

# The Experience of Parents as Their Children with Developmental Disabilities Transition from Early Intervention to Kindergarten

Michelle Villeneuve

*Queen's University*

Céline Chatenoud

*Université du Québec à Montréal*

Nancy L. Hutchinson

*Queen's University*

Patricia Minnes

*Queen's University*

Adrienne Perry

*York University*

Carmen Dionne

*Université du Québec à Trois-Rivières*

Elaine B. Frankel

*Ryerson University*

Barry Isaacs

*Surrey Place Centre, Toronto*

Alvin Loh

*Surrey Place Centre, Toronto*

Joan Versnel

*Dalhousie University*

Jonathan Weiss

*York University*

### **Abstract**

Despite recognition of the importance of parent involvement to enable meaningful inclusion of young children with developmental disabilities in education contexts, few Canadian studies have reported how parents experience this collaboration. Recent research suggests that the transition process is critical to the early school experiences of children with developmental disabilities yet challenging for their parents. The purpose of this paper is to report preliminary data from HELPS Inc, a Canadian multi-method research project describing Health, Education, and Learning Partnerships Promoting Social Inclusion of young children with developmental disabilities. In this paper we present parents' perspectives on inclusion and collaboration with case study findings based on the experiences of three families in one Ontario community. The data demonstrate the unique experiences of and meanings of collaboration held by individual families, and highlight the challenges these differences pose for healthcare providers and educators committed to involving parents in the transition into school and for inclusion of young children with developmental delays and disabilities.

*Keywords:* Inclusive education, developmental disability, collaboration, parent involvement.

### **Précis/Résumé**

Malgré la reconnaissance de l'importance de la prise en compte et de la collaboration avec les parents pour permettre une véritable inclusion des jeunes enfants ayant un retard de développement ou une déficience en contextes éducatifs préscolaires et scolaires, peu d'études canadiennes rapportent comment les parents vivent l'expérience de cette collaboration. Également, même si des recherches récentes suggèrent l'importance du processus de transition préscolaire-scolaire relativement au parcours éducatif inclusif des enfants ayant un retard de développement ou une déficience, ce processus semble se constituer encore en un défi pour les parents. Le but de cet article est de rapporter l'analyse préliminaire des données de HELPS Inc., un projet de recherche multicentrique canadien et impliquant une méthodologie mixte permettant de décrire le travail des intervenants en santé, en éducation et leurs partenariats d'apprentissage pour favoriser l'inclusion sociale des jeunes enfants ayant un retard de développement ou une déficience. Dans cet article, nous présentons les perspectives de parents sur l'inclusion et la collaboration en se basant sur les résultats de l'étude de cas relatifs à trois familles dans une communauté de l'Ontario. L'analyse des données documente les expériences uniques de collaboration de chacune des familles et le sens que ces familles individuelles leur attribuent. Les chercheurs mettent en évidence les défis que ces différences expériences et perceptions de collaboration autour du jeune enfant posent pour les prestataires de services en santé et en éducation et qui collaborent avec les parents pour réussir la transition du jeune enfant ayant un retard de développement ou une déficience vers l'école dans une perspective inclusive -

*Mots-clés:* éducation inclusive, la collaboration, la participation des parents.

*Authors' Note*

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## Introduction

In Canada there has been considerable change over the past three decades in early childhood intervention, care and education delivery approaches for young children with disabilities (Crawford, 2005; Irwin, Lero, & Brophy, 2004; Villeneuve, 2011). Young children with developmental delays and disabilities (DD) now frequently attend inclusive early childhood education (ECE) programs and inclusive schools; they are most often educated alongside their non-disabled peers in all contexts (Frankel & Underwood, 2011; Hutchinson & Martin, 2012). Inclusive education aims to support cognitive, physical, and social dimensions of healthy development and has been accepted as best practice for children with disabilities since the 1980's (Koster, Nakken, Pijl, & vanHouten, 2009; Irwin, Lero, & Brophy, 2004; Lupart, 1998). Inclusion is predicated on the belief that all children and families have a right to services within typical environments, is supported by international conventions, provincial legislation and local policies, is guided by sensitivity to the diverse cultural and linguistic priorities of families, and is developmentally based on the unique needs of the child (Frankel, Gold & Ajodhia-Andrews, 2010). However, for many families, inclusion of children with DD in regular education brings both successes and challenges (Dionne & Rosseau, 2006; Hutchinson & Martin, 2012). One of the challenges is in assuring that the individual developmental, educational, health and social interventions required by the child and family are incorporated into the inclusive experience.

Since the 1990's there has been growing recognition of the importance of providing professional services and supports in early childhood education for young children with special needs to facilitate the transition to kindergarten (Conn-Powers, Ross-Allen, & Holburn, 1990; Odom, Buysse, & Soukakou, 2011) and recognition that

such collaboration facilitates inclusion in regular education programming and classroom routines (Cook & Friend, 1991; Villeneuve & Hutchinson, 2012). Although research recognizes the importance of cross-sector and interprofessional collaboration among healthcare providers, educators and families, limited research has investigated parent experiences of collaboration across the healthcare and education contexts during the transition to school.

Research has documented that parental involvement and satisfaction, and the nature of collaborative work among professionals are often different in early childhood service contexts than they are in elementary school classrooms (Dunst, 2002; Rous, Teeters Myers, & Buras Stricklin, 2007; Therrien, 2008). For example, ECE educators and healthcare professionals, including occupational therapists and speech and language pathologists, tend to play a large role in the services received by children with DD during the preschool years. In contrast, classroom teachers, special educators, and educational assistants play a major role following the transition to school while children with DD and their families tend to have decreasing contact with healthcare professionals (Rous et al., 2007). Successful transitions, that ensure inclusion for these children, require collaboration, not only among the many professionals working with the child and family, but also between these professionals and the family.

### **Purpose**

This research was conducted by **HELPS Inc**, a project designed to describe **Health, Education, and Learning Partnerships** that promote **Social Inclusion** of young children with DD as they transition from early childhood service contexts into school. HELPS Inc involves a team of Canadian researchers, who represent many disciplines,

including early intervention, ECE, education, occupational therapy, psychology, and medicine in three provinces. HELPS Inc committed to advancing our understanding of how parental participation and interprofessional collaboration contribute to effective transitions and successful inclusion of children with DD.

This paper reports on the preliminary findings of a comprehensive, four-year, multi-method study conducted in three provinces (Ontario, Quebec, and Nova Scotia) each of which has developed a different approach to meeting the inclusion needs of young children with DD. In this paper, we focus on the perspectives of parents of children with DD on their experiences collaborating with professionals during the period of transition from early intervention services and ECE into school. We report case study data on the experiences of parents of three children with DD in a mid-sized Ontario city. Case study findings, contextualized by the parents' perspectives on inclusion for their child, contribute to research and policy guidelines on school transition for students with DD by offering insight into parent experiences of collaboration over the course of the child's transition to and inclusion at school. Implications for practice are discussed.

The HELPS Inc study also involves surveys completed by parents, early childhood educators, healthcare providers, and educators in three provinces, and an additional 10 case studies conducted in diverse contexts (i.e., a large urban center in Ontario, rural and urban Quebec, and Nova Scotia). Future analyses will report multiple stakeholder perspectives concerning the transition of young children with developmental delays and disabilities from preschool contexts to school. Case study findings, presented here, will inform future directions for HELPS Inc in the conduct of further cross-case analyses as this project draws to a close in 2014.

Recent thinking about inclusion as a complex and multidimensional concept highlights that inclusion should not refer to a *place*, but should describe an active *process* that promotes child development by providing services and supports to facilitate participation of all students (Ainscow, 2000; Friendly & Lero, 2002; Smith, 2007). The abbreviation DD refers to developmental delays and disabilities including delayed milestones, physical disabilities, sensory impairments, and intellectual disabilities including autism spectrum disorders. Although delays are apparent in preschoolers, formal diagnosis of disability may not occur until the child has started school. By transition, we mean the process of children moving from preschool contexts to school contexts, including the planning meetings prior to the move and the child's and family's experience during the first year of school. Collaboration with parents refers to parents being encouraged to take an active role in and to participate in decisions about their child's education and healthcare.

### **Literature Review**

While inclusive education has been widely advocated by both policy makers and researchers, progress toward effective implementation, especially for children with DD, has been slow (Ainscow, Farrell, & Tweddle, 2000; Kavale & Mostert, 2003; Smith, 2007). Advancement of inclusive education practices has been reported in both early childhood and educational research in three key areas: (a) access to regular educational settings, (b) participation in learning activities and interaction with peers, and (c) special educational services and healthcare professional supports (Hutchinson & Martin, 2012; Odom, Buysse, & Soukakou, 2011). However, a coherent vision of best practices for

achieving inclusion outcomes for young children with DD is still lacking (Alquraini & Gut, 2012; Hanvey, 2003; Villeneuve, 2011).

Increasingly diverse student demographics have changed the nature of special education supports to enable success for all children (Hamon, Kasa-Hendrickson, & Neal, 2009). Coordination between education, child care, developmental services, and healthcare sectors is needed to support educational achievement for students with developmental disabilities and other special education needs (Clark & Crandall, 2009). Recognizing that collaboration between parents, healthcare providers and educators can have a significant impact on healthy child development, school readiness, and educational achievement, current research on inclusive education advocates that the success of inclusive education is less about the characteristics of the children and more about the collaborative skills and relationships of adults (Frankel, 2006; Irvine, Lupart, Loreman, & McGhie-Richmond, 2010; Villeneuve, 2011).

Transition planning guidelines from provincial ministries of education (e.g., Alberta Education, 2006; Healthy Child Manitoba, 2002; Ontario Ministry of Education, 2005; Gouvernement du Québec, 2010) emphasize the importance of parent involvement and interprofessional collaboration to facilitate transition of preschoolers into the education system. However, a major challenge to cross-sector service coordination and collaboration is the complexity of the service system that encompasses a number of government ministries (e.g., health, education, children and youth) (Villeneuve, 2009). These organizational factors create challenges even when government initiatives consolidate responsibilities for services in one ministry (Tetreault et al., 2012). Structural and administrative barriers can limit professionals' awareness of each other's roles and

responsibilities and can limit the use of services and supports to ensure school readiness, as well as academic and social inclusion (Villeneuve, 2011).

For parents, navigating this array of service systems designed to support children with DD as they transition from early childhood services into school-based services can be overwhelming (Janus, Kopechanski, Cameron, & Hughes, 2008; Janus, Lefort, Cameron, & Kopechanski, 2007; Rous, Hallam, Harbin, McCormick, & Jung, 2007). Often, the professional supports familiar from the early childhood years change when the child enters school (Rous, et al., 2007; Therrien, 2008). Parents also transition from the family-centred services provided by the health and developmental service sectors and develop new relationships with school-based providers who use different models (Dunst, 2002). During this period of transition, professionals must share information and coordinate services to ensure continuity of supports (Janus et al., 2008). But how do parents view this critical collaborative relationship with professionals?

### **Qualitative Studies of Parent Perspectives**

Qualitative studies of parents' experiences of collaboration with healthcare providers and educators tend to focus either on the preschool context or on experiences following the transition into school. In an example of the first, James and Chard (2010) reported the findings of interviews about the experiences of seven parents in Ireland with participation and partnership in an early intervention service for children with physical disabilities. Overall, the parents were "relatively" satisfied but suggested that the program did not meet their needs for support at critical times, and did not provide enough information or adequate continuity of care. Parents reported meaningful partnerships with individual professionals but were less positive about collaboration with the team of

professionals. In a study designed to understand parental priorities for inclusive ECE settings in the southern United States, Hurley and Horn (2010) found that their ten parent participants most valued their children being “active participants in all classroom routines and activities,” as well as participation in “a high quality early childhood program,” that provided “accommodations and adaptations” (p. 342). One parent expressed that “children absorb how we [i.e., adults] act versus what we say,” suggesting it is critical that all professionals involved in an ECE program embrace inclusion of all children.

Paige-Smith and Rix (2006) conducted case study research with three children with Down syndrome, aged 3 to 4 years, making this study similar to the current study. They interviewed parents of the children about how they and their children participated in early intervention programs to support learning. The themes identified in the interviews pertained to experiences with a range of professionals and emphasized (a) the role of communication, (b) partnership with professionals, (c) inclusion or the active acceptance of the child in a mainstream program, and (d) the parents’ roles as educators. The parents elaborated on tensions they experienced in their roles as both parents and therapists or educators for their children; this was an overarching pattern that the authors viewed as encompassing all four themes previously mentioned. These families lived in the south of England, in a small town or the surrounding rural area.

In a recent intensive interview study, parents of children with DD were asked about their involvement in their child’s education in elementary school (An, 2011). These parents, who lived in a large metropolitan area in the Midwestern United States, reported three themes: advocacy, involvement, and positive but superficial relationships. Because the parents were asked to discuss primarily their experiences with their children’s physical education, these findings may not represent parents’ views of their working

relationship with the homeroom teacher. In an American longitudinal study of the experience of transition into kindergarten of a large nationally representative sample of children with disabilities, Carlson and her colleagues (2009) reported that in telephone interviews, parents' perceptions of ease of transition varied by race/ethnicity and family income. Parents reported that the transition was smoother when schools initiated actions, like transition planning meetings, to facilitate the process. They also said that their children's social skills and behaviours played a role in their transition to kindergarten. Finally, an Australian multi-method study focused directly on the transition of young children with intellectual disabilities to inclusive kindergarten programs (Kemp, 2003). In interviews, the parents reported experiencing a high degree of collaboration with professionals but were concerned most about the "adequacy of the orientation visits" that parents and children made to kindergarten programs.

### **Summary**

Qualitative studies begin to show the diverse issues that emerge when parents of children with a range of DD express their perspectives on collaborating with professionals in ECE and educational contexts and on the transition of their children from ECE to kindergarten. It can be seen that parents think coordination among education, child care, developmental services, and healthcare sectors is vital to support children with DD, a theme emphasized in transition models by researchers like Clark and Crandall (2009). In recent years, Canadian researchers have examined parent experiences of transition to school for children with special needs with an emphasis on improving transition policies (e.g., Janus et al., 2008; Janus et al., 2007). Although these researchers have combined survey and interviews with families, these studies have not directly

addressed collaborative actions to support inclusion at school. Instead, emphasis has been on the child's adjustment at school and parent perspective on the quality of services. Canadian researchers have called for more systematic research to further investigate the effectiveness of collaboration with parents to support successful transition to school (Janus et al., 2008).

### **Method**

A multiple-perspective case study approach was used to explore the transitions of three preschoolers with DD as they entered kindergarten. Focal participants were identified through purposive sampling to ensure diversity of DD and of family contexts. Family contexts included both urban and rural settings, varying levels of educational attainment by parents, and a range of family structures (i.e., guardianship, two-parent families) and family sizes (from one sibling to five). The three families live in, or in the rural area surrounding, one middle-sized Ontario city. Interview and observation data were collected over 14-months as we sought to describe parents' experiences in ECE environments, during the transition planning meetings prior to kindergarten and during the first year of school. We observed the three children in preschool, school, and in their home. Interviews were conducted with the parents/guardian and education and healthcare professionals in each case. This approach was ideal for describing change over time without having to reduce the complexity of the experience (DePoy & Gitlin, 1998). Inductive analysis (Patton, 2002) identified the theme of inclusion in each case study. A second pass through the data provided the parents' experience of collaboration with professionals including their satisfaction with this experience. The experiences of the

families were then compared to understand the similarity and differences reported using cross-case analysis procedures outlined by Stake (2006).

*Participants.* The focal participants for this study included a four-year-old girl with Down syndrome (Abby) and her mother, a five-year-old boy with autism and hearing loss (Brady) and his aunt who was his guardian, and a four-year-old boy with global developmental delays and fragile health (Tristan) and his mother. To provide a robust account of these parents'/guardian's experiences of collaboration, some data are included about other family members and about healthcare and education professionals who worked with each child and family.

*Procedure.* Three research assistants completed data collection under the supervision and guidance of three co-investigators to ensure consistency in approach across the three cases. Many interviews were conducted with each mother/guardian between spring 2010 and spring 2011; 6 with Abby's mother, 8 with Brady's aunt (guardian), and 6 with Tristan's mother. In the cases of Abby and Brady, all interviews were transcribed verbatim; in Tristan's case, his mother requested that the research assistant take extensive notes during interviews. At her request, summaries were shared regularly with Tristan's mother. The children were observed in ECE, kindergarten, and in Abby's and Brady's cases, in the home. Abby was observed 11 times for a total of 29 hours, Brady 10 times (25 hours), and Tristan 11 times (30 hours). Interviews were conducted with some of the health care professionals and educators who worked with these children; in some cases more than one interview was conducted with an individual: Abby (3 with health care workers, 6 with educators); Brady (4, 22); Tristan (8, 9). We also obtained reports from preschool healthcare and ECE workers and from each child's

school during the kindergarten year. Debriefing was conducted bi-weekly with the full team of investigators at this research site during data collection and analysis.

Analysis of the qualitative data (facilitated by Nvivo software) involved two major stages. In the first stage, data were analyzed *within each case*, allowing us to describe the key characteristics of the child, family, preschool and school contexts, and transition planning activities for each focal participant. In this stage, parent perspective on their child's inclusion was described as was their experience collaborating with early intervention service providers and educators. Codes, categories, and themes were developed through a process of clustering and re-clustering (method of constant comparison, Patton, 2002) for each case, independently, but in the context of bi-weekly discussions of emerging findings. In the second stage, *cross-case analysis* was conducted to examine similarities and differences in each case in order to better understand the phenomena being studied (Stake, 2006). For the purpose of this paper, parents' experience of collaboration in the context of transition from early intervention services to school was the phenomenon examined in the cross-case analysis. In the cross-case analysis, emphasis was placed on describing parent experiences within the context of expectations these parents held for their child's inclusion at school.

## **Findings**

### **Parent Perspectives on Inclusion**

Before we report parents' experiences of collaboration with educators and healthcare professionals, we provide a contextualizing account of the families and their experience of inclusion for their children—Abby, Brady, and then Tristan.

*Abby.* Abby lived with her five older brothers and two parents, both of whom had post-graduate university degrees. Abby's parents valued education. This was apparent in the way they surrounded Abby with alphabet puzzles, books, and educational games. Her brothers played an integral role in her learning; her mother described how each boy was assigned time to spend with Abby after school "teach[ing] her things that will be lifelong or that will help her learn" (fieldnotes). Before Abby's birth, her parents read extensively about Down syndrome and how to best prepare Abby for school and for life. Abby's mother reported that she and her husband continued to attend conferences on Down syndrome, to read the latest research, and to use this knowledge to advocate for Abby. Abby's mother expressed their desire to have Abby included in a regular kindergarten, explaining: "if she's in the classroom she's learning, even just from the children, just their behaviour, just their mannerisms, just their day-to-day things." At home the focus was on helping Abby with life skills and, as she approached school age, with kindergarten readiness skills (learning letters and songs, along with cutting, pasting, and colouring). The family ensured that Abby had supports and services to optimize her preschool education, including a support worker, a consultant, and an individual program plan (IPP) at daycare. Her mother believed that beginning kindergarten with the same skills as her peers would support inclusion and requested full placement in a regular education class. Abby's kindergarten teacher observed that "academically she's doing really well," and the special education teacher noted that, "she's actually performing higher than most of the other junior kindergarten children." However, her teacher described Abby's play: "She's solitary [during] play, always. If you left her by herself she would sit and look at a book for most playtimes." While the researcher observed

Abby interacting socially at home, this was rarely observed in preschool or kindergarten. What Abby did at school reflected her parents' focus on academic inclusion.

*Brady.* Prior to his second birthday, Brady and his two brothers began living with their aunt and her two sons. By five years of age, Brady had been diagnosed with severe bilateral sensorineural hearing loss, congenital CMV (cytomegalovirus), seizures, and autism. He wore hearing aids and used basic sign language to communicate. Brady was the youngest of five boys, all with some disability—one of his cousins had autism and the other three boys had learning disabilities. We observed Brady participating in an ECE program with a high ratio of educators to children that focused on the inclusion of children with disabilities, particularly autism. His aunt and ECE teachers described him as “determined when he wants something,” happy, friendly, busy, and a bit stubborn (fieldnotes). Guided by adults with expertise in autism and hearing loss, Brady participated in the classroom and on the playground, and interacted with peers using simple signs.

Brady's aunt described his inclusion while he was in ECE, in enthusiastic terms, when she said, “the other kids are happy to see him.” She reported that Brady “loved to just even sit and watch his peers,” that the ECE staff “[always ensured that] he's included in stuff,” and she hoped that, in kindergarten, Brady would “stay in the classroom with his peers as much as possible.” In her view, “[It is] always good to have the peer interaction and to have the peers modelling different stuff for him.” Brady's ECE program met his needs, emphasizing inclusion, particularly inclusion of children with autism, and benefitting from regular input by a specialist in inclusion of young children with hearing loss. Brady used signs, a picture exchange communication (PEC) book, and an FM system (which was passed to the children) to communicate.

Brady was placed in a regular kindergarten with a full time educational assistant, but increasingly spent time in a special education classroom. The researcher observed that, in the busy kindergarten, Brady engaged in limited communication with his peers and teachers. No one used sign, although Brady's guardian had informed them of the signs he used at home. Despite efforts of the staff, particularly the educational assistant, to involve Brady in the classroom and the playground, Brady "engaged less" with the children and adults than he had in ECE (fieldnotes). In kindergarten, the teacher expressed positive views of inclusion "for every child; they're all included," and was observed to say to the children, "Brady's your friend...we're all different, somehow"; she urged them to talk to Brady in "the same way you would speak to your other friends." Brady's aunt reported, "They're trying to include him in what they're doing and trying to see how much they can get him to do on his own." However, she observed, as the researcher did, that between ECE and kindergarten, information about Brady's use of signs and of PEC was lost, and the FM system was no longer used consistently. In May of kindergarten, the school asked Brady's aunt to make a videotape of the signs she used with Brady at home; she reported Brady used over 100 signs, while the school reported he used "three or four." Without effective means of communication, Brady's aunt's wish for inclusion for Brady (that he "stay in the classroom" and "interact with his peers" as much as possible) slipped away as he spent increasing amounts of time in a special education classroom as the kindergarten year progressed.

*Tristan.* Tristan lived with his parents and older brother in a rural farming community. During his first three years, significant medical issues and long hospitalizations limited his development. Tristan received speech and language, occupational, and physical therapy from an early age due to global developmental delays.

After Tristan's health stabilized, his parents and healthcare professionals reported large gains in language, mobility, and independence. His home was filled with games and books, and his mother tried to include Tristan in play and recreational activities whenever his health allowed; she valued "friendship and social skills" (fieldnotes). He enjoyed playing with trucks, riding his tricycle, and bouncing on the trampoline with his brother. Tristan's parents enrolled him in a 25-hour school readiness program for rural children who had not attended ECE programs, which focused on school routines and social skills. Tristan's easy-going nature and sense of humour contributed to his comfort with the staff and other children, and he participated fully. Prior to the start of school, his mother took Tristan to the school frequently and arranged for physiotherapy sessions to take place at the school's playground. For the first weeks of kindergarten, an educational assistant was in the classroom with Tristan; after that he received assistance only for personal care and medical procedures. He participated and was accepted by his peers, with classmates often "saving him a seat" and asking him to play. Tristan experienced some difficulty with the academic content and in completing tasks independently.

Tristan's mother's perspective on inclusion changed over the course of his kindergarten year. Initially she expressed a view of inclusion similar to that held by Brady's aunt and shared by healthcare workers that emphasized the development of age-appropriate skills and social interaction with peers. Later she came to place more emphasis on learning and academic inclusion, a view somewhat like that held by Abby's mother. Prior to the start of kindergarten, the only option Tristan's mother considered was placement in a regular classroom with his peers from the community. The small rural community school was welcoming and sociable. His mother had worked closely with healthcare providers prior to school entry. However, because of Tristan's limited

mobility, he struggled to keep up with his peers on the playground. Tristan had improving, but still fragile, health so he had personal care and medical needs that required adult assistance (e.g., tube feeding). His mother advocated that as much of this care, as possible, take place in the classroom, to keep Tristan with his peers. After Tristan acquired an infection early in the year, the administration insisted that Tristan be removed from the classroom for some of these services, causing him to miss some classroom activities. When he returned to the classroom, he expressed frustration because he was still completing activities already finished by the rest of the class. As a result, Tristan tended to rush and to learn less than he might. Increasingly, Tristan's mother asked that the teacher expect more of Tristan academically. The teacher also recognized the growing gap between Tristan's accomplishments and those of his peers, and she asked his peers to support the quality of his work, not simply the completion. In this small kindergarten class, his peers took on the role of checking Tristan's work before he submitted it and of showing him their work so he could see what was expected. It became clear to the researcher that the emphasis for Tristan's inclusion changed over the year he was in kindergarten.

In summary, these three families all valued inclusion of their child with their peers in a regular kindergarten program. What differed was the emphasis of the families. Abby's parents, who were well-educated and valued education highly, emphasized academic inclusion believing it would lead to social inclusion as well. Brady's aunt, his guardian, recognized the importance of communication and socialization to a boy with hearing loss and autism and emphasized social inclusion, believing it would contribute to Brady learning academically as well as socially by observing his peers. Tristan's mother

shifted her emphasis from social interaction with peers to academic learning as she recognized a growing gap between Tristan and his peers, academically.

### **Parent experiences of collaboration with healthcare and education professionals.**

In providing descriptions of parents' views of inclusion, we have reported findings from the three individual cases. However, to describe parents' experiences of collaboration throughout the transition to school, we move to reporting cross-case findings to highlight the fundamental similarities in these experiences, while acknowledging a few unique experiences that may have resulted from the characteristics of the children and their families.

Cross-case findings illustrate the complex navigation process that parents encountered during their child's transition into school. Parents reported many positive experiences collaborating with professionals during the transition process, especially during the preparation phase for transition into school. Descriptive accounts of the transition process highlight numerous areas in which educators' collaboration with parents could be enhanced to support continuity of services for the three focal children and their families upon entry to school. These findings are discussed in the three phases of transition experienced by families in these case studies: (a) preparation for transition; (b) the transition planning meeting; and (c) entry to school.

*Preparation for transition.* In each case, preparation for transition was characterized by (a) professional support for parents to prepare them with information to take to the school transition planning meeting and (b) emphasis on developing school readiness skills in the children to prepare them for entry to school. Abby's mother and Tristan's mother attended a transition workshop in February. The workshop for clients of

the child development centre was organized by the healthcare providers in collaboration with representatives from the local school boards and Community Living organization. Families listened to speakers who provided information about the transition to school, procedures such as identification of special education needs and developing IEPs, and they interacted with other parents of children with DD also experiencing the transition to school. Families also had the opportunity to meet with representatives from each school board to learn about their approaches to inclusive education. The workshop emphasized strategies that families could implement with their children to develop school-readiness skills. It was explained that once their child was registered for kindergarten, the school would organize a transition planning meeting to begin the process of planning for the child's entry to school. Parents were advised about sharing information about their child with educators (e.g., instruction on how to prepare an *All About Me* book for their child). While valuable information was provided, Abby's mother voiced a frequent concern of parents about "so much information" in one workshop.

Additionally, Abby's and Tristan's families were supported by the centre-based early intervention healthcare team through (a) a re-assessment of their child and (b) a formal interdisciplinary team meeting that included the parent. The team meeting focused on providing families with re-assessment findings, sharing successes and progress made by the child, and on obtaining informed consent to share written reports with educators. At the team meeting, therapists also strategized with families about which health providers should accompany them to the school transition planning meeting. Both families found the re-assessment information and team meeting supportive.

Since Brady was not currently receiving therapy services through the local child development centre, his aunt did not attend the transition workshop. However, she did

receive similar support to prepare herself and Brady for the transition to kindergarten from the staff of Brady's inclusive ECE program, particularly from the resource teacher, and from a community-based deaf and hard of hearing (DHH) support worker and a social worker at the local Community Living service. These professionals had long-term involvement with Brady and his family. The ECE resource teacher met individually with Brady's aunt to inform her about planning for transition into school and helped her to create an *All About Me* book to share with educators at Brady's school. Brady's aunt was effusive in her praise of these professionals, proud of the book she had created, and eager to share it with the school. As in the other two cases, this team worked with Brady's aunt to identify which service providers should accompany her to the school transition meeting. They also prompted Brady's aunt to register Brady early for kindergarten.

During the six to eight months before entry to school, each family received support to prepare their child with "school readiness skills." Abby received 1:1 instruction for one hour weekly from an enhanced support worker, who implemented an IPP developed by an ECE resource teacher. The IPP included academic learning tasks, but, according to Abby's mother, this intervention was less intensive than the school-readiness intervention already provided by Abby's family. Brady was transferred into the kindergarten readiness program, at his ECE, with his peers who would also be transitioning to kindergarten. This program introduced classroom routines and learning activities that would be encountered in kindergarten (e.g., circle time, desk work). The ECE resource teacher developed an IPP for Brady and supported the ECE teachers implementing its learning strategies. Peer mediation was introduced whereby peers learned how to scaffold activities for Brady, using signing or PEC for Brady to indicate his choices. Brady was also receiving intensive behavior intervention from a separate

community organization at the time of transition. Tristan's mother enrolled him in a 25-hour school-readiness program operated by the regional Community Living service intended to expose children to the routines and class activities typical in kindergarten. Tristan's mother also worked intensely with Tristan during this time to prepare him for what to expect at school and to enable him to play on the playground at the school.

Each family expressed satisfaction with the support they received to prepare for transition to school with Abby's mother and Tristan's mother taking considerable initiative to supplement this support. Brady's aunt relied on the guidance of his ECE resource teacher and the efforts of his ECE program, to prepare him for school, while she continued her focus on using signs with Brady at home so he had a means of communication. In all three cases, early intervention service providers supported families to begin the transition planning process. Providers in each case emphasized the importance of sharing up-to-date information about the child that could be used at the transition planning meeting to develop individual education programs for the child in the school context. In every case, early intervention providers made a plan with families to accompany them to the transition planning meeting in order to support parents in sharing information about the child. As a result of their preparation, parents understood that the purpose of transition planning was to ensure that educators would be prepared, come September, to receive the child with all the necessary supports and services for the child's inclusion at school already in place.

*Transition planning meeting.* A transition planning meeting was held, in the spring, at the elementary school that each child would attend; it was organized by the special education team of the school district. Early intervention service providers

attended the meeting with permission of the child's family. In each case, an education administrator from the school board chaired the meeting and documented information and actions into a transition action plan.

Table 1. Participants at School Transition Meeting

Setting	Tristan	Abby	Brady
<b>Home</b>	Mother, Jessica	Mother, Collette	Aunt/Legal Guardian, Alison
<b>Early Intervention Services</b>	Child Development Centre: <ul style="list-style-type: none"> <li>• SLP</li> <li>• PT</li> <li>• SW</li> </ul> Community Care Access Centre <ul style="list-style-type: none"> <li>• Case Manager</li> </ul>	Child Development Centre: <ul style="list-style-type: none"> <li>• SLP</li> <li>• OT</li> </ul> Community Living: <ul style="list-style-type: none"> <li>• ECE resource teacher consultant</li> </ul>	Community Living: <ul style="list-style-type: none"> <li>• Deaf and Hard of Hearing (DHH) Consultant</li> <li>• Social worker</li> </ul> Day Care <ul style="list-style-type: none"> <li>• ECE resource teacher</li> </ul> IBI Program <ul style="list-style-type: none"> <li>• Autism consultant</li> </ul>
<b>School</b>	School Board: <ul style="list-style-type: none"> <li>• Special Education Coordinator for School Board</li> </ul> School: <ul style="list-style-type: none"> <li>• Vice Principal</li> <li>• Special education teacher</li> </ul>	School Board: <ul style="list-style-type: none"> <li>• Special Education Coordinator for School Board</li> </ul> School <ul style="list-style-type: none"> <li>• Principal</li> <li>• Special education resource teacher</li> <li>• Classroom teacher</li> <li>• Education Assistant</li> </ul>	School Board: <ul style="list-style-type: none"> <li>• Special Education Coordinator for School Board</li> <li>• DHH teacher</li> </ul> School <ul style="list-style-type: none"> <li>• Vice Principal</li> <li>• Special education teacher</li> </ul>

Note: SLP = speech and language pathologist, PT = physical therapist, OT = occupational therapist, SW = social worker, DHH = deaf and hard of hearing, ECE = early childhood education, IBI = intensive behavioural intervention.

Table 1 identifies all individuals in attendance at the transition planning meeting for each focal participant. The receiving school's special education team and district special education representatives provided school representation at the meeting. Only in Abby's case did the classroom teacher and education assistant, who would ultimately provide direct instruction and support for Abby at school, attend the meeting.

In all three cases, service providers shared written reports (e.g., therapy assessment reports and IPP documentation) with the special education coordinator and supported parents' sharing information about their child during the meeting. These documents provided specific information about the child including areas of strength, developmental needs, goals, intervention or learning strategies, and recommendations. Brady's aunt, and Tristan's mother, also provided educators with the *All About Me* book they had prepared. In each case, educators used a transition action plan to guide the discussion and to document decisions for actions that would be taken following the meeting. At all three meetings, educators primarily sought information from families that would help them to make decisions about class placement and about planning the human resources and material supports that would be required to support the children at school (e.g., amount of education assistant support; transportation; personal care needs such as feeding and toileting). Although specific documents were collected from early intervention providers, they were not used at the meeting to generate IEPs for school.

The school transition meeting for each focal child involved a process in which educators gathered information from parents and early intervention service providers. Immediately following the school transition meetings, the three parents/guardian who had attended expressed general satisfaction with the process—especially the opportunity they had to share specific information about their child with educators—and with outcome of the meeting, as they viewed it then. As discussed below, it became apparent over time that parents and education administrators had different expectations for the outcomes of information sharing at the school transition planning meeting. It also became apparent that although parents were well prepared for the planning phase of their child's transition to school, they were less informed about and involved with decisions about their child's

actual entry to school and individual education planning for their child. All three families accepted that the transition planning meeting was their first introduction to the special education team. In subsequent interviews parents reported that they left transition planning meeting with “the expectation that, after considering all the information they had received, school administrators would contact us” to continue discussions about their children’s entry to school. Although each family used slightly different words, they all expected that educators would involve them to support the development of an IEP for their child at school.

*Entry to school.* Over time, all three parents realized that although they shared considerable information with educators about their children at the transition planning meeting and they had received a lot of general information about special education supports, they did not have specific information about their child’s inclusion at school. All three parents described how, as the start of the school year approached, they became increasingly anxious about their child’s entry to school. Each experienced their own “crisis.”

Sometime after the transition planning meeting, Abby’s mother received a call from the school informing her that arrangements were made for Abby to take the “access bus.” This decision was made despite her expressed goal (communicated at the transition planning meeting) for Abby to ride the regular school bus with her brothers. This “crisis,” as she described it, challenged her view of inclusion and of what it meant for professionals and parents to collaborate to make decisions about a child’s schooling. After consulting with her sons and confidently making “a family plan” for Abby’s safe transport to school, her mother convinced the school to follow her wishes for inclusive

transportation. As September approached, Abby's mother still had not heard from the school about Abby's class placement.

Hearing nothing from the school, she went to the school in the last week of August to learn who Abby's teacher would be, sharing with the researchers that she expected more follow-up from the school after the spring transition meeting.

At the end of term one, Abby's mother reported that she received, through her child's agenda, an IEP documenting Abby's individual learning goals. A note asked her to review and respond to the IEP. Despite her experience with the education system for her sons, Abby's mother realized that special education was new for her and she wondered aloud about whether social goals could be included on Abby's IEP or if it was strictly for academic learning. She questioned the IEP expectations for Abby to respond when called upon during group learning activities "3 out of 4 times," stating to the researcher, "I expect Abby to participate 100% of the time." Without a clear understanding of her role in the IEP, Abby's mother wasn't sure how her goals for Abby could be included in an IEP and she was unsure about how to "respond" to the IEP.

In late August, Brady's aunt still had no news about Brady's first day of school and was urged by the ECE resource teacher to contact the principal. To her surprise, the school had decided to delay Brady's entry to kindergarten by two to three weeks due to concerns about his CMV and to their misplacing the detailed information that they had received at the transition planning meeting. In Brady's case, there was considerable turnover of the education staff between the time of the transition planning meeting and his entry to school. Not one of the individuals in attendance at that meeting was on staff in September. When the school showed no knowledge of the information in the *All About*

*Me* book that she had so carefully and proudly prepared, she asked plaintively, “Where did all that information go?”

Tristan’s mother visited the small rural school regularly, where her older son already attended, so she also received a surprise when she visited and learned that Tristan was to be removed from the classroom for his medical procedures, against her wishes, and the school wanted Tristan to travel on an access bus apart from his brother who travelled on a regular school bus. Again, these surprises ran counter to Tristan’s mother’s ideas about social inclusion and to her expectations for collaboration—that she would be consulted and involved in meetings to reach these decisions, not told of decisions reached by educators in her absence. After intense discussions, Tristan did ride the school bus with his brother, and the school tried to perform his health procedures in the classroom, whenever feasible, until Tristan became ill early in the school year.

Each family described advocating vigorously for their view of inclusion for their child and for greater collaboration and involvement in all decisions about their child. The expectations that parents described, to our researchers, were for ways of communicating with educators about their child’s education program and for more frequent contact and involvement in their child’s inclusion at school. Their experiences of collaboration until this point had been in a system where, essentially, they received individualized family-centred service driven by the family’s goals for their child. In this context, families had direct and frequent face-to-face contact with early intervention service providers. When they encountered the school, the child became one of many in a classroom and the role of parents shifted. The parents reported that they wished for more information about the kinds of supports and services that could be available to their children, about the decisions that were to be made, and about special education procedures such as IEPs.

They experienced difficulty knowing how to support their children effectively when they were unaware of teacher expectations. This challenge was pronounced in all three cases since the children themselves were unable to effectively communicate with their families about their school activities. All three parents advocated for more detailed information in their child's agenda. Brady's aunt used a communication book to share information with the education assistants. Tristan's mother initiated the use of a picture communication book so that she could engage Tristan in conversation about his day. Abby's mother insisted on using the agenda to communicate with the teacher, as she did with her older children.

In summary, all three parents found it challenging to arrange frequent and informative meetings with teachers and to exchange meaningful information with the school. In all three cases parents perceived a lack of communication on the part of educators; parents had to initiate contact with educators to follow up on decisions taken following the school transition planning meeting and they developed strategies for meaningful communication about their child's experiences at school. These parents felt they had been left to navigate their child's entry to school alone. Even though all three families had experience with the education system for their other children, they needed information specific to the needs of their child with DD. Importantly, all three parents expected more details from teachers about their child's inclusion at school because their children could not communicate this to them.

### **Discussion and Implications**

Consistent with a number of transition planning guidelines developed through Canadian ministries of education (e.g., Ontario Ministry of Education, 2005), planning

for the transition of children with DD in these Ontario case studies began up to eight months prior to the start of school and involved families in the process. The involvement of families is illustrative of their commitment to the practice of inclusion and their advocacy to support their child's participation at school (Guralnick, Nevell, Hammond & Connor, 2008). Transition planning activities supported families to develop tools for communicating with educators about their child's strengths and needs (e.g., *All About Me* book). The greatest successes with parent involvement and interprofessional collaboration to support transition occurred through formal planning meetings in which one or more key representatives from the healthcare and early childhood sector, who knew the child and their family well, engaged together with families and educators at the receiving school to share critical information about the child's strengths and needs. In each case there was evidence of (a) cross-sector service coordination (e.g., workshop/1:1 support for families involving health, developmental services, and education sectors) to prepare families for the transition and (b) interprofessional collaboration (e.g., interdisciplinary representation at the transition planning meetings) to prepare educators with information about each child. However, following the transition planning meeting, there was limited communication with parents, even though planning for the child was going on within the education system.

Findings from the Ontario case studies provide depth of understanding about parent perspectives on their child's inclusion at school and deepened understanding about how these goals informed parent expectations for more frequent and sustained communication and collaboration with educators. All three parents felt uninformed and uncertain about their involvement in supporting their children's inclusion at school. In the absence of follow up from educators about their child's transition into school, all three

families were faced with a “crisis” that they needed to manage and navigate during their child’s entry to school. Findings from the three Ontario cases provide illustrative examples of parent perspectives concerning the importance of communication and information sharing with families as a cornerstone of high quality transition and inclusion (Odom et al., 2011).

Transition planning guidelines developed across numerous provinces identify the importance of transition as a process rather than a one-time event and recommend the identification of a key facilitator to support families with service coordination and system navigation during the transition planning process. Findings from these cases illustrate that each family had a team in the preschool context to support them in preparing for transition. However, following the transition planning meeting, families in this study were unsure of who they could contact for more information about their child’s education program. Although transition planning guidelines all recommend that someone be appointed at the transition planning meeting as a key person to support families with navigating the transition, no such person was identified in any of these three cases. Case study findings exemplify how key professionals supported parents during the preparation phase of transition. However, our findings also illustrate the need for a key facilitator in the school context who can support families throughout the first year of the child’s transition and underscore transition to school for children with DD as a process for both the child and their family (see Janus et al., 2008). The importance of special educators fulfilling a case management role was also identified in case study research on collaboration in school-based occupational therapy practice (Villeneuve & Hutchinson, 2012). In that study, parents recognized the need for a key person, with understanding of the school system, who can share critical information about the nature of special

education services and supports. Participants in that study recognized that teachers who have experience teaching children with developmental disabilities are best positioned to use their experience to support families with navigating the education system, not only during transition into school, but throughout each transition from one school year to the next.

Our findings are illustrative of the differences in service delivery models discussed by Dunst (2002), showing that families come to rely on the frequent contact and level of involvement they engage in with early childhood providers whose services are oriented toward family-centred models of service delivery. This is very different from the way in which schools provide services. It is important to recognize that each of these families had long-term involvement with professionals in the preschool context. In contrast, educators were just beginning to get to know the children in these case studies as members of a classroom. Nevertheless, these cases help us to understand ways in which educators can support parents to be an active partner in their child's inclusion at school. Recognizing that special education planning may be new for families, educators should:

- Provide families with specific information about special education policies and procedures as well as the roles and responsibilities of all educators involved in the child's education program. Educators should be explicit about how families can contribute to individual education planning for their child.
- Initiate a formal planning meeting at the start of the school year so that parents and educators directly involved with teaching the child (e.g.,

classroom teacher, educational assistant, special education teacher) can share information and plan together.

- Recognize that transition is a process for the family as well as the child. Classroom teachers should involve families of children with special education needs in orientation events for parents of all children in their classroom.
- Appoint a key facilitator from the school should who can work with the classroom teacher and family to develop mutually agreed upon methods of communicating about the child's inclusion and participation at school.

### **Limitations and Directions for Future Research**

This paper was limited to reporting parent perspectives of their collaboration with early intervention service providers and educators from three case studies at only one site where the HELPS Inc research was conducted. While this study contributes to the research on transition by examining the process of transition across sectors from early intervention services into school, longitudinal studies are needed to further explore the nature of parent collaboration with educators following the transition of children with DD into school. Additional analyses of survey and case study data from this project are in process to explore differences in parent perceptions of collaboration according to child characteristics (e.g., type of disability; level of maladaptive behaviour) as well as parent involvement in advocacy, the role of parent distress and parents' use of formal supports and their knowledge about disability. Interprovincial differences in these variables will also be explored. Further analyses of all 13 case studies will be conducted to examine the similarities and differences experienced by parents across the regions

studied. In addition, future analyses from the HELPS Inc study will explore the nature of sustained interaction among professionals across the service sectors and will address continuity of health and developmental services and supports available to support inclusion during the transition of children with DD to school.

### **Conclusion**

There is clear consensus from clinicians, educators and policy makers that all children, irrespective of any special needs requirement, should be provided with opportunities to interact with their peers in social, educational and community settings from as early as possible in development. This goal is critical if young children with developmental delays and disabilities are to reach their full potential and become fully integrated into society. In order to meet this goal, cross-sector knowledge transfer about DD and strategies for promoting social inclusion are needed with parent-professional collaboration being a key component of the process. This paper describes early findings from in-depth case studies which will provide the foundation for future research with parents and professionals with a view to promoting the inclusion of young children with developmental delays and disabilities during the transition into school.

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