

Making ABA More Accessible to
Children With Autism in Ontario

By Autism Resolution Ontario
April 2, 2009, World Autism Awareness Day

Our Goal:
To ensure early, fair and universal access to appropriate treatment (ABA)
for children in Ontario with autism as needed, where needed

For Autism Resolution Ontario's goal to be fully realized, a series of changes must take place in the way things currently work. This isn't one simple solution, but a substantial reorganization of the patchwork ad-hoc approach that currently exists into a well thought out series of integrated services, managed and delivered to a standard of excellence and designed to address the specific developmental needs of each child. At the same time, ARO is fully aware of the financial limits of the public purse. As will be shown, our solution shows that more efficient use of existing autism services resources would allow for a well-designed program of services that would have a reasonable cost, and indeed, will generate major cost savings over the long term.

The building blocks of the ARO solution are as follows:

1. Early detection and immediate intervention
2. Pre-school intensive intervention
3. Smooth and personalized transition to school
4. A well designed and professionally delivered school-based program

1. Early Detection and Immediate Intervention

A well-coordinated program that starts as early as possible, is well designed and, critically, has no wait time, can be developed at a reasonable cost.

Research tells us that the sooner a child is diagnosed and intervention begins, the more likely they are to be integrated into a normal school environment at an earlier age. Thus, early intervention is the key to overall cost reduction. Today, there are waitlists for diagnosis, and wait lists for intervention, which together mean that a child who has been identified as having a developmental delay waits for at least three years (and likely more) for any services at all. These are the most critical years for children to achieve developmental progress, and today in Ontario, they spend them waiting.

Solutions:

Ontario should adopt mandatory early screening for autism as per the recommendations of the American Academy of Paediatrics: once at 18 months, and once at 24 months.

A simple tool that can be adopted is The Checklist for Autism in Toddlers (CHAT) developed by Cambridge University in the UK for use by family practitioners and nurses. This is a short questionnaire which is filled out by parents and a primary health-care worker at the 18-month developmental check-up. It aims to identify children who are risk for social communication disorders. CHAT is a cheap, quick and easy-to-administer test, and has been shown to be an effective screening measure. Further information about CHAT can be found on the website of The National Autistic Society: <http://www.nas.org.uk/nas/jsp/polopoly.jsp?d=128&a=2226>.

There should be no delays, and no waitlists, for an initial diagnosis of autism.

Ontario currently lacks qualified developmental paediatricians; however, other professionals can diagnose autism, including suitably trained psychiatrists, psychologists and neurologists. Ontario should include a psychologist's assessment for autism with a paediatrician's referral under OHIP. In addition, all paediatricians in Ontario should be trained to perform the basic assessments needed to confirm a diagnosis, so fewer additional specialists are required to complete the process, or are needed only in complex cases.

Ontario's Ministry of Health, with the cooperation of the relevant professional colleges, should create a web page listing all qualified medical doctors and psychologists who can perform an assessment and render a diagnosis as a reference site for all, to ensure efficient and effective use of the province's available resources.

2. Pre-school Intensive Intervention**Once a child has been identified as possibly having a developmental delay, early intervention services should start, even as the child waits for a formal diagnosis.**

All children who show signs of developmental delay and autism should be immediately eligible for intensive early intervention programs.

There are a number of jurisdictions where early intervention is recognized as something that must start as soon as a problem is identified, even if not fully confirmed. California (see The Lanterman Act, http://www.dds.ca.gov/ConsumerCorner/docs/LA_Guide.pdf) and New Jersey are two such examples.

The administrators and providers of ABA funding from the Ministry of Children and Youth Services should be separated to allow for better, more efficient, fairer and more transparent administration and delivery of services.

Today, the nine agencies that administer Ontario's Autism Intervention Program (AIP) provide services under what is referred to as the Direct Services Option (DSO), and administer a Direct Funding Option (DFO) in which parents hire approved providers and are reimbursed according to specific guidelines. As reported in Auditor General of Ontario's Nov. 2004 Report on the Review for the Standing Committee on Public Accounts: Intensive Early Intervention Program for Children with Autism, the DFO program is much more efficient than the DSO, as the nine agencies have consumed a large amount of money in overhead, and while more than 1,000 children waited for service, money went unspent.

In addition, none of the nine agencies follows a common set of procedures or guidelines, and a child who moves between their coverage areas can lose funding simply because no "spot" is open in their new area. The Auditor's report also found large discrepancies in supervision requirements between DSO and DFO, with DFO providers requiring more supervision than DSO providers. Furthermore, the additional supervision is not fully covered by DFO funding.

The Government of Ontario should create one agency, independent of all organizations delivering therapy under the AIP, to administer the program for the entire province.

By creating a single administrative agency, the government would be able to establish a common set of standards, administrative procedures, policies and programs so that services would operate in the same manner and with the same criteria, no matter where in Ontario a child lives. Overhead costs would be centralized and accounted for separately from service delivery, so the true cost of services would be clear.

Current DSO agencies should be able to continue as DFO service providers. Moving to a 100% DFO approach would allow more children to be provided with ABA sooner for the same money.

The new agency would be responsible for all administration and disbursement of funds, and would have a mechanism for service providers to invoice it directly for approved hours, removing the burden on parents to be involved in accounting, paperwork and money transfers. The funding formula could then be amended so that all families would have the full cost of their funded hours covered, and not, as is the case today, just DSO families.

The new administrative agency would be responsible for any initial assessments for eligibility, any ongoing assessments of children, and quality assurance reviews/audits of service providers. Today, DSO providers are not independently audited or reviewed, but they have the role of reviewing DFO providers, leading to the strong possibility of conflict of interest. Proper oversight and fully independent quality audits must be implemented to ensure consistency among service providers.

The administrative agency could assess children as soon as they are identified, so long as they are appropriately staffed. Currently, those performing assessments of new clients are also involved in service delivery, and lack sufficient time to do both. With provincial resources that are able to travel to regional clinics, all of Ontario can be guaranteed a certain level of service.

A provincial agency that can see all the data from across the province can and must fund services where they are needed. Currently, each agency gets a budget for its region and, as the Auditor found, rather than shifting unused money to areas that needed it, the current system lets money to go unspent while children wait.

A provincial agency can set standards for the training and certification of ABA therapists and supervisory staff. The new agency should first consider the existing certifications such as Board Certified Behavior Analyst (BCBA) and Board Certified Associate in Behavior Analyst (BCABA) – the industry gold standards – and the programs currently available in several Ontario community colleges. The Autism Special Interest Group (ASIG) ABA Consumer Guidelines (http://abainternational.org/Special_Interests/AutGuidelines.pdf) should be consulted as a guide to decide what qualifications are necessary for people overseeing ABA/IBI programs.

Quality indicators measured for preschool and school-aged ABA programs should be implemented for services delivered by any provincially funded provider, public or private, including schools. One principle of ABA is data collection regarding individual progress, and children with autism already qualify for periodic psycho-educational assessment within the schools, so this requirement should have minimal cost implications.

3. Smooth and personalized transition to school

Create an effective transition program between IBI programs and schools for those who can be served in schools. Recognize that a one-on-one approach will remain necessary for some children, and that new school-based programs will have to be developed. Where individuals cannot be accommodated in schools, allow them to remain in appropriate programs.

With an effective public school program in place, there is no reason to hold all children in IBI beyond their normal entrance to Grade 1. However, rather than assuming transitions should simply be age based, a set of guidelines should be developed to determine the most suitable transition to school. A child's transition plan should be flexible and allow for gradual integration, if that's appropriate.

For this to work, it is important that schools be mandated to cooperate with IBI service providers and allow them into schools in an instructor-therapist capacity, and not merely as observers or advisors. It is also important that children in transition have access to a wide range of schools so that they can be geographically appropriate and not require excessive bussing, and that therapist involvement is not made impossible simply due to logistical constraints.

Ontario schools must be required and encouraged to create a range of appropriate new programs, special classrooms and alternative schools to accommodate children with autism who do not fit into current special needs programs that were not designed with autism in mind. Today, many children with autism are placed in classes such as "Mild Intellectual Disability" or "Learning Disabled". These placements are often not appropriate, and worse, the presence of children with autism in these classes where they are not well served can also affect service provided to children for whom the classes were intended. Ontario already has many alternative schools catering to students with different needs, and most of these schools serve much smaller populations than the number of children affected by autism.

Adopting a funding policy along the lines of that recommended in the 2004 Fraser Institute report, *Let the Funding Follow the Children: A Solution for Special Education in Ontario* (www.fraserinstitute.org/commerce.web/product_files/LettheFundingFollowChildren.pdf) would allow and encourage private schools to develop places for children with autism. This approach would provide a range of educational options to supplement offerings provided by public school boards. Autism is complex in manner in that it is impossible to create a profile of "an" autistic child. While the school boards will be able to provide solutions that fit many children, there will be exceptions, and special needs children should be able to take their public education dollars with them to programs offered elsewhere that are a better fit for them. As noted in the report, this is also a cheaper alternative for the province.

4. A well designed and professionally delivered school-based program

Effective and professionally delivered ABA must be provided in Ontario schools at all grade levels.

The Ministry of Education must speed up the implementation of IBI pilot classrooms and move quickly to establish IBI classrooms across the province. All boards should, by the 2010/11 school year, have IBI pilot classrooms in place.

Make the classrooms follow the students: today, there is no connection between where special needs classes are placed and where students come from. As a result, special needs students are often on

busses for an extraordinary amount of time. This is bad for the kids in all sorts of ways, and adds unnecessary costs to school boards. Principals decide what kinds of classrooms are going to be placed in their schools – and thus there are often noticeable gaps among special education classes in different schools. Similarly, special education classrooms are often moved every few years, simply because the school principal changes, or an administrator feels that the school has “had the classroom for long enough”.

All schools should be required to accept children with autism in small groups of similar-level children with a shared educational assistant (EA) (e.g. three kids, one EA) into regular classes, with withdrawal as needed for more intensive one-on-one work, and integration the rest of the time. EAs must be adequately trained in ABA and supervised by a qualified ABA expert. Wherever possible, a home school placement or family of schools placement must be considered. IBI pilot classrooms, and eventual permanent classroom programs, should allow for inclusion when possible, with the children being directly supported in the inclusive environment by the IBI-trained classroom staff member.

School boards need the authority to implement classrooms and programs where they make sense geographically and demographically, and not by where they can convince the principal to accept one. If necessary, legislation must be enacted to require boards to distribute special needs classrooms and programs geographically based on the needs of the student population.

Allow a child’s outside ABA therapists (senior therapist or program director) into schools in the same way that other professionals are permitted (speech-language pathologists, occupational therapists) with explicit rights to evaluate individual children in their classroom setting and make recommendations to teachers, educational assistants and school administration. While schools do have PDD/ASD teams, their staff members are not familiar with the individual child in the same way as a dedicated therapist, and simply can’t make the best possible recommendations based on brief assessments or observations. As well, their teams do not include BCBA or BCBCAs – these professionals must be included on these teams, as they are best equipped to work with children’s ABA therapists help them learn and excel.

Create a special class of Special Needs Assistants (SNA) who are fully ABA-trained by one of the accredited college programs. Assign these SNAs to classrooms where there are children with autism in an integrated setting as well as to ABA classrooms or other autism-specific programs. Make these credentials, or certification such as BCABA, mandatory. Just as teachers must have specific qualifications in order to teach, in the case of children with autism, ABA is a different manner of teaching and different qualifications are required.

Children should be directly supported in the inclusive environment by ABA-trained staff who are overseen by a BCBA certified supervisor. The Autism Special Interest Group (ASIG) ABA Consumer Guidelines should be consulted as a guide to decide what qualifications are necessary for people overseeing ABA/IBI programs in the schools.

Integration must always be a goal. Children in autism classrooms should be integrated as and when possible, with increasing levels of integration an explicit objective. Research supports integration as the most effective approach to enhancing the social development of children with autism, and to increasing their chances as adults of integrating into society.