As a starting point, could you outline the aims and objectives of the project ‘Health education and learning partnerships promoting social inclusion of children with developmental delays and disabilities’ (HELPS Inc)?

The Canadian Institutes of Health Research (CIHR)-funded HELPS Inc Emerging Team has brought together an exciting inter-professional group of researchers from five universities in Kingston and Toronto, Ontario; Montreal and Trois-Rivières, Québec; and Halifax, Nova Scotia. The overall focus of the project is the inclusion needs of young children with developmental delays or disabilities (DD) as they make the transition into elementary school. Our objectives are fourfold: we are tracking the development (adaptive skills, maladaptive behaviour and health) and social inclusion of young children in educational and social contexts; gathering information from parents about their knowledge of DD; assembling data from healthcare and education professionals as well as professionals in training; and developing educational resources to address identified needs.

Four of the HELPS Inc team members, Drs Adrienne Perry, Barry Issacs, Jonathan Weiss and Patricia Minnes, are members of another CIHR-funded team (GO4KIDDS-Great Outcomes for Kids Impacted by Severe Developmental Disabilities) investigating similar issues but focusing on the needs and experiences of older children with more severe disabilities and their families.

How much of an impact could quality training for healthcare and education professionals make for children with DD?

A key part of successful inclusion involves collaborative work among the adults that support it. Therefore, quality training for healthcare providers and educators needs to incorporate opportunities to learn from, with, and about each other.

Preliminary findings from HELPS Inc indicate discrepancies in areas of knowledge across healthcare disciplines, which reflect differences in curriculum.

The knowledge gleaned from quality training must be utilised in practical learning activities focused on working together to achieve inclusion goals for children. Drs Michelle Villeneuve and Nancy Hutchinson at Queen’s University are working towards this goal by developing strategies to provide such opportunities for occupational therapists and educators.

Data from the HELPS Inc survey assesses parent satisfaction with services, support networks and their perceived positive gains as a result of having a child with DD. What can you tell us about your work in this area so far?

In recent years, Canadian childcare centres have begun to create policies to support the inclusion of children with disabilities, however, to date there is considerable variability. Preliminary results from the HELPS Inc survey underline...
the importance of informal as well as formal support during the transition into school. It is crucial to promote parent involvement by inviting them to contribute to information gathering and programme planning for their child. Educators can support families by helping them to understand the education system and how special education services are provided. The shift from one service system (Healthcare) to another (Education) can be stressful, however, early HELPS Inc findings indicate positive parent ratings of healthcare professionals and teachers in terms of encouraging parent involvement.

The HELPS Inc team uses a combination of quantitative and qualitative research, which offers a well-rounded, wide-ranging mixture of data. How were the surveys used by the team and what other strategies were used to collect research information?

Quantitative analyses have been conducted to explore factors including child predisposing factors (gender, disability) and parent psychological factors (stress, health, coping) as predictors of child social inclusion (social/recreational participation). Qualitative research has focused on in-depth case studies. Interviews were held with parents and observations were conducted of the children in early childhood contexts and in elementary school settings. In some locations, interviews were conducted with the key healthcare professionals.

What have been the greatest successes of the project to date?

The first achievement of this project has been the development of an interdisciplinary team of researchers who bring different perspectives including psychology, education and healthcare (ie., paediatrics, rehabilitation therapy) to the topic of inclusion. Another major success has been the recruitment of over 200 parents across three Canadian provinces to complete our survey, as well as the commitment of parents, educators and healthcare professionals involved in our case studies.

Developmental disabilities

Making the transition from home to school life can be one of the biggest challenges faced by young children with developmental delays or disabilities, not to mention their parents. A multi-centre team in Canada is looking at strategies that may help to ease this difficult journey of 11 experts from five other centres with backgrounds ranging from education, medicine, nursing, occupational therapy and clinical psychology. HELPS Inc is using qualitative and quantitative research methods to explore issues experienced by parents, healthcare professionals and educators when helping to promote social inclusion of children with DD as they transition into school. “When a child makes this transition, parents face challenges related to discontinuity in service delivery,” explains Minnes. “While family-centred approaches are frequently found in health services for pre-schoolers with DD, the model changes when children enter school. Parents then often have less involvement with educators than they did with healthcare professionals.”

FROM THE MOMENT they are born, babies are programmed to learn fundamental skills such as speaking, socialising or walking in predictable sequences. With encouragement, instruction and support, these achievements usually progress at certain stages in a child’s development. Allowing for some variance, problems arise when a child falls behind on one or more of these milestones, which can be an indication of developmental delay or disability (DD).

Global developmental delay is estimated to affect between 5 to 10 per cent of the childhood population, and can be associated with diagnosis of syndromes such as autism, Down syndrome and fragile x syndrome. The families of these children often report feeling anxious about finding the right support, and when the time comes to start school, the transition from home to school life can be particularly stressful.

THE STORY SO FAR

The need for greater knowledge and training of healthcare professionals and educators to better meet the unique needs of individuals with developmental disabilities has been well documented in the literature. With this in mind, Professor Patricia Minnes from the Department of Psychology at Queen’s University in Ontario, Canada, is leading HELPS Inc, a research team

WITH FAMILIES AT THE CORE

Seeking to address these challenges associated with transitions between home and school, the HELPS Inc team recognises that parents are particularly knowledgeable about their children’s needs. As a result, they are gathering information from parents through questionnaires, interviews and case studies to explore the development and social inclusion of young children. They also are asking parents about their knowledge of their child’s developmental delays or disabilities, their satisfaction with services, what they find stressful or challenging and how they encourage social inclusion for their child.
The overall focus of the project is to address the inclusion needs of young children with developmental delays or disabilities (DD) as they make the transition into school, looking specifically at: social inclusion of young children with DD; families; professionals, healthcare and education professionals in training; development of educational resources.

**OBJECTIVES**

The focus on three major areas relating to Family, Educators and Learners. Dr Minnes’s research focuses on student mentoring, communication and collaboration and the needs of parents and professionals in training. “Collaboration between families, healthcare providers and educators needs to be established as early as possible in a child’s development, and early in the careers of professionals,” outlines Minnes. “The aim of these materials is to increase knowledge and positive beliefs, and to provide an interdisciplinary perspective to promote greater social inclusion, using collaboration with parents as the critical link.”

**THE METHODS**

To date, HELPS Inc’s cohort of around 200 parents has completed online or paper questionnaires. Approximately a third of these families have completed the surveys a second time after a period of six months. Similarly, 12 families have been recruited for case studies across five centres in Ontario, Quebec and Nova Scotia. In addition, some 1,200 healthcare and education students in training have completed surveys, focusing on their knowledge, experience, training in DD and their perceived competence.

“HELPs Inc’s team members work together either on the survey or the case study team and some members participate on both,” Minnes explains. “Research assistants in each site and a data analyst are also active contributors to these meetings. Across the three years of this study to date, researchers have collaborated primarily through team meetings where issues such as recruitment strategies, methodological issues and results of data analyses are discussed.”

The researchers are still collecting data on the projects ongoing within HELPS Inc, and results to date are varied, but it is apparent that enhanced availability of information about DD is required. The overall study has also highlighted the need for increased emphasis on student mentoring, communication and collaboration from multiple perspectives, and social inclusion. “One of the challenges of research in this area is the lack of a consistent definition of social inclusion in the literature,” asserts Minnes. “For the purposes of our project, we are measuring inclusion as participation in social and recreational activities. The literature on the impact of parenting a child with a developmental disability has suggested that parents may become isolated from family and friends. As a result, our surveys also ask parents about their own social inclusion and its relationship to the participation of their child.”

**THE FINDINGS**

In one section of the study, carried out in the Quebec province, Drs Carmen Dionne and Céline Chatenoud found that playtime with peers is limited for many children with developmental disabilities. “Although the majority of children go on outings in the community with their parents, few of these children played on sports teams, or took lessons,” Dionne affirms. Parent satisfaction with recreational opportunities for their children is mixed. Preliminary qualitative findings indicate that parents report both successes and challenges, acknowledging that discovering appropriate activities and having to educate school staff can be challenging.

Preliminary survey findings indicate that healthcare and education students have some knowledge of autism and Down syndrome, however, additional training is needed especially in less common or less obvious developmental delays or disabilities.

**WORKING WITH SCHOOLS**

The HELPS Inc project is also keen to investigate the role schools play to ensure children and families feel supported. “We are looking at the strategies schools use,” outlines Minnes. “These strategies include transition planning meetings, or ‘individual education plans’, which are used by some schools.”

Transition meetings between primary school staff, families and preschool service providers are crucial because they give the school the opportunity to learn more about a child's needs and strengths. In many cases, however, each stakeholder comes to the meeting with varying expectations. HELPS Inc highlights the importance of making these different and often competing expectations transparent so that meaningful information is exchanged with a view to achieving shared goals. Ultimately, collaboration and communication amongst parents, educators and healthcare professionals are viewed as critical to facilitating the transition into school and to promoting social inclusion of young children with DD.

Collaboration between families, healthcare providers and educators needs to be established as early as possible in a child’s development and early in the careers of professionals.