

Transition to School

Experiences of Children with Intellectual Disabilities and their Families

Early experiences at school set the stage for later academic and social success.

by Tess Clifford



Sending a child to school for the first time is an exciting and anxiety-ridden experience for any parent. For parents of children with intellectual disabilities, including autism, it is even more difficult.

The goal of many early intervention programs and services for preschool-aged children with intellectual disabilities is to prepare them for school. There are, however, very few reports documenting the experiences of children with disabilities and their families through this transition. As a Master's student funded by Autism Ontario, I was able to contribute to this literature. My interest was primarily related to examining changes in several areas of the children's and their families' lives during the transition, and to identify possible predictors of successful transition to school.

Twenty-one parents of children with or at risk for intellectual disabilities who were entering school for the first time in September 2006 volunteered to participate in this study. There were 19 mothers, one grandmother and one father, with the average age being 34. Each parent completed three one-hour telephone interviews, the first in the summer before school started, the second in the late fall, and the third in the late winter. Parents were asked a variety of questions about their child's skills and abilities, the services and supports they used and their own personal experiences. The parents were also asked to complete a survey about their child's quality of life, and each parent nominated a teacher to provide some information about the child's functioning at school.

The families involved lived in a variety of communities across southeastern Ontario. The children included six girls and 15 boys with an average age of

4½. The majority of children were diagnosed with Autism Spectrum Disorders, but there also were children with Down Syndrome, developmental delay, Rett Disorder, and several other neurodevelopmental disorders. The children were somewhat delayed in their daily living skills, but did not have many problem behaviours.

The parents in this study generally coped very well and reported only mild stress. Most reported stresses were associated with financial and insurance issues. The parents agreed with many positive statements about how their lives had changed because of their child, such as, "I have learned to speak out for my child," and "I am more compassionate towards others." As well, parents were generally satisfied with their child's quality of life.

The families involved in the study reported using several services prior to their child starting school (e.g., speech-language therapy, behavioural management services, occupational therapy). However, the average number of services used decreased during the time of transition from between three and four services before school started to less than two later in the school year. Although this is not particularly surprising, it is important information for families since many services geared toward preschoolers discontinue after the child begins school. Many parents reported frustration with lost or changing services. Our research team will interview these parents again in a year, and will examine if the number of services used continues to decrease, increases or stabilizes.

Another component of this study involved examining the child's involvement and support in various areas. In general, it was found that the needs

of the children were supported in many areas including medical services, education, home and recreational activities. However, more than half of the parents reported that their child was not involved in any organized social activities (e.g., sports, clubs or lessons), and was not seeing a dentist on a regular basis. Several parents indicated that their child was not involved in organized social activities because he or she would need one-to-one support and they were not sure it would be provided. When parents were asked why their child was not seeing a dentist the majority indicated that it would be very difficult for their child (e.g., "he would not be able to sit still") and some suggested that oral health was not a major concern since the child did not have any adult teeth. Although these findings are worrisome it is not clear if these experiences are atypical for this age group.

Some very interesting findings emerged regarding the child's quality of life and school readiness skills. Parental involvement in support groups was correlated with satisfaction with the child's quality of life and school readiness scores. Parents involved in support groups were more satisfied with their child's quality of life, and their children also had higher scores in the physical health and wellbeing domain of the school readiness measure. Previous research has found that parents involved in support groups generally see their child with a disability more positively than those who are not involved, and may therefore be more likely to indicate satisfaction with their child's quality of life. It is also possible that in some cases physical health and well-being may limit the child's involvement in the community, which may then lead to lower scores in quality of life. The relationship between parent support group use and school readiness and quality of life is not yet completely understood. Future research should examine these variables more thoroughly.

Our research will continue over the next year and will interview parents of children with and without developmental delays. More information about the experiences of all families during the transition to school should give us a clearer understanding of the experiences of families of children with special needs.

In conclusion, this project provides some information about the experiences of children with autism and other disabilities and their families as the child transitions into school. We have learned that the experiences of these families vary widely. Further research is needed to provide a better understanding of the changes that take place during the transition to school and the predictors of successful transition. It would seem that parental involvement in support groups should be encouraged. With continued research we may be able to provide recommendations beneficial for families of children with intellectual disabilities attending school for the first time.

This project was funded by the South Eastern Ontario Community – University Research Alliance in Intellectual Disabilities (SEO CURA in ID), which includes partners from across southeastern Ontario as well as collaborators from other areas. The community partners are primarily developmental service sector agencies across the six-county catchment area and the primary researchers are based at Queen's University in Kingston. The complete list of researchers and partners can be found at www.seocura.org. Our vision is to augment the quality of life for individuals with intellectual disabilities and their families through enhanced inclusion, sense of belonging and support. Our goals are that research findings be used to inform policies and practices of service providers and government ministries and that the partnering experience inform future research areas and approaches.

Funding for SEO CURA in ID was provided by a grant from the Social Sciences and Humanities Research Council of Canada [#833-20003-1008].

We would like to thank the staff at the community agencies involved in recruitment for their ideas and assistance, and the families who participated for sharing their experiences with us.

The views expressed in this study report are not necessarily the views of all SEO CURA in ID partners, researchers, collaborators or members or the Social Sciences and Humanities Research Council of Canada which funded the study.