

Intensive Early Intervention Program for Children with Autism: Background and Design of the Ontario Preschool Autism Initiative

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Abstract

In 1999, the Ontario Ministry of Community and Social Services (MCSS), now called the Ministry of Community, Family and Children's Services (MCFCS), introduced a major initiative to provide Intensive Behavioural Intervention (IBI) to children with autism aged 2 to 5 years. This article will describe the background to this preschool autism initiative, as well as the specific nature of IBI, and highlight some of the accomplishments over the first year, as well as some of the implementation challenges experienced.

The Ontario government has, over the past few years, been focussing on early intervention for young children through a number of "early years" initiatives, based on the research evidence of neural plasticity and the effectiveness of early intervention (McCain & Mustard, 1999). This includes designing and implementing an exciting new program for young children with autism, the largest, most comprehensive program of its kind in the world. This new investment in services for young children with autism is intended to address a particular service gap identified in Ontario in recent years by parents and professionals alike, by providing funding to build province-wide capacity to deliver high quality intensive behavioural intervention services (IBI), integrated within the existing service system. Through centralized provincial training and education initiatives, it also addresses the need to develop greater professional expertise in early identification and diagnosis.

The objectives for the program are noted in the Program Guidelines (ISCD, 2000):

"The objectives for young children with autism are to ensure that they: receive a thorough and accurate diagnosis as early as possible; have an individualized service plan based on their strengths and needs; receive high quality individualized intensive behavioural intervention, where required; make a smooth and effective transition into school programs and/or other services for older children; and demonstrate measurable gains and

improvements by age six. The objectives for the system are to: deliver services that are responsive to families' needs and concerns; develop the capacity of regional programs to provide effective, evidence-based, intensive behavioural intervention to young children with autism; develop effective links with other services and supports to ensure that children with autism and their families have access to service coordination, information, and other necessary services; evaluate the Intensive Early Intervention Program for Children with Autism and institute a program of continuous quality improvement; and develop the capacity to identify and diagnose children with autism earlier and more effectively." (p.6)

In keeping with the priority of MCFCS to provide services to those most in need (MCSS, 1997), this initiative is intended to provide IBI to children with autism or a disorder which would be considered toward the more severe end of the continuum known as Autism Spectrum Disorder. That is, children diagnosed with Autistic Disorder and some children diagnosed with PDD-NOS are eligible; they do not have to have "severe autism" as is sometimes mistakenly quoted. The services are primarily intended for children up to and including the age of 5. However, children who are between 5 and 6 six years old when they enter the program are eligible to receive 12 months of service if, based on an individual assessment, intensive services will help them function in school.

In the fall/winter of 1999, the Ministry established a competitive tendering process (as is currently used for many government initiatives) to select service providers in the nine MCFCS regions of the province as well as a provincial training organization. This process was completed and contracts finalized in spring/summer 2000. The Ministry contracted with the Behaviour Institute, a private agency with expertise in providing IBI and in training, to deliver a province-wide training program for staff and a number of related training activities designed for staff, parents, and others (see below). The nine new "regional programs" include various types of organizations (MCFCS agencies, children's treatment centres, hospitals, or combinations thereof), sometimes with local agencies as subcontractors or partners, and with quite different organizational structures in each region. The program is now administered through the local MCFCS Regional Offices, similarly to other transfer-payment agencies, but there is also a policy coordination function maintained by the Special Needs Branch of the Integrated Services for Children Division. All regional programs are required to follow the Program Guidelines and their service contracts, which were negotiated with the MCFCS Regional Offices. The Clinical Directors of all regional programs participate in the provincial Clinical Directors' Network, which was established to develop and implement clinically sound and consistent practices regarding issues such as assessment/diagnosis guidelines, eligibility, determination, setting and intensity decisions, supervision expectations, approval of private providers, and so on. Regional programs began hiring staff and doing assessments of children in the

summer of 2000 and IBI began to be delivered in late summer/fall 2000. Staff shortages have been a challenge, as have large waitlists for assessment and service. However, funding for the program was recently increased to almost \$60 million (and will be over \$78 million by 2006-07). Consequently, another wave of hiring was initiated in summer/fall 2001 and another one is underway at the time of writing. The program has been in operation for approximately two years in most locations and hundreds of children are receiving IBI.

Intensive Behavioural Intervention

Regional programs are expected to provide intensive behavioural intervention (IBI) based on the Program Guidelines (see excerpt below), which were developed by examining the research, seeking consultation, and examining the practices in other jurisdictions.

Research

The Guidelines were based largely on the research literature on a variety of autism interventions (e.g., Hefflin & Simpson, 1998; New York, 1999), on "best practices" in assessment and diagnosis (e.g., Filipek et al., 1999), and, especially, on empirical evidence on intensive early intervention (for reviews see Dawson & Osterling, 1997; Green, 1996; Harris & Handleman, 1994; Powers, 1992; and Rogers, 1996). A careful attempt was made to base the Guidelines on empirical evidence whenever possible and not to make arbitrary decisions for which there is, as yet, no adequate basis in research.

Consultation

Approximately 200 Ontario service providers and parents, either individually or through meetings organized in conjunction with the Autism Society of Ontario, attended consultations and focus groups. Information packages were distributed to over 300 additional relevant organizations and individuals during the fall of 1999. Feedback was overwhelmingly positive including commendation for the IBI orientation, the research basis, the family focus, the centralized training, and the close monitoring and evaluation process. Some concerns were expressed about the capacity of the community assessment resources, the eligibility criteria, the capacity of Ontario service providers in terms of IBI expertise, the direct funding option (both philosophically and logistically), and the transition to school issue.

Practices in other jurisdictions

A telephone survey was conducted of 20 U.S. programs providing IBI to young children with autism, including a variety of program models (home-based, centre-

based, integrated, University-affiliated, research-funded, government-funded, privately funded, etc.). Also, regular contacts were made with the other provinces in Canada (some of whom were considering pilot projects or had nonspecific funding conduit programs, but none of which had a provincial program at that time). Finally, policy statements of autism-related organizations and government bodies in other jurisdictions were examined, notably the Clinical Practice Guidelines recently developed for the State of New York (New York, 1999).

Nature of the regional programs

As noted in the Program Guidelines,

"The program should have enough flexibility to allow the best use of local resources and expertise, and to exercise clinical judgement in developing particular parameters of intervention for particular children and families. At the same time, however, there is an expectation that regional programs will have a common philosophy and approach (i.e., IBI) and will provide a common standard of service quality consistently across the province." (p. 12)

Based on these three sources of information, the regional programs are expected to provide IBI services which:

- begin as early as possible after early identification or diagnosis;
- are "intensive" in nature (i.e., are a direct service for many hours per week [usually 20 to 40]);
- flow from a thorough diagnostic, developmental, and functional assessment;
- are based on best available scientific evidence on efficacy, safety, and appropriateness;
- use systematic behavioural teaching methods to build up skills (including, when appropriate, discrete trial teaching in one-to-one structured programming using techniques of applied behaviour analysis such as positive reinforcement, task analysis, modelling, and prompting);
- use other systematic methods, when appropriate for the child's skill level or stage of progress, such as small group instruction or activity-based learning, and capitalize on naturalistic teaching opportunities across a variety of people and settings;
- include, from the outset, planning for generalization, independence, and flexibility in children's behaviour and skills as well as teaching functional, relevant skills they will need in natural settings;
- use a curriculum which is comprehensive in scope (i.e., it provides teaching in all areas including social, play, cognitive, language, self-help, and so on) and is developmental in sequence;
- include a particular focus on the social-communicative deficits and

differences which are characteristic of autism, including a wide variety of techniques to promote joint attention, social interaction, and intentional communication, using a variety of expressive communication modalities as clinically appropriate (e.g., picture exchange, words, gestures, and so on) and encouraging a variety of communicative functions to be developed (e.g., requesting, protesting, initiating, commenting, and so on);

- are individualized to reflect the child's developmental level, strengths and needs, and likes and dislikes (i.e., the specific goals, the motivators and the teaching methods are chosen based on what is appropriate for the particular child);
- are data-based and monitored frequently using behaviour observation methods such as graphing, inter-observer reliability, and so on, so that clinical decisions are based on data (e.g., to determine when the child has progressed enough to have specific goals, specific methods of instruction, or larger program parameters adjusted and/or to make the transition to less formal training and/or a more natural setting);
- use an ethically sound, positive programming approach to treat any serious problematic behaviours (e.g., self-injury, aggression), based on a comprehensive biopsychosocial assessment, including but not limited to functional analysis, in accordance with MCSS standards and other ethical and professional guidelines;
- are delivered by well-trained staff who are monitored and evaluated by highly trained experts;
- occur in a variety of setting(s);
- involve the parents/caregivers directly in the child's treatment and give them the training they need to supplement the program at home (when possible and appropriate), to manage their child's behaviour, and to have meaningful and rewarding interactions with their children;
- include careful planning and support to help the child function in or make the transition to other settings, such as integrated child care or school, including teaching the child the "survival skills" needed for the next setting (e.g., participating in circle time, raising one's hand to get the teacher's attention);
- are coordinated and integrated with other services the child or family may need or desire;
- are sensitive to the family's values and preferences, cultural context, and language, including being available in French in designated areas; and do not include other unproven or experimental approaches including, but not limited to: the Developmental, Individual Difference, Relationship (DIR) model (also known as "floor time"), Sensory Integration Therapy, Music Therapy, Touch Therapy, Auditory Integration Training (AIT), Facilitated Communication (FC), the Miller Method, diet or hormone therapies."

(pp. 12-13)

The behavioural intervention should be provided at an appropriate level of intensity in appropriate setting(s), depending on the child, family and community. Setting(s) could include home, specialized classrooms (centre-based), and community child care centres or schools in some cases. The intensity (usually operationalized as the number of hours of intervention per week) and setting(s) of each child's program should be primarily a clinical decision made by the regional program and the family, based on the research and the Guidelines, and taking into account the following factors:

- the child's age, health issues, and tolerance for intervention;
- the child's developmental level, severity of autism and interfering behaviours;
- the stage of therapy the child is at and rate of progress made;
- the parents' values and priorities and their level of participation in the child's IBI; the availability of options depending on their community and location;
- the principle of having children placed in the most naturalistic, least restrictive setting in which the child can learn and function effectively and of maximizing the benefits of setting(s) a child may already be in.

Regional programs must offer families the option of funding to purchase intensive behavioural intervention services privately and assist them in its implementation. To receive funding, parents must provide information about the child's assessment and diagnosis and the regional program may undertake any further assessments required to confirm eligibility and work with the family to develop an Individual Service Plan for the child. They will also review/observe the child's private behavioural intervention to determine whether the private therapy meets provincial guidelines as noted above and, in particular, to ensure it is properly supervised. If the private therapy meets these requirements, the regional program must provide the funding based on the level/intensity of service recommended in the child's Individual Service Plan. This direct funding option is more popular and available in some regions than others, due to the location of appropriately trained supervisors, accounting for approximately one-third of children's programs at the time of writing.

Training

Integral to the autism initiative has been the central coordination of staff training. The province-wide training program for staff was intended to assist the regional programs in the initial years of the new program and to ensure consistency throughout the province. As noted earlier, the Ministry contracted (via a competitive tendering process) with the Behaviour Institute, which developed training manuals and teaching materials (in English and French) and hired several MA or PhD level training supervisors, who have been delivering the training in various locations throughout the province over the past year. To date, over 600 instructor-therapists and senior therapists have completed this training.

The training consists of a two-week intensive training course which includes lectures, videos, demonstrations, role plays and exercises and involves reading a manual and a text book and completing a pre- and post- test, which must be passed. Then staff are expected to work with children for a period of 1 to 3 months, under the supervision of the regional program senior therapist and psychologist. During this time they can send a videotape of a session to the Behaviour Institute for feedback (optional) and then they are scheduled for their in vivo evaluation, which results in feedback being given to the staff and their supervisor and recommendations to the regional program in terms of future learning plans for the staff person.

The Behaviour Institute also developed a package for parent training sessions and have trained senior staff in each region to use these materials with parents in their area. There are also a variety of other short- and long-term advanced training options for regional program staff being developed.

In addition to the direct training of staff for the IBI initiative, training and education of the broader service delivery system is essential to achieving the goals of this autism initiative. The Ministry, through the Integrated Services for Children Division, is working in consultation with universities and community colleges, regulatory colleges, continuing education organizations, provincial professional associations and regional programs to develop broader training and education strategies. These training and education initiatives are aimed at ensuring that professionals across the province have up-to-date knowledge of best practices in the autism field. Furthermore, they form part of the capacity-building strategy of the autism initiative in supporting programs designed to train future professionals for the initiative and for the field.

Monitoring and Evaluation

Careful monitoring of the Intensive Early Intervention Program for Children with Autism was built in to its design, so as to ensure that the program achieves its goals and objectives related to children and families and makes efficient use of public resources. A mandatory information system has been developed to track children and their services. The Ministry has been monitoring the program carefully and making adjustments as needed based on the data, even in the early stages. The next step is that tools and processes are being developed to measure the quality of the intensive behaviour intervention provided and to do quality assurance audits of regional programs' services. The information being collected will also provide the basis for an in-depth study in the future of the short- and long-term outcomes for children and families in the program. A program of this magnitude and scope has considerable potential to contribute to the literature regarding the effectiveness of IBI and presumed interactions among child characteristics and intervention characteristics.

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Disclaimer

The views expressed here represent those of the author and do not necessarily reflect the position of the Ministry of Community, Family and Children's Services of Ontario.

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