Transition into School: Experiences of Children with Intellectual Disabilities and their Families

by

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Abstract

A successful transition into kindergarten is of the utmost importance, as it marks the beginning of formal education and paves the way for future academic and social outcomes. The transition into school is considered to be a challenging and anxiety-ridden time for most children and their parents; it is expected therefore, to be particularly difficult for children with an intellectual disability (ID). These children have deficits in cognitive and adaptive functioning that affect their academic and social skills. Despite the apparent difficulty for children with ID and the importance of this time in their lives, the transition into school has been a relatively under-researched topic.

Nineteen parents of children with ID participated in three one-hour phone interviews throughout the transition into school. The aims of the study were 1) to describe this group of children with ID and their families as the children entered school, 2) to investigate changes in characteristics of the child, resources, and perceptions of the parent during the transition, and 3) to examine relationships between these variables and the child’s quality of life and school readiness. Although the results are based on a small sample, they do provide some preliminary information about the experiences of children with ID and their families throughout the transition into school. Only adaptive behaviour scores and the number of services accessed changed significantly during the time of transition. Furthermore, it was found that adaptive behaviour was correlated with school readiness skills, as were physiotherapy and speech-language therapy use. The only variable that correlated with the child’s quality of life was parental involvement in parent support groups. Implications and directions for future research are discussed.
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Chapter 1

Introduction

The transition into school is a critical time in the life of young children as evidenced by the abundance of early intervention programs available in Canada and the United States, and the specific focus of many programs on preparing children for school. Although successful transition into school has been recognized as an important goal of early intervention (Kemp, 2003), there has been little research examining this transition for children with intellectual disabilities (ID). The purpose of this study was to gain information about the experiences of children with ID and their families during the transition into school. Variables that change over the time of transition and those that are associated with successful transition also were examined. The findings will be discussed in terms of their relationship to the literature in the field and the subsequent recommendations for future research. To begin, a brief definition of intellectual disability will be provided, followed by a description of the theoretical framework that forms the basis of this study, and a summary of the previous research on the transition into school and related research on children with ID.

Intellectual Disability

Intellectual disability (ID), also known as developmental disability, refers to significant limitations in both general intellectual functioning and adaptive functioning with an onset prior to the age of 18 years (American Psychiatric Association, 2000). Adaptive functioning or adaptive behaviour refers to an individual’s daily living skills, typically including communication, social, self-care, and motor skills. When compared to their typically developing peers, individuals with ID present with more behaviour
problems (Baker, McIntyre, Blacher, Crnic, Edelbrock, & Low, 2003), which may also be referred to as maladaptive behaviour. Typically, children are diagnosed with ID in the preschool and early childhood years. Clinically, when the origin of a young child’s deficits is not easily identifiable by a genetic marker or clear neurological impairment, and the prognosis is not clear, the term developmental delay may be applied. Technically, the term developmental delay refers to deficits above the 2nd percentile in at least two areas of development (i.e., cognitive development, speech and language development, social and emotional development and motor skill development). Developmental delay is a term restricted to children under the age of 7 years, recognizing that they are developing slowly and may be able to catch up, however, often these children (who do not catch up) go on to be diagnosed with ID. Researchers frequently include children with developmental delay in the ID group when examining the experiences of preschool aged children since the diagnoses are related and often overlap (e.g., Baker, Blacher, & Olsson, 2005). The prevalence of ID is about 1-2% in the general population worldwide; however, different estimates are often obtained depending on the source (i.e., government agencies or research studies); (Australian Institute of Health and Welfare, 2004). Developmental delay is the most common disability in children under 5 years of age in Canada, with about 1.1% affected (Statistics Canada, 2003; Note: In this survey ID was not a category for children under 5 years of age). It is thought that the deficits associated with ID will affect the success of a child’s transition into school. Findings from previous research on predictors of successful transition, as well as related research on children with ID will be discussed following a brief introduction to the theoretical framework of this study.
Theoretical Framework

The Double ABCX model (McCubbin & Patterson, 1983) was originally adapted from Hill’s ABCX model (1949) incorporating several factors that influence family adaptation to crisis events. The Double ABCX model has been employed widely in the ID literature as a way to conceptualize and organize variables (e.g., Minnes, 1988; Saloviita, Italinna, & Leinonen, 2003; Shin & Crittenden, 2003). Typically the model is used to examine the influence of characteristics of the child (a stressor) (A), the family’s resources (B), and the meaning and methods of coping the family associates with the stressor(C) on family outcome or well-being (X). One of the advantages of this model is that it incorporates changes over time. Pile up of stressors (aA), family resources for meeting the demands associated with the stressors (bB), and the meaning the family assigns to the situation (cC) affect family adaptation over time (xX). The Double ABCX model has been used in studies examining adaptation to adoption of a child with ID (Shin & Crittenden, 2003), accounting for stress in parents of children with ID (Minnes, 1988; Saloviita, et al., 2003), and empowerment in parents of children with ID (Nachshen, & Minnes, 2005) among other studies.

Recently, in examining the transition to adulthood, Blacher (2001) proposed a model in which the primary outcome was family well-being which was influenced by a secondary outcome; transition success. In this model (see Figure 1) individual (child) characteristics remained as the A factor, while the family resources (B from other models) was broadened to include the environment and culture, family meaning and coping (C) became more specifically family involvement in the transition. These three
variables were thought to be influential in transition success, which was in turn hypothesized to influence family well-being.

Figure 1. Blacher’s (2001) Theoretical Framework

Given that the Double ABCX model has been widely used in the field of ID to examine relationships between a number of variables and changes in these variables over time (e.g., Minnes, 1988; Redden, McDonald, & Kysela, 1992;), it has been adapted for application to the preschool population for the current study (See Figure 2). For the purposes of this study the influence of characteristics of the child (A), resources (B) and parents’ perceptions (C) on transition success (X) will be evaluated, with changes in each factor (aA, bB, cC, and xX respectively) being measured over time. These three variables have been associated with transition success in research on the transition into school, and have also been linked to each other in research on children with ID and their families. This theoretical framework will serve as a system for organizing the variables measured in this study to describe the participants, measure changes over time, and evaluate the effectiveness of this model in predicting transition success.
The transition into school has been researched in the normative population (e.g., Dockett & Perry, 2004; NICH, 2004; Sy & Schulenberg, 2005) with particular focus on outcomes following early intervention for children who are considered “at-risk” due to socioeconomic status (e.g., Anderson, et al., 2003; Redden et al., 2001). These studies, including those focusing on the Head Start program, often exclude children with ID because of their more complex needs and poor prognosis (Beauchesne, Barnes, & Patsdaughter, 2004). Despite the continuing research interest in the transition to school, there is no consensus of opinion regarding the beginning and end of the transition period (Kemp, 2003). It is recognized that a transition period includes: 1) planning prior to the actual transition, 2) the point of change from one service to another, and 3) the period immediately following the change (Lazzari & Kilgo, 1989) The length of the planning and follow-up periods, however, has not been agreed upon. In practice, planning for the entry to school tends to begin up to a year before school start, though follow-up may last a few months if it occurs at all (Kemp, 2003). In general, it has been found that variables
related to characteristics of the child, resources, and perceptions of the parents are all associated with adjustment to and success in school.

Characteristics of the Child (a factor)

A number of characteristics of the child may impact the transition into school; including adaptive and maladaptive behaviour. In the past, studies have compared across disability types (i.e., Down syndrome, autism, developmental delay); however this is often done without considering individual differences in functioning level or behaviour problems (Granlund & Roll-Pettersson, 2001). In general, adaptive and maladaptive behaviour scores should provide a better understanding of a child’s functioning, and have been found to predict school achievement (Ramey & Ramey, 2004). Thus far, research on the transition into school has suggested that a child’s skills are important determinants of that child’s success (Kemp, 2003).

Child Skills. The academic achievement and social adjustment of at risk children who completed a Head Start program have both been found to be important predictors of promotion to Grade 1 (Mantzicopoulos, 2003). Another study that surveyed teachers, however, indicated that social adjustment was considered to be of more importance for success in kindergarten (Dockett & Perry, 2004). Classroom, social and self-help skills have been deemed critical for successful inclusion in kindergarten by teachers, and have been correlated with teacher reported successful integration (Kemp & Carter, 2005). Due to the nature of their cognitive and adaptive behaviour deficits, children with ID are at risk for a number of negative outcomes, including academic difficulties, social and behaviour problems, which are likely to have a detrimental effect on their transition to school.
In a rare study investigating predictors of successful transition into school for children with and without ID, it was found that self-regulation and social skills were important for predicting adaptive transitions into school; where an adaptive transition involved having few teacher-reported problem behaviours and positive student-teacher relationships (McIntyre, Blacher, & Baker, 2006). The authors found that children with ID had less adaptive transitions and fewer self-regulation and social skills; also social skills significantly predicted adaptation to school even after accounting for IQ and adaptive behaviour (McIntyre, et al., 2006). Unfortunately there has been little research examining the transition into school for children with ID, particularly focusing on predictors of success.

Maladaptive Behaviour. Researchers have not yet examined the role of maladaptive behaviour in predicting adaptation to school, however, problem behaviour has been used as a proxy for measuring adaptation to school (McIntyre, et al., 2006), that is, children with fewer problem behaviours were considered to have a more adaptive transition. Although researchers have not examined directly how behaviour problems affect the transition into school, it has been found that higher levels of problem behaviour are associated with more parental stress (Floyd & Gallagher, 1997) and poorer marital adjustment (Baker, et al., 2005). It has been suggested that behaviour problems may have a similar effect on teachers and classmates (McIntyre, et al., 2006). Clearly, it is important to consider both adaptive and maladaptive behaviours when examining the influence of characteristics of the child on the transition into school.
Resources (b factor)

Level of support is an important variable when examining the experiences of children with ID and their families. It is believed that if appropriate supports in the cultural and physical environment are available, the negative effects of disability may not manifest (Renwick, Schormans, & Zekovic, 2003). In fact, many definitions of adaptive behaviour include a clause that adaptive behaviour may change depending on the demands and supports of the environment. Resources that may impact the transition include: early intervention for the child prior to school entry, direct supports for the child during the transition and at school (e.g., educational assistant, speech-language therapy), and supports for the parent (e.g., respite, parent support groups).

Early Intervention. Early intervention programs are frequently employed for young children at risk for ID and have been demonstrated to be effective treatment options if they are of high quality and comprehensive (Baker & Feinfeld, 2003; McCollum, 2002). “Early intervention includes systems, services and supports designed to enhance the development of young children, minimize the potential of developmental delay and need for special education services, and enhance the capacity of families as caregivers.” (Baker & Feinfeld, 2003, p.1). However, there is considerable diversity in the types of early interventions offered. They may include very specialized services such as speech therapy, or intensive behavioural intervention for children with autism, or more broadly focused programs like inclusive and supportive preschool placements. Previous research has found that early intervention programs can be beneficial in preparing children and families for the transition into school (Fox, Dunlap, & Cushing, 2002).
Supporting Needs. For the purposes of this study, community integration is
defined from an acculturation perspective (i.e., whether disability-related needs are
identified and supported in a way that facilitates involvement in the community). Surveys
of parents and teachers of children with ID entering school have found that appropriate
support is considered an important component for successful transition (Kemp, 2003).
Integration of people with ID has been a focus in the field for the past several decades,
and is considered beneficial for both the individual and society (Salisbury, 1990).
Although there has been considerable research focusing on the integration of adults and
adolescents with ID in a number of domains (e.g., Buell & Minnes, 1994; McConkey,
Abbott, Walsh, Linehan, & Emerson, 2007; Minnes, Buell, Feldman, McColl, &
McCreary, 2002; Myers, Ager, Kerr, & Myles, 1998), research concerning children has
focused largely on school and preschool inclusion (e.g., Guralnick, Connor, Hammond,
Gottman, & Kinnish, 1996; Meyer, 2001; Odom, Zercher, Li, Marquart, Sandall, &
Brown, 2006). This research has concluded that inclusion of children with disabilities
may not always be easy and may require the support of adults at a variety of levels
(Odom, 2002).

Studies on the transition into school for the normative population have found that
support provided in school is an important predictor of success. In particular, young
children benefit from well-managed classrooms with more emotional support and more
sensitive and involved teachers (NICHD Early Child Care Research Network, 2003).
Classrooms with more teacher-led structured instruction tend to lead to less peer
interaction and children who are more anxious and unhappy (NICHD Early Child Care
Research Network, 2003). Although it is well accepted that it is important to support the
needs of children with ID, there has been no published research to date examining how support in the classroom and other areas of life affects the transition into school for these children. Children with ID may benefit from the same supports as their typically developing peers, however, due to the nature of their delays they may also require different types of supports, which may not be consistent with the needs of their peers (e.g., children with ID may benefit from more structure).

**Support for Parents.** In terms of examining support for parents there have been no specific studies evaluating the effects of supports for parents on the transition into school; however, the benefits of these supports in general have been noted. Following regression analyses researchers have concluded that perceived helpfulness of formal support (i.e., professional services and social organizations) predicted mobilizing the family to acquire and accept help in the community, which in turn predicted strength and family closeness (Greer, Grey, & McClean, 2006). Some specific services, such as respite and parent support groups, have been shown to mediate the negative effects of perceived stress for parents of children with ID (Herman, & Marcenko, 1997, Kwai-Sang Yau & Cecilia, 1999). Previous research has found that pre-school services which support both children and their parents have been associated with positive outcomes for the family as the child enters school.

**Parents’ Perceptions (c factor)**

Caregivers of children with ID often experience considerable stress due to worries and demands related to their child (Floyd & Gallagher, 1997; Minnes, 1998). Several perceptions of parents of children with ID may influence the transition into school; including perceived stress, coping strategies, and positive appraisals. Of all the
factors examined, researchers have most commonly found that severity of behaviour problems in children with ID is the strongest predictor of parenting stress (Baker et al., 2003; Floyd & Gallagher, 1997; Hassall, Rose, & McDonald, 2005; Nachshen, Garcin, & Minnes, 2005). Caregiver stress is expected to affect the children being cared for especially if positive coping strategies are lacking (Baker, et al., 2003; Hadadian, & Merbler, 1996), and positive coping strategies have been shown to lower stress in parents of children with ID (Jones & Passey, 2004). Furthermore, it has been found that positive perceptions are correlated with positive coping strategies (Hastings, Allen, McDermott, & Still, 2002) and can moderate the negative effects of behaviour problems on the parents (Baker et al., 2005). Although it is clear that perceived stress, coping and positive appraisals all influence the well-being of parents of children with ID, the role of these variables in the transition into school is not as clear. It is possible that these factors may influence the child’s well-being, particularly quality of life, throughout the transition.

Studies with typically developing populations have found that parent perceptions and behaviours are important variables when examining adjustment to school (NICHD Early Child Care Research Network, 2004; Sy & Schulenberg, 2005). Research has indicated that the most competent and least problematic children from the teachers’ perspectives had fathers who were sensitive and supportive of their children’s autonomy and mothers whose parenting beliefs support self-directed child behaviour (NICHD Early Child Care Research Network, 2004). Furthermore, it has been found that parenting behaviours, including involvement in school (both at school and at home), are influenced by parents’ beliefs and children’s achievement throughout the transition into school (Sy & Schulenburg, 2005).
Transition Success (x factor)

Quality of Life. Quality of life has become a prominent measure of outcome in studies examining individuals with ID and their families (e.g., Raphael, Brown, Renwick, & Rootman, 1996; Renwick, et al., 2003; Zekovic & Renwick, 2003); however much of the literature on quality of life for children has focused on developing conceptual frameworks or models (Renwick, et al., 2003; Zekovic & Renwick, 2003). Researchers acknowledge that considerable work must be done to develop tools that can accurately measure quality of life for children (Eiser, Mohay, & Morse, 2000; Zekovic & Renwick, 2003). Currently, conceptual models and measures based on them are being developed and evaluated; however, a major difficulty lies in developing tools that can be used with young children. Often information is collected from proxies, such as parents or other adults who know the child well; though it has been found that in adults self-report and proxy response do not have high agreement (Schalock, 2004). At this point, it seems that proxy reports from parents are the most common, and possibly only, way to collect information about a young child’s quality of life.

Renwick and colleagues (2003, p. 111) have divided quality of life into three main domains: 1) “Being-who the child is perceived to be, 2) Belonging- the child’s connections to people and places, and 3) Becoming- the child’s nurtured growth and development”. These domains are ultimately related to the child’s identity, integration, and support. Literature in this area indicates that there are several factors which may affect a child’s quality of life throughout the transition into school (i.e., child characteristics, caregiver characteristics, and supports and resources) (Kemp, 2003; Renwick, et al., 2003). It has been suggested that a good relationship between the child,
the family environment, and the broader environment will lead to a better quality of life for the child (Renwick, et al., 2003). Unfortunately to date, there has been little empirical research evaluating this model or quality of life for young children with ID, therefore it is considered to be an important component of the current study.

**School Readiness**. School readiness is an important outcome measure in research and practice involving young children (La Paro, & Pianta, 2000). Tests of school readiness are typically used to measure and predict a child’s pre-academic skills and behaviours, but the components of these tests are quite broad. In the past few years it has become common practice for children in Ontario kindergarten classrooms to be assessed for school readiness (Duku, & Janus, 2004). This assessment is useful for identifying children who may have higher support needs in Grade 1 and beyond. In some states in the United States, school readiness is used to make decisions about placement in either kindergarten or special-education intervention programs (Augustyniak, Cook-Cottone, & Calabrese, 2004). Since school readiness involves a measurement of a child’s abilities, particularly academic, social and language skills, and is often the basis of future placement, it is expected to be a useful tool for measuring the success of the transition.

*Changes over Time*

**Changing Characteristics of the Child (aA factor)**

To date, there have been no published studies investigating changes in children with ID and their families during the transition into school; however, researchers do suggest that transition planning should begin 6 to 12 months prior to school entry and continue for at least 2 or 3 months (Kemp, 2003). The majority of the longitudinal research on young children with ID has found that gradual improvements in adaptive
behaviour are typically observed over time (Hauser-Cram, Warfield, Shonkoff, & Kraus, 2001), while maladaptive behaviour has been found to be relatively stable over time (Baker, et al., 2003). However, it is unclear how a major change in environment coupled with the developmental changes that often coincide with this transition may interact.

*Changing Resources (bB factor)*

The transition to school is often referred to as a change from one service to another (Kemp & Carter, 2000). Children are typically leaving individualized early intervention programs and familiar settings, to enter a new environment within the school system. Often the new environment is more structured and formal, and demands a greater level of independence from the child. Although the main approach in preparing for the transition to school has been to teach children the skills that will be needed in the new environment, it has also been recognized that changes in the environment may be necessary to support the child (Kemp & Carter, 2000). It has been found that when children with ID enter school the gap between their skills and those of their peers becomes more obvious (Hauser-Cram, et al., 2001), thus increasing awareness of their support needs.

*Parents’ Perceptions  (cC factor)*

Both positive perceptions and perceived parental stress have been found to remain relatively stable over time (Baker, et al., 2003). However, parental stress can depend on child characteristics (Hauser-Cram, et al., 2001) and on the context or level of support available to the parent (Plant & Sanders, 2007). Since the transition to school is a time of change, careful planning in order to minimise stress for the children and families involved has been recommended (Kemp & Carter, 2000). Although there have been no
published studies to date examining changes during the transition into school, other longitudinal research provides information on which to base hypotheses. Research on changes in coping strategies over time has found that when coping is measured based on situation-specific reports changes are frequently observed, as the coping strategies used depend on the demands of the situation (Ising, Weyers, Reuter, & Janke, 2006). Therefore, it can be expected that during the time of transition the differing situations encountered will be reflected in different coping strategies.

*Quality of Life*

Researchers have suggested that quality of life is strongly related to the services provided, and therefore should change as services change (Schalock, 2004). Some research has investigated changes in the quality of life of adults with ID following a change in services and found that significant changes in quality of life have been observed (Dagnan, Ruddick, & Jones, 1998). Since the transition to school marks a change in services, changes in quality of life should be associated, although the direction of these changes is not clear. Presumably if the services provided following the transition are more supportive of the child, and involve a higher degree of inclusion in the community increases in quality of life would be observed; however, if the reverse was true decreases in quality of life may be found.

*Summary*

In summary, the published research on predicting successful transition to school has largely focused on the normative population and found that the academic and social skills of the child, the classroom support and the parent’s attitudes and behaviours are related to success in school. In the only study to date evaluating the predictors of
successful transition for children with ID (McIntyre, et al., 2006), self-regulation and social skills were found to be the most important predictors of adaptive transition (i.e., teacher reported absence of behaviour problems). To date, there have been no comprehensive studies investigating the role of the three main variables; child factors, resources, and parental perceptions during the transition to school, although the variables have been linked individually and are hypothesized to affect the transition to school. The Double ABCX model proposed for this study, has not been evaluated previously.

**Objectives and Hypotheses**

As this research is exploratory in nature, one of the main goals was to describe a group of children with ID and their families as the children entered school in South Eastern Ontario throughout the period of transition. Since child characteristics, resources and parental perceptions were all expected to contribute to transition success, variability in each of these factors was important to examine as it was hypothesized to contribute to variability in transition success.

As discussed above, changes in children with ID and their families during the time of transition have not been evaluated, however, given the changes in services, environment, and the development of these children during the time of transition it was expected that changes in the children and their families would be observed. In particular, it was hypothesized that changes in the child’s behaviour, services and supports, integration and overall quality of life would be observed. As well, it was anticipated that there would be changes in the stress and coping methods of the parents over time.

The majority of research on the transition into school has focused on predicting successful transition. As outlined above the child’s skills, resources and parents
perceptions have been linked to transition success. It was hypothesized that factors relating to the child’s adaptive functioning, early intervention use, support at school, support for the parent, parental stress, coping, and positive perceptions would be important for predicting quality of life and school readiness. The final objective of this study was to evaluate the proposed Double ABCX model (see Figure 2) to determine whether it can provide an accurate understanding of this sample during this time period.
Chapter 2

Method

Participants

Nineteen parents of children with or at risk for intellectual disabilities who were entering school for the first time in September 2006 (18 mothers, 1 father; \( M = 34.31 \) years, \( SD = 6.51 \)) were included in this study, only one parent from each family was permitted to participate. The children included 5 girls and 14 boys ranging in age from 43 to 67 months (\( M = 56.26 \) months, \( SD = 7.64 \)) with a variety of diagnoses, including autism spectrum disorders, Down syndrome, developmental delay, Rett disorder, and several other neurodevelopmental disorders. Parents were recruited through information packages sent by agencies serving children with ID in South Eastern Ontario on behalf of the research team, as well as through a newspaper article announcing the study. Two additional participants were lost following the second interview; one chose to discontinue because of time commitments and the other moved and did not provide the researcher with her new contact information.

Procedure

With the approval and assistance of several agencies throughout South Eastern Ontario, a recruitment package was sent to parents of children with ID or developmental delay who were entering school in September 2006. Participants returned a signed consent form to indicate interest in participating and were contacted via telephone to complete their first interview. In total, the participants completed three 1 hour phone interviews; the first in the summer before school started, the second in late fall, and the third in late winter. Each interview consisted of the measures listed below with the
exception of the Quality of Life Scale which was sent to parents after each interview to be completed by hand. During the second interview the parents were asked to nominate a teacher who could provide further information about the child’s functioning in the classroom. A consent form and questionnaire were mailed to the teachers in March 2007.

**Measures**

*Characteristics of the Child (a factor)*

*Demographic information.* Participants provided demographic information pertaining to themselves (i.e., date and place of birth, relationship with the child, level of education, and occupation), their child (i.e., date and place of birth, sex, diagnosis) and the family (i.e., household income, family constellation) during the initial interview.

*The Scales of Independent Behavior-Revised Early Development Form (SIB-R EDF; Bruininks, Woodcock, Weatherman, & Hill, 1996).* This scale was used to assess adaptive and maladaptive behaviour. The SIB-R EDF provides an age equivalent adaptive behaviour score, general, internalized, asocial and externalized maladaptive behaviour scores, and a support score which combines the two main domains. The SIB-R has been standardized on a normative population, including a sample of children with ID, and is reported to have good to excellent internal consistency, high test-retest reliability, and good inter-rater reliability (Bruininks, et al., 1996). The Early Development Form was adapted from the full scale SIB-R by the original authors to provide a quick overall screen of developmental age of children from infancy to age 6.

*Resources (b factor)*

*Services and Supports questionnaire.* This measure was developed by the primary investigator for use in this study. The questionnaire includes a list of direct services
which are often available to young children with ID and their families (e.g., daycare, speech therapy, respite services, parent support groups). Parents were asked about current use of the services as well as to rate satisfaction with each service on a 5-point Likert scale ranging from 1 (very unsatisfied) to 5 (very satisfied).

AIMS Interview- Child Version (Minnes, Buell, & Solish, 2005). The AIMS Interview is a structured interview measuring community integration from an acculturation perspective. Information about whether needs are identified and supported in several domains (i.e., medical, additional medical, dental, educational, living arrangements, recreational, social activities, and religious activities) in a way that facilitates community participation is used to identify an individual as either integrated, segregated, assimilated or marginalized. Parents are asked a series of ‘yes or no’ questions followed by prompts to provide more information; in each domain parents were also asked if there were other supports in this domain that the child needed. The category of integration is scored if disability-related needs are identified and supported and, if the person is involved in the community; whereas segregation is when the disability-related needs are identified and supported, but the person is not involved in the community. If the person is involved in the community but their disability-related needs are not identified and supported, they are rated as being in the assimilation category. Finally, an individual is considered marginalized if their disability-related needs are not identified or supported and the person is not involved in the community. Research to date indicates that the AIMS Interview when referring to adults with ID has sound psychometric properties, including discriminant and concurrent validity (Minnes, et al., 2002). Data gathered in pilot studies of children with ID and acquired brain injuries (Alvarez, Minnes
& Benn, 2003; Solish, Minnes & Kupferschmidt, 2003) has demonstrated good face and content validity and inter-rater reliability. For the purposes of this study the Volunteering and Employment Opportunities domains were not used as they do not apply to children in this age group.

Parents’ Perceptions (c factor)

The Family Stress and Coping Interview (FSCI; Nachshen, Woodford & Minnes, 2003). The FSCI is a measure of stress in which caregivers are asked to rate the stressfulness of 22 issues on a four-point Likert scale ranging from 0 (Not Stressful) to 3 (Extremely Stressful). For the purposes of this study two items (i.e., 15. “Dealing with _____’s sexuality.” and 16. “Work placements and employment for ________.”) were removed as they refer to issues not likely to be relevant to preschoolers. The individual items on the FSCI can be summed to create a total score, and a mean score can be calculated. The results of research to date with the FSCI demonstrate high internal consistency ($\alpha = 0.89$), high test-retest reliability ($r = 0.8$), and face validity (Nachshen, et al., 2003).

The Life Management Survey Part III-Parental Changes Subscale (Parental Changes; Scorgie & Sobsey, 2000). The Life Management Survey is a 59 item survey that was created based on themes that emerged from qualitative interviews with 15 parents of children with disabilities who had been identified as “good copers.” The Life Management Survey is divided into three subscales: Effective Strategies, Parent Characteristics, and Parental Changes. The Parental Changes subscale was used for the current study as a measure of the positive impact of the child with ID on the family. This subscale includes 18 items which examine themes related to the positive parental
transformations associated with personal changes (e.g., “I am stronger as a person”), changes in relationships (e.g., “I have made many close friendships with people I never would have met otherwise”), and changes in perspective (e.g., “I have learned what is really important and valuable in life”). Each item is rated on a 5-point Likert scale ranging from 1 (Strongly Disagree) to 5 (Strongly Agree). There have been no measures of reliability completed for Life Management Survey to date, although it is considered to have good content validity based on high levels of disagreement with a contrast item.

The Ways of Coping Scale (WAYS; Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986; revised by McColl & Skinner, 1995). The WAYS is a 31 item measure of coping strategy use in which participants are asked to describe a particularly stressful event they have experienced related to their child, and rate the relative frequency with which they applied a variety of coping mechanisms. Participants were asked to rate each item on a 4-point Likert rating scale ranging from 0 (did not use) to 3 (used a great deal). The items correspond to one of the following strategies; problem-focused, perception-focused, and emotion-focused coping as referred to by Pearlin and Schooler (1978). Although the WAYS is considered to have acceptable internal consistency ($\alpha = 0.61$ to 0.79), the authors indicate that test-retest and inter-rater reliability are not relevant given the expected changes in coping strategies in different situations.

(x)Transition Success

Quality of Life for Children with Developmental Disabilities (QOL; Renwick, et al., 2002). The QOL questionnaire developed for parents of children with ID, was used to provide a measure of overall quality of life. The questionnaire includes 60 statements in three domains: Being (i.e., the person the child is perceived to be), Belonging (i.e., the
child’s connections to people and places), and Becoming (i.e., how the child’s growth and development is nurtured). Following each statement, the parent is asked to answer three questions; 1) “How much does this statement apply to your child’s situation right now?”; 2) “How important is this for your child?”; and 3) “How satisfied are you with the way things are?”; by choosing an appropriate response from a 5 point Likert scale from (1) not at all to (5) extremely. Scores of overall satisfaction in each domain (i.e., Being, Belonging and Becoming) were calculated. Due to the nature of this questionnaire it was sent to parents by mail for self-administration following each interview.

*The Early Development Inventory* (EDI; The Offord Centre for Child Studies, 2005) The EDI is a measure of school readiness that is completed by the child’s teacher. It assesses readiness to learn at school in three domains: physical well-being, language and cognitive skills, and social and emotional development. There is also an additional scale measuring the child’s special problems. The instrument has undergone a number of evaluations and has been shown to have high test-retest reliability (ranging from $r = 0.76$ to $r = 0.96$) and very high intra-teacher reliability (range $r = 0.70$ to $0.95$) in several locations at several times.
Chapter 3

Results

Describing participants (Time 1)

Families. The nineteen families included in this study varied in socioeconomic status. Although a large portion of the participants (42.1%) indicated their annual household income to be less than $25,000, 15.8% indicated their income to be over $95,000, and the other 42.1% ranged between $25,000 and $65,000. In terms of parental education, 89.5% had at least a high school diploma, while 73.6% had a post secondary degree or diploma (college 52.6%; university 10.5%; professional degree 10.5%).

(a) Child Characteristics. There was also considerable variability in the diagnoses of the children with some having multiple disabilities. The majority (12) were diagnosed with autism spectrum disorder, five with developmental delay, two with attention deficit hyperactivity, one each with Down syndrome and cerebral palsy, as well as four children with rare neurodevelopmental conditions. Scores on the SIB-R indicated that overall, the children were functioning below their chronological age in terms of adaptive behaviour, however, scores regarding maladaptive behaviour were relatively low, indicating few behaviour problems (See Table 1).

Table 1. Descriptive Statistics for SIB-R Adaptive and Maladaptive Behaviour at Time 1

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chronological Age (months)</td>
<td>56.26</td>
<td>7.64</td>
</tr>
<tr>
<td>Adaptive Behaviour Age Equivalent (months)</td>
<td>35.26</td>
<td>17.14</td>
</tr>
<tr>
<td>General Maladaptive Index</td>
<td>-11.95 a</td>
<td>7.79</td>
</tr>
</tbody>
</table>

a This score falls within the “Marginally Serious” range.
(b) Resources. The families were using a number of supports and services including daycare/preschool (100%), speech therapy (94.7%), respite services (47.4%) and parent support groups (57.9%; see Table 4 for complete list of services). The majority of children were integrated, that is their needs were identified and supported, in most domains measured (i.e., medical, additional medical, education, and recreational activities). However, in the dental services and social activities domains the majority were marginalized (i.e., not receiving the service). Interestingly, no one was rated as segregated in any of the domains, but the majority of children were rated as assimilated for religious activities. In the living arrangements domain half of the children were assimilated and the other half were integrated (See Table 2).

Table 2. Frequency of Integration, Segregation, Assimilation, and Marginalization at Time 1

<table>
<thead>
<tr>
<th>Domain</th>
<th>Integration</th>
<th>Segregation</th>
<th>Assimilation</th>
<th>Marginalization</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical Services</td>
<td>11</td>
<td>0</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td>Additional Medical</td>
<td>10</td>
<td>0</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Dental Services</td>
<td>6</td>
<td>0</td>
<td>1</td>
<td>12</td>
</tr>
<tr>
<td>Education</td>
<td>16</td>
<td>0</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Living Arrangements</td>
<td>10</td>
<td>0</td>
<td>9</td>
<td>0</td>
</tr>
<tr>
<td>Social Activities</td>
<td>6</td>
<td>0</td>
<td>9</td>
<td>0</td>
</tr>
<tr>
<td>Recreational Activities</td>
<td>19</td>
<td>0</td>
<td>1</td>
<td>12</td>
</tr>
<tr>
<td>Religious Activities</td>
<td>2</td>
<td>0</td>
<td>6</td>
<td>0</td>
</tr>
</tbody>
</table>

*a* Refers to organized activities such as sports, lessons and clubs.

*b* Refers to activities which the child and family are involved in such as playing games, going to the park, watching television.

(c) Parents’ Perceptions. The parents reported mild levels of stress ($M = 1.22, SD = 0.47$) on the FSCI. The most stressful issues were dealing with financial and insurance issues ($M = 2.05, SD = 1.07$) and finding opportunities for the child to make friends ($M = 1.81, SD = 0.93$). Parents indicated using a number of coping strategies and were found to
use problem-focused ($M = 17.37, SD = 7.11$) and perception-focused ($M = 17.89, SD = 7.42$) strategies more than emotion-focused ($M = 11.58, SD = 5.55$). In terms of positive parental changes, parents generally agreed with the statements in each category; personal ($M = 3.94, SD = 0.71$), relational ($M = 3.55, SD = 0.74$), and perspective ($M = 3.71, SD = 0.72$).

(x) Transition Success. Generally, the parents reported satisfaction with their child’s quality of life in all three domains measured (See Table 3). In terms of school readiness as reported by teachers, the children scored considerably lower than a large group of typically developing children used to evaluate the psychometric properties of the instrument (Janus & Offord, 2007). When comparing across domains there was relative strength in physical well-being ($M = 5.96, SD = 2.19$) with social and emotional skills ($M = 4.46, SD = 1.19$) being somewhat better than cognitive and language skills ($M = 3.63, SD = 2.13$).

<table>
<thead>
<tr>
<th>Domain</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>The person your child is perceived to be a</td>
<td>3.58</td>
<td>0.76</td>
</tr>
<tr>
<td>Your child’s connections to people and places b</td>
<td>3.51</td>
<td>0.45</td>
</tr>
<tr>
<td>How your child’s growth and development is nurtured c</td>
<td>3.64</td>
<td>0.58</td>
</tr>
</tbody>
</table>

Note. Scores reflect parents mean rating of satisfaction within each domain based on a 5-point scale (1 = not at all satisfied to 5 = extremely satisfied).

a “Being”, b “Belonging”, c “Becoming”

Changes over time

To evaluate changes during the time of transition a repeated measures ANOVA using summary and domain scores (i.e., SIB-R General Maladaptive Index, SIB-R Adaptive behaviour total score, number of formal services used, FSCI mean stress,
WAYS problem-focused coping score, WAYS perception-focused coping score, WAYS emotion-focused coping score, Positive Changes personal changes score, Positive Changes relational changes score, Positive Changes perspective changes score, QOL satisfaction with “Being” domain, QOL satisfaction with “Belonging” domain; QOL satisfaction score with “Becoming” domain) as dependent variables and time as the independent variable was calculated. To examine changes in categorical variables (i.e., AIMS domain identifications) over time Pearson Chi Square was calculated using the AIMS identification (Integrated, Segregated, Assimilated or Marginalized) within each domain as the dependent variables and time as the independent variable. Many of the variables were not found to change significantly over time.

(aA) Child Characteristics

Adaptive behaviour scores increased significantly over time \((F(2,18) = 6.45, p < .01\), see Figure 3). Although there were not significant changes in maladaptive behaviour over time, the scores for the three time points are presented for interest (Figure 4), as some trends emerge.

Figure 3. Age Equivalent Adaptive Behaviour Scores over Time
(bB) Resources

There were no significant changes in community integration over time. However, the mean number of services used decreased significantly \((F(2,18) = 8.56, p < .01,\) see Figure 5). The Tukey HSD post-hoc analysis revealed that only the difference between time 1 \((M = 3.26, SD = 1.52)\) and time 3 \((M = 1.89, SD = 1.45)\) was significant, although the least significant difference test (LSD) found that there was also a significant difference between the number of services used at time 1 \((M = 3.26, SD = 1.52)\) and time 2 \((M = 2.21, SD = 1.72)\). The number of participants accessing each service also decreased over time, although the changes were not significant (See Table 4).
Figure 5. Mean Number of Services Used over Time

Table 4. Frequency of Service Use over Time

<table>
<thead>
<tr>
<th>Service</th>
<th>No. of Participants Using Service</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Time 1</td>
</tr>
<tr>
<td>Parent Support Group</td>
<td>11</td>
</tr>
<tr>
<td>Respite Services</td>
<td>9</td>
</tr>
<tr>
<td>Behaviour Management Services</td>
<td>3</td>
</tr>
<tr>
<td>Social Work</td>
<td>8</td>
</tr>
<tr>
<td>Psychology</td>
<td>7</td>
</tr>
<tr>
<td>Speech-Language Therapy</td>
<td>18</td>
</tr>
<tr>
<td>Physiotherapy</td>
<td>4</td>
</tr>
<tr>
<td>Occupational Therapy</td>
<td>13</td>
</tr>
<tr>
<td>Early Intervention Programs a</td>
<td>5</td>
</tr>
</tbody>
</table>

*a Early Intervention programs include school readiness programs and Intensive Behavioural Intervention for children with autism spectrum disorders.

Parent’s Perceptions

There were no significant differences in perceived parental stress, positive changes, or coping strategies over time. Interesting trends in coping strategies are displayed in Figure 6.
Figure 6. Frequency of Use of Coping Strategies over Time

*Transition Success*

Quality of life did not change significantly over the three time points.

*Predicting Quality of Life and School Readiness*

Since the sample size was small, it was inadvisable to complete multiple regression analyses in order to evaluate the model. Pearson two-tailed correlations, however, were calculated to examine the relationships between the independent variables (SIB-R Adaptive behaviour total score, early intervention use, support at school, parent support group use, FSCI mean stress, WAYS problem-focused coping score, WAYS perception-focused coping score, WAYS emotion-focused coping score, Positive Changes personal changes score, Positive Changes relational changes score, and Positive Changes perspective changes score) and the dependent variables (QOL satisfaction with “Being” domain, QOL satisfaction with “Belonging” domain, QOL satisfaction score with “Becoming” domain, EDI Physical health and well-being domain, EDI Cognitive and language skills domain, and EDI Social and emotional skills domain). Very few
variables were found to be correlated with either quality of life or school readiness. Only the significant correlations are reported below.

(a) Child Characteristics

Age equivalent adaptive behaviour was positively correlated with all three domains of school readiness; physical health and well-being \((r = .725, p < .01)\), language and cognitive skills \((r = .635, p < .05)\) and social and emotional skills \((r = .572, p < .05)\), that is higher adaptive behaviour scores were associated with higher school readiness scores.

(b) Resources

Use of several services was correlated with school readiness. Physiotherapy use was negatively correlated with both physical health and well-being \((r = -.627, p < .05)\) and language and cognitive skills \((r = -.549, p < .05)\). Speech-language therapy use was negatively correlated with language and cognitive skills \((r = -.569, p < .05)\). Involvement in parent support groups was the only variable correlated with satisfaction in any of the quality of life domains; specifically “Being” \((r = .537, p < .05)\) and “Belonging” \((r = .572, p < .05)\). Following this finding, a one-way ANOVA was computed with involvement in parent support groups as the independent variable and satisfaction with each quality of life domain (i.e., “Being”, “Belonging”, and “Becoming”) as the dependent variables. Parents involved in support groups differed significantly from those who were not involved in their scores on both the “Being” and “Belonging” domains \((F(1,16) = 6.48, p < .05\) and \(F(1,16) = 7.79, p < .05\) respectively. Parents who were involved in parent support groups were more satisfied with their child’s quality of life (“Being” \(M = 3.94, SD = 0.68\), “Belonging” \(M = 3.75, SD = 0.36\), than those who were
not involved in support groups (“Being” $M = 3.14$, $SD = 0.64$, “Belonging” $M = 3.23$, $SD = 0.41$; See Figure 7). As well, involvement in parent support groups was positively correlated with the physical health and well-being domain of the school readiness measure ($r = .560$, $p < .05$).

![Graph showing satisfaction with quality of life domains based on involvement in parent support groups.]

* $p < .05$

Figure 7. Satisfaction with Quality of Life Domains Based on Involvement in Parent Support Groups

(c) Parents’ Perceptions

Mean parental stress was negatively correlated with the physical health and well-being domain ($r = -.548$, $p < .05$) such that parents who reported higher stress had children with lower physical health and well-being scores.
Chapter 4

Discussion

Given that this is the first study known to investigate the experiences of families of children with or at risk for ID transitioning into school in Canada, the results provide some initial information. The participants represent families and children with considerable variation in socioeconomic status, diagnoses, ability levels and experiences. However, since this study was based on a relatively small sample drawing many conclusions would be premature.

*Participant characteristics (Time 1)*

*Characteristics of the Child (a factor)*

As expected, the children in this study were functioning below their age based norms in both adaptive behaviour and school readiness skills, consistent with their diagnoses.

*Resources (b factor)*

Proponents of inclusion have argued that integration of people with ID is not only ideal, but should be considered the only option. The effects of inclusion on children with ID and their typically developing peers are both difficult to measure and hotly debated, however, it is now generally accepted that inclusion is beneficial for children with ID and does not cause noticeable harm to their peers (Stahmer & Carter, 2005). Research on inclusion for children with ID has focused almost exclusively on integration in preschool and school settings (e.g., Guralnick, et al., 1996; Meyer, 2001; Odom, et al., 2006). The current study examined community inclusion in a number of domains, and the findings raise a number of issues. In this study, the majority of children were not involved in
organized social activities or visiting the dentist regularly. The main reasons reported by parents for the lack of participation in organized social activities were the need for financial and one-to-one physical support. Previous research on inclusion in social activities for older children with ID has found that while the majority of the school-aged children sampled were integrated in social activities, most were receiving support from their caregiver alone or their caregiver and a paid worker (Solish, et al., 2003). This finding suggests that the concerns of parents in the current study regarding one-to-one support for their child may be validated, but also points to some possible differences in inclusion in social activities based on age.

When asked why their child was not seeing a dentist regularly, the main reasons parents provided were the anticipated difficulty for the child (e.g., “he would not be able to sit still”, “he would become very upset”), and a notion that oral health was not a priority since the child had not grown any adult teeth. Studies consistently find that the prevalence of oral health problems is higher in individuals with ID than in the general population, and individuals with ID are less likely to receive appropriate dental care (Owens, Kerker, Zigler, & Horwitz, 2006). A number of barriers to prevention of dental disease in individuals with ID have been identified and include informational (i.e., caregivers are not aware of the importance), physical (i.e., individuals are physically unable to use toothbrushes or other tools), and behavioural barriers (i.e., individuals may be resistant to performing oral health routines) (Glassman & Miller, 2003).

It is also notable that in some domains of the AIMS (i.e., medical services, living arrangements and religious activities) there were a number of families where the parents, rather than professionals, were the only people providing support for their child. This
situation was categorized as assimilation. In a sense, these children were being treated as any other child their age. When asked for qualitative information about why their child did not receive the type of support he/she needed, many parents stated that they could not expect a volunteer at their religious activity to learn how to support the child. However, parents were much less forgiving with their physicians, indicating that they expected a physician to know how to interact with a child with ID, or to provide extra support for a child with high medical needs. This lack of medical support is consistent with findings from previous research suggesting that among other barriers to quality health care, physicians do not receive enough training for working with people with ID (Lennox, Diggins, & Ugioni, 1997). However, it is also possible that other systemic problems with the health care system, such as too many patients and not enough time, prevent the physicians from providing the type of medical care these parents expect.

Interestingly, no children were rated as segregated in any of the domains of the AIMS prior to entry to school. This finding reflects policies of inclusion supported by the Ontario Ministry of Education, which indicates that placement in an integrated setting (i.e., regular classroom), should be given preference over a segregated class, assuming it is preferred by the parents and will meet the needs of the student (Ministry of Education, 2001). This preference for integration has been adopted by other agencies and the views of the general public, and is reflected in the data presented here.

*Parents’ Perceptions (c factor)*

Previous research on families of children with ID has found that perceived parental stress is most strongly linked with child behaviour problems (Floyd & Gallagher, 1997; Hassall, et al., 2005). Since the parents in this study reported relatively few child
behaviour problems their reports of milder stress are not surprising. Similarly, findings from previous studies using the FSCI indicate that on average parents of children under the age of 21 years reported relatively mild stress (Nachshen, et al., 2003). Other researchers have found that parents who report lower stress use more positive coping strategies (Jones & Passey, 2004). The parents in this sample reported using a number of adaptive coping strategies, and were more likely to use problem- and perception-focused strategies than emotion-focused strategies, a finding that is similar to that of previous research (Glidden, Billings, & Jobe, 2006). The most common strategies reported by parents were “made a plan of action and followed it” and “reminded myself how much worse it could be.”

Research on families of children with ID has concluded that parents who use positive coping strategies have more positive perceptions of their child and their child’s role in the family (Hastings, et al., 2002). Furthermore, it has been found that positive perceptions can moderate the negative effects of behaviour problems (Baker et al., 2005). Parents in this study agreed with many statements about positive changes in themselves (i.e., personal), in their relationships with others (i.e., relational) and in the way they view life (i.e., perspective). This finding is consistent with the original research involved in the development of this survey where the majority of parents agreed with most of the positive changes in all three domains (Scorgie & Sobsey, 2000). Similarly, previous research has found that parents agree with many statements related to the positive aspects of caring for a child with a disability, such as seeing the child as a source of happiness, strength and family closeness, and a source of personal growth (Greer, et al., 2006).
Quality of Life

Parents in this study reported generally being satisfied with their child’s quality of life, scoring on average within the ‘satisfied’ range (3.60 on a scale from (1) ‘not at all satisfied’ to (5) ‘extremely satisfied’); in a sense parents were neither overly satisfied nor dissatisfied. This finding is in agreement with previous research which has found that although the quality of life scores for children with ID were significantly lower than their typically developing peers, they were not extremely low or in the dissatisfied range (Watson & Keith, 2002).

Changes over time

Characteristics of the Child (aA factor)

In the current study the prediction that changes in many of the variables over time would be observed was not supported. It is likely that the sample size limited the detection of relatively small changes over time, consequently trends were presented. Previous longitudinal research on children with ID has largely focused on changes in cognitive development over time, mainly from infancy through the toddler years in children with Down syndrome (e.g., Dameron, 1963; Dicks-Mireaux, 1972; Reed, Pueschel, Schnell, & Cronk, 1980). The main finding from these studies indicates that children with ID do not make gains in development at the same rate as typically developing children, and specifically it has been found that the deficits become clearer in the preschool years. However, more recently it has been found that communication skills, social skills and daily living skills, all components of adaptive behaviour, increase gradually over time in children with developmental delay or Down syndrome with average gains between .16 and .24 months per month from age 3 to 10 years (Hauser-
Cram, et al., 2001). Similarly, gradual gains in adaptive behaviour were observed in the current study.

There have been few studies examining changes in behaviour problems for children with ID over time. One study which followed three-year-old children with ID for a year found that behaviour problems remained relatively stable over that time period (Baker, et al., 2003). However the trends presented in the current study suggest that problem behaviours peaked after the start of school before declining. Since the former study did not examine changes over a time of transition, it is possible that the differing results are related to the transition into school. That is, children in the current study required an adjustment period following the transition to school before their behaviour stabilized.

*Resources (bB factor)*

There are some well developed early intervention and public health programs which target preschool aged children in Ontario, such as speech-language therapy, resource consultants with childcare centres, and intensive behavioural intervention for children with autism. Typically children are no longer eligible for these services once they have started school, and when equivalent services are provided in schools they tend to be less comprehensive and less intensive. Consistent with these facts and the hypothesis, the number of services used by children with ID and their families declined significantly following the transition into school. Although this finding is not surprising, this change in service availability has important implications for these children and their families. Anecdotally, many parents reported frustrations with the system because services were discontinued. It may be beneficial to consider changes to the system to
create a more continuous and comprehensive system in which preschool services continue until the school board has begun to provide the equivalent service. At the very least, professionals should prepare parents for the possible termination of services.

It is now considered standard practice for children with ID to be integrated in classrooms with typically developing peers (Ministry of Education, 2001). The only published research on inclusion for young children has focused on preschool and school environments, although the benefits of inclusion in all areas of life have been recognized (Guralnick, et al., 1996). It was hypothesized that as children began attending school, an integrated environment, parents may seek changes in the support and service their child received outside of school. Furthermore, it was felt that since the skill gap between a child with ID and their peers becomes more obvious upon entry to school (Hauser-Cram, et al., 2001) that changes in support for the child may occur and translate to changes in inclusion. However, no changes in the child’s community inclusion over the course of the transition were found. It is possible that changes in community integration may take place over a longer period of time, as the families are exposed to more opportunities and expectations.

*Parents’ Perceptions (cC factor)*

A few studies have examined changes in parental adaptation over time and have found that changes in perceived stress depend on the type of stress measured; that is, studies have found no changes in stress related generally to the life of the parent (Hanson & Hanline, 1990; Warfield, Kraus, Hauser-Cram, Upshur, & Shonkoff, 1999), but changes in stress related to the influence of the child have been observed (Hauser-Cram, et al., 2001). One study examining both negative and positive impacts of the child found
that there was high stability in the negative impacts (or perceived stress) parents associated with their child over the year of the study (from child age 3 to 4 years) and moderate stability in the positive impacts (Baker, et al., 2003). Furthermore, research using the FSCI has found that in a group of older parents (i.e., mean age 64 years) perceived stress was relatively stable over the course of a year (Nachshen, et al., 2003). However, none of these studies focused on the experiences of families during the child’s transition to school.

In this sample, there was no significant difference in perceived parental stress throughout the time points measured, although it was predicted to change as changes in the environment and child, factors that influence stress, were expected. It has been documented that parental stress is strongly linked to behaviour problems (Baker, et al., 2003; Floyd & Gallagher, 1997; Hassall, et al., 2005; Nachshen, et al., 2005), which did not change significantly during this study. It has also been found that personality factors, specifically optimism, which are considered relatively stable, are related to parental stress (Baker, et al., 2005). As well, the positive changes parents associated with having a child with ID did not change over time, a finding which was consistent with the hypothesis. Much less is understood about the positive perceptions parents associate with caring for a child with ID. However, as mentioned above, parents’ reports of positive impact have been found to be relatively stable over time, and it is quite possible that they are associated with some personality factors. Since there has been no previous research investigating these variables throughout the transition into school this possibility cannot yet be confirmed.
Finally, although this finding was not statistically significant, it appears as though parents were using more coping strategies shortly after their child began school than either before school started or later in the year. Changes in the coping strategies individuals identify at different assessment times are not uncommon when situation specific measures, like the Ways of Coping Scale, are used (Ising, et al., 2006). It has been found that both stable factors and situational factors influence coping behaviour (Terry, 1994), and some have reported that situation has a stronger influence (De Ridder, & Kerssens, 2003). The specific finding that the number of coping strategies used tended to increase at the second time point may be indicative of the types of situations parents were dealing with at this time point (e.g., increased problem behaviour, issues with school personnel etc.) that required the implementation of more coping strategies.

*Transition Success (xX factor)*

Quality of life is an outcome related to the services provided to individuals with ID, and it has been found that changes in service delivery can lead to changes in quality of life. For example, in a study of adults with ID leaving a hospital setting to live in homes in the community increases in quality of life were observed over a 5 year period (Dagnan, et al., 1998). Although the transition to school may not be as monumental as the transition from an institution to the community, it does represent an important change in services which was hypothesized to influence the quality of life for the children involved. However, statistically significant changes in quality of life over time were not observed. It is possible that changes were less likely to be noted, since quality of life was measured from the parent’s perspective rather than the child’s actual experiences However, it is
also possible that changes take place over a longer period of time as with community inclusion.

*Predicting Quality of Life and School Readiness*

*Characteristics of the Child (a factor)*

As hypothesized, adaptive behaviour was associated with all areas of school readiness. Since, adaptive behaviour is a measure of daily living skills, which includes many of the skills needed for school readiness (e.g., ability to communicate needs, ability to complete self-care tasks independently) this association is not surprising. As well, previous research has found that social skills, a component of adaptive behaviour, predict adaptation to school (McIntyre, et al., 2006).

*Resources (b factor)*

When examining the other correlates of the school readiness domains, the results also make intuitive sense; it would be expected that children who are receiving physiotherapy would have poorer physical health and well-being scores, and that children who are receiving speech-language therapy have poorer language and cognitive skills. The positive association found between involvement in parent support groups and quality of life and school readiness is important. It is possible that those parents who were involved in support groups have different parenting skills and beliefs, personality factors, or perceptions of their child and his/her needs. Previous research has found that when compared to scores before involvement in support groups, parents reported more positive perceptions after involvement in parent support groups (Singer, et al., 1999). Others have found that involvement in parent support groups can buffer the effects of stress on families of children with disabilities (Kerr & McIntosh, 1999). In addition, the finding
from previous research that high perceived helpfulness of formal social supports was associated with seeking more support (Greer, et al., 2006) suggests that parents involved in support groups may be more likely to seek out other supports and services, further enhancing their child’s quality of life. Unfortunately, no published research to date has investigated the differences between parents who are involved in support groups and those who are not; although we would expect that some may exist. The results of the current study coupled with previous research suggest that parents of children with special needs seem uniquely qualified to help each other, therefore professionals should consider referring parents to support groups in addition to traditional professional service (Ainbinder, et al., 1998; Kerr & McIntosh, 1999).

Parents’ Perceptions (c factor)

In the current study perceived stress was the only parental perception associated with transition success. Specifically, higher reported parenting stress was related to lower physical health and well-being scores, which suggests that parents of children with higher physical needs were more stressed by their child’s needs. This association also has been found in previous studies (Plant & Sanders, 2007), in which it was found that not only did severity of behaviour problems and level of disability affect perceived stress, so too did difficulty of caregiving tasks.

Limitations and Future Directions

Although a study on the transition to school for children with ID examining all of these variables has not been completed before, components of the findings replicate previous results. As this study is the first of its kind, it provides initial information related to the experiences of children with ID and their families as the child transitions to school.
There are several limitations to this study which must be acknowledged when interpreting the results, but lead to several recommendations for future research.

**Sample Size**

A major limitation of this study is the small sample size which is due mainly to difficulties with recruitment. Researchers in general have found that it is difficult to recruit people with ID and their families (Lennox, Taylor, Rey-Conde, Bain, Purdie, & Boyle, 2005). Initially, the estimates of eligible cases for participation in this study may not have been accurate. As a number of families were involved with multiple agencies, they may have been counted several times. If the number of eligible families was overestimated so too was the number of expected participants. Furthermore, the time demands of this study were considerable, approximately 3 to 4 hours, particularly for parents of children with high needs. The size of this sample makes it difficult to draw many conclusions based on these data.

Although a considerable amount of data was collected from the participating families, as each of the participants was interviewed three times, the proposed analyses were based on obtaining a sample size three to four times as large. As a result, the final sample size yielded relatively low power (.752) even if a large effect were detected; therefore it was inadvisable to complete some of the proposed analyses (i.e., multiple regression). Promising trends were presented where it was likely that the sample size limited the ability to detect smaller changes over time.

In order to address the limitation of sample size, this project will be continued with the goal of recruiting more families of children with ID transitioning to school. It is likely that with more detailed analysis of data from a larger sample, important changes
and relationships may be identified, and the proposed model of transition can be evaluated. Although some preliminary information can be obtained from the current data, with continued data collection it is expected that we may obtain a better understanding of the experiences of children with ID and their families as the child transitions to school.

Generalizability

A further limitation of this study is the lack of generalizability of the data. A specific difficulty in obtaining a representative sample was encountered as recruitment was limited to children who had been receiving services within the community, since there was no other way to contact families who may not have been involved with agencies prior to the start of school. Furthermore, there is likely a selection bias in terms of those parents who volunteered to participate in the study. Within this sample there was a lack of variability in scores, particularly on the quality of life, positive changes, and parental stress measures, which may reflect the fact that all of the families were involved with pre-school agencies and were self-selected to participate. One would assume that families who were interested in participating would be less stressed, and have more resources available to them; however, interestingly a wide range of socioeconomic statuses was still found within the sample. With further research on this population it may become possible to study the differences in transition success between families of children who were identified prior to school start with those who were not.

It is difficult to interpret some of the findings presented without comparative data from a typically developing population. For example, the numbers of children identified as either marginalized or assimilated on the AIMS seem quite high. It is not clear how the involvement of these children compares to their typically developing peers. Although this
was outside of the scope of the current study, it will be addressed in future research. As this project continues a control group will be added in order to provide a better understanding of the effects of the transition into school on all families, and how the experiences of families of children with and without ID may differ.

**Measures**

A further limitation with this study involved the measures employed. Unfortunately a number of the measures used have not been thoroughly evaluated for psychometric properties when used with preschool aged children and their families (i.e., Child AIMS Interview, services and supports questionnaire, Ways of Coping, Positive Changes, and Quality of Life). The main reason for using these measures is a paucity of other measures of the same constructs, which have been as specifically developed or adapted for children with ID and their families. Most of these measures are in the process of being formally evaluated and have been used in a number of studies; however, given the small sample sizes typically obtained in studies in ID it will take several to develop a true sense of psychometric reliability and validity.

A specific limitation with measurement in this study is that it relied primarily on parent report, which may not be as reliable as observational data. However, information from the teachers measuring the child’s school readiness correlated well with parent reported adaptive behaviour, suggesting that these scores are valid. For a large part of this study, parental perceptions were the focus, so receiving information solely from the parents was sufficient, though it may be beneficial in future studies to confirm service delivery, particularly at school, as parents may not be aware of the services their child is receiving while at school. The measurement of quality of life for children using the
parents’ perspective poses particular difficulties, as the scores are based on the parents’ perceptions rather than the child’s experience. In this case, it would be very difficult to collect information from the children about their own quality of life given their age and developmental level. For the purposes of this study quality of life really represents the degree of support and inclusion that the child receives, which at this age is based substantially on the exposure to people, experiences and activities that the parent chooses or is at least aware of.

The measures, and variables, chosen for this study may not represent those variables that change over the transition into school, and this may explain why there were few changes observed. Although there are many changes in the lives of families as their child enters school for the first time, these may not have been affecting all of the variables measured in the current study. Furthermore it is possible that factors that may change were not measured. With further longitudinal research examining changes during the transition into school this possibility can be evaluated.

Another challenge for this study was related to the lack of consensus regarding a definition of transition, the transition period and understanding what constitutes a successful transition. In addition, there is no clear consensus on the markers for the beginning and end of the transition to school period (Kemp, 2003). However, the transition to school has been identified as a shift from one service to another, and is generally thought to include the periods before and after the change (Kemp, 2003). It is possible that participants in the current study needed to be followed for a longer time, or that the times of measurement were too far apart, essentially missing the peak time of stress and change. As well, there are challenges to defining and measuring a successful
transition to school, as the definition seems to be individualized and contextually dependent (Dockett & Perry, 2004). In the current study it was felt that the measures used provided information about the child’s well-being and potential at school, however, it is possible that other measures could have provided a better representation of successful transition.

Future Directions

Child and Family Characteristics. Several interesting findings emerged from the current study and warrant future investigation. In general, the results of this study suggest a need to emphasize the variability of experiences of children with ID and their families. This supports findings from previous research that a number of variables are likely to affect the family and child well-being (e.g., Hassall, et al., 2005). The focus on individual differences in children with ID and their families should continue to be emphasized in future research.

Supports. Previous studies examining predictors of successful transition into school have reported that the role of the teacher and the support he/she provides can be important for predicting child well-being (NICHED Early Child Care Research Network, 2003). Examining teacher variables, such as emotional and physical support, was outside of the scope of this study, however, would be useful in future research. One would expect that if certain characteristics are beneficial for children without ID (e.g., sensitivity) children with ID would also benefit, but the interaction between teacher and child characteristics would be important to evaluate. Research has shown that the parents of these children report more stress than parents of typically developing children, so we would assume that this stress could be felt by others in the child’s life, such as classmates
and teachers (McIntyre, et al., 2006). Furthermore, parents have reported that the attitude of the teacher is an important variable in predicting successful transition (Kemp, 2003). It has been found that teachers’ attitudes about inclusion of children with ID in the classroom depend on the teacher’s perception of how well the child is supported in the classroom (Jull & Minnes, 2007). Therefore, it seems as though a number of other variables related to the teacher’s attitudes and behaviours may impact the transition into school.

Services. The finding that the number of services available to families decreased during the time of transition, while not surprising, is important as it affects the lives of these families. Future research focused on evaluating the direct effects of service loss or change during the transition to school would be beneficial. Furthermore, it may be valuable to evaluate the effect or influence of a variety of early intervention programs, including preschool and specialized services, to determine if any of these components are related to successful transition to school. It would be important to include children who have not been involved in early intervention programs or preschool in these types of studies in order to examine the role of exposure (i.e., to classroom routine and structure), as compared to skill attainment (i.e., learning to follow directions when spoken to directly).

Finally, the results indicate that parental involvement in parent support groups is associated with several positive outcomes for the child. Positive outcomes for parents involved in support groups have been reported previously in the literature (Kerr & McIntosh, 2000), however, researchers have not investigated factors which differentiate those parents who become involved in support groups from those who do not. These
results raise concerns and questions about those parents who are not involved in support groups (given the benefits associated with involvement), and suggest that further research should focus on comparing the needs and experiences of parents who are involved in support groups with those who are not, so that the needs of all parents can be met.

*Parents’ Perceptions and Behaviours.* Although this study evaluated the relationship between parental perceptions and successful transition to school, other studies have found that both the parents’ perceptions and behaviours are related to success in school (Sy & Schulenburg, 2005). Parental involvement in school may be based on a number of factors, such as perceived stress and coping, beliefs and values related to formal education, and experience with other children. In the current study information was collected about the perceived stress and coping, and the family constellation (i.e., older siblings who have gone to school), however since information about involvement and beliefs related to school were not collected the relationship between these variables could not be evaluated. As this project continues, we will be asking parents about their involvement with their child’s school and their beliefs about school in order to address this issue.

*Conclusions*

The findings from this study offer initial Canadian information about the experiences of children with ID and their families as the child transitions into school. Although conclusions are limited by a small sample size, some information about the changes expected throughout the transition into school and the variables associated with quality of life and school readiness has been provided. Many of the findings are consistent with the literature in ID, however, they also provide new information about
this age group. It is expected that further research on this topic, including comparisons to typically developing peers, will provide greater understanding of this important period of transition for preschoolers and their families.
References


Factors Contributing to the Successful Transition of Preschoolers with Intellectual Disability into School

Thank you for your interest and assistance in our study, here is some information about the study that may be useful for you.

What is this study about? We want to learn what the transition into elementary school is like for children with intellectual disabilities or at risk for intellectual disability (i.e., developmental delay), and their families. We also want to know what can help make the transition easier.

What is an intellectual disability? An intellectual disability, also known as developmental disability, involves significantly subaverage intellectual functioning (i.e., IQ of 70 or below), and deficits in adaptive functioning. Intellectual disabilities include Down syndrome, Fragile X syndrome, and autism spectrum disorders (including PDD-NOS).

What is developmental delay? A developmental delay involves deficits in two or more areas of functioning such as cognitive development, speech and language development, social and emotional development, fine motor skill development, gross motor skill development. Developmental delay is usually indicated when a child does not meet developmental milestones by the expected time period. These children may also be referred to as being “at risk for intellectual disability”.

Who would we like to talk to? We would like to speak with parents of children with an intellectual disability or developmental delay who are attending school for the first time in September 2006. The children may be entering Junior Kindergarten, Senior Kindergarten or Grade 1.

What does my agency need to do? We are asking that you send one of the information packages provided, to the parents of eligible children. These packages include an information sheet for parents, copies of the consent form and a stamped envelope. After the parents have received this package they can contact us if they are interested in participating. The rest of our contacts will be directly with the parents.

What will happen to the information collected? Once all of the information is gathered, over a 9 month period, we will be preparing a report on our findings. Your agency will receive a copy of the report. Also, you will be invited to attend an information session where the results of the study will be presented and you will be able to meet with representatives from the other agencies who are involved with the project.

What if I have questions? If you have any questions about the study please contact Tess Clifford at (613) 533-3059 or 4tc29@qlink.queensu.ca.

Thank you for your help. We look forward to working with you.
Appendix B. Information Letter and Consent Form for Parents

Transition into School Project

Information Sheet for Parents

What is this study about? We want to learn what the transition into elementary school is like for children with special needs, and their families. We also want to know what can help make the change better.

Why should you participate? You can help us understand the experiences of your child and your family. After talking to many parents we hope to understand what the transition into school is like for most children with special needs, and how it can be made better. After the third phone call you will be given $25 as a thank you for your time, you will also receive a small gift for after each of the first two interviews.

Who would we like to talk to? We would like to speak with parents of children who are going to school for the first time in September 2006.

How long will it take? We would like to talk with you 3 times, 1 phone call every 3 to 4 months starting the summer before school starts. Each phone call will last between 1 ½ and 2 hours. We may ask you if you are willing to be contacted again within the next 24 months for a 1 ½ to 2 hour follow-up interview.

What will you be asked to do? We will ask you some questions about your child’s skills and activities, your experience as a parent, and the services you have used. We will also ask you to nominate a teacher who can answer some questions about your child.

What will happen to my information? The information we gather is private. We will keep all of the information confidential. No one will see your answers except members of the research team. The information will be kept in a locked filing cabinet. When the information is put in the computer there will be no names with it and the information will require a password to be accessed.

None of the information you provide us about you or your child will be shared with any other individual or group. (Note: we are under the same legal requirements as other professionals to report evidence of potential abuse.)

After gathering all of the information we will be writing a report on the group results to give to parents and other people involved in the study. Your name will not be in any of the information and no one will know your answers to our questions.

Many of the questions we ask will require you to think carefully about the experiences and behaviours of your child. We anticipate that this will not be overly distressing. If in hearing these questions, however, you should experience any concern, you may choose not to answer. You may also stop the process at any time. You may even ask that
information you have provided up to that point not be used. If you should experience any feelings of anxiety or distress following the interview we encourage you to call the TALK Distress and Information Line, (613) 544-1771, or Canadian Mental Health Association (416) 484-7750. Should you withdraw from the study before the end of the 3rd interview you will still receive our token of appreciation for each interview you completed.

**How can I become part of this study?** If you would like to be a part of this study, you will need to fill out the consent form below and send it back to us in the stamped envelope enclosed. We will send you back a copy for you to keep.

**People you can contact for more information:**
Tess Clifford, Project Leader, (613) 533-3059
Dr. Patricia Minnes, Project Supervisor, (613) 533-2885
Hélène Ouellette-Kuntz, SEO CURA in ID Director, (613) 548-4417 ext. 1198 or 1-866-656-4417 x. 1198
Dr. Joan Stevenson, Queen’s University General Research Ethics Board Chair, (613) 533-6288

**Transition into School Project: Consent Form**

I have read and understood the information sheet.
I have had the study explained to my satisfaction.
I have had my questions about it answered.
I understand that I may refuse to participate or withdraw at any time without any penalties of any kind.
I understand that my information will be kept confidential.
I understand that I can contact the people listed above if I have any questions.
By completing this form I agree to participate in three 1½ to 2 hour interviews.

Participant Name (Please Print): ____________________________________________

Address:_________________________________________________________________

________________________________________________________________________

________________________________________________________________________

Phone Number: __________________________________________________________

What is the best time to reach you? _______________________________________

Participant Signature: ____________________________________________

Date: ___________________________
As a participant in our study – Transition into School – we are pleased to extend a $25.00 participant fee as compensation for your time. We hope that this will assist with recouping the costs of any childcare needed while surveys and interviews are completed.

The Financial Services Department at Queen’s University requires a Social Insurance Number in order to process this request. If you would like to receive this participant fee, please record your SIN on the line below and return it to us along with your signed consent form. Please note that we will ONLY use this number for the purposes of providing you with the $25 participant fee. Your information will NOT be shared with any other parties and will NOT be kept on file. If you have any concerns or questions, feel free to contact us at any time at (613) 548-4417 x. 1207, or toll free at 1-866-656-4417 x. 1207.

Thank you again for your participation in our study. We appreciate your help.

Name: ____________________________________________________________

Mailing Address: __________________________________________________

SIN #: ____________________________________________________________

Please mail these two forms in the envelope provided, a copy of the consent form will be returned to you along with your participant fee.
Appendix C. Interview Booklet

**Transition into School Telephone Interview Guide and Administration Booklet Interview 1**

**General Instructions:**

This booklet is to be used for telephone interviews with parents and guardians who have volunteered to participate in the Transition into School project. Before starting the interview, make sure you have a copy of the signed Consent Form for the individual you will be interviewing. The layout of this booklet is designed to optimize consistency in data collection. Please read all instructions before making the phone call. Follow the format in order and as directed. Make sure you have a complete interview package and blue-ink pen before starting the interview. **DO NOT WRITE THE STUDENT or PARENT or GUARDIAN’S NAMES ON THIS BOOKLET.**

Starting the Interview:

Conduct the interview in a distraction-free area. Make the phone call. IF NO ANSWER, use the tracking sheet to record the attempt. IF ANSWERED, continue. **Note the start time of the interview in the space provided at the top of the “START” page.** Introduce yourself and verify that you are talking with the individual who is identified on the Consent Form. To begin the interview, **follow the script on Page 2.**

Administration of Instruments:

In addition to the demographic data, there are five primary instruments used in this interview. Two of the instruments, SIB-R and Child AIMS, are separate from this booklet. As well the Quality of Life measure will be sent to the parent after completing this interview. At the end of the interview you will be prompted to tell the parent we will be sending this questionnaire soon. **It is important to follow the instructions for each of the instruments. Do not score these instruments as part of the interview.**

Completing the Interview:

After completing the interview, do a quick check to make sure no steps or parts of the interview have been missed. **Follow instructions on page 15.** Ask the parent or guardian if he or she has any questions or comments before ending the call and thank him or her for talking with you and answering the questions. Be sure to give contact information provided at the end of this booklet and remind the parent we will be contacting them again in a few months to complete the next interview.

Post-interview Instructions:

After the call has terminated, complete the Interviewer section on the back inside cover of the booklet including any comments about the interview you feel may be important (e.g., parent was distracted several times by family members). **After scoring, put the interview booklet and other instruments in the participant’s Minnes Lab folder. Return Cover Page, Tracking Sheet copy of Consent Form, and Completion Sheet to the CURA office ASAP.**
Interviewer Instructions: Read the italicized statement shaded in grey to the parent or guardian. Mark responses where indicated. Answer any questions he or she may have at this time about the interview. Be sure to confirm consent and verify the identity of both the person you are talking with and the child who is the person of interest.

Hello, is [name of parent or guardian] available? [If asked to identify self, state your name and that you are affiliated with a Queen’s University research group.]

☐ No, not available. Thank the person on the phone and tell him or her that you will call back later – note on telephone tracking sheet.

☐ Yes, available or speaking. Continue when interviewee is on the phone.

[If interviewee is not the person who answers phone, when person comes to the phone verify he or she is the interviewee.] Is this [name of parent/guardian]?

☐ Yes – confirmation

This is [your name] with the Department of Psychology at Queen’s University. We sent you a letter about the study we are currently conducting to learn more about the transition into school for young children. I understand that you volunteered to do a telephone survey as part of this research. Is this a good time to do the interview?

☐ No – Ask when would be a good time to call again and note on telephone tracking sheet. Thank the person and tell him or her you will call again at the agreed time. IF THE PERSON CHANGED HIS OR HER MIND AND DOES NOT WANT TO DO AN INTERVIEW, NOTE REASONS.

☐ Yes – confirmation

Good, thank you. You have a preschool aged child with special needs, right?

☐ Yes – confirmation

Alright, do you have any questions that I may be able to answer about the project? [respond to any questions]

If you need to stop for any reason, let me know. Also, if there are any questions you don’t feel comfortable answering, that’s OK, but I hope you will want to complete the survey. First we’ll start with information about you and your child.
Demographic Information

Information about the Parent (Person being interviewed)

1. What is your date of birth? ___/___/______
   (dd)/(mm)/(yyyy)

2. What is your place of birth? (town/city) __________________________
   (province/state) _______________
   (country, if other than Canada) ________________________________

3. Gender
   1… Male
   2… Female

4. What is your marital status?
   1… Single
   2… Married
   3… Separated
   4… Divorced
   5… Remarried
   6… Widowed
   7… Common law partner
   8… Married
   9… Separated

5. What is your relationship to the child with special needs?
   1… Parent
   2… Guardian
   3… Other
   If other, please state _____________________________

6. What is the highest level of education you completed?
   1… Less than grade 9
   2… Grade 9 (Jr. High School)
   3… Grade 10 or 11 (Partial High School)
   4… High School Diploma
   5… Some college (at least one year)
   6… Community college certificate
   7… University degree
   8… Some post-graduate training
   9… Graduate or professional degree

7. What is your current occupation or job title? ___________________________

8. What is your job description? ___________________________

9. In which of the following ranges does your annual household income fall?
   1… $25,000 or less
   2… $25,001 - $35,000
   3… $35,001 - $45,000
   4… $45,001 - $55,000
   5… $55,001 - $65,000
   6… $65,001 - $75,000
   7… $75,001 - $85,000
   8… $85,001 - $95,000
   9… $95,001 or more
10. Who else lives in your home? Check box if the person has special needs.

<table>
<thead>
<tr>
<th>Relationship</th>
<th>Gender</th>
<th>Age</th>
<th>Person with SN</th>
</tr>
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<tbody>
<tr>
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**Information about Child**

11. What is the name of your child with special needs?

12. Gender?  1…Male  2…Female

13. What is [child’s name]’s date of birth?  ___/___/____

(dd)/(mm)/(yyyy)

14. Where was [child’s name] born (town/city) ___________ (province/state) ___________ (country, if other than Canada) __________________________________________

15. Has [child’s name] always lived with you?  1…YES  2…NO

16. If NO, where did [child’s name] live before his or her present home? ________________________________________________________________

17. Does [child’s name] have a diagnosis for his/her special needs?  1…YES  2…NO

18. If YES, What is it? (circle all that apply):

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Date of Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Autism Spectrum Disorder</td>
<td></td>
</tr>
<tr>
<td>b. Down Syndrome</td>
<td></td>
</tr>
<tr>
<td>c. Fragile X Syndrome</td>
<td></td>
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<tr>
<td>d. Developmental Delay</td>
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<tr>
<td>e. Cerebral Palsy</td>
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</tr>
<tr>
<td>f. Epilepsy/Seizure Disorder</td>
<td></td>
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<tr>
<td>g. Psychiatric Disorder, specify:</td>
<td></td>
</tr>
<tr>
<td>h. Behaviour Disorder</td>
<td></td>
</tr>
<tr>
<td>i. Mobility (e.g. uses wheelchair)</td>
<td></td>
</tr>
<tr>
<td>j. Vision Impairment</td>
<td></td>
</tr>
<tr>
<td>k. Hearing Impairment</td>
<td></td>
</tr>
<tr>
<td>l. Other:</td>
<td></td>
</tr>
</tbody>
</table>

19. Who provided the diagnosis?

1…Family Physician  2…Medical Specialist  3…Psychologist

4…Other _______________________________________________
20. How satisfied are you with the diagnostic services you have received?
1…Very unsatisfied 2…Somewhat unsatisfied 3…Neither Satisfied nor unsatisfied
4…Somewhat satisfied 5…Very satisfied

21. a. Is [child’s name] currently in daycare/preschool? 1…YES 2…NO

b. If YES, what kind of program? 1…Specialized 2…Regular

c. Is there a resource teacher or classroom aid? 1…1:1 in class 2…for whole class in class
3…withdrawal from class 4…NO

22. How satisfied are you with the daycare/preschool program?
1…Very unsatisfied 2…Somewhat unsatisfied 3…Neither Satisfied nor unsatisfied
4…Somewhat satisfied 5…Very satisfied

23. a. Is [child’s name] currently in an early intervention program? 1…YES 2…NO

b. If YES, what kind? 1….School readiness 2…Intensive Behavioural Intervention
3….Other__________________________

24. How satisfied are you with the early intervention program?
1…Very unsatisfied 2…Somewhat unsatisfied 3…Neither Satisfied nor unsatisfied
4…Somewhat satisfied 5…Very satisfied

25. Has [child’s name] attended school before? 1…YES 2…NO

If YES, Why is he/she no longer attending?__________________________________________

26. What school will child be attending in the September? __________________________________

27. Has your child used any of the following specialized services? How satisfied are you with this service? 1…Very unsatisfied 2…Somewhat unsatisfied 3…Neither Satisfied nor unsatisfied
4…Somewhat satisfied 5…Very satisfied

1…Occupational therapy
2…Physiotherapy
3…Speech therapy
4…Psychology
5…Social Work
6…Community behaviour management services
28. Have you used any respite services?  
   1…YES  2…NO  
   If YES, is it  
   1…In home  2…Out of home

29. How satisfied are you with respite services?  
   1…Very unsatisfied  4…Somewhat satisfied  
   2…Somewhat unsatisfied  5…Very satisfied  
   3…Neither Satisfied nor unsatisfied

30. Have you used any counseling or support programs?  
   1…YES  2…NO  
   If YES, is it  
   1…Counselling  2…Support Groups  3…Online Support Group

31. How satisfied are you with counseling/support programs?  
   1…Very unsatisfied  4…Somewhat satisfied  
   2…Somewhat unsatisfied  5…Very satisfied  
   3…Neither Satisfied nor unsatisfied

Scales of Independent Behavior – Revised Early Development Form (SIB-R)  
(Enclosed Instrument)

**Interviewer Instructions:** Go to the SIB-R form included with this booklet. Check the Participant Code (located on the front of the SIB-R form in the top right hand corner to make sure it matches with the Code on the front of this booklet. If the codes do not match, cross out the code on the SIB-R form and write-in the Code on the front of this booklet. **DO NOT FILL IN OTHER INFORMATION ON THE FRONT OF THE SIB-R FORM.**

Follow the instructions below. Start with Item 21.

Read the following to the parent before beginning the SIB-R.

For the next set of questionnaires, I will be asking you to rate the questions using a variety of scales. It might help if you write down the scale when I first explain it to you. Do you have a pen and paper?  
If No, Ask if they would like to get one.  
If Yes, **Okay. Let’s continue.**

For this next part, I am going to be asking you about some tasks. We want to find out how well [child’s name] does each task completely, without help or supervision. If you have never seen [child’s name] perform a task, or if he/she has never had a chance to do the task, tell me how you think he/she could do the task now, without help or supervision.
We will use four choices to describe how well [child's name] does each task. The scale is from 0 to 3.

3 means that [child’s name] does the task very well, always or almost always, without being asked.

2 means that [child’s name] does the task fairly well, or about ¾ of the time, and may need to be asked.

1 means that [child’s name] does the task, but not well, or about ¼ of the time, and may need to be asked.

Finally, 0 means that he/she never or rarely performs the task even if asked.

You don’t need to memorize this. I will explain the rating system whenever you need me to.

Do you have any questions before we begin?

If yes, answer question. If no, let parent know that they may ask questions at any time.

Alright, let’s begin

Begin with item 21. If the first four consecutive items are not rated 3, return to Item 21 and work backward until four consecutive items have been rated 3 then return to highest item number rated and continue. Continue until four consecutive items are rated 0 or until the last item has been administered.

To complete the problem behaviour section read the following

Some of the following behaviors are common of certain ages and are not of concern. Sometimes they cause a problem. I am going to ask you about each type of behavior.

Start with question 1, read the question and examples.

Please feel free to interrupt me when I get to the most appropriate response.

Read responses.

Once you have completed administration of this instrument, take a quick look to see if all applicable items have been answered. After you have completed administering the SIB-R, mark the box indicating it has been completed and move on to the next instrument or section of the interview. Do not score this instrument.

SIB-R completed □
Child AIMS Interview
(Enclosed Instrument)

Interviewer Instructions: Go to the AIMS instrument included with this interview booklet. Check the Participant Code (located on the front top right hand corner of cover page) to make sure it matches with the Code on the front of this booklet. If the codes do not match, cross out the code on the AIMS and write-in the Code from the front of this booklet. **DO NOT FILL IN OTHER INFORMATION ON PAGE 2 OF THE AIMS.**

For each service domain, read the set of questions in the order presented. Mark or record the person’s response where indicated. Use the name of the person of interest where blanks are inserted into the question or statement. Be sure to clarify all responses before recording. Once you have completed administration of this instrument, check to see that all applicable items have been answered. After you have completed administering the AIMS, mark the box indicating that it has been completed and move on to the next instrument or section of the interview.

AIMS completed [ ]

Ways of Coping Scale

*Please think about a particular difficult situation you have faced in the past 3 months related to your child’s special needs. Please describe it in a couple of sentences:*

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

________________________________________________________________________

*Now I am going to read several items and I would like you to indicate whether or not you used that approach in that difficult situation. Please choose whether you used the approach (0) not at all, (1) used some what, (2) used quite a bit, or (3) used a great deal.*

<table>
<thead>
<tr>
<th>Item</th>
<th>Not at all (0)</th>
<th>Used Somewhat (1)</th>
<th>Used quite a bit (2)</th>
<th>Used a great deal (3)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Talked to someone to find out more about the situation.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>2. Looked for the silver lining; tried to look on the bright side of things.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>3. Turned to work or substitute activity to take my mind off things.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
4. Made a plan of action and followed it.
   Not at all (0)  Used Somewhat (1)  Used quite a bit (2)  Used a great deal (3)
   0 1 2 3

5. Told myself things that helped me feel better.
   0 1 2 3

6. Tried to get the person responsible to change his or her mind.
   0 1 2 3

7. Talked to someone who could do something concrete about the problem.
   0 1 2 3

8. Was inspired to do something creative.
   0 1 2 3

9. Tried to keep my feelings to myself.
   0 1 2 3

10. Changed something so things would turn out right.
    0 1 2 3

11. Changed or grew as a person in a good way.
    0 1 2 3

12. Expressed anger.
    0 1 2 3

13. Stood my ground and fought for what I wanted.
    0 1 2 3

14. Came out of the experience better than I went in.
    0 1 2 3

15. Let my feelings out somehow.
    0 1 2 3

16. Drew on my past experiences; I was in a similar situation before.
    0 1 2 3

17. Maintained my pride; kept a stiff upper lip.
    0 1 2 3

18. Got away from it for a while; tried to rest or take a vacation.
    0 1 2 3

19. Knew what had to be done, so doubled my efforts to make things work out.
    0 1 2 3
20. Rediscovered what is important in life. | 0 | 1 | 2 | 3

21. Tried to make myself feel better by eating, drinking, smoking, using drugs or medication. | 0 | 1 | 2 | 3

22. Came up with a couple different solutions to the problem. | 0 | 1 | 2 | 3

23. Asked a relative or friend I respected for advice. | 0 | 1 | 2 | 3

24. Avoided being with people in general. | 0 | 1 | 2 | 3

25. Went over in my mind what I would say or do. | 0 | 1 | 2 | 3

26. Accepted it, since nothing could be done. | 0 | 1 | 2 | 3

27. Kept others from knowing how bad things were. | 0 | 1 | 2 | 3

28. Thought about how a person I admire would handle this situation and used that as a model. | 0 | 1 | 2 | 3

29. Prepared myself for the worst. | 0 | 1 | 2 | 3

30. Made a promise that things would be different next time. | 0 | 1 | 2 | 3

31. Reminded myself how much worse things could be. | 0 | 1 | 2 | 3
# Parental Changes Scale

The following statements express how some parents feel they have been CHANGED through the experience of parenting a child with special needs. Please use the following scale to indicate the amount to which you agree or disagree with the following statements. With 1 being strongly disagree, 2 being disagree, 3 being not sure, 4 being agree, and 5 being strongly agree.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Not Sure</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I have learned to speak out for my child.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>2. I have learned that I can achieve rather than feel powerless.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>3. I am more compassionate toward others.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>4. I have made a career change, which has lead to greater vocational satisfaction.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>5. I am a stronger person.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>6. I am more confident.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>7. I take better care of myself.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>8. I have stronger spiritual convictions now.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>(e.g., personal spirituality, faith in god)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. I have made many close friends with people I would have never met otherwise.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>10. I have learned to see life from a different perspective (learned what it is like to live in someone else’s shoes).</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>11. I have made a difference in the lives of other people (through advocacy/promoting changes).</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>12. I make the most of each day rather than living for the future.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>13. I celebrate life more now (rather than just merely surviving day to day).</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>14. I have a different and more authentic view of what it means to be successful in life.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
15. I have learned what is really important and valuable in life.

16. I have developed new skills that have helped me do a better job in my career/vocation.

17. I have developed attitudes that have helped me to do a better job in my chosen career/vocation.

18. My marriage has emerged stronger.

Family Stress and Coping Interview (FSCI)

Interviewer Instructions: Read the italicized statement below and then each “stressor” statement as listed and mark the stress ratings given by the parent or guardian. Where blanks appear, use the name of the child.

Instruction for Interviewee:

For the next questions, I am going to list some issues that you may or may not have encountered in your experiences as a parent of a child with special needs. You may have dealt with some of these issues in the past, and some you may be thinking about for the future. I’m going to ask you to rate a series of issues in terms of how stressful they are to you on a scale of 0 to 3. Where 0 is not stressful, 1 is mildly stressful, 2 is moderately stressful, and 3 is extremely stressful. It is important that you tell me how stressful these issues are now, at this time in your life. Please use the scale to help you decide on a rating. You can choose not to answer specific questions if it makes you uncomfortable. Also, if you find the issues too upsetting, or if you feel that you cannot complete the interview and wish to stop, we will do so, and can set up an appointment to continue at another time.

Not Stressful | Mildly Stressful | Moderately Stressful | Extremely Stressful
---|---|---|---
0 | 1 | 2 | 3

1. The diagnosis of [___________] as having special needs

2. Explaining to others about [___________]’s special needs

3. Your feelings about the cause of [___________]’s special needs

4. Dealing with friends/family/people in the neighbourhood on a day-to-day basis

5. Dealing with doctors and other allied health professionals
6. Dealing with legal professionals

7. Dealing with __________’s teachers and the educational/preschool system

8. Creating and/or finding opportunities for __________ to make friends and participate in activities

9. Deciding on the best level of integration for __________

10. Making the decision concerning residential accommodation in the home or in the community

11. Meeting the needs of your (other) children

12. Meeting your own personal needs

13. Meeting the needs of your spouse/partner

14. Maintaining satisfying friendships

15. Long-term planning for residential accommodation for __________

16. Planning for wills, trusts, and guardianships

17. Planning for emotional and social support for __________

18. Transportation

19. Day to day assistance with care of __________

20. Arranging time apart from __________

21. Being away from __________

22. Dealing with financial and insurance issues

That’s all the questions I have for you. We will be sending you a package with your payment for participation, a copy of your consent form, and a questionnaire for you to complete by hand. It should take about 15 minutes to complete this questionnaire. We decided to send it to you rather than do it over the phone because it is easier to complete by hand, and will shorten the length of the phone call. Is that alright? [Note if parent asks it takes about 20-30 minutes to complete over the phone]
[If the parent says yes, say Good. You should be receiving the questionnaire in the next couple weeks. Please send the send it back in the envelope provided as soon as possible. Proceed to the Instructions for Ending the Interview]

[If the parent would like to do the questionnaire over the phone, tell them you will have to schedule another time to talk and set it up.]

Okay. Before you go I’d just like to check that I have your correct address. [Check consent form, record address on Completion Page]

Also, would you be interested in receiving our newsletter? [Record answer on Completion Page].

☐ COMPLETED INTERVIEW – GOES ALL THE WAY TO THE END

Thank you very much for taking the time to talk with me. Do you have any questions for me; or, something else you want to tell me?

[Answer any questions you can]

____________________________________________________
________________________________________________________________________
________________________________________________________________________

If you have any questions or think of anything afterward, our contact information is on the consent form, and any other information you have received from us. Thanks again for helping us. We look forward to talking with you again in a few months.

☐ INCOMPLETE INTERVIEW – STOPPED BEFORE REACHING THE END

OK, we can stop now. Thank you for answering our questions. Do you want to continue at another time?

[If, “yes,” make arrangements and note on tracking sheet. Ask if they have any questions before hanging up and answer as best you can.]

[If, “no,” thank them for their time and read the following statement.]

If you have any questions or think of anything afterward, please contact us at 613-533-3059. Our contact information is on the consent form and any information we have sent to you. Thanks again for helping us.

END OF INTERVIEW
Appendix D. Information Letter and Consent Form for Teachers

What is this study about? We want to learn what the transition into elementary school is like for children with intellectual disabilities or at risk for intellectual disability (i.e., developmental delay), and their families. We also want to know what can help make the transition easier.

What would we like you to do? One of the families participating in this study has identified you as the teacher who knows their child best. They have given us permission to contact you for more information about their child, particularly related to how the child functions at school. We would like you to complete the Early Development Instrument for this child.

What will happen to my information? The information collected will be confidential, and we will ask that you do not indicate the child’s name or your name anywhere on the form; rather we will ask you to use the participant number we give you. Only members of the research team will have access to the information you provide, and this information will be kept in a locked filing cabinet. When the information is put in the computer there will be no names with it and the information will require a password to be accessed.

None of the information you provide about the child or yourself will be given to anyone without your written permission, unless this information is required by law. It is the law that professionals must report a suspicion of child abuse.

After gathering all of the information we will be writing a report to give to parents, teachers and agencies involved in the study. Your name will not be in any of the information and no one will know your answers to our questions. You will receive a copy of the report, and you will be invited to attend an information session where the results of the study will be presented and you will be able to meet with representatives from the agencies and schools involved with the project.

How can I become part of this study? If you are willing to be a part of this study, you will need to fill out the consent form on the next page. We have also included the Early Development Instrument and the Teacher’s Guide for the instrument, please complete the instrument and send it and the consent form to us in the envelope provided.

Thank you very much for taking the time to read this letter. We look forward to working with you. If you have any questions about the study please contact Tess Clifford at (613)548-4417 ext. 1207 or 1-866-656-4417 ext. 1207, or 4tc29@qlink.queensu.ca

You can also contact the following people for more information:
Dr. Patricia Minnes, Project Supervisor, (613) 533-2885
Hélène Ouellette-Kuntz, Research Director, (613) 548-4417 ext. 1198 or 1-866-656-4417
Dr. Joan Stevenson, Queen’s University General Research Ethics Board Chair, (613) 533-6288
Transition into School Project: Teacher Consent Form

I have read and understood the information sheet. I have had the study explained to my satisfaction. I have had my questions about it answered. I understand that I may refuse to participate or withdraw at any time without any penalties of any kind. I understand that my information will be kept confidential. If I have any questions I will contact the people listed above. I agree to participate by completing this form.

Teacher Name (Please Print): ________________________________________________

Address:______________________________________________________________
______________________________________________________________
______________________________________________________________

Phone Number: _______________________________________________________

Teacher Signature: _____________________________________________________

Date: ___________________________________________________________________
Appendix E. Debriefing Letter for Parents

**Thank You for Participating in the Transition Into School Project**

In this study we want to learn what the transition into elementary school is like for children with intellectual disability or developmental delay, and their families. We want to know what kinds of things affect their experience. Some of the things we are looking at are; the child’s skills and abilities, the impact of caring for a child with a disability on the parent, the services used by the family, and how involved the child is in the community.

We also want to know what can help make the transition to school better for children with intellectual disabilities and their families. We expect that the transition experience will be better for children with more adaptive skills, parents who are influenced more positively by their child, and families that receive services that are well-matched to their needs. Understanding the factors that affect the transition into school for children with or at risk for intellectual disabilities may help in planning for these children both at school and in the community.

As you were told before, your answers to all of the questions will be kept private. Your name has been replaced by a code, so that your answers can not be related to your name. Only people who work on this study will have access to the information collected.

We understand that it is hard to answer these types of questions, and we appreciate your willingness to participate in this study. Sometimes people find that the questions asked may be upsetting. If answering any of the questions led you to feel distressed or upset and you would like to speak to someone, please contact one of the following:

<table>
<thead>
<tr>
<th></th>
<th>Phone Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>TALK – Distress and Information Line</td>
<td>(613) 544-1771</td>
</tr>
<tr>
<td>Canadian Mental Health Association</td>
<td>(416) 484-7750</td>
</tr>
</tbody>
</table>

Since all the information is collected we are sending you a final report explaining what we learned from this study (see next page). If you have any questions about the study, please feel free to contact Tess Clifford (613-533-3059, 4tc29@qlink.queensu.ca) or Dr. Patricia Minnes (533-2885, minnesp@post.queensu.ca). You may also contact Dr. Joan Stevenson, Queen’s University General Research Ethics Board Chair, (613) 533-6288 if you have questions that are not answered.

Thank you very much for participating!
Appendix F. Debriefing Letter for Teachers

Thank You for Your Help with the Transition to School Project

Thank you for taking the time to complete the questionnaire for our project. Our study would not have been complete without your help.

In this study we want to learn what the transition into elementary school is like for children with intellectual disability or developmental delay, and their families. We want to know what kinds of things affect their experience. Some of the things we are looking at are; the child’s skills and abilities, the impact of caring for a child with a disability on the parent, the services used by the family, and how involved the child is in the community.

We also want to know what can help make the transition to school better for children with intellectual disabilities and their families. We expect that the transition experience will be better for children with more adaptive skills, parents who are influenced more positively by their child, and families that receive services that are well-matched to their needs. Understanding the factors that affect the transition into school for children with or at risk for intellectual disabilities may help in planning for these children both at school and in the community.

As you were told before, your answers to all of the questions will be kept private. Your name has been replaced by a code, so that your answers can not be related to your name. Only people who work on this study will have access to the information collected.

We have included a brief report about our findings for your interest. If you have any questions about the report or our study please feel free to contact Tess Clifford at 4tc29@qlink.queensu.ca or 613-533-3059.

Thank you very much for participating!