

Nova Scotia's
Early Intensive
Behavioural
Intervention
Program

The Panel's Report

Introduction

The first time a child says “I love you” is an emotional milestone that most parents will never forget. When you wait five years to hear those words—as can be the case for a parent of a child with Autism Spectrum Disorder—the impact is even more profound.

While many of us take the ability to connect with those around us for granted, some Nova Scotians have a different experience. For those with Autism Spectrum Disorder (ASD), the inability to connect, to communicate, is part of everyday life. Individuals with ASD experience differences and/or delays in the development of communication and social skills and will exhibit intense or unusually rigid interests and behaviour. It can be challenging for both the children and their families. That’s why Nova Scotia introduced the Early Intensive Behavioural Intervention Program (EIBI) in 2005. The program is unique in this country—and it’s getting results.

“When our child was given the tools/strategies to deal with daily challenges, he became more confident and less anxious. This reduced stress for our whole family.”

The program was introduced ten years ago with a budget of \$4 million. Developed and designed here at home, the program offers a graduated, family-centred model of care. Direct services are provided for one year, followed by professional consultation up until and through the initial period of school entry. Children receive 15 hours of direct service each week in the first six months; this is *gradually* reduced to ten hours weekly for the next three months and then to five to six hours a week for the last three months. Treatment is provided where children live—in their homes, day cares, and the community. Parents are also trained as part of the program. When resources allow, other caregivers

and early childhood educators involved in the care and education of the child are also trained. Following this direct and hands-on treatment phase, consultation and support services are available from the EIBI team and can include problem-solving and booster sessions for parents and caregivers.

What truly sets Nova Scotia's model apart from other jurisdictions is the use of Pivotal Response Treatment (PRT). PRT is a scientifically validated treatment that uses motivational strategies and the principles of Applied Behaviour Analysis (ABA) to teach children. The main focus is on developing communication, play, and other functional skills, taught at a level appropriate to the child. Treatment is focused on the areas that help to advance skill development.

Meeting the Growing Demand

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Funding for the EIBI program was doubled to \$8 million in 2011, in response to the fact that only half of the children needing treatment were receiving it. However, based on current estimates, even with the additional funding the program cannot keep pace with the growing number of children needing treatment today. ASD has been diagnosed with increasing frequency; the boundaries of the “spectrum” are now more broadly defined, and there is also greater professional and public awareness, leading to earlier identification. Global estimates suggest a prevalence of about one in 100 (1 per cent), and as high as 1 in 68 in the United States. Nova Scotia is following that same trend, seeing increases in the number of children being referred and diagnosed with ASD.

To be eligible for the program, children cannot yet be in school. Long waits for assessment and treatment, and late diagnosis, shrink the limited window of opportunity to take advantage of the program. As a result, parents and families have expressed concerns that many children will have to delay entry into school in order to access services.

With this in mind, the Minister of Health and Wellness appointed a panel of experts to provide advice on the path forward. Specifically, the panel was asked to review evidence related to early intensive treatment for children with ASD and how Nova Scotia’s EIBI program measures up to the evidence related to school readiness—for children in general and for those with special needs. The panel was also tasked with examining the data on the number of children waiting to access the EIBI program, their ages, and the options for school entry within the context of the growing number of children diagnosed with ASD.

Background

For a child with ASD, early intervention is critical. Without it, developmental difficulties may become more pronounced, often causing additional problems. Over the last several decades, early intervention programs have been developed using strategies informed by the scientific principles of learning, and in keeping with evidence as outlined in the National Autism Centre's standards report.

More recent evidence indicates that intervention programs should be carried out, as much as possible, in natural settings. In other words, behavioural therapies should be provided in settings typical for young children, such as playgrounds, daycares, and, of course, at home. To maximize learning, similar strategies should also be used by the parents when interacting with their children—exactly the approach used in Nova Scotia.

"My family has certainly benefitted from this program. I couldn't have asked for better workers, they seemed to be a perfect fit. So energetic, knowledgeable, and creative. Both children looked forward to visits (only one in program). They have changed our lives with their hard work and dedication, and together we figured out strategies that seem to be working."

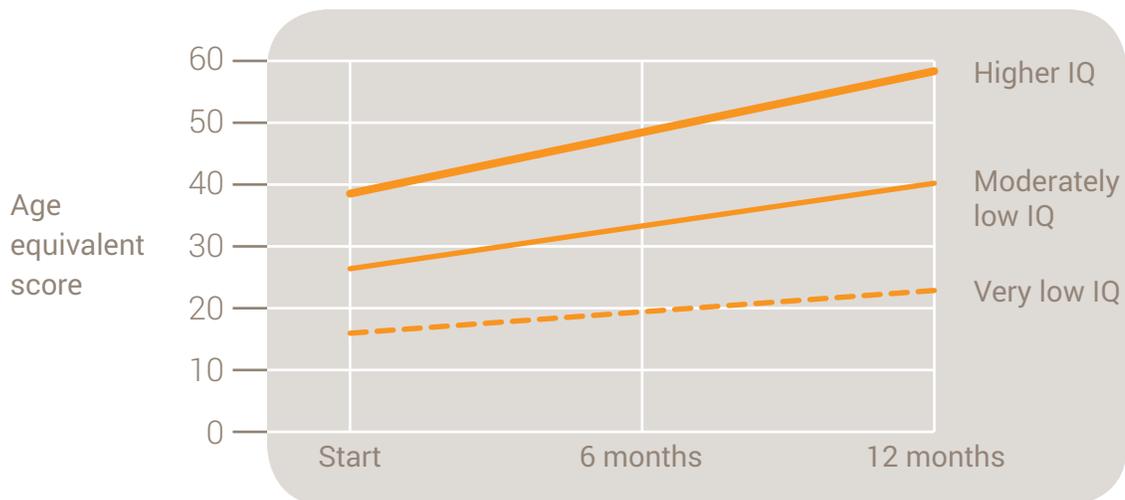
Although most research involves only small groups, knowledge and expertise is growing. For example, promising results have been found in a small high-quality research study (The Early Start Denver Model) of toddlers with ASD where both parents and therapists implemented interventions in natural settings. Children who were in this program for two years made larger gains in cognitive ability and behavioural skills than a control group of similar children receiving the usual care in the community. Similar gains were not evident when a short, parent-only implemented version of the program was studied and outlined in the *Journal of the American Academy of Child and Adolescent Psychiatry*.

Like other provinces, Nova Scotia is challenged to provide high-quality EIBI for the growing number of children needing it. Nova Scotia's program requires scarce professional expertise and significant resources.

While several jurisdictions do not have evidence of the effectiveness of the programs they are delivering, Ontario and Nova Scotia are exceptions. Nova Scotia's EIBI program was designed using evidence-based aspects of effective interventions— notably ABA strategies in natural settings and parent training. Once children receive a clinical diagnosis, they are eligible for the program, regardless of severity (unlike Ontario's program).

Nova Scotia's program is shorter and less intensive than most EIBI programs, yet it's showing positive results. According to study, outcomes for 118 children who participated in Nova Scotia's program are comparable to the outcomes for those who participated in more intensive programs.

Over the course of the year, on average, Nova Scotia's participants gained skills faster than expected (based on pre-treatment skill levels). This was the case for expressive and receptive language as well as intellectual abilities. The chart below illustrates the change in intellectual ability scores during 12 months of the program.



Average gains over 12 months of EIBI (shown in months of development) on a measure of intellectual abilities, for groups of children with different IQ levels at the start of EIBI.

The chart illustrates data for groups of children divided according to their level of ability at the start of the program. In the group with the highest pre-treatment ability, intellectual problem-solving skills increased at almost double the rate seen in children with typical development. In other words, Nova Scotia's participants exhibited nearly two years of gains in just one year.

Before treatment and after 12 months, parents provided reports of everyday behaviour, severity of ASD symptoms, and other problems. Over the course of the treatment, adaptive and communication skills increased significantly, with larger gains than reported for longer programs of similar intensity, such as one reported from Sweden. Among children in the Nova Scotia program who had the highest pre-treatment abilities, ASD symptoms became less severe, and behaviour problems were reduced for all children after treatment.

The results of the treatment are impressive.

"The EIBI program was amazing for my family and my son ... so happy I did this program, made a huge difference with my life ... my life is not so stressful anymore, learned so much and I keep doing what the girls taught me ... we're not giving up and my boy is shining so much."

Provincial EIBI teams are seeing twice as many children today as they were prior to 2011. Unfortunately, the number of children waiting for treatment has also increased. While new resources provided to the program in 2011 increased capacity, the number of pre-school children diagnosed with ASD has also doubled.

For families awaiting treatment, it can be a difficult process. Because such a large number of older children need the program before they enter school, parents are becoming increasingly concerned about the fact that the program will require some children to delay school entry by one year, beginning school at age six.

The transition to school is an important developmental milestone for children and their families. That's true for all families—it's a new reality for the parents and for the children. Entering grade primary means entering a more academically oriented and socially complex environment as children take on the new and different role of student. In a comparison of school versus pre-school activities, one finds that children are expected to complete more tasks independently, follow large group instruction, and work and play cooperatively with less teacher support. The ratio of teachers to children also changes, from 1:8 in childcare settings to 1:25 or more in school. Early childhood programs are often more family-focused and foster more informal contact with parents. Parents of children with special needs, including ASD, often find school staff less accessible than pre-school service providers, although school staff continue to be supportive. Services are often available but delivered differently, making the transition difficult for families.

"This is a fantastic program. We looked forward to every visit and every team meeting."

Children with ASD may find it more difficult to transition from pre-school to primary, given their challenges with social understanding, communication, and interaction skills. Families of children with ASD have indicated that they wish to become partners with the school to ease the transition, and would like to see the skills developed in special programs such as EIBI incorporated into program planning over the longer term. Transition meetings become critical, to allow pre-school childcare providers, school staff, and family to foster understanding around the new school environment and to identify the skills and behaviours that are fundamental to success. Program planning should also identify needed school supports, such as speech language pathology, learning centre, or resource support.

"Before EIBI we always wondered if we were doing the right things, and second-guessing ourselves. EIBI gave us assurance and confidence in our own abilities as parents."

School Readiness

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Any parent can attest to the fact that children develop in different ways and at different rates. When looking at school readiness, usually multiple factors are considered. More recently, school readiness is considered in the context of ready families, ready communities, ready services, and ready schools. Specifically, five areas are identified for school readiness:

Physical well-being and motor development—addresses growth and development, health, and physical abilities

Social and emotional development—refers to a child's understanding of themselves and other people, ability to interact with others and express emotion, and capacity to self-regulate

Approach to learning—refers to a child's motivation to learn, engagement and persistence with tasks, demonstration of curiosity, and interest in learning

Language development and literacy—includes communication skills related to listening, comprehension and communicating, understanding of print concepts, phonemic awareness, and story sense

Conceptual knowledge and application—refers to imagination, thinking, problem-solving, and an understanding of how the world works

Along with these five concepts, the importance of home stimulation, including the supports and resources available, must be considered. This is especially true for families of children with ASD, as the stressors for them can be significant.

Age has traditionally been a factor when considering school readiness. Age of school entry varies around the world. In Nova Scotia, children who are 5 by December 31st are eligible to attend grade primary in September of that year. However, children are not

required to attend school until they are 6. Numerous studies have looked at age as a factor affecting school performance. A landmark study by the U.S. National Institute of Child Health and Human Development (NICHD) indicates that the age of entry was unrelated to social and emotional functioning. Age may have an impact on cognitive-academic skills, with older students having a small advantage at the start of school and up to grade 3. This study clearly finds that age of entry is minimally important when compared to the other factors that predict school readiness.

“Both of my boys took part in this program five years ago. The program was intense, involving a lot of home visits and meetings. It was worth every second when our 5½-year-old began to talk. Our other son had a more difficult time. We were still impressed with the program because it helped one of our boys. I feel compelled to write this now, five years later, because our son is finally beginning to talk. It has been happening over the last year or so. This is highly credited to the things we learned from participating in the EIBI program.”

School readiness looks at task performance such as responding to instruction, orienting to materials, and engaging with peers in group activities. In studies that looked at parents' and teachers' expectations of readiness skills, parents were more focused on traditional skills, such as knowing letters and numbers, while teachers focused on task performance, such as whether the child is able to communicate wants, needs, and ideas. Teachers also look at whether the child demonstrates interest and curiosity in learning, and in whether he/she follows directions, pays attention, demonstrates sensitivity to self and others, and has the ability to self-regulate emotions without being disruptive. These are considered to be the skills that set a child up to successfully learn the academic and social curriculum in school. They are also the skills targeted in Nova Scotia's EIBI program.

ASD and School Entry

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Not surprisingly, children with ASD demonstrate a range of strengths and challenges. Although all individuals with ASD share certain challenges, each individual is affected differently. Children with ASD are potentially vulnerable, at-risk learners who are at a disadvantage when it comes to acquiring the skills needed for school readiness. The differences in social communication and language and the challenges in play skills and imitation, along with restricted or atypical interests, can make the transition to school difficult. Meeting expectations when it comes to task performance and approaches to learning may also be problematic.

Research shows that children with ASD entering school tend to do well on some literacy skills such as receptive vocabulary and can identify letters, words, and numbers. However, they perform significantly less well on behaviours related to working and playing independently, accepting decisions of others, motivation, sharing, and self-control. Children with ASD have difficulty with a number of self-regulatory processes that can affect behaviour and peer and school engagement. Intervention programs for these children prior to school entry can help prepare them for the demands and challenges of the school setting.

"We had an amazing team who seemed genuinely concerned and focused."

Results indicate that Nova Scotia's EIBI program effectively accelerates the development of most pre-schoolers with ASD, and demonstrates results competitive with other published programs. Children are taught to initiate interactions and communicate more effectively with adults, family, and peers. Ensuring that families are integral members of the treatment team and are coached in Pivotal Response Treatment (PRT) enables a focus

on the functional skills of social interaction and communication in real-life environments. Qualitative evidence gathered from the families in the program reveal themes of reduced parental stress and worry, increased confidence in parenting skills, and improved family relationships. All of these aspects are identified as important for school readiness.

Research is continuing. To tailor the program to better meet the needs of children and families, we are studying which children benefit most from the current program. As well, a Canadian Institutes of Health Research (CIHR) grant is examining the cost-effectiveness of the Nova Scotia program compared to the more traditional EIBI model offered by independent agencies used in New Brunswick. The results of this study will be the first Canadian data documenting the returns from public investment in EIBI for pre-schoolers with ASD.

While Nova Scotia's program addresses many of the critical components of school readiness, the program is designed to benefit children across a full range of functioning. We know that development in the early years is critical for all children. EIBI provides an opportunity to influence development for individuals with ASD in a very positive direction.

Conclusion

We know the funding increase of 2011 did increase capacity, with more children accessing services. However, as more children are diagnosed with ASD, not all children needing services will receive them. Teams are currently providing intensive service to only a third of eligible pre-schoolers. Given current circumstances, teams will not be able to provide the intensive year to all of the older children waiting, and fewer children will be provided with treatment at a younger age. As a result, some children will be old enough to enter school before accessing these services, and more families will be faced with the decision to defer school entry or decline EIBI.

The lack of capacity to provide services to the oldest eligible children in September 2015 poses an immediate problem. The original objective of the additional funding was to provide access to services for all eligible pre-schoolers. The increase in diagnosis compromises this objective.

Other challenges have arisen as EIBI teams focus on treatment for older pre-school children. The assumption was that the increased capacity in 2011 would allow more children to be seen in a timely manner. Instead, families of younger children are enduring the stress of waiting, and are then in a position of having to decide to defer school or decline participation in the program. Deferring school can have financial consequences for families who struggle to afford childcare. There is also an emotional burden that families endure. The beginning of school is an important life marker. Families are often in the vulnerable position of coming to terms with the impact of having a child with ASD while also having to make a decision about an important transition in their child's life. If school is delayed, that's another milestone delayed. Yet, choosing school entry over EIBI could potentially have a negative impact on the child's long-term success.

In conducting this analysis, the panel recognizes:

- Access to timely diagnosis is an additional critical issue relating to EIBI access.
- Access to additional and coordinated supports such as early childhood education, early intervention, and mental health services contribute to optimal outcomes for children and families.

We also base our advice on the following assumptions:

- The number of children receiving a diagnosis of ASD has increased, and a higher proportion of children diagnosed are under 3 years old.
- Total capacity of the current EIBI program with all positions filled is approximately 90 children in the intensive phase.
- All children diagnosed with ASD should be eligible for the program, no matter their severity of symptoms or level of ability.
- The number of children who have been diagnosed and are waiting for program access and those awaiting diagnosis represent a snapshot in time, and numbers will fluctuate.
- Based on current numbers, many 4- and 5-year-olds will require EIBI within the next year, putting undue strain on the system in order to catch up with demand. Current resources cannot address the immediate or long-term needs of all these families.
- Recruitment at the program supervisor level will be a challenge, particularly in the rural areas.

The panel wishes to provide the following advice to the Minister of Health and Wellness to better meet the needs of those living with ASD.

- If possible, these children should receive the full year of EIBI prior to school entry with no delay in school entry.
- In some circumstances and for a variety of reasons, some children will receive a diagnosis closer to school eligibility; in these cases, a child should receive a full year of EIBI even it means a delay in school entry.
- No child should receive less than six months of EIBI.
- If a child is to receive the minimum six months of treatment prior to starting school, the process should begin by March that same year.
- Additional staff will be needed to address the increasing number of children who have been diagnosed and await services. Given recruitment challenges, it is recommended that recruitment for required positions be posted as early as possible.

Nova Scotia's EIBI program has broken new ground, and continues to do so, benefitting children around the province. Demand has now outstripped capacity, however, despite doubling resources for the program in recent years. Nova Scotia's program is proving to be one of the most cost-effective programs in the country. As was noted in the One Nova Scotia report, it is widely accepted that schooling at the elementary, junior high, and high school levels provides the crucial foundations for all further learning, and the jurisdictions that develop the best public education systems essentially give their citizens a head-start on "learning a living." If we are to set the foundation for those with ASD to learn a living, additional resources will be needed, to ensure that no child is left behind.

Panel Members

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