaptive functioning, and emotional responsiveness in 48 adolescents and young adults with ASD via parent interview at two time points spanning seven years (12-13 years of age and 19-20 years of age), McGovern and Sigman confirmed that adaptive behaviour levels were lower for individuals in their ASD sample than for individuals in normative samples. Further, significant improvements in most areas of adaptive behaviour, with the exception of the communication domain, were reported from middle childhood through young adulthood. These
improvements were associated with cognitive functioning, and were also related to the percentage of time the children with ASD spent in play with peers in the middle childhood years.

McGovern and Sigman (2005) summarized their long-term longitudinal study by positing that the observed improvements in the adaptive functioning of children and adolescents with ASD could be accounted for, at least in part, by the individual’s intellectual functioning and opportunities for social engagement. However, because all data were collected from parent reports, they advised that future research should incorporate direct observation over multiple time points to rule out the possibility that parents simply habituate to their children’s behaviour and, as a result, see it as less severe than in the past. An additional limitation of this project is that it did not examine continuity and change in ASD in relation to environmental contexts (educational, therapeutic, familial, and cultural factors). To address this issue, the authors recommended that future research incorporate environmental measures (e.g., intervention measures, familial assessments) to flesh out the degree to which the development of children with ASD is associated with their intervention experiences. The present study is part of a larger longitudinal research project that is integrating such recommendations.

In their prospective longitudinal study of young children with social and language characteristics suggestive of ASD, Eaves and Ho (2004) examined the stability, reliability, and validity of early ASD screening over a two-year period. As part of this research, the authors also investigated how the children’s cognitive skills, language, and adaptive behaviour changed over time. Eaves and Ho assessed prospectively a sample of 49 children screened as being at-risk for ASD at 2½ years and at 4½ years on measures of cognitive and adaptive functioning, as well as diagnostic and treatment variables (e.g., types of intervention, number of hours of treatment). Results indicated general stability in the children’s clinical diagnoses between time points (i.e., 39 of the children remained in the same diagnostic category, 5 exhibited more signs of ASD, and
5 exhibited fewer signs of ASD). Eaves and Ho (2004) also found that cognitive ability improved significantly by more than 20 IQ points in about one third of the children over time, while another third declined over 20 IQ points.

Contrary to the findings from McGovern and Sigman (2005), and of particular interest in light of the present study, Eaves and Ho (2004) reported that adaptive behaviour decreased over time in children who had been diagnosed with ASD, while children who had not been diagnosed with ASD at Time 1 had improved adaptive behaviour at Time 2. This was true in the children’s overall adaptive behaviour as well in every subdomain of adaptive behaviour, namely communication, socialization, daily living skills, and motor skills. Additionally, no relationship was found between the amount of treatment the children had received and the amount of change on assessments of autistic behaviour, cognitive abilities, or adaptive functioning.

The authors explained the decrease in adaptive functioning for the children with ASD by hypothesizing that lower levels of adaptive functioning become more apparent as children grow and become more accountable for their everyday behaviour. Eaves and Ho also addressed the lack of relationship between treatment and positive outcomes by postulating that the specific nature and number of hours of treatment may not be as important in predicting gains as the characteristics of the children themselves, such as the severity of ASD. However, another plausible explanation for this finding is the pooling of the children’s treatment data into only two treatment measures, namely Applied Behaviour Analysis (ABA)/non-ABA and hours of intervention (which combined many different types of intervention, including preschool or daycare, speech-language therapy, behavioural consultation, home based ABA, government funded services, and privately funded services). Despite this aggregation of diverse forms of intervention, the authors themselves acknowledged many variations in the implementation and quality of each intervention. Given that even very small differences in intervention variables may
be associated with dramatically different outcomes only a few years later (Koegel, Koegel, & McNerney, 2001), the pooling of these intervention variables may have masked true relationships between the amount of time children spent in various interventions and improvements in the children’s functioning in the study. The authors recommended that future research efforts must examine which components of EI affect which domains of functioning for which children.

Overall, it is clear that children with ASD demonstrate considerable deficits in adaptive behaviour, and that adaptive behaviour is an important area to be addressed within EI. However, the results of these studies create uncertainty as to the actual impact specific EI models have on adaptive functioning. Ultimately, what remains to be seen is which EI components have the most impact on adaptive functioning for children with ASD.

Children with cerebral palsy and other muscular disorders. Cerebral Palsy (CP) is a permanent, non-progressive developmental disorder resulting from damage to specific areas of the brain before, at, or shortly after birth (Berrin et al., 2007; Sayer et al., 2001). Depending on the type and severity of brain injury, individuals with CP may exhibit a number of functional problems including difficulties with movement, muscle function, feeding, cognitive functioning, problem solving, and play (Berrin et al., 2007; Manuel, Naughton, Balkrishnan, Smith, & Koman, 2003; Sayer et al., 2001). CP is divided into four major classifications to describe the different associated movement impairments including spastic, dyskinetic, ataxic, and mixed (Bax et al., 2005). These classifications reflect the area of the brain damaged and the resulting symptomatology. Of these subtypes, spastic CP is most common, making up approximately 85% of cases (Panteliadis & Strassburg, 2004). CP has three diagnostic subtypes that reflect which parts of the body are most affected: Spastic hemiplegia, in which one side of the body is affected, spastic diplegia, in which the lower limbs are more affected than upper limbs, and spastic
quadriplegia, in which all four limbs are affected (Berrin et al., 2007). Across these classifications and subtypes, children with CP report significantly lower health-related quality of life than healthy controls, reflecting the numerous health complications associated with this disorder (Berrin et al., 2007; Varni et al., 2005).

A number of recent medical, educational, and mental health research has focused on CP and issues related to the disorder, including updated definitions and classifications; pain, fatigue, and school performance; family functioning; parental stress; mothers’ representations of their relationships with their children; and quality of life and self-concept (see Bax et al., 2005; Berrin et al., 2007; Diamond & Kontos, 2004; Manuel et al., 2003; Russo et al., 2008; Sayre, Pianta, Marvin, & Saft, 2001; Varni et al., 2005). Daily functioning is an important consideration within each of these topics, and several researchers have examined elements of adaptive behaviour in children with CP. For example, Diamond and Kontos (2004) studied families of toddlers with CP, Down syndrome, and nonspecific developmental delays, and demonstrated lower levels of overall adaptive and motor functioning in children with CP than in children with other developmental disabilities and children without CP. However, only the motor subdomain of the Vineland Adaptive Behavior Scales (VABS; Sparrow, Balla, & Cicchetti 1984) was administered in this study, creating questions about other areas of adaptive functioning for children with CP. In a similar vein, Sayre and her colleagues (2001) examined mothers of children with CP, specifically in terms of the mothers’ representations of their relationships with their children, parenting behaviour, and feeding sensitivity. Here again, the VABS (Sparrow et al., 1984) was administered as part of the assessment battery. However, only overall adaptive behaviour was analysed and reported, providing information about the children’s global levels of adaptive functioning, but providing no details about the children’s specific patterns of adaptive behaviour. Ultimately, little information is available about global adaptive profiles in children
with CP. As such, the present study sought to provide a preliminary picture of the adaptive profile in children with CP across domains of daily functioning as they are directly relevant to intervention services for these children (Berrin et al., 2007).

*Children with down syndrome.* Down syndrome (DS) is the most common genetic disorder and the most frequent cause of cognitive impairments (Wishart, 2007). In the majority of cases, DS is caused by an extra chromosome 21, which leads to a number of developmental delays and functional deficits (Fidler et al., 2006). Considerable research has been devoted to describing patterns of functioning and outcomes associated with DS (Fidler et al., 2006). Much of this research has centred on deficits in verbal processing in individuals with DS (Byrne, Buckley, MacDonald & Bird, 1995; Cascalla, 2005; Dykens, Hodapp, & Finucane, 2000; Hesketh & Chapman, 1998; Laws, 1998, Kamiloff-Smith, 2007). In addition, researchers have shown that individuals with DS show relative strengths in visuo-spatial processing, and that these skills are typically stronger than verbal processing skills in individuals with DS (Fidler et al., 2006; Jarrold, Baddeley & Hewes, 1999; Klein & Mervis, 1999; Wang & Bellugi, 1994; Wishart, 2007).

In terms of verbal abilities, many individuals with DS exhibit severe language delays, including a discrepancy between expressive and receptive language and large deficits in vocabulary size (Berglund, 2001; Chapman & Hasketh, 2000; Fidler et al., 2006). Children with DS also show particular deficits in the development of grammar, and many individuals with DS struggle with early stages of morphological and syntactic development (Abbeduto et al., 2003; Fowler, 1990). The majority of children with DS experience a prolonged period of unintelligible speech, often until age 5 or 6 (Miller & Leddy, 1999).

Another pattern of development in DS involves difficulties with motor skills and motor planning (Jobling, 1999). Specifically, Jobling (1998) found that children with DS show delays
in the development of aspects of gross motor and fine motor skills. Relative weaknesses have also been demonstrated in motor planning, or praxis (Mon-Williams et al., 2001).

Despite these language and motor delays, many children with DS show strengths in social functioning (Fidler et al., 2006; Gibbs & Thorpe, 1983; Rodgers, 1987; Wishart, 2007). Individuals with DS may also show relative competence in developing interpersonal relationships (Freeman & Kasari 2002) and may use these relative strengths in social skills to compensate for weaker domains of functioning (Fidler et al., 2006; Pitcairn & Wishart, 1994).

Taken together, the documented communicative, social, and motor characteristics in children with DS suggest a provisional adaptive profile for this population. In their recent investigation of behavioural phenotypes in DS, Fidler et al. (2006) compared the learning and adaptive behaviour of eighteen 2 to 3-year-olds with DS to a comparison group of nineteen 2 to 3-year-olds with mixed developmental disabilities, and a second comparison group of 24 typically developing children. The purpose of this study was to map the behavioural characteristics and outcomes associated with DS to gain a better understanding of the early developmental trajectory of this disorder. As assessed by the Mullen Scale of Early Learning (Mullen, 1995) and the VABS (Sparrow et al., 1984), the children with DS in this study did show relative strengths on direct developmental measures in the areas of visual processing and receptive language, and relative weaknesses in gross motor skills and expressive language. In terms of adaptive behaviour as reported by the children’s caregivers, the children with DS in this study showed relative strengths in socialization and relative weakness in communication and motor skills. Thus, Fidler and her colleagues presented clear evidence of an adaptive profile associated with DS.

As an adjunct to this emergent profile, Wishart (2007) and Cebula and Wishart (2008) have recently presented reviews of empirical evidence that children with DS do exhibit
limitations in at least some aspects of socio-cognitive development, including the misuse or underuse of social skills in interpersonal learning contexts. With this in mind, there is a need to refine what is known about social functioning in particular within adaptive profiles in DS, and to try to better map out these profiles to help determine what approaches offer the most promise for improving outcomes for children with DS receiving EI services (Wishart, 2007).

Children with fragile X syndrome. Fragile X syndrome (FXS) is a genetic disorder that impairs development and is the most common inherited cause of mental retardation (Hagerman, 2002; Mazzocco et al., 2006). FXS results from a mutation on the X chromosome and, as such, is diagnosed through DNA analysis (Roberts, Hatton, & Bailey, 2001). As FXS is carried on the X chromosome, more males than females are affected because males have only one X chromosome, whereas females have two and are thus less likely to have two mutated chromosomes (Roberts, Hatton, & Bailey, 2001). Due to males’ higher prevalence in FXS, the bulk of the research on FXS has been conducted with males.

Most males with FXS have moderate to severe mental retardation and a host of behavioural issues, including stereotyped behaviours, attention deficits, hyper-arousal, sensory processing difficulties, anxiety, and atypical social functioning such as social avoidance, social anxiety, and deficits in social language (Bailey, Aytch, Odom, Symons, & Wolery, 1999; Boccia & Roberts, 2000; Mazzocco et al., 2006; Roberts, Boccia, et al., 2001). Conversely, females with FXS tend to be less affected, almost always to a lesser degree than boys with the syndrome (Roberts, Hatton, & Bailey, 2001). Females with FXS may appear normal or may have mild to moderate mental retardation and may exhibit atypical language use that impacts social functioning (Mazzocco et al., 2006). These problems correspond to impairments in adaptive functioning for males with FXS, and to a lesser degree, females with FXS. However, compared to research examining adaptive behaviour in other syndromes (e.g., ASD, DS), relatively little
recent work has examined important life skills in children with FXS (Dykens, 1995; Kau, Meyer, & Kaufmann, 2001; Roberts, Hatton, & Bailey, 2001).

Based on the available research on examining adaptive behaviour in FXS, boys with FXS show steady growth in adaptive skills throughout childhood, reach a peak of adaptive development in late childhood and early adolescence, and then show declines from this point (Dykens et al., 1993). Further, males with FXS show relative strengths in daily living skills (Dykens et al., 1993; Wolf-Schein et al., 1987) and older males with FXS show relative weaknesses in socialization (Dykens et al., 1993; Wolf-Schein et al.). Male toddlers with FXS tend to demonstrate at least moderate delays across developmental milestones, including sitting, crawling, walking, and first words; show moderate to severe functional impairments in social skills, behaviour, receptive and expressive language development, and hypotonia; and tend to exhibit mild to moderate autistic behaviour (Philofsky, Hepburn, Hayes, Hagerman, & Rogers, 2004; Roberts, Hatton, & Bailey, 2001). Although such research is suggestive of a likely adaptive profile for males with FXS, the interpretations that can be drawn from such findings are limited due to outdated research which has not been revised. Thus, the present research project aimed to examine the FXS adaptive profile in an EI context.

Children with global developmental delay. There is a scarcity of research examining developmental profiles in children with Global Developmental Delay (GDD). Even so, in recent literature, GDD is usually defined as a delay of two standard deviations or more below the mean on age-appropriate, standardized, norm referenced testing in two or more domains, including motor, cognitive, communication, personal/social, or activities of daily living (Shevell, Majnemer, Platt, Webster, & Birnbaum, 2005). Compared to the skill attainment of chronological peers, GDD is associated with age-specific deficits in adaptation and learning skills (Eapen et al., 2006; Shevell et al., 2005). It typically describes children who have
heterogeneous etiologic profiles and in practice is sometimes used as a “catch all” diagnostic
class when intellectual disability is present but other developmental disorders have been ruled
d out (Shevell et al., 2003).

Recent research efforts have focused on identifying children with GDD, describing their
development, and examining the possible benefits of EI for young children with the diagnosis. In
one such study, Shevell and his colleagues (2005) undertook a prospective cohort study of 48
children with GDD in their preliminary investigation of developmental delay subtypes. The
children were assessed on measures of developmental and functional status, first at a mean age of
3.4 years and again at a mean age of 7.3 years. Overall developmental status for the group was
found to be more than two standard deviations below the mean on the Battelle Developmental
Inventory (BDI; Newborg, 2004), with the majority of the cohort performing 1.5 standard
deviations below the mean on the individual domains of the BDI. As such, the developmental
status of the group was significantly below expected levels based on chronological age.

In terms of functional status, or the children’s actual behaviour in everyday activities
pertaining to individual and social competence, group means were again well below normative
means on the VABS (Sparrow et al., 1984). Here, relatively stronger performance in the
socialization domain was noted compared with communication and especially daily living skills.
The authors noted that, although many children in the cohort scored below the clinically
meaningful cut-off on the VABS, the children’s adaptive profiles were nonetheless better than
would be predicted based on their developmental status. Shevell et al. (2005) interpreted this
finding to mean that, to some degree, the children were able to compensate for their
developmental impairments. The authors hypothesized that the children were able to compensate
either through modification of everyday tasks and/or through environmental adjustments that
enabled them to perform some activities independently. Ultimately, however, Shevell et al.
(2005) indicated that children with an early diagnosis of GDD had persistent significant difficulties in development and adaptive functioning. In addition, their review of the literature revealed a lack of prospective studies characterizing the outcomes of young children diagnosed with GDD.

Two exceptions to the shortage of research in GDD are a cross-cultural study of preschool children diagnosed with GDD in the United Arab Emirates (Eapen et al., 2006) and a multidisciplinary initiative aiming to strengthen current definitions of and diagnostic procedures for GDD (Ghosh, 2008). In terms of the cross-cultural research, Eapen et al. did not directly examine developmental or adaptive profiles in children with GDD. However, they did establish the prevalence and correlates of GDD in the United Arab Emirates. Specifically, Eapen and her colleagues reported that prevalence rates in the United Arab Emirates mirrored those of other developing nations at 8.4% (±2.06%). The authors also found that GDD diagnoses were associated with pregnancy and birth complications, poor maternal education, familial developmental problems, traumatic events, and behavioural problems in children. Based on these findings, Eapen et al. posited that ascertaining individual, psychosocial, and family risk factors was an important step in gathering clues regarding predisposing, precipitating, and perpetuating factors relevant to this population. In accordance with previous research (Majnemer, 1998), they also highlighted the need for a programmatic approach for children with GDD.

The multidisciplinary GDD initiative, launched in 2007, involves an international working group comprised of representatives of Developmental-Behavioural Pediatrics, Child Neurology, Child Psychiatry, General Pediatrics, Psychology, Epidemiology, Speech-Language Pathology, Occupational Therapy as well as administrators and coordinators involved in the care of children with developmental difficulties. The purpose of the project is to come to an international multidisciplinary agreement about the population of young children presenting with
persistent global developmental delays (S. Ghosh, personal communication, August 7, 2008). The team has sought to delineate international consensus criteria for diagnosis and management of children with developmental impairments and will be engaging in pilot research geared at elucidating the features, prevalence, and etiology of GDD (S. Ghosh, personal communication, August 7, 2008). Unfortunately, published findings are not yet available as this work is currently underway in Australia, Brazil, Canada, China, Colombia, Finland, Iceland, Kuwait, Malaysia, Sweden, Turkey, the United Arab Emirates and the United Kingdom.

Referral rates for EI services are rising among children with nonspecific GDD (Eapen et al., 2006; S. Ghosh, personal communication, August 7, 2008), creating a need to further understand the diagnosis. In the interim, researchers have acknowledged that GDD is a heterogeneous condition and children with GDD and other delays are often referred for nonspecific EI services regardless of their specific etiology (Shevell et al., 2005). Therefore, examining the actual adaptive profiles of children within this group was deemed important to inform service providers and researchers alike about the real presentation of this group in EI contexts.

Children with Williams syndrome. Williams syndrome (WS) is a genetic disorder caused by a deletion of approximately 25 genes in the 7q11.23 region of chromosome 7 (Brock et al., 2007). WS is characterized by unique cognitive, personality, and adaptive profiles, as documented in a number of studies of children and adolescents with WS (Brock et al.; Dykens, 2003; Farran & Jarrold, 2003; Mervis & Klein-Tasman, 2000; Mervis, Klein-Tasman, & Mastin, 2001; Mervis et al., 2003). Specifically, most individuals with WS have mild to moderate intellectual disability, with strengths in auditory rote memory and language and extreme weakness in visuo-spatial construction relative to overall intellectual ability (Farran & Jarrold; Mervis & Klein-Tasman). Indeed, language abilities are considered by most researchers to be a
relative strength for individuals with WS (e.g., Bellugi, Lichtenberger, Jones, Lai, & St.George, 2000; Brock et al.; Mervis et al., 2001).

Mervis and Klein-Tasman (2000) thoroughly reviewed research on the personality profile in WS in their review of cognition, personality, and adaptive behaviour in individuals with WS. Specifically, they described evidence that children with WS demonstrate high gregariousness, empathy, sensitivity to criticism, and anxiety, as well as strong affinity for others and a marked lack of social inhibition. The authors reported that these and other features of cognition and personality in individuals with WS are thought to contribute to their documented difficulties in establishing and maintaining friendships.

Of particular relevance to the present study, Mervis and Klein-Tasman (2000) also described an adaptive behaviour profile in WS, including strength in socialization skills and communication skills, and marked weakness in daily living skills. This general profile was expounded by subsequent research on 4- to 8-year-olds with WS by Mervis, Klien-Tasman, and Mastin (2001), who elaborated that the deficits in daily living skills exhibited by children with WS were even more pronounced for children who were assessed to have weak motor skills. The authors theorized that this weakness, combined with children’s significant visuo-spatial difficulties and low tolerance for frustration, led to a general reluctance to attempt daily living skills such as dressing, cleaning, or preparing food and ultimately contributed to their weak daily living skills. Overall, as reported by Mervis and Klein-Tasman and Mervis et al. (2001), the adaptive profile in children with WS is consistent with both the cognitive and personality profiles associated with this disorder. Since children with WS often receive EI services through childhood (Brock et al., 2007), the documented adaptive profile in WS was explored within the current study.
Children with other developmental delays. PDDs, CP, DS, FXS, GDD, and WS account for many of the disorders that are typically seen in EI contexts (Shevell, Majnemer, Rosenbaum, & Abrahamowicz, 2001). As such, these particular groupings were identified for evaluation in the present study. However, this does not imply that adaptive profiles in developmental disorders other than those identified are not relevant to EI service providers and researchers. Thus, the inclusion of children with diagnoses outside of the outlined groupings was identified as an option if such children were identified for participation through the recruitment procedures of the present study.

**EI for Children with Developmental Delays**

The provision of EI programming for children with developmental delays is based on the notion that the early years are a time of critical importance for child development (McCain et al., 2007; McCollum, 2002). For children with developmental delays, the provision of interventions during this early period is considered best practice because the first years of life provide a basis for the development of future skills and competencies (McCain et al.). Indeed, most health care providers attempt to identify children with developmental and behavioural problems as early as possible in order to confer the potentially enormous benefits of EI as such services provide the treatment and information necessary to facilitate optimal child development (Blackman, 2002; Eaves & Ho, 2004; Glasgoe & Robertshaw, 2007; Guralnick, 1998; Reynolds et al., 2007). The importance of EI for young children with developmental delays is becoming more strongly advocated in the field by researchers and practitioners given the significance of early neurological development (Blackman, 2002; McCain et al., 2007).

Accordingly, many EI services exist for children with developmental delays (Blackman, 2002; Diamond & Kontos, 2004; Guralnick, 1997; McCollum, 2002). Services tend to be cross-categorical, rather than disability-specific, and aim to prevent, improve, or remediate limitations
Adaptive Functioning

related to a disability or delay (McCollum). EI programmes comprise services from numerous disciplines, including assistive technology, audiology, medicine and nursing, nutrition services, occupational therapy, physiotherapy, psychological and psychiatric services, special education (modified curriculum and instructional practices), speech pathology, social work and family services, transition services, and vision services (Autism Treatment Services of Canada, 2006; Individuals with Disabilities Education Act, 2004). As such, diversity is inherent in EI programming, particularly with respect to the intensity, setting, therapeutic goals, combination of services provided, clientele, and overall approach of treatment (McCollum).

Despite such diversity, most EI programmes are developed to target children with biological or environmental risks as well as those with established deficits (Blackman, 2002; Majnemer, 1998). These programmes usually share common goals, including the treatment of cognitive, social, emotional, physical, and behavioural difficulties and the provision of parent education, guidance, and emotional support (Blackman; McWilliam & Scott, 2001). Ultimately, EI programmes for children with developmental delays comprise a collection of systems, services, and supports delivered to children and families in the context of coordinated community and familial involvement (Blackman).

Two common overarching goals of EI are to enhance child development and to facilitate and support family functioning (Bailey, et al., 1999; Blackman, 2002; Carpenter, 2005). In terms of the child’s development, EI programmes are intended to minimize and prevent cognitive, emotional, and physical limitations of children that have been disadvantaged by biological or environmental factors (Blackman, 2002). Over the past several decades, treatment efforts for children with developmental disabilities have emphasized a variety of approaches to remediate the core deficits associated with particular conditions (e.g., Baranek, Boyd, Poe, David, & Watson, 2007; Bryson, Rogers, & Fombonne, 2003; Eaves & Ho, 2004; Gabriels, Hill, Pierce,
Rogers, & Wehner, 2001; Guralnick, Neville, Hammond, & Connor, 2008; Hanson, 2003; Harris & Delmolino, 2002; Lovaas, 1987; Odom & Wolerey, 2003; Smith, 1999; Wishart, 2007). An emphasis on adaptive behaviour is a common thread among these approaches (Carter et al., 1998; Guralnick, Connor, Neville, & Hammond, 2006). For example, many intervention programmes for children with developmental delays seek within their curricula first to minimize maladaptive behaviour such as tantrums and self-injury, and then to improve adaptive skills such as functional communication, socialization, compliance, flexibility, and life skills (see Leaf & McEachin, 1999; Guralnick, 2005; Lovaas, 2003; Maurice, Green, & Luce, 1996; Slavin et al., 2006).

In terms of familial functioning, EI service providers usually offer a variety of supports to families, including education about the child’s disorder or condition, training in strategies to help foster optimal development, and provision of resources to support therapeutic interventions and to help parents better cope with the stressors associated with raising a child with special needs (Dunst, 2000; McCollum, 2002). Familial support in EI is necessary to decrease family and child stress and foster family members’ competence and self-confidence, ultimately increasing positive child outcomes, (Blackman, 2002; Bruder, 2000; Carpenter, 2005; McWilliam & Scott, 2001). To this end, interventions that seek to ameliorate children’s adaptive behaviour can play a key role in improving family functioning. Improvements in children’s actual day-to-day adaptive behaviour can increase the child’s compliance, minimize the child’s behaviour problems, decrease parent stress, and improve overall family wellbeing (Abbeduto et al., 2004; Baker et al., 2003; Diamond & Kontos, 2004; Guralnick, Neville, Connor, & Hammond, 2003; Keogh, Garnier, Bernheimer, Gallimore, & Keogh, 2000; Symes, Remington, Brown, & Hastings, 2006). For example, in their study of a behavioural parent training program for parents of children with developmental disabilities, Plant and Sanders (2007) found that such programmes successfully
reduced children’s observed negative behaviours across settings and improved parental competence and satisfaction in the parenting role as compared with a waitlist control condition. In this regard, it appears that as children’s daily functioning improves, the better parents are able to cope with the demands of raising a child with developmental delays. Taken together, these support the evaluation of the impact of specific interventions targeting adaptive functioning in EI programming for children with developmental delays.

*The Impact of EI on the Adaptive Functioning of Children with Developmental Delays: What We Do Know*

Although there is evidence that an assemblage of EI services in early childhood is beneficial for young children with developmental delays (Blackman, 2002; Green, Brennan, & Fein, 2002; Lovaas, 1987; McCain et al., 2007; Weiss, 1999), variability in outcome research is common (e.g., Bibby et al., 2002; Dawson & Osterling, 1997; Smith, 1999, Lovaas, 1987). Indeed, results from studies of EI effectiveness for children with developmental delays raise questions regarding the influence of a variety of factors on EI outcomes. These include pre-treatment variables such as diagnostic category, cognitive functioning, severity of impairment (Eaves & Ho, 2004; McGovern & Sigman, 2005), family variables such as parent stress (Blackman), service provision variables such as therapist training and attitude toward the child (Symes et al., 2006), and treatment variables such as intensity, duration, and type (Gabriels et al., 2001). While the literature is replete with plausible methodological explanations for the variation in outcome findings (e.g., pooling outcome measures across domains, divergent samples and/or measures, collapsing treatment data into a single measure such as hours of intervention only), such inconsistent results create uncertainty as to the actual effectiveness of EI on specific areas of child functioning. Additionally, questions remain in terms of what components of EI programmes most influence treatment outcomes for children with developmental delays (Green...
et al., 2002; Guralnick et al., 2008; McCollum, 2002; Weiss, 1999). As such, research efforts geared at identifying, describing, and developing the active ingredients of effective EI programming for children with developmental delays are needed (Charman & Howlin, 2001; McCollum). This is especially true since even very small differences in intervention variables may be associated with dramatically different outcomes only a few years later (Koegel et al., 2001). Such research efforts must examine what components of EI affect what domains of functioning, and for which children (Casto & White, 1993; Guralnick et al., 2006).

There has been an intense debate concerning how to best assess the effectiveness of EI programmes (Carpenter, 2006; Guralnick, 1998). As EI studies differ in target populations, length, and intervention quality, it is more prudent to assert that the effectiveness of intervention depends on the specific variables of each case than to claim more broadly that EI is “effective” (McCollum, 2002). Trying to assess whether EI programmes are successful is a substantial task that is made difficult by the wide array of services and programmes that constitute EI (Bailey et al., 1999; Carpenter, 2006; Saracino, 2007). Researchers have suggested that smaller, controlled studies that focus on specific interventions and circumstances be validated and the results be compiled thereafter (Bailey et al., 1999). However, even well-designed, small scale studies are difficult to develop as EI is comprised of many multifaceted variables that make results challenging to decipher. Further, ethical restraints prevent researchers from designing studies in which children not receiving EI services act as control groups, making causal interpretations difficult.

Nonetheless, in his discussion of EI from a global perspective, Blackman (2002) reviewed data showing that persistent benefits of EI tend to be socially-based while cognitive and motor gains are often more transient. This finding is directly relevant in the context of adaptive functioning, because social improvements resulting from the provision of EI services to
children at risk for or with delays suggest that research should consequently focus on the impact of EI on children’s adaptive functioning and development.

Given that one of the central goals of EI programmes for children with developmental delays is to improve the child’s and family’s daily functioning (Blackman, 2002; McCollum, 2002), assessing the impact of EI on adaptive functioning is a crucial element in evaluating the overall effectiveness of EI for these children. Unfortunately, limited information is available about factors that might predict improvements in adaptive behaviour for children with developmental delays, even within EI contexts (Bryson et al., 2003; Fidler et al., 2006; McGovern & Sigman, 2005). Therefore, examining the effect of EI on the adaptive behaviour of children with developmental delays is an important step in ascertaining the overall impact of EI for these children and their families.

Before the effect of EI on the adaptive behaviour of children with developmental delays can be fully evaluated, it is necessary to develop a thorough understanding of the adaptive patterns and profiles of children with developmental delays who are receiving EI services. While adaptive functioning profiles in children with certain types of developmental delays have previously been documented in normative and clinical samples, including PDDs, DS, and FXS (Carter et al., 1998; Dykens et al., 1993; Fidler et al., 2006; Sparrow et al., 2005), less information is available about such patterns within a wider range of specific diagnostic categories amongst children with developmental delays who are receiving EI services (Hauser-Cram et al., 2000; McCollum, 2002). For this reason, and as a first step in the process of examining change over time in the adaptive functioning of children with developmental delays in EI contexts, the present study consists of an analysis of these patterns and profiles within several diagnostic categories within the framework of EI.
Present Study

The present study has been designed to investigate patterns of adaptive functioning in children with developmental delays who are receiving EI services. Such an analysis of patterns and profiles is a crucial first step in determining what works best for whom in terms of improvement in adaptive behaviour for children with developmental delays who receive EI. Two key research questions were outlined at the outset of the study, with general expected results gleaned from previous research in the field.

1) Are previously documented adaptive profiles maintained in a sample of children who are receiving EI services? What patterns of relative strengths and weaknesses emerge within these profiles? The main goal of the study was to determine if and how children with different developmental delay diagnoses exhibit unique adaptive profiles within EI contexts. Along these lines, children’s levels of adaptive functioning in specific domains (i.e., communication, socialization, life skills, motor skills, and maladaptive behaviour) were examined and expounded. With respect to this research question, the emergent profiles were evaluated in light of previously documented normative and clinical profiles of adaptive functioning within children with specific diagnoses (e.g., PDDs, DS, WS) to ascertain whether these established profiles were maintained in the sample of children who were receiving EI services. The profiles were also assessed with attention to the pattern of relative strengths and weaknesses that emerged within each diagnostic category.

2) What are the adaptive profiles of children within diagnostic categories that have not previously been documented in EI contexts? What patterns of relative strengths and weaknesses emerge within these profiles? When previously documented or current profiles were not available for children with particular diagnoses (e.g., CP, GDD, FXS), emergent patterns of adaptive functioning in children with these diagnoses were described in a first attempt to sketch
an outline of their adaptive patterns. Adaptive profiles were also evaluated with attention to patterns of relative strengths and weaknesses to provide a preliminary conception of the assets and needs of children with conditions for which adaptive behaviour is less well understood.
Method

The present study is a part of a larger study, the Canadian Early Intervention Research Initiative, which is spearheaded by Dr. Ingrid Sladeczek of McGill University and Mr. Daniel Amar of Yaldei Developmental Centre. A central component of this larger study, entitled *A Dynamic Assessment of Early Intervention Models in Children with Developmental Delays: Creating a Paradigm Shift in Early Intervention Policy and Practice*, is the longitudinal assessment of children with developmental delays who are receiving EI and their families. The purpose of the longitudinal component of the larger study is to assess change over time in several domains of children’s and families’ overall functioning with the intent of using this longitudinal data to document the need for a paradigm shift in Canadian EI policy. It is hoped that data from *A Dynamic Assessment of Early Intervention Models in Children with Developmental Delays* will contribute to the creation of a national blueprint for Canadian public policy in EI for children with developmental delays and their families. The project was approved for ethical acceptability from the Education Ethics Review Board of McGill University in November 2006 (see Appendix A).

Currently underway, the larger study is employing a longitudinal panel research design, assessing the same participants over at least three time points. Within this design, participating children and families are assessed at 6- to 12-month intervals to allow the Canadian EI Research Team to examine change in functioning over time. That is, over the next several years, Time 2, Time 3, and possibly Time 4 data will be collected and, along with the already collected Time 1 data, will be analysed within a prospective longitudinal explanatory model to evaluate what EI variables have the most impact on outcomes for children with developmental delays.

In the context of the longitudinal study, the present investigation centres on the examination of patterns of adaptive functioning and adaptive profiles in children with
developmental delays who are receiving EI services. While adaptive functioning profiles in children with certain developmental delays have previously been documented in normative and clinical samples (Carter et al., 1998; Fidler et al., 2006; Sparrow et al., 2005), less information is available about such patterns within a range of specific diagnostic categories in those children with developmental delays who are receiving EI services (Hauser-Cram et al., 2000; McCollum, 2002). As such, the unique contribution of the present study to current literature in the field includes an analysis of adaptive patterns and profiles in children with developmental delays who are receiving EI services.

The present study focused on providing an accurate picture of the adaptive characteristics of several groups of children with developmental delays. This type of analysis is a vital component of the larger longitudinal study, since examining change over time in a group requires an accurate and thorough description of the group’s start point. As such, the current investigation of patterns and profiles of adaptive functioning in children with developmental delays receiving EI services utilized a cross-sectional, descriptive research design based on Time I data collected through the larger longitudinal study.

Participants

Within the context of the Canadian EI Research Initiative, approximately 150 children diagnosed with various developmental delays and their families are being recruited from six EI centres in Ontario and Quebec. Recruitment procedures first included identification of and initial contact with potential EI centres in Ontario and Quebec. Subsequently, several meetings and teleconferences were held between the Canadian EI Research Team and centres that were interested in participating. The purpose of these meetings was to present the research proposal, discuss benefits and risks to participants, review the project’s ethical clearance through McGill University, establish necessary documentation for each centre’s internal ethics review, confirm
the parameters of the centre’s participation in the study (e.g., main contacts, guidelines for
testing, reporting procedures) and evaluate and revise participant documents according to the
needs of the centre, (e.g., invitation to participate, informed consent). Once this process was
complete, invitations to participate and informed consent forms were sent by the main contact at
each EI centre, usually the principal or executive director, to eligible families receiving services
from that centre (see Appendix B). Parents and guardians were asked to review these documents
and to indicate their willingness to participate by returning a signed consent form to the centre.

The many steps of the recruitment process necessitated staggered data collection amongst
EI centres. As such, the present study comprises parent data from three of the six centres, as
these were the first to complete the recruitment process and only their data were available at the
time of the present analyses. Performing this type of preliminary analysis before all Time 1 data
were collected was considered important to confirm the feasibility of future analyses and to
ensure that data were analysed in an ongoing manner. Of the three centres, one was a school-
based centre that provided multidisciplinary special education and therapeutic services to
children and adolescents with learning, intellectual, and behavioural difficulties in Montreal,
Quebec; one was a not-for-profit community-based centre that provided multidisciplinary
intervention services to children with special needs in Montreal, Quebec (n = 19); and one was a
not-for-profit community-based centre that provided multidisciplinary special education and
individualized therapies to children with physical and developmental challenges in Thornhill,
Ontario. Each of the three centres staffed psychologists, speech-language pathologists,
occupational and physical therapists, special education teachers, and educational assistants.
Children who were enrolled in EI programmes at the three centres received comprehensive
services from professionals in each field.
In electing to participate in the study, each child’s parent(s) or guardian(s) agreed to participate in several two- to three-hour parent interview sessions, each to be conducted at 6- to 12-month intervals over the subsequent three years. A battery of eight parent questionnaires and one semi-structured parent interview were to be completed by the parents during or after this session. Parent(s) also consented for their children to be assessed on a battery of standardized and dynamic child measures during each interval. As detailed below, the present study focused on information obtained via one of the questionnaires and the semi-structured interview at the first interview session.

All families ($N = 60$) were receiving EI services from one of the three EI centres. All children were aged birth through nine years, and all had been diagnosed with a developmental delay prior to participation in the study and had documented delays in at least two areas of development. Participants were matched to one of six diagnostic categories: PDDs, CP and other muscular disorders, DS, FXS, GDD and other delays, and WS. These broad categories were defined by the Canadian EI Research Team to provide a broad framework within which to organize participant’s diagnoses. However, these diagnostic categories did not preclude children with other diagnoses from participating, as the option to examine the adaptive functioning of children with other conditions was open throughout the recruitment phase. All participants lived in urban centres in Quebec and Ontario.

Measures

The procedural design for the present study involved the administration of a parent questionnaire to obtain demographic information, including child age and diagnosis. A thorough parent interview was also administered to assess participants’ adaptive functioning.

Child and Family Questionnaire. This measure was adapted by the Canadian EI Research Team from Sattler (2002) as well as the Developmental Progress Clinic Intake Questionnaire
from the Montreal Children's Hospital. It includes both open and closed-ended questions concerning family data, developmental history (e.g., pregnancy, infancy, sleeping, feeding patterns, milestones such as crawling, talking, walking), child medical history, family medical history, general child health, the child’s behaviour (e.g., tantrums), the child’s activities (e.g., interactions with siblings), and the child’s previous and current education and treatments or interventions. The Child and Family Questionnaire is not a standardized measure, rather, it is a straightforward and comprehensive survey that can be used to gain important background information on the child with developmental delays, his or her family background, and his or her treatment history. It is completed with the child’s primary caregiver(s) as the respondent(s), and it can be administered either as an interview or via self-report. It was selected for use in the present study as it offers important data regarding participants’ demographics and diagnoses, both of which were relevant to the current examination of adaptive patterns and profiles among children with developmental delays.

Vineland Adaptive Behavior Scales, Second Edition, Survey Interview form (Vineland-II; Sparrow, et al., 2005). The Vineland-II, Survey Interview form, is a widely used assessment of adaptive behaviour for individuals from birth through age 90. It has a mean of 100 and a standard deviation of 15. It is administered in a semi-structured interview format which does not require the participation of the individual whose adaptive functioning is being assessed. Instead, a respondent who is familiar with the individual’s behaviour is interviewed to evaluate the individual’s performance of day-to-day activities that cannot be adequately measured through direct administration of tasks. This format promotes response elaboration and can draw out more information than a directly administered or self-report standard rating scale.

The Vineland-II consists of eleven adaptive functioning subdomains, which are grouped into four domain composites, including Communication, Daily Living Skills, Socialization, and
Motor Skills. Each of the eleven subdomains yields standard scores that sum to produce domain composite scores. Within each subdomain, a number of age-related items are used to assess the individual’s functioning in each area. Items are scored by the examiner on a 3-point frequency scale, which comprises scores of 2 (usually), 1 (sometimes), and 0 (never). Typically, administration begins at the age cutoff nearest to the individual’s age, and, once a basal of four consecutive scores of 2 has been established, proceeds consecutively until a ceiling of four 0 scores has been reached or until all items of that subdomain have been rated. If the basal is not established within the individual’s age range, items within the previous age ranges are administered in reverse order until the basal has been established. For the purposes of the present study, and in accordance with the administration guidelines of the Vineland-II, start points were sometimes modified because the individual’s level of functioning was significantly below his or her chronological age. For example, some subdomains were administered from the start point of “< 1 year” although the child was five years old due to the child’s level of functioning.

Norms for the Vineland-II were obtained using a representative American sample of 3,695 individuals aged birth through 90 years, assessed at 242 sites in 44 states. Based on the Current Population Survey, March 2001, a number of demographic targets, including sex, race/ethnicity, socioeconomic status, geographic region, community size, and special-education program placement were applied to the norm sample. Within this sample, more individuals were included at the younger end of the age range to account for the more rapid development of adaptive behaviours in younger age groups. As such, the Vineland-II is highly sensitive, even at low levels of adaptive functioning, which is of particular benefit to the present study as it targets children with developmental delays from birth to age nine who may have low levels of adaptive functioning. Individuals with disabilities or other special conditions were eligible for inclusion in the normative sample for the Vineland-II, and are represented proportionally to the incidence of
the disabilities or special conditions in the general population. In addition to the normative sample, seven clinical samples, including individuals with mental retardation, autism, attention-deficit/hyperactivity disorder, emotional/behavioural disturbance, learning disability, and visual and hearing impairments, were also defined to test the measure’s validity in identifying adaptive behaviour deficits in these populations.

The extent to which the items in Vineland-II domains and subdomains reflect a common underlying dimension of adaptive behaviour (internal consistency reliability) was examined using the split-half method in seven age groups. Of the 77 internal consistency reliabilities calculated for the Survey Interview form, more than half were equal to or greater than .90 and only six were below .80. This is generally considered to be strong evidence of internal consistency. Subdomain retest reliability coefficients were also high with most values exceeding .85. Finally, the consistency of scores obtained from the same respondent by different examiners (inter-interviewer reliability) was explored by having two different examiners conduct semi-structured interviews with 148 respondents on two separate occasions. These values were lower (domain reliabilities averaged .75) and more variable (subdomain reliabilities ranged from .48 to .92) than the test-retest reliability results, suggesting that there was an effect of examiner on Survey Interview form scores. The semi-structured nature and conversational format of the Survey Interview form explain these results. Thus, thorough examiner training was incorporated to ensure that the assessment was administered correctly in the present study.

Sources of evidence for the validity of the Vineland-II included test content and structure, response process, clinical groups, and the test’s relationship to other measures. The adaptive behaviours and skills measured by the Vineland-II are closely linked to the instrument’s theoretical structure and definition of adaptive domains, which are supported by both the...

The test’s development, standardization data, and factor structure lend support to the representativeness, developmental sequence, item-scale structure, and overall validity of the adaptive behaviours measured by the Vineland-II. Thorough evaluations of measurement bias, including sex differences, differences by socioeconomic status, and ethnic group differences were also conducted to establish the test’s freedom from measurement bias.

Additionally, the internal structure of the Vineland-II was examined via intercorrelations of subdomain, domain, and composite scores. Generally, correlations between subdomains were moderate, ranging from the .40s to the .70s, indicating that adaptive behaviours in different subdomains were related to each other in a predictable fashion. Confirmatory factor analysis was also used to evaluate the fit of the test’s structure to the normative data obtained, and the results of this analysis support the validity of the Vineland-II’s theoretical structure. Well-established systematic relationships between Vineland-II scores and external clinical group membership and clinical group performance were demonstrated via clinical profile consistency (for example, children in specific clinical groups demonstrated similar profiles). Finally, the convergent validity of the Vineland-II was demonstrated by examining its relationship to other relevant measures, such as the Vineland Adaptive Behavior Scales (VABS; Sparrow et al., 1984), the Adaptive Behaviour Assessment System, Second Edition (ABAS-II; Harrison & Oakland, 2003), the Behaviour Assessment System for Children, Second Edition (BASC-2; Reynolds & Kamphaus, 2004), with the correlations for most pertinent subscales ranging from .50 to .90. Divergent validity was established via weak correlations between the Vineland-II and the Wechsler Intelligence Scale for Children, Third Edition (WISC-III; Wechsler, 1991), with most
correlations ranging from near zero to the .30s, which indicates that adaptive behaviour measures differ markedly from measures of intelligence.

Overall, the Vineland-II is a comprehensive assessment of the personal and social skills required for everyday living. It is particularly useful in evaluating an individual’s overall daily functioning and monitoring that individual’s progress, and is considered a reliable and valid measure of adaptive behaviour in children with developmental delays (Sparrow et al., 2005). As such, in the context of both A Dynamic Assessment of EI Models in Children with Developmental Delays and the present study, the Vineland-II was selected as the primary measure of participants’ adaptive functioning.

Procedure

Parents who elected to participate in the study returned signed informed consent forms to their child’s EI centre. Forms were then forwarded by the centres to the Canadian Early Intervention Research Team. Once the Canadian Early Intervention Research Team received the signed forms from the centre, a graduate-level research associate contacted consenting parents to arrange an interview session. Each interview session was conducted between March and December 2007 by graduate-level research associates who were trained in interview protocol through role plays, test manuals, and group training sessions. One or two research associates attended each interview. For the most part, interviews were conducted in families’ homes or at the child’s EI centre (in some cases, interviews were conducted by phone or at a different location selected by the parent(s), such as a coffee shop). General procedures, right to withdraw, and limits to confidentiality were reviewed at the beginning of each interview session.

Following the introduction, the interviewer(s) shared with parents the contents of a parent questionnaire package containing the measures to be completed by the parent(s) during or following the interview session. Each parent questionnaire package included eight parent
questionnaires, including the Child and Family Questionnaire, and the Vineland-II Survey Interview form (see Table 1 for a complete list of parent questionnaires). The eight questionnaires could be administered by the interviewer(s) or completed independently by the parent(s), while the Vineland-II Survey Interview form was always to be administered in a semi-structured interview format. At this stage of the interview, parents and interviewers discussed and agreed upon an administration schedule, identifying which measures parents would complete with the interviewers, in what order, and which measures the parents would complete independently. Typically, the Vineland-II Survey Interview form was administered first, as it required the greatest time commitment (usually 60-90 minutes). This varied only if parents expressed a preference to complete a shorter measure at the beginning of the interview due to a family routine, scheduling conflict, or personal reasons (e.g., some parents preferred to start with a short questionnaire to garner a sense of accomplishment before beginning the Vineland-II).

With respect to any effects variations in administration may have produced, the research team agreed that the parents’ comfort in completing the measures was of utmost importance, and that any potential sequence effects were likely to be negligible due to the concrete nature of the measures. That is, both measures ask factual questions about the child’s adaptive behaviour, demographics, history, milestones, and therapies, and are not likely vulnerable to significant sequence effects.

Once parents completed the Vineland-II and the Child and Family Questionnaire, the measures were scored and entered into the project’s database. The Vineland-II was scored by graduate-level research associates and trained undergraduate-level research volunteers using the publisher’s Score ASSIST software. The Child and Family Questionnaire did not require scoring; instead, the relevant individual questionnaire items (e.g., demographic and diagnostic items) were input directly to the database. The accuracy of the data used in the present study was
established via a rigorous score-checking procedure. Specifically, all Vineland-II scores and all Child and Family Questionnaire items were double checked by graduate-level research associates who had not scored or entered the original items. Scores or items that required corrections were flagged for a third check by another graduate-level research associate. This process was repeated until no further corrections were required.
Results

Descriptive Statistics

The parents or guardians of 60 children with developmental delays who were receiving EI services ($N = 60$) completed the Vineland-II, Survey Interview Form (Sparrow et al., 2005) and the Child Family Questionnaire as part of the comprehensive assessment protocol within the larger longitudinal study. Of these children, 36 were boys and 24 were girls. The children’s ages ranged from 9 months to 10 years, 2 months, with a mean age of 6 years, 3 months ($SD = 31.83$ months). Respondents were primarily mothers ($n = 54$), while the remaining respondents were fathers ($n = 4$) or female relatives who were the child’s primary caregivers ($n = 2$, 1 grandmother, 1 aunt).

Children were recruited from three facilities that offer EI services for children with developmental delays and their families. The centres were selected because they met the criteria for providing EI services to children with developmental delays and were willing to participate. The three centres included one specialized school for children and adolescents with learning, intellectual, and behavioural difficulties in Montreal, Quebec ($n = 19$), one not-for-profit community-based EI centre in Montreal, Quebec ($n = 19$), and one not-for-profit community-based EI centre in Toronto, Ontario ($n = 22$). All children were identified by their EI directors for participation in the longitudinal study, indicating that they each had documented delays in at least two areas of development. The children were grouped into six syndrome-specific categories, namely a PDD group, a CP and Other Muscular Disorders group, a DS group, a FXS group, a GDD and Other Delays group, and a WS group. Groups were delineated based on what is currently known about adaptive profiles in children with developmental delays. As one of the ultimate goals of both the present study and the larger longitudinal project is to assess the type of EI programming children with developmental delays actually receive, we did not attempt to
recruit children with particular conditions. Instead, we employed a social systems epidemiological approach to recruit and group participants (Feldman et al., 2007; Kiely & Lubin 1983). That is, children were eligible for the study if they had documented delays in two or more areas of functioning and were receiving EI services reserved for children with or at risk for developmental delay. As such, children’s diagnoses were taken “as-is” from parents and EI providers based on the child’s most recent diagnostic assessment or evaluation. The children were then grouped into the most appropriate general diagnostic grouping. This approach necessitated the removal of the FXS group as none of the 60 children recruited were diagnosed with this condition. It also required the exclusion of three children, two whose diagnoses (i.e., hypoxic ischemic encephalopathy and primary carnitine deficiency) were rare, etiologically different from each other, and diverged substantially from the defined diagnostic groupings, and one whose diagnosis was withheld. The sample breakdown of diagnostic category is summarized in Table 1.
Table 1

*Breakdown of Diagnostic Groupings*

<table>
<thead>
<tr>
<th>Diagnoses comprised in diagnostic groupings</th>
<th>Number of children</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total Pervasive Developmental Disorder</strong></td>
<td>21</td>
</tr>
<tr>
<td>Autism Spectrum Disorder</td>
<td>15</td>
</tr>
<tr>
<td>PDD- Not Otherwise Specified</td>
<td>4</td>
</tr>
<tr>
<td>Rett’s Disorder</td>
<td>1</td>
</tr>
<tr>
<td>Asperger’s Disorder</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total Cerebral Palsy and muscular conditions</strong></td>
<td>7</td>
</tr>
<tr>
<td>Cerebral Palsy</td>
<td>5</td>
</tr>
<tr>
<td>Severe Hypotonia</td>
<td>1</td>
</tr>
<tr>
<td>Nemaline Myopathy</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total Down Syndrome</strong></td>
<td>7</td>
</tr>
<tr>
<td><strong>Total Global Developmental Delay and other delays</strong></td>
<td>21</td>
</tr>
<tr>
<td>Global Developmental Delay</td>
<td>8</td>
</tr>
<tr>
<td>Developmental delay</td>
<td>2</td>
</tr>
<tr>
<td>Intellectual disability</td>
<td>3</td>
</tr>
<tr>
<td>Brain damage</td>
<td>1</td>
</tr>
<tr>
<td>Communication delay or disorder</td>
<td>3</td>
</tr>
<tr>
<td>Attention Deficit/Hyperactivity Disorder (AD/HD)</td>
<td>1</td>
</tr>
<tr>
<td>At-risk or yet to be diagnosed</td>
<td>2</td>
</tr>
</tbody>
</table>
### Diagnoses comprised in diagnostic groupings

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Number of children</th>
</tr>
</thead>
<tbody>
<tr>
<td>Williams syndrome</td>
<td>1</td>
</tr>
<tr>
<td>Excluded diagnoses</td>
<td>3</td>
</tr>
<tr>
<td>Hypoxic Ischemic Encephalopathy</td>
<td>1</td>
</tr>
<tr>
<td>Primary carnitine deficiency</td>
<td>1</td>
</tr>
<tr>
<td>Diagnosis withheld</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total sample</strong></td>
<td><strong>60</strong></td>
</tr>
</tbody>
</table>

Within the PDD group, 15 children were diagnosed with “Autistic Disorder,” “Autism,” or “Autism Spectrum Disorder” (hereafter referred to as ASD), 4 with PDD-Not Otherwise Specified, 1 with Asperger’s Disorder, and 1 with Rett’s Disorder. These children were grouped because their diagnoses fall within the PDD category in the Diagnostic and Statistical Manual of Mental Disorders- 4th Edition- text revision (DSM-IV-TR, American Psychiatric Association, 2000), for a total of 21 children in the group. However, scores from the ASD subgroup and the Other PDD subgroups (PDD-NOS, Asperger’s Disorder, Rett’s Disorder) were also analysed separately to determine if adaptive profiles differed by subgroup.

The five children diagnosed with CP were paired with two children diagnosed with other muscular disorders, one with severe hypotonia and the other with nemaline myopathy. These children were grouped because they all had disorders characterized primarily by non-progressive muscular deficits. However, since the conditions were etiologically different, scores from both
the CP subgroup and the Other Muscular Disorders subgroup were also analysed separately to determine if differing adaptive profiles emerged for either subgroup.

The seven children diagnosed with DS were grouped together. Each child was reported to have DS without any secondary or additional conditions.

The GDD and Other Delays group comprised 21 children with a number of diagnoses, including 8 children diagnosed with GDD; 2 children with non-specific developmental delays; 3 children with intellectual disabilities; 1 child with brain damage due to viral encephalitis; 3 children with communication disorders, specifically: language delay, communication disorder, and dysphasia; 1 child with Attention Deficit/Hyperactivity Disorder (AD/HD); 1 child with a number of disorders including Tourrette’s Disorder, AD/HD, Post Traumatic Stress Disorder (PTSD) and Reactive Attachment Disorder; and 2 children undiagnosed but identified as “at risk” for developmental delays. All children in the GDD and Other Delay diagnostic grouping met the inclusion criteria of having documented delays in at least two areas of development.

Although the sources of these children’s delays were diverse and in some cases were non-specific, the children were included together in one GDD and Other Delay category because they were each classified as having developmental delays and were each deemed eligible to receive EI services from the participating centres. Since EI service providers often encounter children with non-specific or highly varied diagnoses, and because such children are often grouped together in classrooms or treatment groups in EI contexts, we elected to analyse the adaptive profiles of children with such diagnoses together in the GDD and Other Delay category.

The sample included only one child with WS. Although a single case does not provide statistical power and limits generalizability (Johnson & Christenson, 2004), this participant was included since the present analyses were intended as a preliminary examination of adaptive
profiles in children with developmental delays receiving EI services. Expanding current understandings of adaptive patterns in children with WS by cautiously exploring only one child’s profile was deemed worthwhile, especially compared to the alternative of excluding this child’s data entirely because no other families of children with WS elected to participate in the study.

None of the 60 children recruited were diagnosed with FXS. As such, the adaptive profile within this diagnostic grouping could not be included in the present analyses.

In addition to the children who were matched to these diagnostic groupings, two children were diagnosed with conditions that did not correspond to the outlined diagnostic categories. One child had hypoxic-ischemic encephalopathy, a rare condition in which perinatal asphyxia causes damage to the brain and spinal cord, which may cause developmental delays (Raju, 2006). The other child had primary carnitine deficiency, a rare genetic metabolic condition that can result in progressive cardiomyopathy, encephalopathy, which may cause developmental delays, and myopathy (Scaglia, 2006). The option to examine the adaptive functioning of children with conditions other than those identified at the outset of this study was open throughout the recruitment phase of the study. However, because hypoxic-ischemic encephalopathy and primary carnitine deficiency are rare, do not consistently result in developmental delay, and are etiologically different (Raju, 2006; Scaglia, 2006), the decision was made to exclude these conditions from the present analyses.

One child’s diagnostic information was withheld by his family, and his mother declined to answer more than half of the items in the Vineland-II (Sparrow et al., 2005) interview. As a result, there was insufficient information about this child and he could not be included in the present study.
Analyses of Adaptive Functioning

Several descriptive statistical procedures were performed using Vineland-II (Sparrow et al., 2005) and Child and Family Questionnaire data to explore different patterns of adaptive functioning within the diagnostic categories outlined above. Procedures included measures of central tendency and measures of variability for each adaptive domain across diagnostic categories. The use of these procedures was deemed most appropriate for the present study because of the study’s cross-sectional, descriptive design. The ultimate goal of such a design is to describe and summarize the characteristics of the sample (Burke & Christensen, 2004). The use of descriptive statistics was considered most suitable for the present study as the research objectives were to analyse and describe the adaptive characteristics of children with developmental delays who are receiving EI services rather than to make comparisons or to investigate differences between diagnostic groups.

In accordance with procedures outlined by Sparrow et al. (2005), children’s areas of relative strength and relative weakness were determined by computing the mean score for each domain. The highest domain average was considered the relative adaptive strength and the lowest domain average was considered the relative adaptive weakness. The transitional domain averages were considered to represent children’s intermediate adaptive skills.

For all descriptive analyses of the children’s Vineland-II scores, standard scores rather than age equivalents were used. Standard scores are derived from raw scores and express how far a participant’s score lies from the mean of the distribution. While age equivalents are also obtained from raw scores, they sometimes violate assumptions of statistical analyses (Sattler & Hoge, 2006). For example, age equivalents do not encompass an interval scale and may be subject to distortion due to patterns of development, especially across domains (Mervis et al.,...
Although age equivalents can be clinically informative, the use of standard derived scores is preferable in statistical analyses (Sattler & Hoge). As such, standard scores were used to analyse patterns of adaptive functioning for each diagnostic group.

Adaptive profiles were depicted graphically for each diagnostic category. Mean Adaptive Behaviour Composites were graphed along with mean standard scores in each of the four adaptive domains. In keeping with procedures outlined by Sparrow et al. (2005), the y axis spans standard scores from 20 to 160. Results of the profile analyses are reported along with graphic representations of adaptive profiles by diagnostic category below.

**Overall EI sample.** The Vineland-II, Survey Interview form, has a mean of 100 and a standard deviation of 15. On average, children in the present sample scored approximately two standard deviations below the normative mean for overall adaptive functioning (Adaptive Behaviour Composite $M = 70.34, SD = 14.30$). Thus, in keeping with the general consensus in the field, the children with developmental delays in this study demonstrated levels of adaptive functioning that were significantly below average. Despite this lower overall adaptive performance, the variability of children’s scores ($SD = 14.30$) was in line with the norm-referenced standard deviation for the Vineland-II ($SD = 15.00$). This suggests that, although the children in the present study scored significantly below children without developmental delays on a measure of their overall adaptive behaviour, adaptive scores were nonetheless normally distributed. Ultimately, our sample of children with developmental delays receiving EI services had no more or less heterogeneity in adaptive scores than typically developing children.

In terms of the adaptive domains measured by the Vineland-II (Sparrow et al., 2005), the children in the present sample again performed below average. Specifically, the mean score on the Communication domain was approximately two standard deviations below the mean
the average score on the Daily Living Skills domain was just under two standard deviations below average \((M = 71.95, SD = 17.63)\), the average score on the Socialization domain was approximately one and one half standard deviations below average \((M = 76.95, SD = 14.80)\), the average score on the Motor Skills domain was more than one and one half standard deviations below average \((M = 73.82, SD = 18.36)\). As evidenced by the standard deviations on all domains but Socialization, the children’s scores deviated from the mean slightly more than did those in the normative sample. The present sample had slightly more heterogeneity in the Communication, Daily Living, and Motor Skills domains than the normative sample. This is likely explained by the pooling of several syndromes with divergent presentations. Accordingly, syndrome-specific analyses, presented below, help limit variance due to differing symptoms in each syndrome.

Figure 1 depicts the emergent cross-category adaptive profile. While this profile is useful in demonstrating that the children studied demonstrated deficits in adaptive behaviour, the utility of collapsing adaptive scores across diagnostic category is limited, as patterns unique to particular diagnoses may be masked by pooling participants’ scores. Syndrome-specific adaptive profiles are presented below to avoid such obfuscation.
Figure 1. Mean Adaptive Behaviour Composite and mean domain scores across diagnostic categories.

*Children with pervasive developmental disorders.* Children in the PDD group (n = 21) had an average Adaptive Behaviour Composite score more than two standard deviations below the mean ($M = 69.10, SD = 14.76$). Motor Skills represented the domain of greatest relative strength for this group ($M = 76.49, SD = 20.19$), although higher variability of scores was more apparent here than in any other domain. Communication represented the area of greatest relative weakness for in this group ($M = 68.00, SD = 17.91$); scores again were slightly more variable than in the normative sample. Consistent with previous literature, Socialization was also an area of relative weakness for the group ($M = 69.19, SD = 12.78$), though the group mean on the Socialization domain was slightly higher than the group mean on the Communication domain. The lower standard deviation here indicates that children’s scores were more homogeneous on
this domain than in any other, as was the case when compared to Vineland-II norms. Daily Living Skills scores were intermediate compared to other domains (%20M = 72.19, %20SD = 19.18) with scores again diverging from the mean to a greater extent than in the normative sample. Thus, the children in the PDD group demonstrated relative strengths on the Motor Skills domain, relative weaknesses on the Communication and Socialization domains, and intermediate abilities on the Daily Living Skills domain. The group also appeared more variable than the normative sample on several of these domains.

To examine the possibility that the inclusion of four different diagnoses in the PDD category obscured domain profiles for diagnostic subsamples, domain descriptives for children diagnosed with “Autistic Disorder,” “Autism,” or “ASD” (ASD subgroup, n = 15) were analysed separate from descriptive statistics for children with other PDD diagnoses, namely Rett’s Disorder, Asperger’s Disorder, or PDD-NOS (Other PDD subgroup, n = 6). On both the Communication and Socialization domains, the ASD subgroup’s adaptive profile diverged from the Other PDD subgroup, with the ASD subgroup scoring lower on the Communication domain (%20M = 67.60, %20SD = 18.01; PDD %20M = 69.00, %20SD = 19.32) and higher on the Socialization domain (%20ASD %20M = 71.07, %20SD = 11.88; PDD %20M = 66.00, %20SD = 15.35). Although the Communication and Socialization domain means for the ASD and Other PDD subgroup were similar to the domain means for the aggregate group (Communication %20M = 68.00, %20SD = 17.91; Socialization %20M = 69.19, %20SD = 12.78), they did result in different profiles for each of the subgroups, as depicted in Figure 2.

Differences in mean scores on the Daily Living Skills domain and the Motor Skills domain did not change the overall adaptive patterns for either subgroup, in that Motor Skills remained a relative strength (%20ASD %20M = 76.87, %20SD = 17.96; PDD %20M = 75.33, %20SD = 26.93) and
Daily Living Skills remained intermediate (ASD $M = 72.27, SD = 18.66$; PDD $M = 72.00, SD = 19.30$) for both the ASD and the PDD subgroups. However, on account of the distinct profiles that emerged due to differing patterns of weakness, the children in the ASD subgroup and the children in the Other PDD subgroup were considered as two separate groups rather than as one PDD group. Figure 2 graphically represents domain averages for the ASD subgroup, the Other PDD subgroup, and the aggregate group.

![Figure 2](image-url)

**Figure 2.** Mean Adaptive Behaviour Composite and mean domain scores for children in the ASD subgroup, the Other PDD subgroup, and the aggregate PDD group.

*Children with cerebral palsy and other muscular disorders.* When considered together, children with CP and other muscular disorders ($n = 7$) had an Adaptive Behaviour Composite
Adaptive Functioning

almost two standard deviations below the mean \( (M = 71.71, SD = 26.28) \) and demonstrated a general pattern of adaptive functioning in which Motor Skills scores and Daily Living Skills scores were lowest \( (M = 57.57, SD = 12.26 \text{ and } M = 65.43, SD = 20.74, \text{ respectively}) \). This is not surprising, given the muscular basis of the children’s disorders. The Socialization domain represented the relative strength for children with CP and other muscular disorders \( (M = 80.14, SD = 18.41) \). Communication scores were also high for the group compared to the children’s mean Motor Skills and Daily Living Skills domain scores \( (M = 75.57, SD = 26.28) \).

As evidenced by standard deviations greater than the normal Vineland-II standard deviation of 15, mean scores were highly variable for children with CP and other muscular conditions on all domains but Motor Skills. This high variability prompted separate consideration of the two diagnostic subgroups included in the CP and Other Muscular Disorders group, namely the CP subgroup and the Other Muscular Disorders subgroup.

When considered separately, a similar general profile of lower scores on the Motor Skills and Daily Living Skills domains with relatively higher scores on the Communication and Socialization domains persisted for the children with CP \( (n = 5) \) and the children with other muscular disorders \( (n = 2) \). However, visual examination of graphic profiles for each subgroup indicated that the subgroups differed considerably. Indeed, scores for children with CP ranged from two to three standard deviations below the mean on all domains (Adaptive Behaviour Composite \( M = 58.4, SD = 15.71; \) Communication \( M = 63.8, SD = 20.54; \) Daily Living Skills \( M = 56.00, SD = 15.77; \) Socialization \( M = 71.40, SD = 13.18; \) Motor Skills \( M = 50.60, SD = 12.26 \)), whereas scores for children with other muscular disorders were in the Adequate range for all domains but Motor Skills (Adaptive Behaviour Composite \( M = 91.00, SD = 5.66; \) Communication \( M = 105, SD = 5.66; \) Daily Living Skills \( M = 89.00, SD = 5.66; \) Socialization
$M = 102, SD = 0$; Motor Skills $M = 75.00, SD = 8.49$). Variability for both subgroups was lower on all domains when adaptive profiles were considered separately for each subgroup. This indicates that children’s scores were less heterogeneous within their respective subgroups and suggests that separate analyses of adaptive patterns were more appropriate than one aggregated analysis. As such, the CP subgroup and the Other Muscular Disorders subgroup were henceforth considered independently. Figure 3 illustrates the subgroup differences by depicting domain averages for the CP subgroup, Other Muscular Disorders subgroup, and the aggregate group.

Figure 3. Mean Adaptive Behaviour Composites and mean domain scores for children with CP, other muscular disorders, and the aggregate group.
Children with down syndrome. On average, children in the DS group scored approximately two standard deviations below the mean for overall adaptive functioning (Adaptive Behaviour Composite $M = 70.86$, $SD = 9.69$). In terms of domain scores, and consistent with previous research, Vineland-II scores for the children with DS (n = 7) were highest on the Socialization domain ($M = 83.00$, $SD = 12.17$). Different from previously documented adaptive profiles (e.g., Fidler et al., 2006), however, the children with DS scored lowest on the Daily Living Skills domain ($M = 67.86$, $SD = 10.14$) and the Motor Skills domain ($M = 67.86$, $SD = 6.69$) and had slightly higher scores on the Communication domain ($M = 75.43$, $SD = 12.11$). Variability in domain scores was low for the DS group, as demonstrated by domain standard deviations that ranged from 6.69 to 12.17, well below the Vineland-II normal standard deviation of 15. This indicates that the extent to which each child’s domain score differed from the corresponding domain mean was lower than in the normative sample for the Vineland-II. Put another way, adaptive scores for children in the DS group were more homogeneous than the normative sample, suggesting that the children in this group were more similar in their adaptive profiles than the general population. Possible explanations for the homogeneity in adaptive patterns for children with DS are explored in the discussion section. Figure 4 graphically depicts adaptive domain mean scores for this group.
Children with global developmental delay and other delays. Although GDD and Other Delays group encompassed the most diagnostic diversity, for the most part, the adaptive scores in this syndrome grouping were normally distributed, as evidenced by standard deviations close to the norm of 15 on all domains. Children with GDD and other delays had an Adaptive Behaviour Composite mean score of 72.29 (SD = 14.19). On average, the children in this group scored relatively high on the Socialization domain ($M = 78.90$, $SD = 14.84$), Motor Skills domain ($M = 77.29$, $SD = 17.58$), and Daily Living Skills domain ($M = 75.24$, $SD = 17.89$), and exhibited a relative weakness on the Communication domain ($M = 69.57$, $SD = 14.33$).

To examine the possibility that pooling GDD with other delays masked differences in adaptive profiles in the GDD and Other Delays diagnostic category, both the GDD and the Other
Delays subgroups were analyzed separately. When considered independently, the children formally diagnosed with GDD had lower Adaptive Behaviour Composite scores than did the children with other delays (GDD $M = 68.75$, $SD = 14.59$; Other Delays $M = 74.46$, $SD = 14.07$).

In terms of domain profiles, both the children with GDD ($n = 8$) and the children with other delays ($n = 13$) continued to demonstrate strength on the Socialization domain (GDD $M = 77.25$, $SD = 15.30$; Other Delays $M = 79.92$, $SD = 15.09$), while children with GDD had lower scores on the Motor Skills domain than did children without GDD (GDD $M = 70.75$, $SD = 15.47$; Other Delays $M = 81.31$, $SD = 18.15$). The pattern of scores on the Daily Living Skills and Communication domains was similar for both groups, although scores for the GDD group were lower (Daily Living Skills $M = 69.88$, $SD = 18.93$; Communication $M = 66.38$, $SD = 14.70$) than for the Other Delay group (Daily Living Skills $M = 78.54$, $SD = 17.13$; Communication $M = 71.54$, $SD = 14.33$).

Upon further inspection, it became apparent that much of the variability in GDD subgroup scores was accounted for by one child with severe impairments in all adaptive functioning domains. When the child’s scores were removed from the analyses, the Adaptive Behaviour Composite mean for the GDD subgroup increased and the variability decreased ($M = 73.00$, $SD = 8.93$). Further, all adaptive domain means for the GDD subgroup increased and variability decreased (Socialization $M = 81.00$, $SD = 11.92$; Motor Skills $M = 75.57$, $SD = 7.89$; Daily Living Skills $M = 75.00$, $SD = 13.15$; and Communication $M = 70.14$, $SD = 10.93$).

However, given that the goal of the present study was to examine patterns of adaptive behaviour in children with developmental delays receiving EI services, this child’s outlying scores were not removed from the analyses to ensure that the data portrayed a realistic picture of adaptive profiles in children with GDD and other delays.
Figure 6 shows the subgroup differences by depicting domain averages for the GDD subgroup, Other Delay subgroup, and the aggregate GDD and Other Delay group. Although differences in adaptive scores emerged when the subgroups were analysed separately, the differences were minimal and the overall adaptive pattern remained intact. As such, the children with GDD and the children with other delays were considered as one group rather than as two separate subgroups.

Figure 5. Mean Adaptive Behaviour Composite and mean domain scores in children with GDD and other delays.

*Children with Williams syndrome.* Because only one child with WS was part of the sample, descriptive statistics could not be calculated for this diagnostic category. The child’s individual domain scores are reported instead. Overall, the child’s Adaptive Behaviour
Composite was more than 2 standard deviations below the mean at 68.00. This child had adaptive scores that corresponded to the adaptive patterns outlined in previous research (Brock et al., 2007; Mervis et al., 2001). The child’s scores were highest on the Communication domain (78.00), slightly lower on the Socialization domain (75.00) and the Daily Living Skills domain (73.00), and lowest on the Motor Skills domain (59.00). Figure 7 summarizes the adaptive profile for this child.

Figure 6. Adaptive Behaviour Composite and domain scores for child with WS.

The emergent adaptive profiles resulting from the adaptive profiles herein are considered in light of previous research in the discussion section below. Results are also examined with regard to the research questions for the present study.
Discussion

The present study was undertaken to investigate patterns of adaptive functioning in children with developmental delays who are receiving EI services. The goal of the study was to determine if and how children with different developmental delays exhibit unique adaptive profiles within EI contexts. Children’s adaptive skills in specific areas, including functional communication, daily living skills, socialization, and motor skills, as well as their overall adaptive functioning were examined within five diagnostic categories of developmental delays, namely ASD and other PDDs, CP and other muscular conditions, DS, GDD, and WS.

Children in each group had deficits in overall adaptive functioning. Furthermore, distinct profiles of adaptive behaviour emerged within each of the diagnostic categories. That is, children with particular syndromes exhibited different patterns of relative strengths and weaknesses in their adaptive behaviour.

A literature review of documented adaptive profiles in children with developmental delays revealed syndrome-specific patterns of adaptive behaviour for children with particular conditions, namely PDDs, DS, FXS, and WS. However, such adaptive patterns have not yet been substantiated in EI contexts. In the present study, emergent patterns of adaptive behaviour were evaluated in light of previously documented profiles of adaptive functioning for children with specific diagnoses, including PDD, DS, and WS, to ascertain whether these established profiles were maintained in the sample of children who were receiving EI services. Previously established adaptive profiles were not available for children with certain diagnoses, including CP and GDD. Thus, the emergent patterns of adaptive behaviour for children with CP and GDD were analysed and described to expand what is currently known about adaptive profiles in these conditions. All profiles were also assessed with attention to the pattern of relative strengths and
weaknesses that emerged within each diagnostic category. Interpretations of the emergent adaptive profiles for each syndrome group, as well as examples of specific patterns of adaptive behaviour that may be exhibited by a child with in each diagnostic category, are presented in turn. (Since adaptive behaviours are age specific, examples reflect the mean age [6 years] of the children in the present study.)

**Previously Documented Adaptive Profiles**

In terms of previously documented adaptive profiles, the question of concern was whether the children in the present study would demonstrate patterns of adaptive behaviour similar to those that had been substantiated in the literature. While comparable patterns emerged for certain adaptive behaviours in all diagnostic groups, several differences also emerged. These patterns are best explored through individual consideration of each diagnostic category.

*Children with pervasive developmental disorders*. Previously documented patterns of adaptive functioning for children with PDDs involve relative strengths in daily living skills, relative weaknesses in socialization, and intermediate motor and communication skills (Carter et al., 1998; Gillham et al., 2000; McGovern & Sigman, 2005). This profile did not emerge in the present study. Specifically, the children in the PDD group exhibited stronger motor skills than daily living skills and weaker communication than socialization skills. A number of explanations for this finding are plausible.

The adaptive skills of the children with PDD in our study may not have mirrored those of children in previous studies because children with a wider range of diagnoses were included in the present diagnostic grouping. That is, several previous studies examined only children diagnosed with ASD (e.g., Carter et al., 1998; Eaves & Ho, 2004), whereas the present study grouped 15 children with ASD, 4 children with PDD-NOS, 1 child with Rett’s Disorder, and 1
child with Asperger’s Disorder. Perhaps the observed differences in the adaptive profile of the children in the PDD group were due to symptom variations among the diagnoses included in this diagnostic category.

Indeed, individual consideration of the emergent adaptive profile for children diagnosed with ASD apart from the children diagnosed with other PDDs revealed different profiles for each subgroup, in that the children with ASD had weaker communication than socialization skills, whereas the opposite pattern was true for children with other PDDs. That is, the children with ASD in the present study demonstrated a different adaptive profile than has been previously documented for children with ASD, as communication rather than socialisation represented their greatest relative weakness and motor skills rather than daily living skills represented their greatest relative strength. On the other hand, the children with other PDDs demonstrated a pattern of communication and socialization that was parallel to the profile that has been previously documented for children with ASD, in that socialization represented a relative weakness and communication was an intermediate skill. The children in both subgroups had similar patterns of better motor than daily living skills. However, on account of their differing patterns of communicative and social functioning, the children in the ASD subgroup and the children in the Other PDD subgroup were considered as two separate groups rather than as one aggregate PDD group.

Concerning the different adaptive profiles in children with ASD, a possible explanation for their better socialization than communication skills and better motor than daily living skills may involve the children’s intervention experiences. That is, the children in this study were all receiving comparable EI services (i.e., full day, multidisciplinary programmes supervised by psychologists, implemented by special education teachers and aides in small group and one-on-
one contexts, and accompanied by individual professional services such as speech-language pathology and occupational therapy), whereas children in previous studies have received more disparate interventions including specialized preschool, nonspecific daycare, general education programmes, special education programmes, speech therapy, occupational therapy, or home-based ABA (Bibby et al., 2001; Eaves & Ho, 2004; Gabriels et al., 2001; McGovern & Sigman, 2005). In receiving such similar comprehensive EI services, perhaps the children with ASD in the present study were able to improve their adaptive skills to the point that their social abilities surpassed their communication skills and their motor skills surpassed their daily living skills. The adaptive profile for children with ASD may thus have differed from previously documented profiles for children with ASD. In other words, perhaps the children’s similar EI experiences account for a slightly different adaptive profile than has been previously documented in children with ASD.

With regard to the Other PDD subgroup, the children with PDDs other than ASD demonstrated an adaptive profile akin to that which has been previously substantiated for children with ASD only, with the exception of better motor than daily living skills. This suggests that the ASD adaptive profile may extend to children with other PDDs, regardless of differing EI experiences. However, since there were fewer children and there was more variability in the Other PDD subgroup, further research is needed to fully examine this possibility.

Notwithstanding the divergent profile in the children with ASD and other PDDs in the present study, the difference in communication and socialization skills for children in the ASD and Other PDDs subgroups was small. Indeed, both communication and socialization were relatively weak compared to the children’s motor and daily living skills. Thus, previously documented weaker adaptive skills remained weak for children with ASD and other PDDs in the
present study, suggesting that, in a broad sense, previously established patterns of adaptive
behaviour in children with PDD were maintained in the present study although some fluctuations
were evident in terms of the children’s relative weaknesses (i.e., Communication rather than
Socialization represented the relative weakness for the ASD subgroup).

The ASD and Other PDD adaptive profiles that emerged in the present study are
particularly relevant in the context of EI programming for children with PDDs, in that
practitioners can develop and tailor interventions for children with ASD and other PDDs
according to the adaptive profiles that are common in ASD and other PDDs. For example,
according to the results of the present study, a 6-year-old child with ASD receiving EI services
may have difficulty with following two- or three-part instructions, answering and asking
questions, expressing emotions, and demonstrating friendship-seeking behaviour with peers. At
the same time, the child may drink from a cup without spilling, eat tidily with a fork or spoon, be
toilet trained during the day, clear unbreakable items from his or her place at a table, help with
simple household chores, count at least ten objects, run smoothly without falling, throw a ball, or
hop on one foot with ease. A child diagnosed with a PDD other than ASD may demonstrate
similar patterns in adaptive behaviour, though to a greater degree for social tasks and to a lesser
degree for communicative skills.

An understanding of the adaptive characteristics specific to children in each subgroup can
enhance EI programming for children with PDD diagnoses, in that instructions, activities, and
learning goals can be structured according to the general adaptive strengths and weaknesses
exhibited by children with PDDs. For instance, within an EI program geared at improving
children’s overall adaptive functioning, intensive communicative interventions (e.g.,
augmentative communication strategies, one-on-one speech therapy) may be particularly
beneficial for the children with ASD, where as children with other PDDs may benefit more from concentrated social interventions (e.g., direct social instruction, modeling, social scripting, social rehearsal). Of course, in an EI context, all children with developmental delays would profit from comprehensive interventions (Blackman, 2002), but knowledge of the unique adaptive profiles common for children with ASD and other PDDs can assist EI service providers in tailoring interventions to meet children’s specific adaptive needs.

To fully substantiate a unique ASD and Other PDD adaptive profiles in children who are receiving EI services requires further investigation. Because the present study is the first step of a larger project examining change over time in the adaptive functioning of children with developmental delays in EI contexts, analyses of the adaptive profile over time in the PDD group will provide more information concerning adaptive patterns in children within this diagnostic category.

*Children with down syndrome.* Previous research has described patterns of adaptive functioning for children with DS and reported relative strengths in socialization and relative weaknesses in communication and motor skills (Fidler et al., 2006; Wishart 2007). Consistent with such research, the children with DS in the present study exhibited relative strengths in socialization. Different from previous research, however, the children with DS had better communication skills than motor and daily living skills. Motor skills and daily living skills represented the group’s relative weakness equally.

A 6-year-old child exhibiting the adaptive profile that emerged for children with DS might exhibit difficulties with toilet training, cleaning up a play or work area after an activity, following household rules, drawing, climbing, and hopping on one foot. A child with this profile might also struggle to follow three-part instructions, use prepositions (e.g., in, on, under)
appropriately, say his or her age and full name when asked. However, this child is likely to demonstrate stronger social skills, such as using words to express emotions (e.g., “I’m happy”), demonstrating friendship-seeking behaviour with peers (e.g., asking, “do you want to play?”), playing simple make-believe activities with others, taking turns when asked during games or sports, or answering appropriately when familiar adults make small talk (e.g., saying “I’m fine” when asked “How are you?”).

The DS group’s weak daily living skills can be understood by considering the overlap between the Daily Living Skills domain and the Motor Skills domain. Many daily tasks (e.g., buttoning, zipping, brushing teeth) require motor dexterity and coordination of movement. Thus, motoric deficits can contribute directly to limitations in the performance of daily living tasks (Mervis & Klein-Tasman, 2000). While poor motor skills have been previously documented in children with DS, the manifestation of equally low daily living skills in the present study helps to further develop the adaptive profile in children with DS. That is, the present finding that children with DS had relatively weak daily living skills adds to previously documented patterns of relative weakness in motor skills to enhance the picture of overall adaptive functioning in children with DS.

When studied outside of EI contexts, children with DS have demonstrated weak motor skills as well as weak communication skills (Fidler et al., 2006; Jobling, 1999). However, in the present study, the children with DS demonstrated intermediate communication skills. This result may be explained by the setting in which the children were assessed. That is, all children in the present study had received some degree of speech and language intervention through their EI programmes. For example, children attending the EI centres in the present study received individualized speech and language therapy from a registered Speech-Language Pathologist (S-
S-LPs also worked with children’s special education teachers and aides to incorporate speech and language goals into daily lesson plans and classroom activities. Such consistent speech and language intervention has not been outlined in previous studies of adaptive functioning in children with DS (e.g., Fidler et al., 2006; Wishart, 2007) and may account for the present group’s relatively better communication skills than groups of children with DS in previous studies. As such, the stronger communication than motor and daily living skills demonstrated by the children with DS in the present study provide preliminary support for the notion that the adaptive profiles of children with DS who are receiving EI services may diverge from previously documented profiles, possibly as a result of their intervention experiences.

The homogeneity in adaptive functioning for the children in the DS group suggests that the emergent adaptive pattern is representative of the children with DS in the present study. The emergent profile in children with DS who are receiving EI services is valuable for practitioners who develop and implement programming for children with DS as it provides preliminary evidence that the children’s adaptive behaviour is amenable to intervention, particularly in certain areas shown to be problematic for children with DS (i.e., communication skills). Further research is needed to fully substantiate this possibility.

*Children with fragile X syndrome.* Although current research in adaptive behaviour among children with FXS is limited, a general profile of poor adaptive functioning across domains has been substantiated for males with FXS. The profile entails relative strengths in daily living skills and relative weaknesses in socialization (Dykens et al., 1993; Roberts, Hatton, & Bailey, 2001). However, since no families of children with FXS have elected to participate in the present study to date, patterns of adaptive behaviour among children with FXS could not be examined in an EI context. However, because further recruitment is underway within the larger
longitudinal study, the possibility of recruiting children with FXS prompted the maintenance of the FXS diagnostic category for the present study.

*Children with Williams syndrome.* In addition to overall deficits in adaptive functioning, previously documented patterns of adaptive behaviour for children with WS involve relative strengths in communication, relative weaknesses in motor skills, and intermediate socialization and daily living skills (Brock et al., 2007; Mervis & Klein-Tasman, 2000; Mervis et al., 2001). In the present study, the one child with Williams syndrome exhibited an adaptive profile that matched the previously documented profile for children with WS. Specifically, the child’s communication skills were widely discrepant with her motor skills. Further, both the child’s social abilities and her daily living skills were more representative of areas of strength than of intermediary or weak adaptive areas, in that the child performed social tasks and daily living tasks nearly as well as she performed communicative tasks.

The results for the WS category in the present study must be interpreted cautiously given that only one child had this diagnosis. Nonetheless, research that provides a detailed account and analysis of an individual case can assist in better describing and explaining the functioning of that individual (Johnson & Christenson, 2004). Although only one child with WS participated in the present study, examining the child’s adaptive profile was valuable in terms of the descriptive goals of the present study.

The adaptive profile for the child with WS matched previously documented profiles for children with this diagnosis, with relative strengths in communication, relative weakness in motor skills, and intermediate socialization and daily living skills. As such, it appears that within an EI setting, a child with WS may exhibit the adaptive profile that is typical for this particular diagnostic group. For example, a 6-year-old child with WS may be able to use phrases with a
noun and a verb, ask questions by changing the inflection of simple phrases (e.g. “me too?”), use at least 50 recognizable words, eat with a spoon, help with simple household chores, show a desire to please others, and play with others with minimal supervision. However, the same child may struggle to run without falling, kick a ball, walk up and down stairs unassisted, colour simple shapes inside the lines, or cut out simple shapes. This information is meaningful for EI practitioners, as it indicates which adaptive areas are relative strengths to be built upon and which areas should be targeted for remediation in therapeutic programming for children with WS.

*Adaptive Profiles Not Previously Documented*

In terms of conditions for which adaptive profiles have not been fully documented, namely CP and GDD, the question of concern was what patterns of relative strengths and weaknesses were exhibited by children with such conditions. Although previous research has indicated particular areas of difficulty for children with CP and for children with GDD (Diamond & Kontos, 2004; Eapen et al., 2006; Sayre et al., 2001; Shevell et al., 2005), researchers have yet to offer a complete picture of overall adaptive functioning in children with these diagnoses. As such, the emergent patterns of adaptive behaviour for children with these conditions were analysed and described by diagnostic category in the present study.

*Children with cerebral palsy and other muscular disorders.* Researchers have substantiated the presence of motor limitations and overall difficulties with adaptive functioning in children with CP (e.g., Berrin et al., 2007; Sayre et al., 2001). However, complete adaptive profiles for children with CP and other muscular conditions have yet to be established in the literature. The present study was intended to provide a preliminary picture of patterns in specific areas of adaptive behaviour in children with CP and other muscular conditions.
The adaptive profile that emerged for children with CP and other muscular disorders consisted of relative strengths in communication and social skills and relative weaknesses in motor and daily living skills. Although the children with CP and the children with other muscular conditions exhibited similar patterns of functioning across, their adaptive performance within domains varied considerably, prompting independent consideration of children in the CP subgroup and children in the Other Muscular Conditions subgroup.

Children in the CP subgroup exhibited significant global deficits in adaptive functioning. The general adaptive profile for this group was consistent with the motor difficulties associated with CP, in that the children exhibited low motor skills. Related to these motor deficits, the children’s performance of daily living skills was also poor, likely because that many daily living tasks require mobility, motor dexterity, and coordination, skills which were weak for the children with CP. Communication was also significantly impacted for the children with CP, though their communicative skills were slightly better and more diverse than their motor or daily living skills. Socialization represented the subgroup’s relative strength, though the children’s social abilities were below the levels that would be expected for age peers.

A 6-year-old child exhibiting the adaptive profile that emerged for children with CP might have particular difficulty with motor and daily living tasks such as standing, walking, climbing, rolling a ball, unwrapping small objects, turning the pages of a book, eating with a spoon without spilling, or using the toilet to urinate or defecate. In terms of communication skills, this child might be able to follow two-part instructions, say at least 100 recognizable words, use words to describe things (e.g., dirty, big), ask questions beginning with what or where, and say correct age when asked, but might struggle to say first and last name when asked, ask questions beginning with who or why, or use possessives in phrases (e.g., “that’s her book”).
Social skills such as answering when familiar adults make small talk, demonstrating friendship-seeking behaviours, sharing toys when asked, and playing with others with minimal supervisions are likely to be within this child’s capabilities, though taking turns when asked while playing games or sports, sharing toys without being asked, and following rules in simple games (e.g., spelling bees, electronic games) might be more problematic for a child with this type of profile.

The profile results for children with CP have implications for EI programming for children with the condition. Because the motor deficits in CP are the result of permanent brain damage, difficulties on the Motor Skills domain may not be substantially remediated through intervention (Berrin et al., 2007; Manuel et al., 2003; Sayer et al., 2001). However, environmental accommodations (e.g., use of assistive technology and modified equipment) may facilitate improvements in daily living tasks, such that children with CP can be better able to complete everyday tasks and may improve daily functioning as a result. In addition, the children’s relative strengths in socialization and communication provide information as to the types of tasks to emphasize (e.g., peer interaction, modified game play, observation, modelling) while implementing interventions to target daily living skill deficits within EI programmes. The children with other muscular disorders exhibited better overall and domain specific adaptive functioning than the children with CP. Specifically, the overall adaptive functioning for the children with muscular conditions other than CP was in the Adequate range as were their communication skills, daily living skills, and socialization. In fact, the only adaptive domain within which the children’s functioning was below the Adequate range was Motor Skills, which is logical given the muscular deficits in the diagnostic category. A 6-year-old child with an adaptive profile similar to that of the children in the Other Muscular Conditions subgroup might have difficulty with motor tasks such as climbing, running, jumping, kicking a ball, completing
simple puzzles, holding a pencil with proper positioning, or colouring simple shapes. However, the child would complete communication and social tasks such as following instructions heard five minutes before, using regular past tense verbs appropriately, saying the month and day of his or her birthday when asked, using words to express happiness or concern for others, acting when another person needs a helping hand, playing simple card or board games based only on chance (e.g., Go Fish, Crazy Eights), or saying “please” when asking for something with ease. Daily tasks requiring motor dexterity and coordination, such as brushing teeth, buttoning large buttons, or demonstrating computer skills necessary to start programmes or play computer games might be somewhat more challenging for a child with this adaptive profile, though daily tasks independent of motor dexterity, such as putting away personal items, following household rules, and saying the current day of the week when asked, would be unproblematic.

The emergent adaptive profile for the Other Muscular Disorders subgroup has implications for EI programming for children with muscular conditions other than CP. That the two children in this subgroup had adequate adaptive functioning in all areas but motor skills indicates that, by and large, the children were able to function normally in everyday settings. Provided that their motor needs were addressed on an individual basis, in terms of adaptive functioning, the children in this subgroup were likely capable of thriving in general educational settings. That is, children with other muscular conditions may benefit from integrated programmes that maintain inclusive classroom practices, such as standard curricular expectations, large group instruction, participation in everyday routines, and involvement with typical peers, while providing adaptations for the physical limitations that are central to muscular disorders. Ultimately, children with muscular conditions other than CP might be best served in
intervention programmes geared at adapting everyday environments to their unique motor needs while maintaining general education placement.

*Children with global developmental delay and other delays.* Limited research has addressed adaptive profiles in GDD. Nonetheless, preliminary studies of developmental status in GDD have documented deficits in overall adaptive functioning, though with relative strengths in socialisation (Shevell et al., 2005). The present study provides further support for this profile. Consistent with previous literature, the children with GDD and other delays exhibited difficulties with overall adaptive behaviour with socialization representing their greatest relative strength. Although slightly weaker than socialization, motor and daily living skills were also relatively strong for children in the GDD and Other Delays group. Functional communication skills represented an area of difficulty for the children in the group.

Researchers have acknowledged that GDD is an etiologically heterogeneous condition (Eapen et al., 2006; Shevell et al., 2005). In accord with the condition’s heterogeneity, the children included in the GDD and Other Delay diagnostic grouping in the present study had received a variety of diagnoses. Nonetheless, the group exhibited normal levels of variability in adaptive functioning, suggesting a more homogeneous adaptive profile for children with GDD and other delays, with fairly level socialization, motor skills, and daily living skills and relatively poor communication skills.

A 6-year-old child with an adaptive profile comparable to that of the children in the GDD and Other Delays group might be able to use words to express his or her own emotions, or imitate complex actions several hours after watching someone else perform them, share toys without being asked, chew with his or her mouth closed, count at least 10 objects, be toilet trained during the day, run smoothly, hop on one foot, and colour simple shapes inside the lines.
Communicative skills such as following if-then instructions, saying first and last name when asked, asking questions beginning with who or why, or using possessives in phrases or sentences may be more difficult for a child with this profile.

Paired with previous research, the emergent adaptive profile for children with GDD and other delays has implications for these children in EI settings. Indeed, children with GDD and other delays, and children considered “at risk” for developmental delays are often referred for nonspecific EI services regardless of the etiology of their conditions (Eapen et al., 2006; Shevell et al., 2005). That children with GDD and other delays exhibited a relative weakness in communication skills suggests that these children might benefit from EI programming that emphasizes functional communication skills and provides consistent speech and language interventions. Further, the children’s relative strengths in socialization, motor skills, and daily living skills indicate areas that can be built upon in EI contexts to support their adaptive development.

GDD is a relatively new diagnosis, and research on the condition is currently limited (Ghosh, 2008; Shevell et al., 2005). Consequently, EI personnel might not be well versed in the typical presentation and adaptive needs of children in the diverse GDD diagnostic category. The current information regarding patterns of adaptive behaviour in children with GDD and other delays can be particularly helpful for practitioners who may be responsible for designing and implementing EI programmes for children with GDD and other delays, but who may have limited background or training in GDD and nonspecific delays. Although more research is needed to fully comprehend the adaptive profiles of children with GDD and other delays, the present research is an important preliminary step in developing an understanding about the presentation of this group in EI contexts.
Limitations and Future Directions

Inherent in any research examining children with developmental delays and the EI services they receive are methodological and logistical limitations (Blackman, 2002; McCollum, 2002). Limitations to the present study are identified below. Future research strategies intended to eliminate or reduce the impact of such limitations are also elucidated.

Sample size. Although the total sample in the present study \((N = 60)\) was substantial in the context of studies of children with developmental delays, the diagnostic groups consisted of relatively small numbers of children. Specifically, the CP and other muscular conditions, DS, FXS, and WS groups comprised fewer than eight children. Thus, wide generalizations regarding adaptive profiles of children with these syndromes receiving EI services are not prudent without additional investigation.

Although larger sample sizes in the CP and other muscular conditions, DS, and WS categories would have facilitated more robust analyses of adaptive profiles for children and more reliable generalization of findings, the descriptive, exploratory nature of the present research did not necessitate substantial or equal sample sizes among groups and subgroups (Johnson & Christenson, 2004). The aim of this study was to begin to describe emergent patterns of adaptive functioning in children with particular conditions who were receiving EI services rather than to produce widely generalizable results based on tentative predetermined adaptive profiles.

Nonetheless, in response to sample size limitations, data collection is ongoing and diagnostic categories with fewer participants can be targeted more intensely during future recruitment phases. The present analyses took place with a limited number of participants \((N = 60)\) due to logistical restraints (e.g., time, recruitment constraints). However, more participants
are being recruited from current and prospective EI centres for children with developmental delays.

*Diagnostic integrity.* Due to logistical constraints, children’s diagnoses were not confirmed by independent assessors. As such, it is possible that in some cases, diagnostic integrity could have been compromised if a child’s diagnosis was inaccurate or outdated. To guard against this possibility, every attempt was made to ensure that each child’s diagnostic classification was based on his or her most recent evaluation or assessment.

Because a social systems epidemiological approach was used to recruit and group participants in the present study (Feldman et al., 2007; Kiely & Lubin, 1983), preparing screening tools and assessments for every possible diagnosis that would emerge during recruitment was unfeasible in terms of personnel, training, and financial resources. Further, because appropriate diagnostic procedures differ for most developmental delays (e.g., complex structured direct observation and caregiver interview for ASD; medical screening for CP; comprehensive physical exam and genetic testing for DS; genetic testing for FXS, and WS; direct cognitive and adaptive assessments for GDD), preparing screening methods for each diagnosis would also have been unworkable given the exhaustible resources available for both the larger longitudinal project and the present study. Ultimately, confirming the integrity of the children’s diagnoses via an independent assessment, though an estimable goal, was outside the realm of this project.

Given the challenges of incorporating independent screening procedures into the present study, measures to ensure diagnostic integrity would be best integrated into narrower studies of specific syndromes rather than the present broad study of children with various developmental delays. Screening via independent assessors is more realistic when the scope of a project
includes one or two diagnoses rather than the larger number of conditions involved in the present study.

Consideration of cognitive functioning. In the present study, children’s adaptive functioning was considered independent of their cognitive abilities. Adaptive behaviour and general mental ability have been found to be related in children with certain developmental delays (Freeman et al., 1999; Sparrow et al., 2005). Analyzing children’s adaptive functioning without considering their cognitive functioning may have obscured real differences in functioning among the children included in each diagnostic category because it is possible that children with higher IQs were being paired with children with lower IQs. If this was the case, the resulting adaptive profiles might have masked distinctive variations in adaptive behaviour based on cognitive abilities.

Information about the children’s cognitive functioning was not available at the time of the present study. However, assessments of children’s cognitive functioning are currently in progress through the larger longitudinal project. In response to the possible limitations created by considering children’s adaptive functioning separate from their cognitive functioning, children’s cognitive data will be incorporated into future analyses of adaptive patterns and profiles to ensure that children who are grouped or compared have comparable levels of general intelligence.

Implications and Conclusion

The present research study is important to the field as it is the first of its kind to examine patterns and profiles of adaptive behaviour in children with developmental delays within an EI context. Developing a thorough understanding of adaptive patterns and profiles in children with developmental delays who are receiving EI services is a crucial first step in determining which
Adaptive Functioning 85

interventions work best for which children with developmental delays in terms of improvements in adaptive behaviour. That distinct adaptive profiles emerged within the five diagnostic categories included in the present study is a significant finding. These results have numerous implications in terms of EI services for children diagnosed with PDDs, CP and other muscular conditions, DS, GDD, and WS.

First, the results can enable EI practitioners to develop a deeper understanding of specific adaptive profiles in children with various developmental delays. Children with developmental delays often receive EI services, but due to high demand and limited personnel (Saracino, 2007), EI practitioners may not have access to detailed evaluations of each child’s adaptive functioning or may not have time to fully scrutinize such assessments. Maintaining a general picture of the adaptive profiles common in children with particular diagnoses can provide EI service providers with a fundamental understanding of the patterns of behaviour that may be exhibited in the children they serve. Such an understanding can support practitioners as they interact with and treat children with developmental delays, as it can inform practitioners’ social deportment, language use, and overall therapeutic approach. This is particularly relevant for practitioners working with diverse groups of children with developmental delays. Such practitioners may see children with many different diagnoses in a short period of time and may benefit from increased awareness of the patterns of relative strengths and weaknesses demonstrated by children with different syndromes in EI contexts.

Second, a deeper understanding of the adaptive profiles of children with various developmental delays can equip EI service providers to develop syndrome-specific interventions or to modify general interventions for children who tend to demonstrate particular patterns of adaptive strengths and weaknesses. The development and implementation of interventions
specifically tailored to children’s syndrome-specific adaptive profiles can be helpful in ensuring that interventions build both on children’s unique adaptive strengths and seek to remediate children’s distinctive adaptive skill deficits. Of course, clinicians must bear in mind that a child with a specific diagnosis may not exhibit the adaptive profile characteristic of most children with that diagnosis, and must ensure that each child’s adaptive functioning is evaluated on an individual basis (Sparrow et al., 2005). However, a treatment program that is tailored to the unique adaptive profiles exhibited by children with specific diagnoses can act as a foundation onto which modifications based on each child’s individual characteristics can be developed.

Third, general profiles of adaptive strengths and weaknesses can help clinicians differentiate between children with specific clinical diagnoses and typically developing children, as well as between children with different disorders (Sparrow et al., 2005). The patterns of adaptive behaviour described herein add to a growing body of research that has examined everyday functioning within a broad range of conditions, in this case, developmental delays. Thus, the present research is valuable as it can contribute to the diagnostic process by providing an additional source of data that can be used to discern whether a particular developmental disorder is present.

Finally, the present account of adaptive patterns and profiles in children with PDDs, CP, DS, GDD, and WS lays an important base for the subsequent evaluation of change over time in the adaptive behaviour of children with these diagnoses as they receive EI services. Indeed, investigating the impact of EI on the adaptive behaviour of children with developmental delays necessitates the development of a thorough understanding of the adaptive patterns and profiles of children with developmental delays who are receiving EI services. In the context of the present study, a more complete understanding of adaptive behaviour in children with developmental
delays who are receiving EI allows us to establish a working baseline for these children. Thus, the present study is an essential first step in the process of examining change over subsequent data points (Time 2, Time 3) in the adaptive functioning of children with developmental delays in EI contexts.

Although more research is needed to fully expound the impact of EI on adaptive functioning in children with developmental delays, the present study is a preliminary venture to this end. The aim herein is to provide a fuller picture of adaptive patterns and profiles in children with developmental delays who are receiving EI services in order to inform EI programming for these children, facilitate differential diagnosis of children with different developmental delays, and make possible the analysis of change over time in the adaptive functioning of children with developmental delays who are receiving EI services. Each of these goals will ultimately assist in the development of a broader picture of which interventions work best for which children with developmental delays.
References


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Appendix A: Certificate of Ethical Acceptability

Faculty of Education – Ethics Review Board
McGill University
Faculty of Education
3700 McTavish; Room 230
Montreal H3A 1Y2

Tel: (514) 398-7039
Fax: (514) 398-1527
Ethics website: www.mcgill.ca/regr/ethics/human

Faculty of Education – Review Ethics Board
Certificate of Ethical Acceptability of Research Involving Humans

REB File #: 719-1006

Project Title: *A dynamic assessment of early intervention models in children with developmental delays: Creating a paradigm shift in early intervention policy and practice*

Applicant's Name: Ingrid Sladeczek  Department: ECP

Status: Faculty  Supervisor's Name: n/a

Granting Agency and Title (if applicable): Max Bell Foundation

Type of Review: Expedited ✓  Full ___

This project was reviewed by: Derevensky/Starke-Meyerring

Approved by:

[Signature]
Robert Bracewell, Ph.D.
Chair, Education Ethics Review Board

Approval Period: [Nov 1, 2006 to Nov 30, 2007]

All research involving human subjects requires review on an annual basis. An Annual Report/Request for Renewal form should be submitted at least one month before the above expiry date. If a project has been completed or terminated for any reason before the expiry date, a Final Report form must be submitted. Should any modification or other unanticipated development occur before the next required review, the REB must be informed and any modification can't be initiated until approval is received. This project was reviewed and approved in accordance with the requirements of the McGill University Policy on the Ethical Conduct of Research Involving Human Subjects and with the Tri-Council Policy Statement on the Ethical Conduct for Research Involving Human Subjects.

11/17/06
Appendix B: Informed Consent Form

RETROSPECTIVE PARENTAL CONSENT FOR PARTICIPATION IN THE CANADIAN EARLY INTERVENTION PROJECT

Dear Parent,

You are being invited to participate in a very important national study to look at the effectiveness of Early Intervention (EI) programs for children with developmental delays in an effort to change government policy in this area.

The study is sponsored by the Max Bell Foundation and is conducted in partnership with Dr. Sladeczek from McGill University, an expert in investigating the effectiveness of interventions, and Mr. Daniel Amar, Research Director at the Yaldei Developmental Centre.

As part of this study we will compare services provided at your Early Intervention Centre to similar centres in Quebec and Ontario.

We are requesting your permission to use your child’s data file. Your child’s name will be deleted and replaced with a code number in order to ensure absolute confidentiality. The list of code numbers and names will only be available to the primary investigators.

Your participation is vital in the development of a National Blueprint for Service Provision for Families and Children with Developmental Delays and this initiative has the potential to significantly impact the services provided to families and children across Canada.

If you agree to participate in the study, please sign the attached Consent Form and return in the self-addressed stamped envelope. If you have any further questions, please do not hesitate to contact, Dr. Sladeczek at (514) 398-3450 or Mr. Daniel Amar at (514) 279-3666.

Thank you for your time!

Sincerely,

___________________________  ______________________________
Ingrid E. Sladeczek, Ph.D.   Daniel Amar, M.B.A.
Primary Investigator    Co-investigator
Canada Early Intervention Project    Canada Early Intervention Project
Associate Professor    Executive Director
School/Applied Child Psychology    Yaldei Developmental Centre

PARENTAL CONSENT FOR PARTICIPATION IN THE
CANADIAN EARLY INTERVENTION PROJECT

Dear Parent,

You are being invited to participate in a very important national study to look at the effectiveness of Early Intervention (EI) programs for children with developmental delays in an effort to change government policy in this area.

The study is sponsored by the Max Bell Foundation and is conducted in partnership with Dr. Sladeczek from McGill University, an expert in investigating the effectiveness of interventions, and Mr. Daniel Amar, Research Director at the Yaldei Developmental Centre.

As part of this study we will compare services provided at your Early Intervention Centre to similar centres in Quebec and Ontario.

We are requesting your permission to participate in the study. Assessment information will be gathered over a two-year period on your child’s functioning in eight areas (adaptive, behavioural-social, cognitive, motor, speech and language, medical/developmental, treatment history, and neurological). Please note there will be no cost to families for these assessments.

Assessment results will be given to your clinical director, who will be sharing the results with you. Your child’s name will be deleted and replaced with a code number in order to ensure absolute confidentiality. The list of code numbers and names will only be available to the primary investigators. For purposes of publication and dissemination of findings only group data will be reported.

Your participation is vital in the development of a National Blueprint for Service Provision for Families and Children with Developmental Delays and this initiative has the potential to significantly impact the services provided to families and children across Canada.

If you agree to participate in the study, please sign the attached Consent Form and return in the self-addressed stamped envelope. If you have any further questions, please do not hesitate to contact, Dr. Sladeczek at (514) 398-3450 or Mr. Daniel Amar at (514) 279-3666.

Thank you for your time!

Sincerely,

Ingrid E. Sladeczek, Ph.D.  Daniel Amar, M.B.A.
Primary Investigator  Co-investigator
Canada Early Intervention Project  Canada Early Intervention Project
Associate Professor  Research Director
School/Applied Child Psychology  Yaldei Developmental Centre
PARENTAL CONSENT FOR PARTICIPATION IN THE CANADIAN EARLY INTERVENTION PROJECT

I agree to participate in the study conducted by Dr. Ingrid E. Sladeczek and Mr. Daniel Amar.

- I understand the purpose of the study and know about the benefits and no foreseen risks that this research project entails.
- I understand that I am free to withdraw at any time from the study without penalty or prejudice.
- I understand how confidentiality will be maintained during this project.
- I understand the anticipated uses of data, especially with respect to publication, communication and dissemination of results.

Name of Child (Please Print) ___________________________________________

Name of Parent or Guardian (Please Print) ___________________________________________

Signature of Parent or Legal Guardian ___________________________________________

Date ___________________________________________